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Growing Old Alone: Disregard, Care and End of Life in St. Croix, U.S. Virgin Islands

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Growing Old Alone:

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A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Anthropology

by

Devin St Clair Flaherty

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ABSTRACT OF THE DISSERTATION

Growing Old Alone:
Disregard, Care and End of Life in St. Croix, U.S. Virgin Islands

by

Devin St Clair Flaherty

Doctor of Philosophy in Anthropology

University of California, Los Angeles, 2018

Professor Christopher J. Throop, Chair

This dissertation addresses possibilities for aging and end of life on the Caribbean island of St. Croix in the unincorporated territory of the U.S. Virgin Islands. Based on fourteen months of ethnographic fieldwork in the territory, the dissertation focuses on experiences of focal participants near the end of life, alongside the familial, institutional, and broader political and historical contexts shaping those experiences. Central to all of these domains, I argue, is disregard. Advancing disregard as a central analytic and phenomenon for understanding aging and end of life on St. Croix, I present a theoretical framework that considers the work of disregard and attention through time—over historical time at the level of the state and over the life course at the interpersonal level. I theorize disregard as manifesting through bureaucratic,

interpersonal, and experiential modes, and illustrate these different modes with ethnographic cases.

Section I, “Introduction and Theoretical Framework,” introduces the study’s aims and methods, situating it within literatures in global aging and the anthropologies of care and end of life, and then advancing a theory of disregard for use within anthropology. Section II, “A History of Disregard,” presents a history of St. Croix from European colonialism to the present, arguing that St. Croix has for centuries been positioned as a disregarded space on the periphery of the nation. Section III, “Bureaucratic Disregard” begins the ethnographic portion of the dissertation through an exposition of the landscape of senior healthcare and services on St. Croix at the time of research followed by two ethnographic cases that show how disregard is disclosed through aspects of Medicare bureaucracy that deeply impact end-of-life possibilities for older adults on the island. Section IV, “Embodiments of Bureaucratic Disregard” presents the case of one woman living on St. Croix whose final months were shaped in large part by the forms of bureaucratic disregard described in the previous section.

Section V “Caregiving and Intimate Forms of Disregard” turns to interpersonal forms of disregard through addressing a common caregiving structure on St. Croix in which only one family member, in the midst of large families, is providing caregiving for an older relative. Section VI “Experiencing Disregard,” turns to the experiential workings of disregard through examining one woman’s embodied, mooded experiences of disregard during the last three weeks of her life. In the conclusion, in addition to a brief integration of the dissertation’s arguments, I speak to how the effects Hurricane Maria—a storm which hit St. Croix one year after fieldwork ended—has dramatically re-shaped possibilities for care on the island. I focus in particular on

how the process of recovery discloses the ongoing role of disregard in shaping experiences and possibilities for older adults on St. Croix.

The dissertation of Devin St Clair Flaherty is approved.

Linda C. Garro

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Keith McNeal

Christopher J. Throop, Committee Chair

University of California, Los Angeles

2018

To my parents,

for this life

And to Kito,

for every day

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I am deeply grateful to everyone who participated in this study. I owe my most profound thanks, however, to the nine focal participants, and to their families. It is an honor to have been brought so closely into your lives, and I will never be the same for it. It is my sincere hope that I was able to provide some care, comfort, and company during what were often difficult times. There is an ache in my heart that I cannot reproduce here the names of those who have passed on. I offer great respect to their memory.

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SECTION 1

Chapter 1

Introduction: Growing Old Alone

"We just leave, our seniors here in the Virgin Islands, out to uh, graze in the pasture until death." It's one month into fieldwork, and I'm interviewing a territorial senator in his office. I was new to St. Croix, and it was one of my first interviews. I had been spending most of my time doing archival research in the local university library. I had requested an interview with this particular senator because local newspapers from recent years had shown him engaged in a number of initiatives supporting the senior population on island. He was particularly famous for his annual senior citizen brunch. But during this conversation, he seemed to feel that his efforts were barely a drop in the bucket. It was a stark image: being left until death.

This bleak outlook on the situation of older adults on St. Croix was to be repeated to me by many in the coming year. "There's a lot of isolation happening with the older population," I would hear from an AARP administrator. "Many are managing alone." "Here you have our elders that are suffering in silence." Statements like these fill my interviews with administrators politicians, and clinical professionals on St. Croix. "Maybe we're just a buncha people here," a hospice administrator would muse, considering her patients, "that nobody really cares about."

This is a dissertation about disregard. It is about how disregard shapes possibilities for aging and end of life on St. Croix, and how it is working at structural, interpersonal, and experiential levels. It is about how disregard constitutes forms of aloneness at all of these levels, and thus how many older adults in St. Croix are, in several senses, growing old alone.

The dissertation is based on fourteen months of ethnographic fieldwork in the U.S. Virgin Islands. During this time, I conducted research among older older near the end of life and also some older adults who were still healthy; I studied family caregivers and professional caregivers for these older adults; I studied the administrators, legislators, policy makers, and clinical workers involved in the form and availability of care and services for older adults on St. Croix, and I studied archival records relevant to the contemporary landscape of care and services available on island. It is because of this wide scope of research activities that I am able to speak to the workings of disregard at these different social strata.

In the midst of global aging, societies around the world are struggling to adjust to and prepare for a major demographic shift. In many nations of the world, older adults (usually categorized as being sixty-five years old are older) will soon be present in the population in larger proportions than ever before in human history. This has lent a new urgency to studies of aging across disciplines, as we collectively try to figure out what effects these new demographics will have on society at large, and what can be done to ease the transition. This urgency is also, however, fueled by the knowledge that vastly more people are in the later stages of life now than ever before. In this context, aging subjectivities and experiences are inhabited by more and more of our collective humanity, and exploring the possibilities and the limitations for growing old in particular social contexts is imperative.

St. Croix is itself an aging society—with 18% of its population over the age of sixty-five at recent estimates—it is nearly a super aging society (The Henry J. Kaiser Family Foundation

2017).[1] This is due both to colonial legacies and to (post)colonial realities[2] (Stevenson 2014) in which patterns of migration draw younger generations off-island, to the American metropole. As part of the unincorporated territory of the U.S. Virgin Islands (U.S.V.I.), St. Croix is subject to unequal treatment, its residents U.S. citizens but not by birthright and not with all of the rights and privileges thereof. A long-time Danish colony, St. Croix was never subject to any nation's regard and investment, and its' continued neglect is visible across domains today from infrastructure, to economy, to healthcare and beyond. The older adults who are left behind when younger generations migrate, therefore, must grow old and face end of life in this landscape of disregard.

This context of scarcity and neglect is the backdrop for the particular instantiations of disregard that I explore in this dissertation. In the context of St. Croix's history and present geopolitical conditions, I explore how bureaucratic disregard operates to limit healthcare possibilities for older adults, and how this substantially affects not just possibilities for, but the realities of life and death for St. Croix residents. I explore interpersonal disregard in the configurations families spread between the island and stateside find for taking care of their ailing older relatives, and the aloneness those configurations can cause. And I explore the experience of disregard near the end of life, probing its constitution as an aspectual perspective rooted in

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[1] A super aging society is usually defined as having 20% of the population 65 years of age or older.

[2] I follow Stevenson (2014) in her use of "(post)colonial." By this term, Stevenson intends to evoke both the haunting of the colonial past in the present (Good et al. 2008), but also "the way that specific forms of governmentality traverse the so-called colonial and postcolonial periods" (Stevenson 2014:5). Specifically, she intends to draw attention to "the way certain colonial attitudes and colonial forms of governance have not actually ended, and in fact are powerfully at work, embedded, as they are, in inherited modes of conduct and care" (Stevenson 2014:5).

embodied and sensory processes of memory, care, and decline. This dissertation thus provides one piece of the answer of how aging and end of life proceeds in our contemporary world.

In doing so, this dissertation brings attention to and carefully examines the hitherto undertheorized phenomena of disregard. Related to but not isomorphic with concepts of exclusion that, drawing on philosopher Giorgio Agamben's writings on *homo sacer* and the state of exception (e.g. Agamben 1995, 2005), have come to dominate anthropological approaches to contemporary forms of power and political subjectivity, the frame of disregard enables a consideration of patterns of attention in the making of social life at macro and micro scales. In this dissertation, I take disregard as both analytic and phenomena. As analytic, I present a framework that foregrounds the work of attention over the course of time, both the historical time of the nation and the interpersonal time of the life course. This processual approach to attention opens up new possibilities for considering how particular social forms, experiences, and other possibilities are brought into being over others. As phenomena, I consider the manifestations and consequences of different forms of disregard in the lives of older adults near the end of life on St. Croix.

Relevant Literatures

St. Croix's history and geopolitical present make it an overdetermined "state of exception" (Agamben 2005). As Trouillot (2003) has argued, the West itself was born through the European colonization of the Caribbean, during which time the West emerged though giving itself an "other" to be defined against. These new logics of modernity, Trouillot (2003) claims, necessitated the creations of “Others” and “elsewheres” that were nonetheless defined by and constitutive of modernity itself. Thus the Caribbean is the original “outside” included within Western projects of modernity.[3]

When the St. Croix was purchased by the United States from Denmark in 1917, it was subject to a slate of emerging legislation, collectively known as the Insular Cases, that created a hitherto inexistant political possibility for American imperialism: the unincorporated territory (see Rivera-Ramos 2001). Just as as the “state of exception” has been, in Agamben’s meaning, defined as the “included outside upon which a community or society constitutes itself” (Hansen & Stepputat 2006: 296), so “a territory, in the legal sense, is a geographical area recognized as being under the jurisdiction but not fully a part of a country and subject to distinct laws and governance” (Goldstein 2014: 14). This ‘exceptional’ legal status of the unincorporated territory, itself undergirded by discriminatory racialized ideologies, was to provide the U.S. with an enormous amount of leeway in its treatment of St. Croix’s residents (see Goldstein 2014). St. Croix has been kept on the economic, social, and biopolitical periphery of the nation ever since its acquisition.

A founding claim of this dissertation is that St. Croix’s ‘exceptional’ geopolitical conditions directly shape possibilities for life on the island, including possibilities for aging and end of life. This line of thinking builds on insights of postcolonial scholars into the ways that bodies are imprinted by modes of sovereignty and the ways that sovereignty itself works through

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[3] While Agamben himself did explicitly address colonialism and postcolonialism in his writings on the state of exception, others have used his thinking on this topic to newly theorize the dynamics of these relationships (Svirsky and Bignal 2012). Shenhav (2012) for instance, argues that while the state of exception was always “embedded within its [Europe’s] modern theory of the state, it was imperialism that provided the main arena in which the state of exception was practiced most vigorously, systematically, and violently” (Shenhav 2012: 19). Here, the colony is presented as the paradigmatic state of exception.

embodied processes (Fanon 2008[1952]; Hansen and Stepputat 2006), *and* into the enduring psychic effects of colonialism on contemporary subjectivities (Bhabha 2004; Fanon 2005[1963]; Good et al. 2008; Stevenson 2014).[4] It is argued that in the contemporary era, the reigning mode of sovereign power is biopolitics, with the very biological life of individuals becoming the site of sovereignty's manifestations (Foucault 1980, 2003; Rose 2007; see also Petryna 2002; Mbembe 2003 Nguyen 2005). As Ong (1999) has argued, however, states dispatch "unequal biopolitical investment" in their citizens: in this "uneven distributions of services, care and protection (...) some subjects are invested with rights and resources [while] others are neglected outright" (Ong 1999 :217). This dissertation builds on these analyses of power in the contemporary world in showing how the very lives and deaths of residents of St. Croix are subject to the "variegated citizenship" (Ong 1999: 217) that exists within the American empire.

In advancing disregard as a crucial analytic while also focusing on it as phenomena, this dissertation offers a novel way of understanding how processes of biopolitical exclusion can come into being. I argue for approaching disregard as a diachronic phenomenon that comes about through patterns of attention over time. At the level of the state, this happens on the scale of historical time, through material, ideological, and legislative media that shape what it is possible for administrations to pay attention to, what their attention is drawn to, and what is left in the shadow of disregard. This reframing of exclusion and exception through the workings of attention and disregard enables an understanding of these phenomena as *processes* that are grounded in the foundational conditions of possibility for human being. That attention is the

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[4] This connection with the body is inherent in Agamben's notion of the "state of exception" as a domain in which persons are reduced to "bare life"

medium through which the world appears to us, and that in paying attention to certain things other things must be disregard, is a basic, but critical condition undergirding individual experience and social life. In attending to this as a shaper of biopolitical processes of exclusion, we gain traction on how such exclusion is enabled through time in a way that privileges the conditions of human experience as the grounds for all social life.

While American (post)colonial disregard is the backdrop for the entirety of this dissertation, and is investigated in depth in the first several sections, a substantial portion of the text is focused on intimate disregard and of the experience of disregard among older adults near the end of life on St. Croix. In these discussions, I continue to approach disregard as a diachronic phenomenon, but one that operates in this context within the timescale of the life course. A primary tenet of this engagement is that patterns of attention and disregard develop over the life course and thus that caregiving practices and end of life experiences among older adults are significantly shaped by these patterns.

In discussing multiple perspectives on how families in St. Croix configure themselves to provide caregiving for their older members, this dissertation argues for disregard as a crucial component for understanding care. In doing so, it contributes to the burgeoning anthropologies of care[5] and of aging[6] particularly with respect to studies of familial caregiving for older adults (e.g. Aulino 2012, 2016; Kostakiotis 2010; Stonington 2012; Van Der Geest 2002). Many recent engagements have focused on how families are negotiating caregiving within contexts of social

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[5] See, e.g., Aulino 2016; Buch 2010, 2013; Kleinman 2007, 2009; Kleinman and Hanna 2008; Kleinman and Van der Geest 2009; Mattingly 2010, 2014; McLean 2007a, 2007b, 2007c; Mol, Moser and Pols 2010.

[6] See, e.g. Buch 2015; Cohen 1998, Danely 2014; Lamb 2000.

change, particularly amidst growing patterns of transnational migration spurred by globalization, all in the midst of global aging (Ahlin 2017; Baldassar 2017; Coe 2015; Koster 2010; Lamb 2007, 2009; Thelen 2015; Yarris 2017a, 2017b). Coe (2015) has argued that migration is as much temporal as it is spatial, and thus caregiving within transnational families is subject to the "entrainment," or temporal coordination of life courses between generations. Research into attention and disregard over the life course furthers this agenda of expanding our understanding practices of of kinship and care over distance This dissertation directly asserts and ethnographically demonstrates that it is through interplays of attention and disregard throughout the life course that felt obligations and responsibilities, and thus practices of caregiving for older families members are established and carried out.

This dissertation also contributes to the anthropology of care by interrogating care's constitution as relying on particular forms of attention. Indeed, in an analytic of disregard, we can think of the phenomenon of disregard as care, directed elsewhere. Conceiving, with Heidegger (2010; see also Mattingly 2010, 2014) as human beings as always already in a mode of care, we are also always already in a mode of disregard. It is not possible to care for everything at once; to care for something is to disregard something else. By introducing the idea that care and disregard are co-constitutive, we approach a more robust conception of caregiving that is more fully grounded in the conditions of human experience.

This element of the project takes partial inspiration from the work of Stevenson (2014) and Biehl (2005, 2012), who have each in their own way introduced forms of disregard as co-constitutive with care. Biehl (2012) argues that the pharmaceutical medicating of family members in Brazil is a form of disregard "disguised as caregiving" (2012: 251). Stevenson

(2014) investigates how the “anonymous care” provided to the Inuit during Canadian colonization was “experienced as murderous” by the Inuit themselves (2014: 18). Stevenson (2014) shows how the Canadian state, in caring for the entire population, disregarded the suffering of particular families. While thinking alongside these works, the approach offered in this dissertation to the interplay of care and disregard is grounded in phenomenological approaches to attention (see Csordas 1993; Duranti 2009; Throop and Duranti 2015; Throop 2003, 2010). In particular, I draw on the work of social phenomenologist Alfred Schutz.

In Schutz’s *Phenomenology of the Social World* (1967), he describes a particular way of being together that he calls the “we relationship.” The we relationship is only possible when two people are, in Schutz’s terms, within reach of each other’s direct experience, they are in “the ‘face-to-face’ situation” (Schutz 1967: 163). In this situation, one can orient toward the other, making the other one’s intentional object. In doing this, one has experiences of the other, which are nonetheless of course still one’s own: “this experience while uniquely my own, still has, as its signitively grasped intentional object, a lived experience of yours which you are having at this very moment” (Schutz 1967: 102). When two people take up this orientation to each other, mutually paying attention to one another, they are in the “we-relationship.”

I want to suggest the we-relationship as the existential opposite of being in a relationship of disregard. While there are many experiential possibilities unique to the we-relationship, one central for what we are discussing here is that it is only within the we-relationship that two people experience the world *together*. In Schutz’s terminology, they “grow older together.” Schutz illustrates this with an example:

> Suppose that you and I are watching a bird in flight. The thought ‘bird in flight’ is in each of our minds and is the means by which each of us interprets his own observations. Neither of us, however, could say whether our lived experiences on that occasion were identical. (...) Nevertheless, during the flight of the bird you and I have ‘grown older together’; our experiences have been simultaneous. Perhaps while I was following the bird’s flight I noticed out of the corner of my eye that your head was moving in the same direction as mine. I could then say that the two of us, that *we*, had watched the bird’s flight.
>
> (Schutz 1967: 165, italics in original)

There is a kind of sharing innate in this relationship. As Schutz notes, it is not that two people have the same experience (the do not share in *that* way), but rather that in being mutually attuned in their orientation toward the world, in growing older together, two people become a *we*.

Just as the mutually attuned attention that constitutes growing older together creates a form of togetherness, so disregard creates forms of aloneness. Disregard excludes, yes, but what I focus on here is how this exclusion is separation, a keeping or pulling apart from which aloneness emerges. This dissertation examines aloneness and disregard as co-constitutive, and as phenomena that emerge and work through time.

This dissertation is thus connected to ongoing anthropological concerns and research into what seems to be the growing aloneness of older adults worldwide (Allison 2016; Danely 2010, 2014; Kawano 2014; Lamb 2009; Mikkelsen 2014; Zhang 2004).[7] I discuss the pervasiveness of being alone in the lives of older adults on St. Croix and connect these conditions to familial configurations and political and historical conditions. However, in linking aloneness with disregard at multiple social strata, this dissertation expands the notion of aloneness, going beyond linking the micro to the macro, but indeed aloneness showing it to be a leitmotif across the historical and geopolitical conditions shaping aging and end of life on St. Croix today. It is in many senses, I argue, that older adults on St. Croix are growing old alone.

Research Activities, Sites, and Participants

Activities and Sites

The ethnographic research on which this dissertation is based took place over the course of fourteen months. I conducted a two-month pilot study in July-August 2014, spending one month on St. Croix and one month on St. Thomas, focusing exclusively on hospice patients, their families, and hospice caregivers (see Appendix B). I then spent twelve months, September 2015-

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[7] Loneliness among older adults is a related, enduring concern of researchers across disciplines (e.g. Gaev 1976; Moore and Schultz 1989; Mullins, Johnson, and Andersson 1989; Peplau et al. 1982; Townsend 1973; Tunstall 1971; Woodword 1988). It has recently been approached as a public health crisis in some countries of the global North (Mikkelson 2014; New York Times 2017b, 2018c). This dissertation does not discuss loneliness per se, as it was not an emotion or state of being that my participants explicitly engaged with. While I am sure that at certain times some of my participants were lonely, this is not how they or others spoke about their experience. I thus hesitate venture that loneliness was a significant way through which they oriented to their situation or the situation of others. In studying aloneness, I leave open possibilities both for loneliness and for solitude. See Mikkelson (2014) for an ethnographic account critiquing notions of loneliness impinging as impinging on experiences of solitude among older men living alone in rural Denmark.

September 2016 conducting an expanded study, based on my pilot study findings, on aging and end of life on St. Croix.

St. Croix is the largest of three main islands in the unincorporated territory of the U.S. Virgin Islands (U.S.V.I.). The other main islands are St. Thomas and St. John. St. Croix is approximately 84 square miles and has a population of approximately 50,600 (United States Census Bureau 2010).[8] In total, approximately 106,400 people live in the U.S.V.I.. (ibid). The current capital of the territory and biggest town in the territory, Charlotte Amalie (pop: 18,500) is on St. Thomas (ibid). The two towns on St. Croix, Christiansted and Frederiksted, are are substantially smaller, with populations of approximately 2,600 and 3,100 respectively (ibid). St. Croix is today, as it has been throughout its history, a largely rural island. St. Thomas is the commercial hub of the territory, and hosts the majority of tourism.

The majority, about 76%, of St. Croix residents are ethnically Afro-Caribbean (U.S. Census Bureau 2018).[9] 15.6% of residents identify as white (ibid). Additionally, 14.4% of the population identify as Hispanic/Latino, with the majority of these residents, 10.3% of the total population of St. Croix, claiming Puerto Rican ethnicity (ibid). English is the official language of the U.S.V.I., and it is the main language spoken there as it has been since long before American acquisition in 1917 (Jarvis 1918: 34). Many varieties of English are spoken.[10]

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[8] St. Thomas, the second largest island in terms of land mass, is almost exactly as populous as St. Croix, and St. John, which is substantially smaller, has a population of about 4,100 (United States Census Bureau 2010). While St. Thomas and St. John are about five miles apart, St. Croix is approximately 40 miles to the south of St. Thomas, and 40 miles East Southeast of Puerto Rico.

[9] Approximately 66% of residents identify as just Black/African American and not also as Hispanic Latino, with the remaining Afro-Caribbean residents self-identifying being Black/Afro Caribbean and Hispanic/Latino.

[10] Spanish is also spoken on St. Croix, due primarily to the significant Puerto Rican population.

During the yearlong portion of the research (September 2015-September 2016), the everyday precarity of St. Croix's healthcare and social services manifested in several acute incidents, announced in local headlines. There was an Emergency Department walkout, in which the staff of the island's only ED left work, protesting workplace conditions. The island's only Medicare certified (and thus affordable) home-health service discharged all of its patients and closed permanently. One of the U.S.V.I.'s few nursing homes, on St. Thomas, lost its CMS certification, and St. Croix's one hospital went through round after round of CMS surveys, each one of which threatened the revocation of CMS certification. It was a tumultuous time, and it felt like much of the care and services available to older adults in the territory was at risk. What I came to learn, however, was that while these specific incidents were indeed threatening, and while much care and services for older adults were truly hanging in the balance, the situation of precarity was itself perduring. St. Croix's recent and more distant history, and the time after research (during which I've continued to follow local news and stay in contact with friends on island), show that healthcare, social services, and other institutions central to maintaining residents' well being are perpetually unstable there. This is due to enduring legacies and (post)colonial practices of disregard whose sources, manifestations and consequences—specifically in forms of aloneness—I trace in this dissertation.

The multiple social strata through which this study traces disregard and aloneness required that I conducted research across a wide variety of sites. My aims were, on one hand, to study the experiences, everyday lives, and trajectories of older adults near the end of life, along with those of their intimates. On the other, I aimed to understand the social structures shaping those experiences, everyday lives, and trajectories at micro, meso, and macro levels. This included detailed attention to the landscape of institutions (primarily healthcare and social services related) both providing and influencing the possibilities for care and social services available to older adults, and to familial networks of caregiving, as well as to the broader structural forces shaping how these forms of care and support were unfolding, and what forms of care and support were simply unavailable. I thus gathered data across many spaces on St. Croix: in people's homes, in the multiple healthcare and human services institutions that serve them, and anywhere I thought I could learn something about the forces shaping possibilities for aging, dying and caregiving and the experiences thereof on-island. A full list of spaces in which research was conducted can be found in Appendix A. In Chapter 6 (after the historical chapters), I provide a map of the landscape of this network that is as comprehensive as possible. I include a description of my ethnographic engagements with each site I discuss, providing a more detailed accounting of my research activities than is possible in an introductory chapter.[11] In what follows, I present a narrative meant to evoke the spread of spaces in which research was conducted, and also the interrelations between many of these spaces.

I attended hearings of the Health, Hospitals and Human Services committee of the U.S.V.I. legislature, and in the offices upstairs interviewed a senator's chief of staff about her experiences of widowhood and how she copes with all the suffering on island that she sees it as her job to help relieve. Around the corner, I filmed conversations with my 81 year-old, semi-bed-bound participant, living in a one-room shack with no running water, lit only by the electricity redirected off the power lines running to the legislature. On the bottom floor of the island's one

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[11] The research sites and activities described in Chapter 6 are further supplemented with additional details in Appendix D.

hospital I spent nights with older adults in the emergency room, waiting hours for care. One floor up, I sat in meetings of a coalition convened just months earlier by a Medicare-contracted entity working toward to improve inter-agency care coordination on island. A couple floors above that, I sat visited older adults in their hospital beds. Down the hallway, I interviewed a physician at the hospital, a native to St. Croix who was also the current medical director at hospice. He saw patients move through these two modes of care, indeed just down the hall was a patient I was visiting regularly— just weeks before she had been his hospice patient. The entanglements within, and between spaces continues, and I aimed to explore as many possible perspectives in this network of caregiving for older adults on St. Croix.

One of the most productive sites within my study was research conducted with and through Shepherd Hospice, one of St. Croix's two hospice services (see Appendix D for details). This was the case for two reasons. The first was that it made recruiting and conducting research with older adults near the end of life and their intimate others much more successful than it otherwise would have been. Due to federal hospice requirements stipulating that an individual must have a certified prognosis of six months of less in order to receive hospice care, most hospice patients are relatively near the end of life.[12] Shepherd's patients thus provided a pool of possible participants who were likely to be at least relatively close to the end of life. My intensive engagements with Shepherd Hospice and its patients thus enabled me to study end of

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[12] It is extremely important that presence on hospice care in no way guarantees one's death within a certain period of time. Death from illness remains extremely hard to systematically predict (save in the day or so before it occurs when individuals will often undergo similar recognizable physical processes). As I discuss in Sections III and IV, the requirement that individuals obtain a certified prognosis of six months or less in order to obtain hospice, is extremely problematic in a place like St. Croix that has very few other options for older adults with certain levels of illness and disability.

life experiences, processes and dynamics across several individuals and families. My research engagements with Shepherd also enabled me to study hospice care itself extensively. Hospice is now a very common form of end of life care in the United States an is centrally regulated by the Centers for Medicaid and Medicare (CMS). Its impact worldwide continues to grow, and it is now shaping end of life experiences and trajectories within communities all over the world (Saunders and Kastenbaum 2009). While the significant benefits that hospice care can bring to individuals and families should not be overlooked, I found found that its practice on St. Croix is frought with unconsidered consequences that are. Indeed, as this dissertation brings to light (Sections III and IV), hospice care is a crucial site in which American (post)colonial disregard for St. Croix's residents manifests.

Participants

Approximately 70 people participated in this study, across all of the homes, organizations, institutions and agencies in which I conducted research. This included 12 family (or friend) caregivers for older adults (5 of whom were older adults themselves) and 12 older adults who were ill and/or disabled and relatively close to the end of life.[13] The study included 17 professional care providers (including nurses, physicians, chaplains, home-healthcare aides) working with older adults, and 19 administrators (including directors of healthcare institutions,

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[13] Although this seems like a one to one correspondence, that was not the case. In some cases, these older adults did not have family or personal caregivers, in other cases they did but those caregivers did not participate in my study, and in one case the older adult had two caregivers.

senior residences, governmental department commissioners, public officials, etc.).[14] The remaining participants were other friends or families of older adults, older adults who were in good health, or long-time residents of St. Croix who were otherwise involved in the topics I was pursuing.[15]

Of these approximately 70 participants, 9 were focal participants, older adults near the end of their life with whom I was able to engage in extensive research activities. The case studies in this dissertation are based around my ethnographic engagements with four of these focal participants. However, the five who are not focused on nonetheless contributed significantly to my understanding of aging and end of life on St. Croix and to the arguments I present here. Descriptions of the nine focal participants can be found in Appendix A.

Organization of the Dissertation

This dissertation is organized into six sections, plus a conclusion. This introduction is the first chapter of Section I, "Introduction and Theoretical Framework" (Chapters 1 and 2). Chapter Two details the guiding theoretical framework for the dissertation, a temporal analysis of the work of disregard and attention. I argue for the work of disregard and attention on two timescales: the historical timescale of the state, and the life course timescale of the person or the

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[14] In some cases, individuals served both as care providers and as administrators. In this case, I have counted them in the role that characterized most of their everyday activities.

[15] For instance, an Afro-Caribbean man in his late fifties who had lived his whole life on St. Croix, whose parents had both died as older adults, and who was married to a woman that had been involved in healthcare public policy for decades; a white woman from the states in her mid-sixties who had been involved in public policy on island for decades (and whose own children now lived stateside); etc.

interpersonal relationship. In detailing the salient qualities of disregard and attention on these timescales, I distinguish them from the concept of ‘recognition’ (or a lack of recognition). I suggest a particular form of aloneness, or being alone, entailed by disregard and discuss its potential implications on these different timescales. Throughout, I draw upon while critically nuancing discourses of ‘exclusion’ or ‘exception’ that dominate current anthropological approaches to state care.

Section II, “A History of Disregard” (Chapters 3, 4 and 5) is the dissertation’s historical section. This section provides a history of St. Croix, from the first European contact (1493) to the time the study took place (2015-2016). Throughout, I draw attention to the ways in which St. Croix was the object of disregard of the nations who claimed ownership of the island. In Chapter 3, I discuss St. Croix as a European colony (1625-1917), an era that was dominated by Danish rule (1733-1917). I describe the mercantile system of exploitative colonialism, through plantation agriculture and African slavery, that defined life on St. Croix during this era. I illuminate Denmark’s patent neglect of the island during this era that sharply limited possibilities for life on island. The chapter ends with a description of the conditions under which St. Croix was purchased by the United States and a discussion of the Insular Cases (1901-1922), a set of cases that created the “unincorporated territory,” a deeply racialized legal distinction that was to forever shape residents of the islands possibilities for inclusion, representation, and care.

Chapter 4 discusses the history of St. Croix as an American unincorporated territory during the bulk of the twentieth century (1917-1980). This chapter builds an empirical case for American disregard vis à vis the island, showing the many forms in which such disregard disclosed itself. It outlines the development of infrastructure, major population shifts, and the stuttering political civil progress on island, while also tracking the status of healthcare through the decades.

Chapter 5 traces these threads through to the present era (1980-2016), providing a recent history of the main conditions and dynamics shaping life on St. Croix today. This includes a discussion of two major disasters that strongly impacted the past few decades on St. Croix, current political and civil conditions, economics, crime, and inter-group relations, continuing to show how these conditions are related to historical trends driven by U.S. disregard. It discusses the precarious state of healthcare on island at the time of research and directly connects this to regulatory and economic limitations entailed by ongoing (post)colonial disregard.

Section III, “Bureaucratic Disregard” (Chapters 6, 7 and 8), begins the ethnographic portion of the dissertation by addressing the topic of American (post)colonial bureaucratic disregard as it is currently shaping possibilities for heathcare for older adults on island. The section begins, in Chapter 6, with a comprehensive description of the landscape of older adult care and services on St. Croix during the time of research. First, I outline five basic orienting conditions that shape care for older adults on island. Next, I discuss the agencies and organizations providing care and services, including the scope of their work and how they are funded. The third section presents the care and services available from the standpoint of an ill or disabled older adult (like my focal participants), marking out significant gaps or limiting conditions on what is available. Throughout, I further explain my ethnographic engagements with these various institutions and the extent to which they were playing a role in the lives of my focal participants.

In Chapters 7 and 8, I present two case studies of the way that the federal Centers for Medicare and Medicaid (CMS), the main body regulating healthcare for older adults on St. Croix, functions as a site of (post)colonial disregard. In Chapter 7, I compare the histories of hospice care and Durable Medical Equipment (DME) provision on island, two forms of care that require CMS certification in order to be affordable. In showing how the unconsidered consequences of CMS regulations and billing schemes made it possible for hospice care to thrive on island while negating the possibility of successfully selling DME, I demonstrate that this form of disregard makes it easier for St. Croix's residents to obtain palliative care oriented toward the death than to obtain medical equipment that would help support their life.

In Chapter 8, I examine the activities of a Medicare-certified Quality Improvement Organization that, during the time of my fieldwork, organized a "DME crisis" workgroup, tasked with making it possible to buy and sell DME within the U.S.V.I.. I show how the workgroup's interactions with other Medicare-contracted entities involved in DME certification and provision disclose some of the inner workings of bureaucratic disregard. Focusing on the disclosure of St. Croix and St. Croix residents as illegible within Medicare's governance, I discuss the relationship between illegibility and (post)colonial disregard in constraining possibilities for change in healthcare for older adults on island.

Section IV, "The Embodiment of Bureaucratic Disregard" (Chapters 9 and 10) traces the workings of bureaucratic disregard as disclosed through the situation of hospice and Durable Medical Equipment (DME) provision into the life and death of one woman, Ruth. When Ruth began to need continuous concentrated oxygen in order to breathe, she could not afford to pay for it out of pocket and so signed on to hospice care, the only purveyor of Medicare-reimbursed oxygen in the U.S.V.I.. In Chapter 9, I discuss Ruth's trajectory onto hospice care within the broader scope of her life. I trace her emergence as a problematic patient among her hospice caregivers and discuss what this trouble disclosed about the peculiar situation of hospice care on St. Croix.

In Chapter 10, I turn to considering two episodes near what turned out to be the end of Ruth's life. These health crises were turning points in Ruth's trajectory, and each one revealed how the logics of hospice care can operate to secure patients as "dying," despite what they or their family might believe or what kind of care they may want. I demonstrate how, in Ruth's case, this became a self-fulfilling prophecy, as treating her as if she was dying and had no hope to live eventually led to her death. I argue, along with her family, that had Ruth been able to access affordable oxygen, she never would have signed up for hospice care.

Section V, "Caregiving and Intimate Forms of Disregard" (Chapters 11 and 12) addresses a pattern common in caregiving for older adults on St. Croix: one member of the younger generation taking care of an older family member without the help of others in the family. In Chapter 11, I present and analyze the narratives of professional home-healthcare workers to deconstruct locally shared understandings of how families come into these configurations of caregiving. I argue that there is an underlying logic in these accounts that indicates the explanatory role of interpersonal attention across the life course, one that is interwoven with the often matrifocal quality of Afro-Caribbean families. I further propose an understanding of local conceptions of distance in the domain of kinship and care that seems to work throughout the life course, further connecting the logics of proximity and distance, obligation and care throughout the life course.

Chapter 12 is a case study of two older adults and their two (respective) family caregivers. One pair is a grandson and grandfather, the other is a father and son. The chapter considers, on one hand, how the configurations of care that families have come to, discussed in Chapter 11, have created forms of intimate disregard that structuring the pervasive aloneness of these older adults in their everyday lives. On the other hand, I analyze the two caregivers narratives' about being a sole family member caregiver to these older relatives. I bring these narratives into conversation with shared local understandings of sole family member caregiving presented in Chapter 11, showing how these men's perspectives on themselves and their situations both converge with and critically comment upon these shared understandings.

Section VI, "Experiencing Disregard" (Chapters 13 and 14) considers the experiences of disregard of one woman, Ms. Hanks, near the end of her life. Chapter 13 introduces Ms. Hanks and describes the central pattern of felt disregard that came to dominate her experience during the last few weeks of her life in the hospital: the feeling that her family was cooking, but that they were not bringing her any food. Through a selected telling of Ms. Hanks's biography, I build a case for how sharing food became so meaningful to her throughout her life course, from childhood, through motherhood, and now into old age. I describe this as a biography of attention, a lived trajectory of how her attention was shaped over time such that her attention in the present was drawn to and stayed concentrated upon certain elements of her experience—in this case, memories of having fed her family and the sharp feelings of unrequited reciprocity now that they were not feeding her.

Chapter 14 focuses on episodes during the last three-and-a-half weeks of Ms. Hanks's life in the hospital. I discuss how her narratives at certain moments disclosed mooded and embodied aspects of her experience of disregard as made possible by the nutritional and gustatory, but also emotional and intersubjective qualities of shared food. I describe how her medical trajectory was intertwined with her refusal to eat hospital food and how the sensations of her declining physical state partially constituted her experience of familial disregard. I end with a discussion of the concept of social death as fundamentally a practice of disregard.

After Section VI, the Conclusion (Chapter 15) summarizes the arguments made in the dissertation and suggests how a focus on disregard (and patterns and possibilities of attention more broadly) could contribute to possibilities for ‘growing older together’ in an aging world. I conclude by addressing the major change that has occurred on St. Croix since the research period on which this dissertation was based: in September 2017, Hurricane Maria hi St. Croix as a Category 5 storm, completely devastating the island. I discuss the workings of disregard, especially for the island’s older adults adults, that have been manifest within the recovery process.

<u>Chapter 2</u>

An Anthropological Theory of Disregard

To theorize disregard is to speak to a phenomenon that spans social scales. In considering St. Croix—as both past European colony and American unincorporated territory—as a space paradigmatic of exception and exclusion, disregard is a geopolitical force definitive of a mode of governance. Disregard is also, however, a shaper of interpersonal relationships and practices, and has an important role in organizing care and caregiving. And disregard is constitutive of lived experience, both in defining how phenomena appear to us and in how we ourselves may be disregarded by others.

In this chapter, I outline an approach to disregard that serves as the main theoretical framework for the rest of the dissertation. This approach takes disregard as both analytic and phenomena. A very important partner concept for disregard within this theoretical framework is *aloneness.* In the field, it was not disregard, but aloneness, that caught my attention again and again. Finding my focal participants so often alone. Having people keep telling me that seniors 'here' were left alone. The aloneness of the island, far away from the continent, politically separated out. Aloneness, too, spans social scales. How did all of this aloneness come to be? How is it maintained? I argue that aloneness is constituted by disregard, and that disregard itself is constituted by patterns of attention and inattention.

This chapter begins by presenting some basic premises of my approach to disregard, and then continues by comparing regard/disregard to the more concepts of recognition/lack of recognition. Next, I present discuss the nature of attention and the entailments that has for a theory of disregard. Until this point, the discussion will have remained at the level of the interpersonal. I then argue for a particular understanding of what we might mean by collective disregard, or disregard at a broader social scale. Next, I turn to discussing aloneness as constituted by disregard at both the macro and micro social scales that have been considered. To conclude, I experienced aloneness brought on by illness and consider how older adults in need of care on St. Croix find themselves at the nexus of multiple forms of aloneness and disregard.

The Basics of Disregard

At its most basic, I conceive of engaging in disregard as *not* paying attention: it is a mode of inattention. However, these verbs can be misleading: “engaging” in disregard and “paying” attention suggests that there is intentional withholding or active turning away from the object of disregard. This is not always the case. Indeed, one of the benefits of employing a concept of disregard is that it offers a spectrum of behaviors and attitudes, from intentional turning away to simply not noticing. This is useful in employing disregard in an ethnographic context as actors’ true or authentic intentions are not necessarily knowable or constant. Furthermore, and equally importantly, it allows the concept to be applied to collectivities (such as “the state”) to whom we can not necessarily attribute capacies such as attitude or intentional action.

I will be arguing for a consideration of attention and disregard as they occur through time, along the life course at the individual or interpersonal level, or through historical time at the level of collective bodies like the state. By “through time,” what I mean is that my primary interest is not on how attention and disregard are organized at any particular moment, but rather on the processes by which attention and disregard, develop and sediment over the course of time. These processes involve material environments and sociocultural contexts as much as they do memory and anticipation, the will, emotions and mood, belief and knowledge, and conscious and subconscious psychological processes. These processes shape particular outcomes of attention: what someone is paying attention to at any given moment emerges out of a history of certain habits of attention and the development of certain embodied dispositions, meanings, and values all of which unfold within and are molded by the sociocultural context (itself emerging out of a patterned history of tradition, expectation, common sense, etc.).[16] Likewise, what states "pay attention to" (a slightly metaphorical usage that I will explain further along) is shaped by the material and bureaucratic contexts they inherit and in which their activities proceed.

Importantly, this shaping is not determinative at either the interpersonal or the state level, and attention can be modulated by the entity whose attention is at issue. This is only possible to a limited extent, however. How these possibilities for attention, and particularly, for disregard, are shaped through time is related both to the nature of attention and disregard themselves and to the material, cultural, ideological and psychological factors that are actually at play in any particular life or particular history. Below, I will discuss the nature of attention and disregard and its role in creating these possibilities and limitations.

Recognition, Attention, and Disregard

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[16] Indeed, Duranti and Throop (2015: 1056) argue for "the organization and regulation of attention as a key dimension of our cultural existence."

Before turning to the nature of attention, it is important to dispel possible misunderstandings about my use of “disregard.” I will do so through comparison to a related concept, that of (a lack of) recognition. Interestingly, while attention and recognition are not synonymous and in fact connote fairly distinct practices, “disregard,” in colloquial usage, is close to “not recognizing.” Here I will highlight the salient similarities and differences between “not recognizing” and “disregarding,” emphasizing the meanings of “disregard” as “inattention.”

‘Recognition’ is both a polysemous term and one whose meaning and significance has been much debated in philosophy.[17] Like recognition, disregard can exist toward a person or people *in general*, or in regards to certain attributes or actions . One can recognize a person as being another human to whom one has certain kinds of basic obligations, or one can fail to do so. Slave owners in the colonial Caribbean treating slaves as if they were chattel property, instead of human beings, is a classic example of this failure of basic human recognition. Even when this basic recognition is achieved, however, there may still be an absence of recognition in regards to certain attributes that are fundamental to a person or group’s identity. This has been the basis of many contemporary social struggles and of identity politics itself (see Iser 2013). Likewise, disregard can be a total lack of attention toward even the existence of someone or something, or can be a lack of attention to certain elements constituting the identity, attributes, or situation of a particular object (a person, group, etc.).

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[17] For instance, Ricoeur (2005:5) cites no fewer than twenty-three meanings of the term in working to construct a “unified philosophy of recognition” (2005: 17). Ricoeur (2005) argues for a conceptual trail between these meanings that discloses a form of mutual recognition as the core of what “recognition” is all about. However, this discussion is not the place to rehearse these many meanings of to dive into the concept’s intellectual lineage. My purpose here is simply to distinguish disregard from a close, and hopefully more familiar concept. For a bibliography of philosophical text related to recognition, and a summary of state of contemporary debates, see Iser (2013).

Disregard and recognition also have in common their implying of obligations toward the object of recognition or attention. To recognize someone (or someone for something or in a certain regard) is to also acknowledge certain duties to act toward that person in ways that accord with that recognition. For instance, recognizing the right of native peoples to have sovereignty over their ancestral lands is not simply a cognitive event in which one acknowledges that this ought to be case, but rather entails a process of ensuring that such sovereignty is actualized. Importantly, however, the relationship between attention and obligation is much looser. Paying attention to someone (or to something about someone or their situation) does not entail particular behaviors to the same extent that recognition does. That is, while we might expect certain actions or attitudes from an actor who we know to be paying attention to certain things, paying attention in itself does not necessarily entail a response. Lack of such a response is not certain evidence of disregard, therefore, although it may give us good reason to believe that disregard is in play.

To “recognize” thus includes acknowledging understanding by acting on certain states of affairs, and to not recognize can mean to actively rebuff them. To “not recognize the laws of this country” is not just to not pay attention to the laws in a strict sense (in which case you may end up following the laws just by accident) but implies intentionally breaking the laws while holding a stance that the laws do not apply to you. This is not the sense in which I mean “disregard.” In the sense I am interested in, if one breaks the laws of a country because one has disregarded those rules, it is because one has chosen not to pay attention to them or one is not aware that they exist. However, knowing that the laws exist, knowing what they are, and choosing to break them anyway is not in the sense I mean, “disregarding” the laws. This is because having this kind of a relationship toward the laws means paying attention to the laws in a certain way (in order to break them). It is taking the laws into account, and then choosing not to abide by them.

It is important to emphasize this point, as much of my arguments in the dissertation to follow depend on it. In what is to follow, when I make claims such as that the United States Congress, in its creation and implementation of Medicare, disregarded residents of the U.S. Virgin Islands, I do not mean that they took the residents of the U.S.V.I. into account and then chose not to include the interest of those residents in the program's implementation. What I mean, first and foremost, is that the U.S Congress did not pay attention to the residents of the U.S.V.I.. in the implementation of Medicare: their attention was on other things. Similarly, when I speak of family members who have moved stateside disregarding their older family members in need of care on St. Croix, I do not mean that they know the extent of the family member's needs and are living their lives in spite of those needs. I mean that their attention is, for the most part, on other things. It will be the case that in some instances, disregard is the consequence of an active turning away, a choosing not to look or not to know. What is crucial here is to distance this sense of disregard from a sense in which one is actively holding something in mind while acting against it (such as not recognizing the law).

The Nature of Attention and Inattention

In order to further clarify the meaning of disregard that I am concerned with here, a discussion of attention is needed. If disregard is the absence of attention, then what is attention? In the words of William James (1952[1891]: 261):

> Everyone knows what attention is. It is the taking possession by the mind, in clear and vivid form, of one out of what seem several simultaneously possible objects of trains of thought. Focalization, concentration, of consciousness are of its essence. It implies withdrawal from some things in order to deal effectively with others...

Of the many aspects of attention discussed in James's chapter devoted to the subject, there are three to which I would like to draw attention (see James 1952 [1891]: 269-275). The first is mentioned in the above passage: attention can only be on certain things at a time, and in order to pay attention to some things, attention must necessarily be withdrawn from others. Second, attention can be involuntary/passive or voluntary/active. Third, attention is not always fully under our control (this is entailed by the second claim). So while we can choose to pay attention to something and make efforts to maintain our attention to it, we are not always successful (although we can be). And, something can grab our attention without our 'permission,' directing attention off of whatever it had been on before the interruption.

These characteristics of attention have important implications for disregard. In paying attention to certain things, we are necessarily disregarding others. And in disregarding some things, we make it possible to pay attention to, and even to care, for others. Because we do not have full control over what we pay attention to, we also do not have full control what, at any given moment, we are disregarding. However, we can also try to pay attention to things, bringing things out of the realm of disregard. Likewise, we can purposefully take our attention off of things, attempting to no longer pay attention to them, making them objects of disregard. When certain objects need our attention and care, we must take that attention away from something else. This can be done with varying levels of precision, awareness, and sentiment.

In examining attention through observations and analysis of life throughout the world, anthropologists have shown that the capacities, habits, and forms of our attention are culturally and socially shaped (Csordas 1993; Duranti 2009; Ochs and Schieffelin 1984; Throop 2003, 2010; Throop and Duranti 2015). Throop and Duranti (2015) discuss in particular how the 'prominence,' or respective relevance, of objects in the environment is a consequence of ongoing processes of socialization. These processes organize both our habitual attention as well as shape what sorts of objects our attention is drawn to in particular contexts.[18] This insight is of particular importance to advancing a concept of disregard as these processes of socialization train us as much into what *not* to pay attention to.

As Throop and Duranti (2015: 1060) note, in interpersonal contexts— when other human beings are co-present with us—they tend to have "very special forms of prominence" for us, in comparison to other features of the context. However, as Throop and Duranti (2015) go on to rightly explain, a variety of aspects of the situation, including who the person is and what else is going on can variously foreground or background any particular individual in our attention at a given time. In the contexts of caregiving that were so often the milieus of my study, a very important aspect of these considerations is how being co-present with someone who is in pain, uncomfortable, or otherwise suffering affects our attention toward them. Indeed, witnessing another's suffering pulls our attention (as Throop and Duranti [2015: 1062] note in the case of

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[18] An aspect of socialization tightly partnered with this is that which introduces us to what kind of objects exist in the first place (see Hallowell 1957).

the shame or anger of others) but it can also be difficult, even excruciating to witness.[19] The suffering that can result from paying attention to the suffering of others can push us to turn our attention away, to disregard the other who suffers as a way of sparing ourselves. In this way, disregard is importantly interwoven with processes of empathy.[20] To disregard can be a method of avoiding experiences of empathy that we know, or that we just expect, will be uncomfortable or painful, even chronically so.

The form, degree, and meaning of our attention toward others' suffering is a deeply cultural affair (see Throop 2008, 2010, 2011, 2012). However, even in cultural contexts in which particular forms of suffering and forms of recognizing and responding to that suffering are embodiments of ethically virtuous ways of being (and thus sought after in certain ways), this does not mean that paying attention to the suffering of another is easy or comfortable. In St. Croix, it became very clear to me that people found it unpleasant, difficult, and taxing to be around older adults in various states of pain, discomfort or immobility, even if they did not have a close relationship with them. For both the professional and family caregivers I observed (as well as those who were not habitual caregivers but who would come by from time to time)

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[19] For discussions of witnessing "world-destroying" pain in an ethnographic context see Throop (2009, 2010). There is much discussion of the private, incommunicable nature of pain (e.g. Frank 1991; Kleinman et al. 1994; Good 1994; Morris 1997; Scarry 1985). However, while pain may challenge and even defeat language's ability to express meaning, this is not the same as pain being wholly isolated to the person experiencing it. Witnessing the suffering of others can be deeply affecting, and is usually at least uncomfortable or unpleasant. While there are many important arguments to be made about the limits of pain's communicability and its implications (for healthcare, empathy, etc.), is important not to discount the ways that one person's can create suffering among others who witness it (cf. Sontag 2003 on the possible effects of seeing *images* of others in pain)

[20] See Hollan and Throop (2008, 2011). While, as claimed by phenomenologists, all face-to-face engagement entails a basic form of empathy through which we recognize other individuals as human beings like ourselves (Depraz 2001; Thompson 2001; Zahavi 2011), here I am referring to the "more layered, interpretively fraught, and hermeneutically rich understandings—at times effortful, at other times, simply given— of others' behaviors, motivations, moods, etc." (Flaherty and Throop 2018). Moments of empathic engagement with someone who is suffering will entail various levels of effortfulness, imagination, understanding and uncertainty.

paying attention to the older adults I was working with was what I can best describe as depleting. While the labor involved in caregiving was itself exhausting and difficult, just witnessing their discomfort or suffering seemed itself to be distressing. It is important to note that this was even the case when the older adult was not making any overt signs of being uncomfortable (which was often the case with most of my focal participants). In these cases the empathic engagement of these caregivers was responding directly to the perceptible somatic state of the older adult in their care, rather than to any cries, moans, or grimaces.

Emplacing this dynamic into the context of people's lives suggests that co-presence with suffering others can be modulated as a way of limiting our attention to and thus possibilities for uncomfortable or even painful experiences of empathy. While the suffering of another can pull our attention when we are co-present together, we can avoid such direct experiences of another's suffering by keeping them out of the range of our perception. In the context of my research, it was easy for others to stay physically distance from my focal participants as they were largely housebound or bedbound. When not co-present, we can attempt to keep our attention away from another who we know to be suffering through a variety of means. This could include, in the context of my study, avoiding activities such as calling or other forms of remote contact, sending remittances, or staying up to date on their health and wellbeing through someone nearby. While I in no way want to suggest a reduction of the complexities of these interpersonal experiences to mere avoidance tactics, it is important to acknowledge, in the context of interpersonal disregard, the toll that paying attention can take. This dynamic is significantly at play in the instances of interpersonal disregard that I discuss in this dissertation, particularly in Sections V and VI.

Another important aspect to consider in an examination of the modulation of attention with the context of a life (as opposed to within a given situation) is how obligations can arise as seemingly entailed by certain forms of attention. The felt partnering of particular obligations to particular forms of attention in particular contexts is certainly cultural through and through. Pertinent here is the range of cases in which one is made aware—it comes into one's attention—that someone needs help. This is a very wide range, and to what extent one feels obligated to take action and what constitutes appropriate action, will differ widely from case to case, between and within communities and individuals. The contexts of interpersonal disregard that I discuss in this dissertation are family contexts, and felt obligations, and their lack, are central.

Collective Attention, Collective Disregard

Considering obligations towards those who need help opens the scope of inquiry beyond the interpersonal to relationships between groups and individuals, or between collectivities or institutions and others, such as the state and its citizens.This brings us to the question of how attention and disregard are to be considered at the collective level. While we have a grasp of what it means for an individual to pay attention or to not pay attention to another individual, what could it mean for the state to "pay attention" or to "disregard" people?

Recent investigations by anthropologists into the way that states "care for" or fail to "care for" particular segments of their population provide a useful starting point (see, e.g. Biehl 2005; Gupta 2012; Stevenson 2014). While care is not identical with attention, the two concepts are closely related. Care requires at least a minimal form of attention, and studies of state care can thus serve as useful proxies for thinking through collective disregard.

One of the few anthropologists to explicitly employ the concept of disregard in ethnographic engagements with state care is João Biehl (2012; see also 2005). In his longitudinal investigation of the life of one woman who has been relegated to a "zone of social abandonment" in Brazil, Biehl (2012) theorizes disregard as being in a close relationship with caregiving. Biehl claims that with the growing "pharmaceuticalization of healthcare" (2007) and the growing expectation that domestic space will be the site of healthcare practice, family members substitute pharmaceutical interventions for relational caregiving. Biehl calls this "forms of disregard, disguised as caregiving," (2012: 251) as they cut the family member being treated out of family life through a process which can end in social death, or "the ex-human" (2012: 262; see also 2005). Excluded from the family, these individuals often end up in "zones of social abandonment," (which I would suggest are spaces of disregard)—institutions that do not officially exist, in which they are left to die as their existence becomes unacknowledged at state or family levels. Here, disregard is a central dynamic in managing unwanted, "superfluous" individuals.

A crucial point of Biehl's analysis is that these zones of social abandonment are not the consequence of any singular intentions, malevolent or otherwise.[21] Thinking through Biehl's incisive analysis within the framework of attention/disregard that I have been arguing for here, we can see that once relegated to zones of social abandonment (physically removed from the rest

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[21] Families, Biehl writes, "feel that they have 'no choice'," (2012: 215), within a confluence of structural processes that render certain categories of people "superfluous" (see Biehl 2005: 47-49).

of society and having undergone processes of disconnection from their families) the workings of attention and disregard maintain these individuals' exclusion. Attention is drawn to other things, few reminders of these individuals exist, and for those who do remember them, paying attention to them (at a distance) is likely uncomfortable or even painful.

While Biehl's analysis is rooted in processes of exclusion, other ethnographic work has shown that wide-scale harm can result from state projects that seek to care for particular populations. Gupta (2012) investigates how it is that the Indian state continuously allows over 100 million of its people to live in abject poverty, despite massive welfare interventions and the fact that "popular sovereignty is constituted through" the nation's poor (2012: 18).[22] Gupta argues that the "specific modality of uncaring," that maintains this status quo is precisely *not* that government employees, bureaucrats, or state elites are themselves inattentive or uncaring to the state of India's poor, but that this form of structural violence is attributable to the everyday workings of bureaucracy itself (2012: 23, see 2012: 33). In this analysis, attention and care, when dispensed through bureaucratic means, are not enough to stop the perpetuation of structural violence.

Like Gupta, Stevenson (2014) explores how particular forms of state care can have devastating effects on those they were meant to serve. Stevenson investigates how policies of welfare colonialism meant to save the Inuit people in fact ripped families apart, caused intergenerational trauma and were "experienced as murderous" (2014: 17). While Stevenson's (2014) and Gupta's (2012) analyses differ, their considerations of coloniality and

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[22] Gupta (2012) is particularly adamant that India's poor are not excluded from society and mounts a critique of reliance on Agambenian analyses of exclusion for explaining structural violence.

(post)coloniality, welfare, care, and (structural) violence align in important ways. In contrast with Biehl (2005, 2012), this work shows that it is not just the state's power to withhold care that is dangerous, but that state care itself can be a site of violence and suffering on massive scales.[23]

The framework of disregard/attention that I am outlining here diverges from this work by shifting the object of focus from what is being done or not done to how courses of action (including care) either become knowable and doable by being brought into attention or kept in the darkness of disregard. Indeed, the metaphor of visibility is a particularly apt one within a framework of disregard (and one I will explore further in Chapter 8). At the level of bureaucracies, attention and disregard are shaped by material contexts, habitual practices, and cultural and ideological forces that impute certain objects with more prevalence than others.[24] Thus, certain potential objects of attention (such as certain segments of society, certain courses of action) are hidden from view, while others attract attention, seeming to be in plain sight. For instance, the fact that the U.S. Virgin Islands does not have, and never in history has had, a voting representative in Congress (and thus does not have the rank to bring bills to a vote) means that members of Congress do not regularly have issues facing the territory brought to their attention. What I mean by this is quite literally that they do not hear the representative of the U.S.V.I. speak very often, they do not see her addressing them, and they do not read words she has written, all which would bring the territory into their attention.

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[23] For Stevenson (2014), this is a matter of de-sentimentalizing care, and of de-partnering care with straightforwardly good intentions, to show what is often the ambivalent nature of care (2012: 176n6-177-178n7; see also Garcia 2010; Han 2012; Scheper-Hughes 1992; Ticktin 2011).

[24] While this framework takes inspiration from the claim that "bureaucratic responses to social violence intensify social suffering" (Kleinman, Das and Lock 1997: x; see also Gupta 2012: 6) my interest is less in bureaucratic *responses* to social suffering as it is in investigating the bureaucratic functioning through which social suffering is made available to the attention (or not) of bureaucracies themselves.

My main argument in considering collective disregard is that over the course of their existence, state administrations, through acts of bureaucracy, construct material and behavioral patterns for themselves that shape what it is possible for themselves to pay attention to. These patterns are sedimented (in the form of written protocols like laws, expectations or 'common sense'[25] about how to proceed) shaping possibilities for attention for future individuals inhabiting those bureaucratic roles. Parallel with the modulations of attention that are built in to a life throughout its course, one of the effects of bureaucratic work through time is that it is both attempting to create opportunities for attention (and disregard—making some things visible while hiding others) while also always in the midst of habitual patterns that shape the everyday flow of attention as well as the scope of possible objects of attention that even come into view.

Culture and ideology figure in strongly, just as in individual lives, in what objects appear as prominent to and attract the attention of bureaucracies. Even when certain objects, such as the U.S. Virgin Islands, do become visible in the workings of American bureaucracy, there are ideological forces alongside the historically sedimented patterns shaping bureaucratic attention. For instance, when the U.S.V.I..'s delegate to Congress does address the body, her words are not attended to in the same way as the words of more powerful members of Congress. The U.S.V.I., as home to mostly poor, black citizens who are felt to be culturally other, does not appear as worthy of attention. In the competition for attention (a phenomenon we discussed at the level of individual experience), it is not only that the U.S.V.I.. is rarely able to make a bid due to historical processes that have systematically hidden it from view, but when that it does, attention

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[25] Gupta (2012) emphasizes the role of an established "common sense" in maintaining mass poverty in India. Forged within a status quo in which hundreds of millions were consistently living in poverty, this common sense holds the background assumption that such levels of poverty are normal and thus unproblematic.

is likely to merely graze over it on its way to objects that exert a stronger attentional pull—objects that feel more pressing, more worthy of attention.

Disregard and Aloneness: Growing Old Alone

The way that these patterns of disregard, at both interpersonal and collective scales, disclosed themselves in the world is through forms of aloneness. There are many aspects of aloneness that were relevant to growing old and approaching the end of life on St. Croix during the period of my fieldwork. Most immediately striking perhaps was that many older adults that participated in my study spent much of their lives physically alone, in a house by themselves (I discuss this most in Section 5). However, there are other forms of aloneness at play as well: historical, geopolitical, and experiential forms of aloneness permeate this work.

I argue that disregard is constitutive of aloneness and that attention constitutes forms of togetherness. These are both processes that sediment through time. Inspired primarily by social phenomenologist Alfred Schutz's (1967) account of "growing old together," I want to suggest that there is a togetherness created by paying attention. Schutz writes that in a moment of growing old together with someone "I see (...) my own stream of consciousness and yours in a single intentional Act which embraces them both" (1967: 103). Here, Schutz is describing paying attention to someone in such a way that your experience is of their experience—although of course you never experience the other's experience as it is for them, only as it is for you. I find Schutz's (1967) description of the "embrace" of one's consciousness around own's one and the other's stream of consciousness in these moments to be very telling. In paying attention to someone, there is a kind of togetherness brought into being.

As I have done in previous sections regarding attention and disregard, I want here to briefly discuss the long-term temporal dimensions of this phenomenon and its manifestations at different social scales. At the individual or interpersonal level, the forms attention or disregard throughout the lifetime, especially from particular people (e.g. parents) can drastically shape one's sense of self, wellbeing, possibility and ease in the world. Participating in the togetherness of attention or experiencing the aloneness of disregard in habitual ways can shape moods and emotional landscapes throughout the life course, defining the very feel of the world and of oneself. Chronic disregard (e.g. in the case of foster children, Biehl's "superfluous" individuals, or older adults in so many nursing homes worldwide) can sediment, transforming individuals like a form of psychological, intersubjectively mediated solitary confinement.[26] While these relationships are often characterized by material neglect that accompanies such disregard, disregard itself keeps something important from individuals.

This process of the sedimentation of disregard also occurs to collectives, on historical scales. Instead of the course of a life, this is the history of a people. Residents of St. Croix have been largely disregarded for centuries by the states who have been responsible for their welfare. While I would certainly not go so far as to say that St. Croix is itself some form of "zone of social abandonment," (Biehl 2005), there are parallels. Disregard excludes. In carrying out one's life in the space that is St. Croix, one is subject to both the legacy of historical (colonial) disregard that has shaped material and social infrastructures and conditions of possibility on the

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[26] See Guenther (2013) for a phenomenological analysis of solitary confinement.

island and the contemporary (post)colonial disregard that is shaping life possibilities in its own ways. While it is extremely important not to level out the differences that race, country of origin, SES, age, health and linguistic capacities (among other socially meaningful features) make for residents of St. Croix's chances for living well, there are significant elements of the geopolitical space itself that all residents must contend with. For instance, no permanent resident of St. Croix is able to vote in federal elections: when statesiders move there, they lose that right. Similarly, when residents of St. Croix (who are also U.S. citizens) become permanent residents in any U.S. state, they are granted the right to vote in federal elections. The space of St. Croix itself, the territory of the territory, carries with it a legacy and ongoing manifestation of disregard that effects, in different ways, anyone who spends extended time there.

The "people of St. Croix" then are not a fixed community of ancestors and descendents who have collectively occupied the island over the centuries. Indeed, the history of massive immigration out of and emigration into St. Croix immediately dismisses any thoughts of this kind. Nevertheless, I want to suggest that those who reside on St. Croix inhabit a legacy of collective disregard, and with that a legacy of aloneness. This geopolitical aloneness is constituted through the island's physical isolation—its territorial boundaries and its distance—from the sovereign nations that have claimed it, its political isolation as a piece treated separately from, and thus ideologically carved out from, the rest of the nation, and the consequences of those forms of isolation in the limited forms of care and possibilities for wellbeing available to St. Croix residents. Rather than consider this as a single moment in St. Croix's history (even an extended one), I propose a diachronic framework for considering the kind of aloneness constituted by political disregard as sedimenting over centuries.

The Aloneness of Pain and Illness

I have discussed the workings of attention and disregard through time at both interpersonal and collective scales, and have returned to those two scales to articulate aloneness as constituted by disregard both levels. I have also discussed how the pain, illness, or immobility of another can impact the modulation of attention over the life course as individuals attempt to control their exposure to uncomfortable or even painful empathic encounters. I will conclude this theoretical discussion by now briefly changing perspectives to engage with the aloneness constituted through pain and illness.

As I have here been arguing that disregard entails a form of aloneness, phenomenologists and psychologists have argued that illness entails experiences of aloneness, isolation or alienation (e.g. Leder 1990a, 1990b, 2016; van den Berg 1966). Good (1997), drawing on phenomenological theory in his analysis of the lifeworlds of those experiencing chronic pain, argues that chronic pain causes the very assumption of a shared world with others to be called into doubt and disjoints sufferer's experience of time in relation to those around them (see also Rawlinson 1982; Toombs 1992, 2001). Leder (1990b) draws on Sophocles's play, *Philocetes*, about a man exiled to an island due to illness, to argue that illness itself is a form of exile. He claims that, like Sophocles's protagonist, those in the midst of illness are subjected to "a threefold exile": "an exile from the cosmos, the body, and the social world," (Leder 1990: 2). My focal participants were themselves in various stages of illness, often ones that included levels of immobility that severely limited or entirely foreclosed their possibilities for venturing out into the social world. While the aloneness of illness is not constituted by disregard, it is intimately related with it. Illness both significantly shapes how others pay attention to the one experiencing it (i.e. as discussed above in regards to depleting empathic engagements) and makes disregard more deleterious, as the one who is ill is the one who needs care.

Older adults experiencing illness near the end of life on St. Croix are thus at the confluence, of many different currents of aloneness: the aloneness of illness, the aloneness of often being by themselves, and the geopolitical forms of aloneness I have described above. Leder (1990b) quotes Sophocles' in describing Lemnos, the island to which one man was exiled, that Leder analyses as "the distant country of the sick, which we all may one day come to inhabit":

> Boy, let me tell you of this island.
> No sailor by his choice comes near it.
> There is no anchorage, nor anywhere
> that one can land, sell goods, be entertained
> Sensible men make no voyages here.
> Yet now and then someone puts in.
> (Leder 1990b: 1, citing Sophocles as translated by Grene and Latimore 1957)

St. Croix is a beautiful island, which many come near by choice, where it is easy to anchor, many goods are for sale, and there is much entertainment. Sensible men do make voyages there. And yet, it is also a space importantly shaped by forms of aloneness. To be ill and near the end of life on St. Croix is thus to be subject to the forms of aloneness illness can bring about at the same time as being subject to interpersonal and geopolitical forms of aloneness that further shape your possibilities for care, wellbeing, experience, and death.

SECTION II

A History of Disregard

Prologue

This section provides a history of St. Croix that situates the period in which this study was conducted (2015-2016) in light of ongoing trajectories. Broadly speaking, the history of St. Croix has been defined by political and economic metropolitan power, including lack of self-rule, and various forms of disregard by the ruling power. All of these currents have shaped possibilities for care for older adults on St. Croix today.

The two nations that ruled St. Croix for any significant period of time are Denmark (1733-1917) and the United States (1917-present). In the European colonial period, (1625-1917), St. Croix existed perpetually at the very outskirts of every nation that attempted to claim it, a geopolitical position that has continued through the American period and which, I argue, is in the contemporary moment both the context for and the product of (post)colonial disregard. Never a major colonial holding, and yet still firmly a part of the system of European mercantilism, St. Croix was valued only for its possibilities for capital production through the means of slave labor on plantations. For the vast majority of this period, it was Denmark who owned and controlled production on St. Croix. When St. Croix had decidedly lost its possibilities for profit-making for the Danish metropole, it was included in the sale of St. Thomas and St. John to the United States, who at that time (1917) sought the military advantage of St. Thomas's excellent harbor for the construction of a naval base to protect American interests. St. Croix has, since its purchase, been undergoing dual processes, both piecemeal and incomplete, and both controlled by Congress: one toward autonomy and self-sufficiency, the other toward incorporation into the American nation. The island's complex and evolving dependence on the United States—a new iteration of its colonial dependence on the metropole—continues today across all sectors of society. Indeed, the contemporary landscape of healthcare and social services for older adults on St. Croix cannot be understood outside of this political and economic dependence.

This section is organized in chronological order. It begins, in Chapter 3, with a discussion of St. Croix's European colonial history, from Columbus's landing in 1493 until the American purchase of the island in 1917. This discussion is focused on conditions on island and the treatment of St. Croix and its residents under Danish rule. At the end of this chapter, I discuss the conditions and motivations surrounding the United States's purchase of the island and take stock of St. Croix's situation at this pivotal moment in its history. Chapter 4 provides a detailed look at the first several decades of the American period, from 1917-1980. This chapter builds an empirical case for the United States's (post)colonial disregard vis à vis the island, showing the many forms in which such disregard disclosed itself. It outlines the development of infrastructure, major population shifts, and the stuttering political civil progress on island, while also tracking the status of healthcare through the decades. In Chapter 5, I trace these threads through to the time of research, discussing recent developments and conditions on St. Croix (1980-2016). This includes a discussion of two major disasters that strongly impacted the past few decades on St. Croix, current political and civil conditions, economics, crime, and inter-group relations, continuing to show how these conditions are related to historical trends driven by U.S. disregard. It discusses the precarious state of healthcare on island at the time of research and directly connects this to regulatory and economic limitations entailed by ongoing (post)colonial disregard. This chapter sets up an in-depth discussion of the possibilities for older adult care that existed on island during my fieldwork (Chapter 6), which cannot be properly understood outside of the context of healthcare on island more broadly, nor outside of the major historical trends that have defined the island's trajectory.

Chapter 3

From Santa Cruz to St. Croix: A Colony Under Seven Flags[27]

(1493-1917)

This chapter provides a history of St. Croix from the first European contact (1493) until the purchase of the island by the United States (1917). I focus on St. Croix as a European colony (1625-1917), with the bulk of the chapter discussing Danish rule of the island (1733-1917). This was an era defined by the mercantile system of extractive colonialism, through plantation agriculture and African slavery, as it was throughout the region. I illuminate Denmark's particular form of colonialism, which was characterized by enduring neglect and disregard of St. Croix and sharply limited possibilities for life on island. The chapter ends with a description of the conditions under which St. Croix was purchased by the United States and a discussion of the Insular Cases (1901-1922), a set of cases that created the "unincorporated territory," a deeply racialized legal distinction that was to forever shape residents of St. Croix's possibilities for inclusion, representation, and care.

The First Five Flags

During approximately the first 200 years of the colonial era, St. Croix existed on the periphery of the colonial enterprise. There is very little known about the inhabitants of St. Croix

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[27] It is a well known fact among St. Croix residents—and a point of pride among some—that St. Croix has been a part of seven different nations throughout its history. At the main shopping mall on St. Croix, the seven flags are flown in a line of flagpoles flanking the driveway that is main the entrance.

before Columbus first set foot there, on his second voyage to the West Indies in 1493. What is known is that the island was originally populated by the indigenous Taino people, who are believed to have been killed off by Caribs making their way from eastern islands toward what came to be known as Puerto Rico and Hispaniola (Lewis 1972:3). It was Caribs that a group of Columbus's crew met and fought in 1493 on the shores of the island he named "*Santa Cruz*". He then sailed north, through islands he named but did not set foot on: "*Las Once Mil Virgines*" (the 11,000 Virgins) (Boyer 2010:5). This group includes the islands now known as St. Thomas and St. John in the U.S. Virgin Islands, as well as the British Virgin Islands.

It is believed that no Europeans again set foot on Saint Croix until around 1625, when small groups of English and Dutch colonizers made their way there, settling on different parts of the island (Boyer 2010:5).[28] For the next seventy years, St. Croix was passed between several European nations, with small groups of settlers attempting to claim the island through bloodshed, before being once again abandoned in 1696. Rotating settlements of the English, Dutch and Spanish remained small, however, with no country investing much attention in building a colony on the island. Beginning in 1650, there was a brief period in which the French made significant efforts to bring settlers to St. Croix in order to build it into a profit-making colony. They did so largely by luring settlers to the island through financial incentives such as tax-relief. This dynamic—of bringing individuals or business to St. Croix through financial incentives, was to prove a very important one through St. Croix's history. This surge of settlement was the beginning of mass sugar and cotton cultivation on-island. However, it didn't last. Upon deeming,

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[28] This makes St. Croix the first of the Virgin Islands to be colonized, although at this time it was not considered to be a part of the Virgin Island group.

in 1696 "that maintaining St. Croix as a French colony was no longer militarily feasible or economically profitable or desirable" (Boyer 2010:8). France moved its St. Croix settlement to St. Domingue (which we now know as Haiti) while nonetheless maintaining claim to St. Croix.

Seventy-one years after its initial European settlement, then, St. Croix had been claimed at one time or another by England, France, The Netherlands, Spain, and the Knights of Malta and yet was now uninhabited. Historical records leave ambiguous the specific fate of the indigenous people that Columbus and his crew battled in 1493, however it seems that by 1696 there were none left on St. Croix.[29] Meanwhile, these European powers (often through their chartered companies) focused their money, troops, and attention on founding and maintaining settlements elsewhere. Throughout the European colonial period it was to be, as it was with France, St. Croix's ability produce profit, and nothing more, that determined its value from the perspective of the colonial powers.

The Danish Era: The Sixth Flag

The Danish era was characterized by plantation economies built on African slavery and a low level of involvement or interest by the Danish state in St. Croix's affairs. Few Danes settled on St. Croix, and thus the Danish state was not drawn to attend to the infrastructural or public health needs of the island. It was a society characterised by absentee landlordism, a form of disregard whose consequences would define possibilities for St. Croix's residents for a long time

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[29] Whether these specific individuals migrated to other islands, died from wounds obtained in the battle against the Europeans, or caught new and fatal diseases from this European contact appears to be unknown.

to come. While for at least a century St. Croix was a profitable colony (largely because of its sugar production), by the mid-1800s it became a financial liability and Denmark was looking to divest itself of the island.

The Establishment of the Danish West Indies

The Danish[30] colonization of St. Croix has its origins in a charter granted in 1670 to the Danish West Indian and Guinea Company by the King Christian V of Denmark. The charter included a direct order to colonize St. Thomas "'and also such other islands thereabouts or near the mainland of America as might be uninhabited and suitable for plantations, or if inhabited, then by such people who have no knowledge concerning us'" (Westergaard 1917:32-33, in Boyer 2010:9). This inclusion of St. Croix as something of an afterthought to the acquisition of St. Thomas is prescient of the islands' later purchase by the United States. At both of these moments, St. Thomas was valued for its financial or military possibilities whereas St. Croix was not considered to be particularly valuable or worthwhile.

Denmark settled St. Thomas in 1672 and the neighboring island of St. John in 1717. In 1733, France was looking for a buyer for St. Croix, as it had purportedly become a den of piracy and other criminal activity (Boyer 2010:12). The Danish West Indian and Guinea Company

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[30] At this time, the countries of Denmark and Norway formed a political union, called Denmark-Norway, governed by the Danish King (however the countries maintained their own currencies, institutions, etc.) The union lasted until 1814. Thus when Denmark began settling the Danish West Indies, the islands belonged to Denmark-Norway, also sometimes known as the "Kingdom of Norway". I have not found this discussed in any texts on the Danish West Indies or the U.S. Virgin Islands. Norway thus seems to have played little if any role in the history of the islands.

purchased the island and sent a group of settlers to inhabit it, with profit as their only motive. As Lewis (1972: 5) writes, it is

> plain beyond a doubt that the Danish tropical colonization was seen by the court officials and the burgher-shareholders who sponsored it as a purely capitalist venture, to be run for profit only and based upon the emergent triangular system of the Guinea slave trade, the West Indian plantation plantation economy, and the controlling Copenhagen import-export emporium.

As we shall see, when the islands were no longer profitable, Denmark sought to rid itself of them.

Despite Danish ownership of the the island, the population of St. Croix quickly became a mix of people from many European nations. This heterogeneous population, although certainly carrying different significance through difference periods of St. Croix's history, was a constant on-island from the mid 17th-century onwards.[31] As Boyer (2010:12) writes, "From soon after the beginning of Danish rule until its end in 1917, the Danes formed only a small proportion of the population." As mentioned above, this was a significant factor driving the Danish state's disregard of the island. Soon after the Danish purchase, large numbers of African slaves were brought to work on plantations, quickly forming the majority of the population (see below). Repeating the strategy of the French, the governor of what was now the Danish West Indies (St. Thomas, St. John, and St. Croix) encouraged European immigration to the island through tax and

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[31] Indeed in 1918, Jarvis wrote that there "is no such thing as a typical Virgin Islander (...) the people are varied, complex, and hard to classify" (Jarvis 1918: 30)

other financial incentives. Already, in 1688, the islands were a mix of mostly Dutch, English, and French settlers, with a few from other countries as well (Boyer 2010:13). Many of these settlers were relocating from other Caribbean colonies, having had "an invitation extended to [them] to come and occupy the lands on easy and attractive terms (Zabriskie 1985[1918]:31). Indeed, the encouragement of immigration from Eastern Caribbean islands to St. Croix was to repeat several times throughout St. Croix's history (although in very different contexts).

Plantation Prosperity

Thus began what in colonial terms was a fairly prosperous time for St. Croix, and was perhaps the most prosperous time in St. Croix's history. By 1749, only sixteen years after Danes began colonizing the island, "all the flat land in St. Croix was under cultivation," with a census two years later listing 120 sugar plantations, 122 cotton plantations, and 1,900 slaves (Boyer 2010:14). Roads were constructed, and the towns of Frederiksted and Christiansted, which until today are the only two towns on St. Croix, were established (Zabriskie 1985[1981]: 31). In 1754, control over the Danish West Indies was transferred from Company to Crown rule. At this time, St. Croix was the most lucrative of the three islands, and so the Danish Crown established the capital of the colony there. The Crown opened the Danish West Indian market, and soon made St. Thomas a free port, ending the Company's monopoly and spurring increasing prosperity in the colony (Lewis 1972:7; see also Boyer 2010:15). A steady influx of European settlers came to St. Croix looking for a piece of the wealth as "[c]otton and sugar production on St. Croix flourished" (Boyer 2010:14).

In terms of the political rule of the colony, the Company had begun administering St. Croix separately from St. Thomas/St. John, and the Crown continued this division. The colony was governed by a Governor-General, appointed by the King of Denmark, and each municipality had its own small municipal council. This administrative division between St. Croix and St. Thomas/St. John was to last until 1954. It was around the time of the transfer from Company to Crown rule that the economies of St. Thomas and St. Croix began to significantly diverge. St. Thomas, with its large, deep natural harbor, had already been growing into an international trading post (Lewis 1972:7; see also Boyer 2010:15). St. Thomas thus became an important center of commerce while St. Croix remained largely an agricultural center of sugar and cotton production. This division, which would remain throughout the history of the islands, is important in tracing the development of attention and disregard in this region vis à vis the metropole.

As was the case in all plantation societies of this era, all of St. Croix's economic prosperity at this time was built on African slave labor.[32] A consequence of this was that Africans brought to the Danish West Indies to work as slaves from very early on formed the majority population. The first slave ship destined for the Danish West Indies arrived in St. Thomas in 1673, the year after the Danish settlers (Boyer 2010: 13). By the time Denmark purchased St. Croix, there were seven slaves for every white person in the (then two-island) Danish West Indies (Boyer 2010: 13, citing Westergaard 1917: 73-75). In 1789, African slaves formed 89%

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[32] Green-Pedersen (1975: 209) estimates that between 1733 (the year St. Croix was obtained by Denmark) and 1802 (the year Denmark's abolition of the slave trade became law), approximately 123,000 slaves were brought to the Danish West Indies from Africa. Of these 123,000, 70,000 were sent to other colonies, and 53,000 stayed in either St. Thomas, St. John, or St. Croix. However, there is some debate about precisely how many slaves were brought to the Danish West Indies. Curtin's (1969) estimates, for example, are lower. See Boyer (2010: 15-25) for estimates from different sources of figures characterizing the slave presence in the Danish West Indies.

of the population in the islands and even in 1835, 33 years after Denmark's abolition of the slave trade had become law, African slaves formed 65% of the population (Boyer 2010:25). Because of the concentration of plantations on St. Croix compared to St. Thomas (and the island's size compared to the much smaller St. John), the majority of these slaves lived on St. Croix. For instance, in 1803, when the slave population was at its peak in the colony, there were 35,727 slaves counted, 27,161 (76%) of whom were living on St. Croix (Boyer 2010: 25). Ever since this time, Africans and the descendents of Africans have formed St. Croix's majority population, however centuries of intra-Caribbean migration mean that many of St. Croix's contemporary Afro-Caribbean residents descend from slaves who lived on different islands and under the rule of a different colonial power.

All in all, it is estimated that the Danish West Indies accounted for 0.3% "of total slave imports during the whole period of Atlantic slave trade" (Curtin 1969:88-89, in Boyer 2010:18). This estimate gives a sense of the relative size of St. Croix compared to other colonial plantation societies: even in its peak years of prosperity, St. Croix remained a relatively small outpost of sugar and cotton production. Its relative economic significance compared to other islands, however, does nothing to mitigate the fact that tens of thousands of people were brought to St. Croix against their will and forced to work by white planters who considered them to be their property. While sources differ on the relative severity of the Danish slave system compared to the systems of other colonial powers (c.f. Lewis 1972: 28-29, Lowenthal 1972: 41), Boyer (2010:26) has claimed that "it is difficult to characterize any slave system as more repressive than that of the Virgin Islands"[33] and has called the Danish slave code (2010:27) "one of the most oppressive measures ever imposed on a people" (Boyer 2010: 27; see also Lewis 1972: 29). This code, supplemented with regulations from various governors throughout the years—regulations always in the planters' interest— was to remain in effect until the 1830s (ibid). Throughout this time, the majority of St. Croix's residents were treated by the ruling power as if they had value only in their ability to produce a profit.

The Beginnings of Afro-Caribbean Culture

Colonial disregard was a deeply racialized phenomenon. During plantation slavery on St. Croix, the African—and then Afro-Caribbean[34]—residents of the island were treated as replaceable workers whose lives held no value to the planters except for the profit that could be exerted through their labor. The death rate remained extremely high as the Danish slave code provided no legal incentives to look after the slaves' welfare or to otherwise care for them in any way.[35] However, this perspective elides not only the humanity of the slaves but also the entire

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[33] Unlike Spain and Portugal, the countries of England, France, The Netherlands and Denmark had no tradition of slavery when they began colonizing the Caribbean. This means that they did not have an existing slave code, whereas Spain and Portugal had "a long legal as well as moral tradition (...) with respect to slavery (Boyer 2010:21). Tannenbaum (1947) has argued that it is this variable, in combination with religious beliefs in each country that impacted the severity of the slave system that arose in each country's colonies. In Tannenbaum's taxonomy of three types, the Danish system, along with the American, British, and Dutch, were the most severe, with the Spanish and Portuguese as the least severe and the French in the middle (see Boyer 2010:22).

[34] Mintz (1974,1996) prefers the term "Afro-American" to describe the transformation that occurred as Africans were brought to the New World.

[35] For a full reproduction of the code, see Boyer 2010: 27-28.

sociocultural world that was in the midst of being created amidst the vast majority of St. Croix's residents. As Mintz writes:

> In spite of the near-industrial character of the plantation, the slaves did create for themselves distinctive ways of life, drawing on their own traditions, and on what the new settings offered them. These new cultures are usually described in somewhat misleading fashion as 'mixed' or 'blended.' They are, in fact, *sui generis* —neither African nor European, but Afro-American. (1996: 38)

While there has been debate as to the origins of contemporary Afro-Caribbean cultural practices and institutions (i.e. whether they can be considered as continuations of African ways of life), here I want to highlight simply the existence of a sociocultural world alongside and interwoven with the social structures of slavery. Indeed, it was during this period, as Olwig (1985: 43-81) has described in the context of the lives of African slaves on St. John that there was the "emergence of an Afro-Caribbean culture."

Of course, much less is known about the lives and experiences of slaves than of planters and other Europeans in the colonies (Mintz 1972; Olwig 1985: 46), and very little if anything is published on the experiences of slaves on St. Croix.[36] Mintz (1996) has famously detailed the importance of the provision plots provided to slaves in becoming "proto-peasants," not only growing their own food to feed their family (it was slaves, Mintz writes who "*created* Caribbean cuisine" [1996:36]) but also engaging in trade and thus building the skills of tradesmen (Mintz

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[36] Although Olwig's (1985) detailed account of the growth of Afro-Caribbean culture during slavery on St. John likey provides a similar picture.

1996: 42). Olwig (1985: 43-81) similarly writes of the importance of the provision ground to the social lives of slaves on St. John, as well as detailing aspects of their fishing, trading, and family and kinship practices. Olwig (1985: 81) summarizes it thus:

> The slaves were essentially leading a double life as plantation laborers and small farmers and fishermen; as chattels of the planters and as members of large family networks; as culture-less, ignorant savages being civilized through legislative reforms and missionizing efforts and as Afro-Caribbeans proud of the cultured they had created and that they regarded as the true basis of their existence (...) The slaves became increasingly impatient with this schizophrenic way of life and were eager to establish their own communities outside the estates.

Alongside the slaves who were relegated to life on plantations, there developed in the Danish West Indies a group of “free coloreds.” Because an environment of great severity in most slave-planter relations on St. Croix made possibilities for slaves to buy their freedom extremely rare, this group at first grew very slowly, mostly as sexual unions between slaves and planters at times created possibilities for the mothers or children in such unions to be given their freedom. However, during the beginning of the 19th century, the number of free coloreds on St. Croix, and in the Danish West Indies overall, grew at an increasing rate, due both to immigration of free coloreds from other islands as well as to natural reproduction within the free colored community (Boyer 2010: 42). Despite their status as “free,” there were nonetheless strict restrictions on the free colored class. In 1816, by which point many free colored people owned property and slaves of their own, 331 free colored men from St. John, St. Thomas, and St. Croix sent a petition to the

Danish crown, “requesting removal of all free-colored disabilities and the granting of full citizenship and equality with the whites” (Boyer 2010: 43). Such a request is only too prescient of the many bids for equality and fair treatment that future U.S. Virgin Islanders would be sending to Washington over 200 years later. Denmark did not grant the petitioners request, however Boyer (ibid) notes that beginning at that time “increasing exceptions to their harsh regulation [were] being permitted.” By 1835, free coloreds made up 25% of the approximately 41,000 residents of the Danish West Indies (ibid). It’s thus crucial that there were a significant number of Afro-Caribbean residents of St. Croix during the plantation era who were not (or no longer) living as slaves, and who thus were occupying their own segment of society and developing their own ways of life (although of course shaped by the broader social context, including both the ways of life of planters and of slaves).

Emancipation and Post-Emancipation Society

St. Croix’s progression out of a slave-labor based society began in some ways with the Danish abolition of the slave trade in 1802, but this was neither a direct nor an immediate precursor to the emancipation of the slaves. By way of a royal ordinance in 1792, Denmark proclaimed an end to the Danish slave trade 10 years hence, in 1802 (it was the first of the European nations to do so). This was an economic decision through and through. A commissioned report (by the “Great Negro Trade Commission”) had shown that the Danish slave trade was not proving profitable due to high death rates and low birth rates on the plantations, and thus the need to continuously import a large number of slaves just to maintain the current population (Boyer 2010: 37). The ten-year lag-time was designed to help planters move into a mode in which slave populations were self-replenishing by way of biological reproduction in the colonies. During this period the Danish crown encouraged the increased purchase of slaves through a variety of methods including authorizing the treasury to extend low-interest loans to planters and allowing female slaves to be imported duty-free (ibid). Between 1792 and 1803, the slave population on St. Croix increased by over 25% (whereas the population had been holding relatively steady for almost two decades previous).[37] However, conditions on the plantations remained deplorable and the death rate among slave remained high, and there was hence a continued market among planters for new slaves. As such, the slave trade in St. Croix continued, albeit illegally, and on a smaller scale. By 1803, the the population of slaves on island had begun to decrease.

When freedom from slavery did come to the slaves of St. Croix, it came by way of rebellion. In the 1830-1840s, several signs indicated that the system of slavery would soon be coming to its end in the colony. These included England's abolition of slavery (1833) and the continuing work of a governor-general (Peter von Scholten, appointed in 1827) dedicated to preparing Danish West Indian society for emancipation, including, for instance, creating a system of free compulsory education for free and slaves alike that was fully functional by 1842 (Boyer 2010: 49-52). In 1847, the Danish crown issued a royal decree that any child born to a slave from that point forward would be free, and that all current slaves would become free in 1858, twelve years hence (Boyer 2010: 57). But, on the 3rd of July 1848, the slaves of St. Croix took matters

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[37] I calculated these figures based on Boyer's (2010:25) compilation of slave populations on each island in the Danish West Indies in various years sourced from by Vibaek (1966: 102-103, 327) and Green-Pedersen (1975: 204).

into their own hands. A slave known as Buddhoe led a revolution in which hundreds of slaves ransacked houses of local political elites and stormed the fort at Fredikersted. There, they threatened to burn down the entirety of the town if they were not granted their freedom within the hour. Governor von Sholten, who supported emancipation, publically read a "Proclamation of Emancipation"[38]. From that moment forward all of the slaves on St. Croix, St. Thomas, and St. John, were free.

Despite the immense significance of emancipation, ex-slaves nonetheless remained economically and politically dominated by whites in post-emancipation St. Croix. Within a month after emancipation, the local administration ceded to planters' demands in establishing regulations forcing blacks (many of whom were still living on the estates) to continue working in the plantations on a yearly contract basis (Boyer 2010: 58-59). This was followed up the next year, in 1849, with the establishment of the "Provisional Act to Regulate the Relations between the Proprietors of Landed Estates and Rural Population of Free Laborers," commonly known as the Labor Act. As most freed slaves had no recourse or other opportunities available to them, they continued working on plantations in what was essential a legally institutionalized "system of serfdom" (Boyer 2010: 59).[39]

Furthermore, even post-emancipation, St. Croix's residents were a long way from political self-determination. Beginning in 1852, new legislation was put into place in order to legally keep political power out of the hands of newly freed blacks. This was a moment at which

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[38] See Boyer (2010: 57) for a copy of the full proclamation.

[39] Boyer (2010: 59) notes that the terms of this contract labor bore many similarities to "the legal relations between alien workers and their employers in the 1960s and 1970s" when the U.S. Virgin Islands provided incentives for workers from Eastern Caribbean islands to come work in their newly established industrial base.

Denmark was opening up, in an extremely limited way, possibilities for "representative" government to the white planter class. Until 1852, "'all decisions respecting local government were made in Denmark'" with a local, six-man burgher council playing a very minor "'advisory and administrative'" role: it had essentially been"authoritarian rule" even for whites in the colony (Tyson 1944: 14 in Boyer 2010: 63). The Colonial Law of 1852—while still keeping the majority of political rule in Denmark—created a 16-man Colonial Council, members of which were to be elected (Boyer 2010: 64). However, the law restricted voting rights to men of a certain income, and of an "unblemished character," which meant that only whites (ibid).[40] This law was proceeded by the Colonial Law of 1863, which once again maintained voting rights in the hands of the white economic elite. In sum, as Boyer (2010: 66) writes, "[i]t is quite evident (...) that the post-emancipation political system continued to foster the rigid social stratification and status differentiation carried over from the days of slavery."

The Decline of the Danish West Indies

The decline of St. Croix (and the Danish West Indies more generally) as a profitable colony began in about 1835. A number of elements encouraged the economic decline of the island.[41] The end of slavery on island contributed to this decline, and when the Labor Act of 1849 was repealed in 1879 (after a large and violent laborer revolt in 1878) many of St. Croix's

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[40] There were also residential and age restrictions on the franchise.

[41] Boyer (2010: 54) cites a number of reasons for the slackening of the agricultural economy, including the European development of making sugar from beets rather than cane (see Mintz 1985), exhaustion of the soil, absentee-landlordism, inefficient milling operations and untimely droughts and hurricanes.

field laborers, no longer held to the land by contracts, migrated off-island (Boyer 2010: 71). Thus, the population of the island too began declining precipitously.[42] Not just the end of slavery, but the forcing of ex-slaves into employment contracts post-emancipation—and the attitudes these policies fostered in these workers—worked against the overall prosperity of the island. As Lewis (1972: 30) has argued: ”the social legacy of slavery remained, after Emancipation, to frustrate the growth of a liberal free enterprise economy.” It is during this period that Boyer (2010:54) has claimed that “from the viewpoint of Denmark, the days of mercantilism in the Virgin Islands were over. The colony was becoming unprofitable and a liability.” It was also during this period that negotiations began between the United States and Denmark for the former to buy the Danish West Indies.

What We Know About Care for the Aging in the Danish West Indies

Very little is known about care for the aging in the Caribbean colonies overall, let alone in the Danish West Indies or in St. Croix in particular.[43] While it has been noted that social scientific scholarship on the history of colonial medicine has largely elided the Caribbean region (De Barros, Palmer and Wright 2009: 2), studies of the history of colonial medicine in the Caribbean are themselves devoid of studies of elderly care. There is a great deal of evidence that life expectancy in the Caribbean colonies—both among slaves and among free people—was low.

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[42] In 1850, two years after emancipation, St. Croix had a total population of 39, 614; by 1911, it was down to 27,086 (Evans 1945: 21 in Boyer 2010: 53).

[43] Although see Zabriskie (1918: 84-85) for a list of sanitation conditions and healthcare facilities in the territory in 1918 and a list of causes of death in the territory in 1915.

In general, births on Caribbean plantations never reached replacement levels (Sheridian 1975), a fact that was certainly true in the Danish West Indies. Jensen (2009) has written about the Danish Administration's establishment of official royal midwives who, in Denmark's anticipation of emancipation and under the financial strain of slave replacement, trained enslaved women to be midwives on the plantation. There are no studies that I have found, however, that address whether there were any attempts within the Danish West Indies to keep older slaves alive and active. Neither are there scholarly reports on how aging free coloreds or planters were cared for in the region. Likely, the high death rates meant that at any given time there were only a small group of aging members of each class, especially on a small island like St. Croix where the population during the Danish era never exceeded 45,000 (Boyer 2010: 53).

A few passing references to the existence of some form of institutionalized care for the aging in the Danish West Indies do exist, but they are unreliable and give far from a complete picture. For instance, in the Emancipation Proclamation of 1848, provision number four (out of four) reads thus: "The maintenance of the old and infirm, who are not able to work is, until further determined, to be furnished by the late owners" (Boyer 2010: 57, citing the proclamation as reproduced in Campbell 1942: 21). From this single mention, it is impossible to know to what extent this practice had been common pre-emancipation on St. Croix, what form care had taken or was to take, or even if this provision was followed in any way.[44]

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[44] Another passing reference is made to care for the aging in another primary source from St. Croix's post-emancipation Danish era. In 1861, as field laborers had begun drifting away from the estates, planters found themselves with an unusually large cane crop and too few workers to harvest it. The planters pushed the Danish government enter into an agreement with the British government to import indentured servants from India. The Bishop of Antigua (at the time a British colony) wrote to the British government, praising the labor conditions on St. Croix. This letter claimed that there were even provided "asylums for the aged and infirm" (Boyer 2010: 67, citing reprint of the letter in Sircar 1971: 137-138). However, Boyer notes that when Indian workers were brought to St. Croix, working conditions were not at all as had been promised (Boyer 2010: 68). It is unclear whether these institutions for the care of the aging were completely fabricated, exaggerated, or did in fact exist to some extent.

However, given the extremely poor public health conditions noted by travelers to the Danish West Indies throughout the Danish era, I believe it is doubtful that there was any institutionalized or regulated care for the aging taking place at all. An indication of how limited the public health resources were on island during this period is the extremely high rate of infant and childhood death[45]. Furthermore, Lewis (1972: 38) describes that in the years leading up to the transfer of 1917, "[s]tandards of public services [in the Danish West Indies] were frequently medieval." He describes, for instance, that "up until the time of transfer, sick persons in St. Croix were transported to town on open wooden carts, exposed mercilessly to the sun" (ibid).

These public ills are demonstrative of Denmark's disregard with respect to their colony.[46] As I have noted, is likely that the fact that never more than a small group of Danes inhabited the Danish West Indies that led in part to Denmark's disregard of conditions of life on-island. Indeed, Denmark's governance of the islands "evinced 'almost no feeling of responsibility for the social problems,'" (Boyer 2010: 111, citing Campbell 1942: 62). This included, after emancipation, "an almost complete neglect of the social and economic uplift of the poor" (Boyer 2010: 111) which is to say the majority Afro-Caribbean population who, coming out of slavery, had extremely few social or material resources with which to survive. It is doubtless that race played a very important part in Denmark's continuing disregard of the island during this period.

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[45] A rate that was estimated at the time to be 64% for children 1-5 years old on St. Croix between 1909-1913 (Lewis 1972: 38)

[46] In arguing for the absence of Danish involvement or upkeep in its Caribbean holdings, Boyer (2010: 63-64) notes that "[t]here were only five physicians on St. Thomas for a population in 1850 of 13,666, and they were generally employed by the year on estates by private families" (Boyer 2010: 64, citing Knox 1966: 202). The Danish state clearly did not take themselves to be responsible for making sure healthcare was available to the inhabitants of their colonial possessions.

Within this context of disregard it seems likely that any care for the elderly must have been taken on at the level of the plantation, likely within slave communities themselves.

St. Croix Becomes American: The Seventh Flag

American Imperialism in the Caribbean at the Turn of the 20th Century

In the centuries during which St. Croix and so many other Caribbean islands were being run as plantation colonies by European powers, the United States, too—England's erstwhile colony—had been taking over indigenous lands. By the end of the 19th century, the ideology and practice of Manifest Destiny had brought Americans all the way across the continent to the Pacific Ocean, and the Northwest Ordinance of 1787 had created a legal process for incorporating these newly settled lands into the expanding Union. As the century came to a close, the United States was at a turning point, shifting from a focus on continental expansion to a new role in the larger region. Although the Monroe Doctrine had been in effect since 1823, the United States had been largely inactive as an international player in the region. This was, however, quickly changing:

> The major explanation for this inaction [earlier in the 19th century] lay in the fact that for a major part of the nineteenth century, the US was preoccupied with *continental* expansion and security, not Caribbean geopolitics. (...) Once that continental expansion, known as Manifest Destiny, was complete, American

> perceptions about its national security and interests turned to the Caribbean." (Maingot 1994:16, emphasis in original)

Expansionists took different tacks in arguing the importance of growing the U.S.'s influence in the Caribbean, from economic, to altruistic, to political, to military, to racial (see Langley 1980: 6-14; Maingot 1994: 16-22). All in all, "[t]he tropics, and the Caribbean specifically, both provided the opportunity and suited the new geopolitical codes emanating from a powerful group of politicians, academics, military and businessmen" (Maingot 1994: 22). It was a time of what has been called "the "'Caribbeanization' of Manifest Destiny" (Merck 1966: 220 in Maingot 1994: 18).

The most famous American interventions during the Caribbean in this era are likely its participation in the Spanish-American War (1898), whereby it won the territories Puerto Rico, Guam and the Philippines and was ceded temporary control of Cuba, and its construction of the Panama Canal (1904-1914) and control of the Panama Canal zone (1904-1977) . Less famous, however, were American attempts to purchase the Danish West Indies, which began as early as 1865.

Three Attempts to Sell the Danish West Indies

The sale of what were to become the U.S. Virgin Islands were motivated by Denmark's desire to divest itself of colonies that had become a financial drain. As Boyer (Boyer 2010: 75) writes,

> Had the Virgin Islands comprised profitable possessions for Denmark, then the Danes might not have sold them to the Americans. Instead, the declining economy--involving increasing expenditures, declining revenues, rising indebtedness, and recurrent budgetary deficits—caused the Virgin Islands to become a liability to Denmark. Accordingly, the very purpose of colonialism, namely, economic gain for the colonizing power, no longer existed for Denmark.

Their purchase by the U.S. was motivated by the fear of European influence in the Caribbean and a desire for the strategic upper hand that St. Thomas's harbor could provide in wartime. St. Croix never held any particular interest to the United States as an acquisition. It was an afterthought, in which the tremendous consequences for the island's residents went completely unconsidered by the U.S. Indeed, as a look at the three attempted sales of the islands shows, negotiations were marked by the United States's committed—even stubborn—stance of disregard against the islands' residents.

The first direct origins of the islands to the United States occurred in 1863. That year, the United States Secretary of State became aware that the islands were at risk of being taken over by Austria due to Denmark's continued military clashes with them (Boyer 2010: 77). The risk of a European power getting a foothold in the Caribbean, and the potential military advantageousness of St. Thomas's harbor, led the Secretary of State, in 1865, to enter into secret negotiations to attempt to buy St. Thomas and St. John (Boyer 2010: 78). As negotiations progressed, St. Croix was excluded from consideration as the United States was most interested in St. Thomas's harbor, and because France, whose permission was needed in order to sell the islands was “cool” to the inclusion of St. Croix (ibid). While a treaty of sale was drawn up and ratified on the Danish side, political complications in the United States left the treaty unratified by the U.S. Senate (Boyer 2010: 80).

Secret negotiations between the two countries resumed in 1900, with continued rumors, and the U.S.’s continued uneasiness, about the possibility of European purchase of the islands. This time, St. Croix was to be included in the sale. While another treaty of sale was drawn up and approved by the U.S. Senate in 1902, a tie vote on the Danish side halted the treaty’s passage (Boyer 2010: 82). Nonetheless, continued U.S. fear of European—particularly German — influence in the Caribbean continued: “Although the evidence was lacking, the fear of German expansion was real enough to persuade American authorities to renew their efforts to acquire the Virgin islands" (Boyer 2010: 83).[47] The outbreak of World War I, and the opening of the Panama Canal in 1914 only heightened the U.S.’s security interests in the region (Boyer 2010: 83-84).

In this wartime atmosphere, the U.S. Secretary of State informed the Danish Minister that if Germany was to invade Denmark, the U.S. would be forced to occupy the Danish West Indies. This threat prompted a renewal of serious negotiations between the two countries. However, there were several provisions of the treaty that Denmark insisted upon and the that U.S. refused. These included primarily the conferral of American citizenship to Danish West Indian residents, free trade between the islands and the continental U.S., and a plebiscite among the islands’

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[47] Langley (1980) notes that in fact there may have been some American intelligence knowledgeable of German military intents in the region. Langley (1980: 30) writes that “Germany had considered an attack as early as 1889, and in 1899 the Kaiser personally ordered a war plan against the U.S.. The Caribbean, and Puerto Rico specifically, would be the first step towards not a conquest of the U.S., but in the Kaiser’s words, ‘a firm base in the West Indies and a free hand in South America, which entails a breach of the ‘Monroe Doctrine.’”

residents regarding whether or not they favored the sale. The Secretary of State rejected all of these conditions, but the hurried conditions of negotiations, including pressure from President Wilson, meant that a condition regarding citizenship did remain. However, American political interests at the time clearly had no interest in the will of the Virgin Islands people or in including them as Americans—the fact the treaty even mentioned their possibilities for future citizenship was itself made possible by an act of disregard, an accidental carry-over in the treaty's rushed re-drafting. The treaty passed through the various steps of ratification in both countries during the end of 1916 and the beginning of 1917, and on March 31, 1917, the the islands were officially transferred to the United States. The final price was $25 million and included all three islands of St. Thomas, St. John and St. Croix.

The U.S.'s purchase of the islands were thus part of a broader American project of security, influence, and self-interest ongoing within the Caribbean region.[48] However, given the timing of the sale, it's not clear that the Virgin Islands had any significant role to play in the United States. Noting that "the United States had begun to covet the Virgins at a time when St. Thomas was one of the most-used harbors of the Caribbean," Perkins (1962:166) suggests that the acquisition of the islands was redundant, and perhaps even pointless in this political moment:

> In 1917, (...) [the islands'] economic value had already been a minus quantity for many years, and their positive strategic value to the United States, with Puerto Rico American, and Guantanamo Bay available for use, had lost significance. Yet

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[48] Maingot (1994: 46) lists "the bases in Cuba and Puerto Rico securing entry into the protective zone of the Panama canal" along with "[m]ultiple interventions in Nicaragua, Haiti, Dominican Republic *and the purchase of the Virgin Islands in 1917*" as all "tighten[ing] the security ring" and creating a strong sense of "territorial invulnerability" for the U.S.(emphasis mine).

> so persistent was the belief in their importance, conditioned by a long history of negotiations, dating from 1867, and such alarm was caused by thought of their possible transfer to Germany, that $25,000,000 was paid for the Danish West Indies without any fresh assessment of either the real necessity for the purchase or of their future value, much less of the problems that would be involved in their government.

Thus even the inclusion of St. Croix into the United States was enacted in a mode of disregard: an afterthought in an acquisition whose purposes, the U.S. didn't seem to notice, had become defunct. Indeed, with this purchase, the islands were transferred from a shrinking colonial power looking to divest themselves of a growing financial liability to a growing imperial power who had very little, if any use for them: from a position of colonial disregard to one of (post)colonial disregard.

Taking Stock: Forms of Disregard from One Metropole to Another

Here I will briefly emphasize the forms of disregard that shaped the condition St. Croix was in when the United States acquired it and how St. Croix landed in a moment in American history that slotted it into new, ongoing forms of disregard.

As discussed above, a pattern of general Danish neglect and disregard of the islands had, for several decades, defined the colony's relationship with the metropole. There was a general "metropolitan lack of interest" in the island possessions; "[n]either Danish government not people had ever shown much active interest in the Antillean dependencies" (Lewis 1972: 40).

This neglect was apparent in the conditions in the islands upon the American transfer. In 1917, the first American governor of the territory, James Oliver, reported on the

> dire conditions of the islands as including very high death and infant mortality rates; unhealthful hospitals, sanitation, water supply, sewerage, and fire prevention systems; woefully inadequate public instruction; and no proper family life. 'The islands are incapable of self-support,' Oliver reported. 'This unfortunate situation is the natural inevitable result of centuries of neglect.'
> (Boyer 2010: 111-112).

This legacy of disregard would strongly shape possibilities for the territory under American rule.

The lasting effects of this neglect were compounded by centuries of forced involvement in the mercantilist economic system of extractive colonialism. The very design of mercantilism is meant to exploit and extract value from the colony in order to enrich the metropole. As Lewis (1972: 6) has written, mercantilism "had as one of its economic functions the prevention of the development of the potentialities of the overseas colonies so that they would not be able to stand on their own feet and become politically independent." The islands thus not only existed at the periphery of the Danish state, outside of its sphere of attention, but were also actively kept dependent on that state through this asymmetric economic system. This combination of disregard and dependence would continue, though in altered form, during the American era.

On the side of the U.S., their initial stance against including Virgin Islands residents in the process of deciding the transfer was both significant in itself and prescient of forms of disregard to come. In the 1867 and 1917 treaties of sale that were created (only the 1917 treaty included St. Croix), the Danish side demanded that a plebiscite be conducted in the islands to determine whether or not the residents were in fact willing to have the island sold to the United States. In both cases, the American Secretary of State refused to include this as a provision. In 1867, the Secretary of State was in “obdurate opposition” of polling the islands’ residents (Boyer 2010: 79). In 1917, the (new) Secretary of State similarly refused the provision, writing that "the American Government could not favor submitting 'the question of transfer of the islands to a vote of the inhabitants.'" (Boyer 2010: 85, citing Tansill 1932: 491-492). There was no plebiscite in the Danish West Indies, and the residents had the islands they lived on sold to the United States without either their consent or their opinion garnered.[49]

The U.S.’s early stance on the possible citizenship of U.S. Virgin Islands residents was equally prescient of ongoing exclusionary policies. The 1867 treaty was to provide a choice to residents of either maintaining Danish citizenship or becoming American citizens (with those not having chosen after two years automatically becoming American citizens) (Boyer 2010: 79). The 1902 treaty, however, had no provision for “citizenship” at all, instead providing a between “‘Danish allegiance and ‘allegiance to the United States’” (Boyer 2010: 82). As the treaty of 1917 was being negotiated, the Danish side pushed for it to include the stipulation that all residents of the island were to become American citizens. The U.S. Secretary of State rejected this stipulation (Boyer 2010: 85). In the final rush to get the treaty signed, what was included was the 1867 stipulation that residents would have a choice between Danish and American citizenship. However, unlike the 1867 treaty that had stated the residents could become “‘citizens

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[49] This disregard of the will of Virgin Islands residents is maintained today in Congress’s refusal to allow them to vote in Federal elections or to have a voting representative at the federal level.

of the United States,'" the version of the treaty that was signed said that they could become "'citizens in the United States'" (Boyer 2010: 88; see Leary 1992: 105-116 for the 1917 treaty in full). Boyer (2010: 88) argues that this change in phrasing had much to do with the ability of Congress to later deny birthright citizenship to U.S. Virgin Islanders.[50]

However, it was not just this one phrase that allowed Congress a great deal of flexibility in its actions—including the granting of Constitutional rights and liberties—vis à vis U.S. Virgin Islands residents. Instead, the purchase of the U.S. Virgin Islands came at a time when the United States was creating unprecedented new law defining a whole set of American territories and residents as exceptional. This doctrine of the exceptional nature of new territories, including the U.S.V.I., allowed Congress an enormous amount of leeway in their treatment of residents of these new territories (see Rivera Ramos 2001: 108-109).

Traditional American territorial expansion—continental expansion—which sought to bring new territory into the Union, was legislated by the Northwest Ordinance of 1787. This law laid out a process for territories settled by Americans to become states, for those states to become part of the Union, and for all states within the Union to have equal rights to those of the original (thirteen) states. It was in 1898, when the U.S acquired Guam, the Philippines, and Puerto Rico through the Treaty of Paris that for the first time the country ruled non-contiguous territories and "for the first time in American expansionist history, no promise was made of either statehood or citizenship" (Boyer 2010: 96-97). While much of the discourse about this difference hinges on the "non-contiguity" of these territories with the rest of the continental U.S., it is abundantly

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[50] To this day, U.S. Virgin Islands residents do not have American birthright citizenship.

clear that the distinction was based in ideologies of racism that positioned the peoples of these territories as unfit for incorporation into the American Union.[51]

The acquisition of these new territories set in motion a group of cases to determine their status, known as the Insular Cases (1901-1922). Through the Insular Cases, American courts "not only adapted to what was perceived as a new situation; it actually created a new legal and political reality" (Rivera Ramos 2001: 106). This was the reality of the "unincorporated territory." This new type of political entity was created through the justification that previous law governing the acquisition of territory was not applicable because there was something exceptional about this "new" form of expansion (see Goldstein 2014: 14-15). In establishing the new status of the "unincorporated territory," these cases set these new territories apart from incorporated territories whose road to statehood was legislated by the Northwest Ordinance (see Goldstein 2014: 15-16). This status created a precedent in Constitutional law for "'a domestic territory that could be governed temporarily, and then later, if necessary, relinquished'" (Burnett 2005: 797, in Goldstein 2014: 16). Goldstein (2014: 16) emphasizes the significance of this new distinction:

> Whereas the promise of statehood supposedly rendered colonization a provisional condition en route to inclusion and equality, 'unincorporation' had the effect of positioning the U.S. island colonies as *an anomaly*, a deviation from the preceding continental development of the nation. (emphasis mine)

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[51] See Chapter 7 for a discussion of how the "non-contiguity" of the U.S.V.I.—it's material presence as a cluster of islands over a thousand miles from the U.S. mainland—continues to figure into governmental logics today (particularly those of Medicare).

Upon their transfer to the United States, St. Croix, St. John, and St. Thomas became the unincorporated territory of the U.S. Virgin Islands. This was a status that by its very definition withheld the normal rights and privileges of those living under the American flag, until such time as Congress granted them.This “anomolous” status was to shape American action and inaction in the U.S.V.I. until the present day.

The definition of the form of expansion that began with the acquisition of Puerto Rico and Guam as exceptional is extremely dubious. Indeed, it is clearly based on ideologies of race cloaked in justifications about the unprecedented nature of such acquisitions. (see Rivera Ramos 2001: 113). Through a change in political ideology from a mode of settler colonialism to one of “exerting influence” in the Caribbean region, the acquisition of these territories could be constructed as “exceptional.”[52] However, it is not clear that conquering new territory truly constituted an “exception” in this era of American political history. Not only did the U.S. acquire the islands of Guam, Puerto Rico, St. John, St. Thomas and St. Croix during this period (in addition to occupying Cuba and parts of several other Caribbean countries) but since 1907, the territory of the Union has in fact grown by 25%, a full 881,457 square miles (Robbins 1967: 201). This fact sheds doubt on the idea that territorial acquisition was no longer an American strategy during this period, and that these territories were somehow “exceptions” to U.S.

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[52] It has even been claimed that the United States’s disinterest in further territorial conquest meant that “[t]he destiny of the Caribbean in the twentieth century would be, then, that of an empire, an empire without colonies.” (Langley 1980: 14).

expansionism[53]. It was, nonetheless, in the mode of "the exceptional" that the U.S. overseas territories, including the U.S. Virgin Islands were governed (see Rivera Ramos 2001).

At the transfer, then, St. Croix was home to approximately 27,000 people, the majority of whom were Afro-Caribbean. Their society had been terribly neglected for decades, as was evident in the economy, public health, institutions, and possibilities for life on-island. Furthermore, as the island had been colonized in order to participate in a system of mercantilism based on slave labor, the island was deeply structurally dependent on a metropole. When this metropole switched to the United States, St. Croix came into the nation as an acquisition that was not only an afterthought to the potentially strategic harbor offered by St. Thomas, but already was legally segregated from the rest of the country, its residents not having parity with American citizens.

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[53] A recent volume edited by Goldstein (2014a), "seeks to place U.S. overseas empire and settler colonialism into the same analytic frame" (Goldstein 2014: 4), pushing back against a hard distinction between these two forms of imperialism in order to see them as two manifestations of the same underlying logics.

Chapter 4

The American Era (1917-1980)

This chapter presents the history of St. Croix as an American territory from 1917 until 1980, tracing the various forms and manifestations of (post)colonial disregard that defined social, economic, and political possibilities for the people of St. Croix. As was the case during the Danish colonial era, this disregard manifested in the context of significant dependency of St. Croix on the metropole. A major theme in the chapter is the tracing of how this ongoing political and economic dependence was managed and related to on both sides of the relationship over time.

There are two forms of independence that economic and political dependence could potentially be a precursor to: economic self-sufficiency and political autonomy, or self-rule. As we will see, the territory's economic self-sufficiency at times became foregrounded as a goal in the U.S.'s relationship with the U.S.V.I., aligning, at least abstractly, with the territory's own goals of escaping the financial control of the metropole. This is, however, something of a two-edged sword: on one hand, the pursuit of this goal could be seen as supporting the U.S.V.I.'s own aspirations for itself; on the other hand, it is a way for the U.S. to divest itself of an ongoing financial liability. It was in the U.S.'s own interest that the U.S.V.I. no longer be reliant on the federal treasury, and it was this interest more than any other that motivated the U.S. to at times actively—although haphazardly and always ineffectively—pursue this goal for the territory.

Political autonomy was another story. It took a long time before the U.S. allowed the territory any form of local democracy or self rule, and it is a process that remains incomplete.

For the U.S., political autonomy for the territory was entangled with economic possibilities for self-sufficiency: the prevailing attitude of the US. throughout the twentieth century was that the territory was not yet fit for self-rule, and that major societal changes, including economic-self-sufficiency, needed to take place before full self-rule could even be a possibility (see e.g. Lewis 1972: 69). Certainly, there is some sense in this stance, and the territory was not ready for political autonomy immediately upon acquisition. However, the reluctance to allow small steps toward self-rule and local democracy was most certainly also shaped by racist ideologies through which Congress saw the residents of the territory themselves as unfit or incapable of ruling themselves. Furthermore, the irony of every measure of self-rule the territory was granted was the very fact that it was *allowed* by U.S.: it was self-rule under the rule of another sovereign.

It is important to recognize just how much control the U.S. had over St. Croix when the island was first acquired. In 1917, it was still grappling with how to govern the territories it had acquired through the treaty of Paris at the end of the Spanish-American war in 1898. There was no clear policy, legislation, or strategy for managing non-contiguous American territories, even after they had been categorized through the Insular Cases as "unincorporated." However, there were two legal stipulations that gave full control of these territories to the U.S. Congress. The oldest was within Article 4 of the Constitution, the Article that in general outlines the relationship between States and the Union. It also outlines the relationship between the Union and Territories. Article 4, Section 3, Clause 2 reads in part: "The Congress shall have Power to dispose of and make all needful Rules and Regulations respecting the Territory or other Property belonging to the United States." The original context of this article was to make clear the relationship between the U.S. Congress and territories (i.e. full control) on the continent before they became states. However, with the advent of the “unincorporated territory,” this passage gave Congress full control over territories indefinitely, as they were not headed toward statehood. Secondly, Article 6 of the Convention between the United States and Denmark for the Cession of the Danish West Indies, the 1917 treaty of sale, indicated that Congress would “‘determine the civil rights and political status of the inhabitants’” (Boyer 2010: 88, citing the convention as replicated in Tansill 1932: 527-537). This form of rule was essentially no different from colonial rule in terms of how much say it gave the islands residents in their own political and civil affairs.

When St. Croix was acquired by the U.S., possibilities for the lives of island residents—and their descendents—were directly in the hands of Congress. The changing scope and form of this legislated political control, de facto economic control are an extremely important frame for understanding the forms of disregard that defined relations between the U.S. and St. Croix through the twentieth century.

Navy Rule (1917-1931)

When the U.S. obtained St. Croix, the country had no “colonial machinery” with which to systematically govern; there would not be a governmental department responsible for attending to the territories, the Interior Department’s Division of Territories and Island Possessions until 1934 (Boyer 2010: 167). The consequence was that the extension of possibilities for political autonomy and civil rights for residents of St. Croix, instead of arriving with American ownership was piecemeal, unsystematic, and often delayed or put off. This intermittent, haphazard process is one of the clearest manifestations of the United

States' (post)colonial disregard vis a vis the U.S. Virgin Islands. The first form of disregarding the issue of the political status and rights of these newly acquired islands and all of their residents was to put it off through the mechanism of military rule.

When the transfer of the Danish West Indies into American hands took place on March 31, 1917, the islands were immediately put under U.S. Navy rule.[54] This was meant as a temporary measure for what was a territory acquired for its potential military advantages in a context in which war was seemingly immanent (indeed, the U.S. entered World War I one week after the transfer [Boyer 2010: 112]). As Boyer (ibid) characterizes it, "[t]he simplest way to administer [the U.S. Virgin Islands] (...) was to put them under military rule and to postpone any consideration of their status and their economic and political development." Navy rule, which lasted until 1931, was characterized by an onslaught of major public health projects alongside an almost total disregard for the economy of the islands and the political will of the people.

Because Congress did not take any immediate action to determine the "political status and civil rights" of Virgin Islands residents, the law of the land remained the Danish Colonial Law of 1906. Among other restrictions, this meant that the franchise remained restricted to an economic elite, with only 5.5% of residents eligible to vote in local elections for the colonial councils (Boyer 2010: 144). The governor of the territory was to be appointed by the President. The first governor, John Oliver, the same who claimed, upon first surveying the islands, that they were at present "incapable of self support," was strongly against extending the franchise in the islands (ibid). Residents of the territory thus remained ruled by an authoritarian military government in which they had no representation.

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[54] Because the naval governor was appointed by Congress, this was actually a hybrid military/civil government.

Furthermore, the Navy was at the time a racially segregated institution that did not accept any African-Americans. Boyer (2010: 119) argues that this amounted to "[w]hite surepmacy" being "imposed on the predominantly black population of the Virgin Islands through military occupation manifested in the intimidating presence of armed marines both in St. Thomas and St. Croix." This racist ideology was evident in the Navy's practices of justice in the territory, from incidents of violence and intimidation to abuses of power in the court system (see Boyer 2010: 114-120).

What had been considered to be the "simplest way" of ruling the islands—relegating them to Navy rule so that their immediate fate did not need to be considered—was a form of disregard that materialized in part through extremely haphazard governance. Lewis (1972: 45) clearly connects the "second-class status" of the territory's "unincorporated" status with the way the islands were governed in these early years:

> The machinery of government (...) bore all the marks of hasty wartime improvisation. In fact, the basic statute of March, 1917, by continuing in effect most of the provisions of the Danish Colonial Law of 1906, perpetuated a Danish constitutional system that went back to 1863 and conferred upon Virgin Islanders the further anomaly of being governed by an odd combination of American sovereignty and Danish institutions (...) The lacunae obviously created by this curious mode of legislating for the new territory had to be filled in by a mixture of administrative edict, congressional enactment (...) and presidential executive order.

This piecemeal governing demonstrated how small of a priority civil rights and conditions of life in the islands were for the U.S..[55]

Areas of Progress

There were, however, some areas of progress during Navy rule. The Navy took on vast projects of public health and infrastructural improvement throughout the territory.[56] Additionally there was—against the odds—some progress made during this era toward securing rights and self-government for Virgin Island residents. In particular, a local codes of laws was drafted and U.S.V.I. residents were granted American citizenship. The laws, drawn up by the still existing "colonial councils" with guidance from a lawyer brought in by the Navy, were not particularly responsive or attentive to local conditions or to the desires of will of U.S.V.I. residents.[57] Nonetheless, the codes did provide Virgin Islands residents with most of the rights of the accused of the U.S.legal system (Boyer 2010: 126). This is not, however, to say that such rights were observed in practice, and indeed there is much historical evidence that they were not (Boyer 2010: 126-128).

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[55] There was even a great deal of confusion in Washington, recorded in Congressional debates of the era, as to whether the islands were "part of" the United States, or simply "a possession of" the United States," and how that distinction ought to steer policy toward and in the territory (Boyer 2010: 139).

[56] The Navy reorganized and improved the hospitals, trained nurses, began sanitation projects, and improved infant and maternal welfare (Boyer 2010: 120). They also constructed an improved water supply system, introduced a sewage system, and improved education (ibid).

[57] The code embodied "almost all the provisions of the Alaskan Code, simply because the lawyer commissioned by the Navy to draft the codes was imported from Alaska [which had become an incorporated territory in 1912] for that purpose" (Boyer 2010: 126).

It was in 1927, ten years after acquisition, that Congress final granted American citizenship to U.S.V.I.. residents. Like all rights and civil liberties provided to Virgin Islands residents, however, citizenship could equally be legally revoked at any time by an act of Congress. Furthermore, the granting of this citizenship itself was marked by the kind of confusion and anomaly characteristic of Washtington's governing of the islands. Many previous legal documents, like the local codes of 1920-1921, had language in them already assuming that Virgin Islands residents were American citizens (Boyer 2010: 139). The acquisition of citizenship was nonetheless a very significant step toward inclusion in the American nation. It did not include at the time, nor does it to this day, the right to federal representation, nor the right to vote for President.

Depression and Emigration

Beginning in 1922, the territory fell into an economic depression that the Navy did nothing to combat (Boyer 2010: 121). On St. Croix, agriculture output fell precipitously as the area of cultivated land decreased and the price of sugar dropped (ibid). Furthermore, the federal government felt it appropriate to extend the Prohibition Act to the U.S.V.I., beginning in 1921 (the year after it was instituted in the continental United States). This forbade the making or sale of rum, one of the island's major exports (made from locally grown sugar cane). Unemployment on-island grew. Despite major public health and infrastructural improvements, the U.S.V.I. were plagued with "rampant unemployment, undernourished children (...) and threatened [with] wholesale starvation" (Boyer 2010: 121-122, citing Francis 1923).

Under these circumstances, emigration from the territory grew, and the population dropped quickly (15.5% from 1917-1930) despite improvements in mortality rates (Boyer 2010: 121). While certainly not all of these migrants moved to the continental U.S., many did, seeking the expanded opportunities and higher wages offered there (Boyer 2010: 168). By 1930 there was a community 20,000 strong of migrants from the Virgin Islands in Harlem (Boyer 2010: 169). At the time, this group almost equaled the total number of people still living in the Virgin Islands (ibid). This was the beginning of a pattern of migration that continues to this day, with many from the Virgin Islands seeking better conditions of life in the American metropole. Even in these early years, this pattern of migration was "attracting many of the able-bodied young adults" to the metropole, further stalling the local island economy. "Those left behind," Boyer writes, "were predominantly children, women, and they elderly" (Boyer 2010: 168, citing Grede 1963: 37). Seventy-five years later, during the year of my fieldwork (2015-2016), the American metropole continues to pull many working-age adults off-island, leaving older adults behind.

The New Deal, the Second World War, Federal Appropriations and Welfare

The economic depression that the territory had fallen into beginning in 1922 had, by 1930, led to "desperate conditions" in the islands (Boyer 2010: 163). A governor's report from 1931 notes that most laborers in the islands were out of work and that 25% of the population was "being kept alive by the Red Cross" by way of food distribution (ibid). None of the sugar factories were operational, and St. Croix had, for the last three years, ceased exporting cotton entirely (ibid). Governor Pearson, in this report, wrote that "Depression was general, serious, and complete" (Parson 1931: 3 in Boyer 2010: 163). This deep economic depression was evident in the poor health of the population: the death rate at the time was three times that of the continental U.S. (Boyer 2010: 163).

New Deal Projects: The End of Federal Appropriations?

During the period of Navy rule, governance of the island had been funded solely through Congressional appropriations. This precarious form of support was not guaranteed by law, and Congress would appropriate sums as they saw fit. Furthermore, Congress desired that the island be economically self-sufficient so that the upkeep of the territory would no longer be a federal expense. I would suggest, also, that self-sufficiency would have ensured that Congress would no longer need spend time and attention on the territory's financial needs, a step forward under a logic of disregard.[58] Thus began, in 1931, a program of public works projects across the U.S.V.I.., aimed at jumpstarting the local economy so as to lead to economic self-sufficiency.[59]

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[58] Lewis (1972: 71) has noted that during this period the U.S.V.I. "became (...) a laboratory for New Deal planners." This was because New Deal programs began in the U.S.V.I. two years before they began in Washington, a fact that Lewis attributes to the disorganized and haphazard way in which the U.S. was approaching its governance of the territories (Lewis 1972: 68). This unprecedented attention to the islands was thus the means toward two ends: the divestment of federal financial liability for the territory and the development of experimental social and infrastructure projects for use on the mainland.

[59] This project was spearheaded by the chief of the U.S. Bureau of Efficiency, Herbert D. Brown, who traveled to the territory and conducted a five-week survey there to determine how conditions could be improved (Boyer 2010: 150; Lewis 1972: 68-69). His report to Congress in 1930 proposed large-scale projects that required an appropriation of $141,000, which was granted.

The item given top priority in this program on St. Croix was the development of a homesteading program (Boyer 2010: 150).[60] At this time, 80% of the land on St. Croix was owned by just twenty people, with all the cultivated land being owned by just 1% of families, and only 5% of those working in agriculture working on land that they themselves owned (Boyer 2010: 162). Lewis (1972: 59) notes that this problem was exacerbated by the American purchase of the islands, as landowners held onto their lands in the hopes of selling them at high prices to potential American speculators. The goal of the homesteading program was to re-distribute this land, and, through a profit-sharing model, make otherwise underemployed field laborers into landowners. The project, under the responsibility of the newly created Virgin Islands Company (VICO), had a rather unsuccessful trajectory over the coming decades.[61] While they were able to reinvigorate, to some extent, sugarcane production on St. Croix, such production never proved profitable. And the situation of land ownership on St. Croix was never truly remedied, which "effectively prohibited the development of the fruit and vegetable industries so urgently needed to offset the irrational dependency upon imported foods" (Lewis 1972: 59). Indeed, as I will discuss later in the chapter, St. Croix, with all of its fertile, arable soil, continues to import the vast majority of its produce—one of the many legacies of plantation colonialism.

Despite the large amount of money put into these programs (the initial grant for VICO alone was $1 million), they did not have the intended effect of bringing the territory closer to

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[60] On St. Thomas, the main program was the "rehabilitation of the harbor" along with intensive planning for tourism. This difference is a good indicator of the two distinct identities and roles of the two islands.

[61] VICO was conceived as a "long range development program" in which the federal and the local governments would work in partnership (Pearson 1934: 16, in Boyer 2010: 177). In addition to its agricultural work on St. Croix (facilitated by the 1933 repeal of prohibition, re-enabling the production and export of rum from sugar cane), it had in its sights the development of the tourist trade, improvement of the education system and "a system of old age and unemployment compensation" (what was to become Social Security; ibid).

economic self-sufficiency. Unemployment remained high as the "various rehabilitation schemes failed throughout to generate full employment" (Lewis 1972: 72). On the contrary, the forms of Washington's intensified financial involvement in the territory's seemed to "ironically" (Lewis 1972: 75) increase, rather than decrease, the territory's dependence on federal support. What were initially rehabilitative efforts shifted into "a permanent dependency relationship with the metropolitan government in Washington" (Boyer 2010: 176).[62]

Political and Civil Strides

The 1930s were a time of substantial progress in the realm of political status and civil liberties in the territory. This was not, however, in any way a planned and systematic unfolding, but rather took the form of three major steps that each had its own different providence. Furthermore, the tension between this progress, and the fact that each measure of progress was only possible once approved by or instigated by Washington was an encapsulation of the relationship of unincorporated territory to metropole.

The first step was the end of Navy rule and the appointment of the territory's first civil governor. This happened in 1931, through an executive order signed by President Hoover. Rather than a principled or planned change, the end of Navy rule came about because of clashes

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[62] Boyer (2010: 176) argues that this failure was at least in part due to a "lack of cultural empathy" among New Deal actors, whereby their interventions were not cognisant of or responsive to local realities. Lewis (1972) argues, to the contrary, that the failure of New Deal programs in the U.S.V.I. had the same basic cause as their failure in the continental U.S. As he writes of the New Deal, "it was not a bold, coherent plan to reshape American economic society root and branch but rather a hasty and improvised response to a sudden crisis" (Lewis 1972: 81)."Without necessarily adopting a notion of "cultural empathy," it seems likely that at least some part of the inability for large-scale economic rehabilitation programs to achieve success was due to disregard for local ways of life that would have impacted the uptake of, interpretations of and motivations regarding these programs.

between the main planner and instigator of the New Deal era projects in the territory and the Naval authorities.[63] With much money having been appropriated for these projects, and the projects seemingly unable to proceed under Navy Rule, President Hoover ended instated civilian government. There were other factors that facilitated this decision, including the fact that World War I had ended and along with that the threat of hostilities from Germany, as well as the period's gradual de-emphasis on naval power (ibid). The change seemingly had nothing to do with rights of U.S.V.I. residents to a civil government. Furthermore, for some time the governors would be white continentals appointed by Washington.

The second major change regarding the territory's governance was the creation, in 1934, of a federal division to deal solely with the affairs of nations territories: the Interior Department's Division of Territories and Islands (Boyer 2010: 183). The creation of this department helped to consolidate and organize relations between the territory and the federal government. Before the creation of this division the territory "had relations with every federal executive department and many other federal agencies" which "posed problems of policy coordination" (Boyer 2010: 183-184). While this change did not affect the territory in terms of political status or rights, it did signal at least some recognition from Washington that the territories, including the U.S.V.I., required some form of specialized attention. This was, however, fourteen years after they were acquired (thirty-six years in the case of Puerto Rico and Guam).

Lastly, perhaps the most significant change was that in 1936 Congress passed an Organic Act for the U.S.V.I., legally transferring them out of the rule of the "Temporary Government of

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[63] Herbert D. Brown personally requested that the president end Navy rule claiming the institution's resistance to attempting to affect change on the territory's economy (Boyer 2010: 151).

the Danish West Indies Acquired by the United States." The Act was based on a draft written by the Lieutenant Governor of the territory and submitted to the federal government in 1932, several years before a version was finally approved by Congress (Boyer 2010: 185-186). The most significant aspects of the Organic Act were the following: the extension of suffrage to all Virgin Islands residents who were U.S. citizens, who were over the age of twenty-one, and could read and write English; a bill of rights extending all but one of the U.S. Constitution;s guarantees to Virgin Islands residents (they were not extended the right for indictment by Grand Jury)[64]; the establishment of two municipal councils (as opposed to colonial councils), and a local legislature and procedures for electing representatives to each; the establishment of the District Court of the Virgin Islands; a tax code that provided for all federal taxes, duties, and fees (e.g. naturalization fees) to be collected in the territory to be returned to the local government (Boyer 2010: 187-189).[65] The Organic Act of 1936 thus enabled an unprecedented level of self-government in the islands.

Despite this significant step toward self-government, however, the U.S.V.I. remained in very important ways still under Washington's control—enough for Lewis (1972: 104) to claim that the Organic Act "left practically untouched the undemocratic machinery of government". The highest posts in government were still to be appointed by the federal government, and all the administrative posts were to be appointed by either the federal government or the (appointed)

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[64] A number of civil rights had already been guaranteed in the Colonial Law of 1906 that had been the law of the land until the Organic Act of 1936, and this was thus not the advent of civil rights in the territory. However, the expansion of civil rights to near-parity with continental American citizens is significant—both for its expansion of these rights, and the fact that they were expanded to achieve near, but not total parity.

[65] Boyer (2010: 187), following Grede (1963), suggests that the Organic Act's tax stipulations are ambiguous as to whether they signal Washington's concession to the territory's ongoing financial dependence on Washington, or the expectation that this revenue would help them become financially self-sufficient.

Governor. Additionally, the President had the right to veto local bills were the local legislature and the governor to find themselves deadlocked.

War-time Economy

By 1937, as federal expenditures related to New Deal projects began to decline (Lewis 1972: 87), yet another aspect of the U.S.V.I.'s relationship with the rest of the United States emerged, as it became deeply involved in pre-war construction projects. The construction of several military bases in the territory in the mid-1930s and early 1940s created a massive number of construction jobs that transformed the economy of the islands "almost overnight" (Lewis 1972: 94) during pre-war and wartime (Boyer 2010: 197). This war-preparedness came to solve the mass unemployment problem that New Deal projects had been unsuccessful at solving.

Jobs were so plentiful that a wave of thousands of workers from the arrived in the territory, many from the British Virgin Islands and other from islands in the Eastern Caribbean. Local authorities waived immigration restrictions, facilitating the rush of workers attracted by the higher rates of pay.[66] Here we see for the first time residents of other Caribbean islands coming to the territory en masse specifically due to its inclusion in the United States (in this case, the American war effort). This is another piece of the migration dynamics that continue in the territory today. With U.S. Virgin Islands residents travelling to the continental U.S. for expanded opportunities, so too do residents of other islands come to the U.S.V.I.. for the expanded

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[66] Although c.f. Lewis (1972: 94) who claims that many of this migrants entered the territory illegally. It is unclear from the comparison of these two texts if local immigration agents were acting illegally in waiving restrictions, or if the waivers were on order of the federal government (as would be the case in future employment booms).

opportunities of a U.S. territory. This migration dynamic shows one of the ways in which the territory is positioned on the periphery of the U.S.: for those outside (often from the Eastern Caribbean), it is the closest and easiest way into the nation; for those there, it is the most distant away from the rest of the nation.

Back to Federal Appropriations

After the war, in 1944, the territory received a $10 million appropriation for “an extensive public works program” by the efforts of the current, continental governor who was very connected to Washington (Boyer 2010: 202). It was to include, among other big ticket items, improvement of medical facilities and sanitation. This injection of funds certainly helped buoy the economy after end of the military construction projects, but was not long until the territory went into a post-war recession (Boyer 2010: 203). Indeed, the economic situation of the Virgin Islands post-war was not much improved, with “most of [the territory’s] ills surviving in virulent, even aggravated, form (1972: 99). The continued emigration of working age adults made it even more difficult to grow the local economy (Boyer 2010: 208). Lewis (1972: 100) summarizes the situation thus:

> [i]n the 1917-1941 period the United States had spent an astonishing sum of $13 million on the islands, social welfare problems remained in many ways worse than before and agricultural developments were a dismal failure. As for the unemployment problem, the war had solved it only temporarily (...)

Furthermore, the latest appropriation evinced a continuation of the same pattern of dependence that the New Deal projects had been aimed at ending: the territory was being funded in large part by unstable sums of money that needed to be requested on a case by case basis and were fully subject to Congress's discretion.

Bt the early 1940s there was a general sentiment of resentment on island for this system of appropriations: "people still felt that they were being treated by wards of a charity and not as citizens entitled to what was rightfully theirs" (Lewis 1972: 98). An editorial in the *Daily News* (still one of the two main newspapers in the territory) from January 1942 articulately expresses this resentment and exhaustion among residents of the territory at the system of appropriations, which left the islands to the whims of Congress (cited in Lewis 1972: 98):

> We have become so deteriorated under this procedure [of garnering appropriations] that we can now judge the ability of our varied administrators solely by the appropriations they have been able to procure, while in Washington...little or no considerations is given to their true ability or experience in Virgin Island affairs. This explains the appalling aimlessness, the total absence of any comprehensive plan of policy set out for these islands. We are simply the victims of political patronage, ever subject to the wiles and caprices of myriad personalities, whose tenure of office is controlled solely by the irrational laws of political expediency.

Around this time, in 1946 the Governor of the territory[67] suggested federal legislation that, by helping the territory acquire revenue through other sources, would do away with the need for

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[67] Governor Hastie, the first African-American governor in the United States.

Congressional appropriations. He argued that the current method of appropriations "indicates the precarious situation in which the question of our police force,...our hospitals,...our sewers,...and the fundamental local services that the community must have our concerned" (Boyer 2010: 208). The suggested legislation, however, was not passed.

On one hand, this local frustration at the system of appropriations expresses the feeling that the "system of territorial government (...) was in reality no system at all, for it was based upon the absence of any clear-cut territorial policy coming from Washington" (Louis 1972: 105). It attests to the form of Washington's continued disregard toward the territory—despite the large number of dollars spent on it. This frustration is also responsive to the truly precarious nature of life in the territory, as the ability to carry on public life in any form was subject to the decisions of a group to whom U.S.V.I. residents were largely objects of disregard. This frustration also implicitly expresses one aspect of what Maingot (1984: 8), in the context of U.S. relations within the Caribbean region, the "psychological ambiguity" of "asymmetrical relationships". This "ambiguity" is, perhaps too simplistically, a tension, within a relationship of dependency, between the desire for self-determination (and thus to throw off the ideological, financial, and political claims of the dominant power), and the understanding that one's continued survival actually depends on the dominant power's continuing support—and thus that to some extent, those ideological and political claims must be respected. This tension, in various forms and degrees, continued to characterize the attitudes of St. Croix's residents toward the United States during my fieldwork.

Enter Welfare

The post-war era was also the time in which the newly established American welfare system had begun to permeate life in the U.S.V.I.. It was to become an extremely important, indeed fundamental, element of financial support for the territory. It came at a time when free medical care in the territory was expanding, due to patients' growing inability to pay.[68] The U.S.V.I. was not automatically included at the time, nor are they today, in all provisions of American Welfare programs. The public assistance titles of the Social Security Act, for instance, which had become U.S. law in 1935 were not extended to the territory until 1950. Nonetheless, the territory does participate in the majority of welfare programs. In 1965, the national health insurance programs Medicaid and Medicare became available to the territories, along with the rest of the country. These programs were instituted through an output of local funds that were "matched" by federal funds at set ratios, and often with local caps that were not always extended to states.

It would be difficult to overemphasize the impact that American welfare had in shaping the U.S.V.I.. Lewis (1972: 117) writes that the establishment of the wide-scale welfare programs put into law through the Social Security Act shifted the United States' governance of the territory into a mode of "welfare state colonialism." This new, large-scale availability of public aid also definitively re-oriented the politics of the territory: "Public policy in Charlotte Amalie [the capital], increasingly became one of persuading Congress of Virgin Islands eligibility for a

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[68] Gov. Hastie also discussed the drain that the expanding need for free medical care among indigent and low-income residents was having on the local government, a further reason to increase stabilize revenues. This pattern was prescient of the substantial role of uncompensated care in attenuating local government revenues in the late 20th and early 21st centuries (see discussion below).

legitimate share of welfare-state benefits." This orientation, although not limited to welfare programs, remained a prominent component of U.S.V.I. politics during the time of my research. Furthermore, as mentioned in the introduction, all of my focal participants were beneficiaries of the American welfare system: seven out of nine were Medicare beneficiaries[69], and many of them received public aid through other welfare programs such as Medicaid (see Chapter 6).

Tourism, Industry and Demographic Change: the 1960s and 1970s

The 1960s and 1970s were a time of enormous transformation in the U.S.V.I.. Unprecedented growth in tourism and industry, and the massive demographic shifts that this growth entailed, caused major shifts in everyday life in the islands. It was also to this period that many of the major ongoing trends in U.S.V.I. life, economy, politics and healthcare during the period of researach can most directly be traced.

Tourism

By the late 1950s, tourism in the territory began to grow (Boyer 2010: 248). There had been an uptick in tourism beginning in 1935 (Boyer 2010: 175), but a number of factors, mostly the Second World War, had stymied the development of the territory as a major tourist destination. By the late 1950s, the rise of commercial jet airliners, the Cuba embargo and cutting

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[69] The only focal participants who were not Medicare beneficiaries were under the age of 65, which is the age at which it becomes available in most cases. These were Ms. Hanks (Chapters 13-14) and Angelica (not discussed in this dissertation).

off of diplomatic relations (which cut Cuba off as a possible destination for American tourists), and the general rise of tourism to the Caribbean all contributed to the onslaught of American tourists to the U.S.V.I. (see Boyer 2010: 248). By 1957, the U.S.V.I. could claim the third highest growth of tourism among all Caribbean islands (Boyer 2010: 247, citing Harman 1957: 3). By 1958, the economy overall was surging and employment was at an all-time high, with "'more jobs than people'" (Boyer 2010: 248).[70] The territorial governor declared that within two years local revenues would match local expenditures, and for the first time the territory would be self-supporting (ibid).

As it turned out, the end of the 1950s were just a preview of the immense growth in tourism the territory would experience throughout the 1960s and into the 1970s, and the immense changes that growth would entail. Boyer (2010: 264) suggests that "[i]t is not an overstatement to suggest that practically every aspect of Virgin Islands life was affected appreciably—either directly or indirectly—by the impact of the tourism boom of the 1960s." Growing economic prosperity in the mainland U.S. (which contributed to more disposable income, earlier retirements, and more leisure time), partnered with the picking up of commercial air carriers of direct flights to St. Croix (1962) and St. Thomas (1966), and increased cruise travel to the Caribbean all facilitated this unprecedented shift. During the decade of 1960-1970, the number of tourists who travelled to the territory grew from 210,000 to 1.5 million each year,

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[70] One of the many signs of unprecedented economic success was that the New Deal company previously known as VICO (by that time having been made an American corporation, "VICORP") recorded, in 1957-1958, its first profits since its establishment over twenty years earlier (!) (Boyer 2010: 248). The economy's massive shift toward tourism and definitively away from agriculture over the next decade, however, spelled the end for VICORP.

an astonishing growth rate of 18% annually (Boyer 2010: 288). By 1970, half of the territory's workforce was employed in tourism, which accounted for 60% of income to the territory (ibid).

Industry

This growth in tourism was accompanied by another major change to life on St. Croix: the arrival of two major transnational industrial corporations to the island, Harvey Alumina (1962) and Hess Oil (1965). The arrival of these two major employers was a direct consequence of the local government's strategy to attract big business to the territory's shores by offering tax incentives (see Navarro 2010). As Boyer (2010: 270) notes, this was part and parcel of the accelerating phenomenon of American-based transnational corporations seeking financial advantages by re-locating operations to "less developed countries throughout the world,"—either due simply to lower costs of doing business, or to the various tax incentives those nations provided in order precisely to beckon such large businesses. Of course in this case, the "less developed" space was not a different country, but a U.S. territory. Alongside the tax incentive legislation,[71] the local government extended "extraordinary benefits" to Harvey and Hess, who built plants and began operations as the first examples of heavy industry in the U.S.V.I.. (Boyer 2010: 270). While the contracts with these companies required that they hire a majority of "local" Virgin Islanders, there was nonetheless a large amount of public pushback against the solicitation of these industrial behemoths to St. Croix. In a process that was largely kept secret

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[71] The local government put into law the "Virgin Islands Tax Incentive Act," which was amended each year from 1961 to 1965 to further encourage private enterprises to set up shop in the territory (Boyer 2010: 269).

despite clear public demands for a hearing, the local government gave Harvey Alumina,1,200 acres of government land for free, on which to build their bauxite processing plant (where aluminum is made). This amounts to having given away to corporate interests approximately 2% of the total land of St. Croix, along the environmentally sensitive South Shore.

The contract with Hess Oil, in 1965, to build what was to become the second largest oil refinery in the U.S., was modeled on the contract with Harvey (Boyer 2010: 271).[72] At a time when major oil companies were rushing to open refineries in the Caribbean[73], Hess incurred great financial benefits by housing its refinery on American, rather than foreign, soil. Hess, which was renamed "Hovensa" after a partnership with Venezuela's state-run oil company, was to become the largest private employer in St. Croix, and a major source of funds for the local government largely through its corporate taxes and those of its many contractors.

By the early 1970s then, the advent of heavy industry on St. Croix also had, along with tourism, a major impact on the economy and the overall status of the islands. By 1970, crude oil from Hess refinery made up 70% of all exports from the territory to the continental U.S., another marker of the "astonishing transformation" of the island's economy in the decade of the 1970s (Boyer 2010: 288).

Unprecedented Demographic Shifts

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[72] Although Hess did pay for the land on which they built their refinery.

[73] This was due to changes in American trade policy.

These major economic shifts had the consequence of causing major demographic shifts in the territory as well. The huge availability of jobs in the tourist sector and the industrial sector caused unprecedented immigration of thousands workers from the British Virgin Islands and the Eastern Caribbean. To give a sense of the level of demographic shift this created, between 1964 and 1968, the number of “alien” workers had doubled, and by 1968 they made up an estimated 45% of the workforce (Boyer 2010: 299). The U.S.V.I. had been, since it’s days as the Danish West Indies, a heterogeneous society, with residents from many countries of the world. However, this era marked the major demographic shift that shaped the makeup of the territory’s population today.

As in decades and centuries past, workers from other islands were encouraged by way of government-provided incentives to come live and work in the territory. Beginning in the 1950s, the local government “consciously pursued policies to import alien workers from poverty-stricken West Indian islands” (Boyer 2010: 298). The federal Immigration and Naturalization Service (INS) partnered with the local government to facilitate the entrance of “nonimmigrant temporary workers” to the territory on an annual contract basis through the so-called H-2 provision. In 1970, Congress enacted a law allowing all spouses and children of H-2 workers to accompany or join them in their place of employment (the so-called H-4 provision). However, this move by Congress did not have take into account the situation of the territory, where H-2 workers by this time formed a very significant subset of the population (potentially close to 30%, see Boyer 2010: 298). Furthermore, a provision by the Department of Labor which took effect later that year extended all H-2 workers stays indefinitely, without the need to renew them yearly. This meant that there was now a group of alien workers and their families allowed to reside in the U.S.V.I. on an indefinite basis.[74] In 1975, H-4 “aliens” (workers and their families) made up 20,000-30,000 (Boyer 2010: 304) of the approximately 96,000 people living in the territory (The World Bank 2018).

Unprecedented Demographic Shifts: 50-60 Years Later

My research on older adults in St. Croix showed what was perhaps an unexpected consequence of these visa programs: many of these families would live out the rest of their lives, grow old and pass away in the territory. Of the four focal subjects who are the foci of the chapters to follow, three of them—Mr. Edwards, Mr. Parker, and Ms. Hanks came to St. Croix from Eastern Caribbean islands during decades of the 1950s-1970s. While none of them spoke to me of “H-2” or “H-4” visas, the timing of their arrival gives little doubt that they were either among those who came to the territory under these immigration programs or contemporaneously. Ms. Hanks, for example, came to the territory in the 1970s by way of her husband who, a few years earlier, had moved from Trinidad to work at the aluminum plant. Her move fits the bill exactly for having been made possible by the H-4 visa program. Mr. Parker also came to the island in the 1970s, beckoned from his native St. Kitts by the glut of available jobs. Mr. Edwards, who immigrated from Antigua, came earlier, in the 1950s. I learned little about Mr. Edwards’ early employment in the islands, but his grandson, Eli, told me that he worked in the cane fields.

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[74] While the federal government had certainly not taken the U.S.V.I. into account when acting on these back-to-back pieces of legislation, they did eventually recognize the impact they had. A 1975 federal government report notes that “[p]robably the most significant impact of the H-4 provision was on the Virgin Islands, where its effect was to promote family reunification on a massive scale.”

It's possible, and I think likely, that he may have worked for VICORP during the phase in which the federally-owned company was needing to bring in agricultural labor from other islands (Boyer 267-268).[75] Ms. Hanks, Mr. Edwards, and Mr. Parker all became U.S. citizens and relied, as they aged, on the American welfare system for much of their care.

The presence of Ruth on St. Croix in her old age—the fourth focal participant who I discuss in the chapters to follow— represents another overlapping demographic trend that occurred in the second half of the twentieth century. As tourism increased in the 1960s, more "continentals" became aware of and visited the U.S.V.I., with more and more moving there permanently. The number of continentals in the territory grew by more than 400% in the years of 1950-1965, whereas the native-born population increased by less than 11% (see Boyer 2010: 265).This increase in the continental presence was largely in the realm of business ownership and operations. Harvey and Hess were stateside companies run by continentals, and many of the businesses that sprang up to cater to the American tourist were themselves owned and operated by (most often white) continentals. In 1970, it was estimated that "[w]hile the whites constitute not more than one-fourth of the population, they own more than half of the land" (Macridis 1970: 194, in Boyer 2010: 318). Ruth did not move to St. Croix until the 1980s. However, this earlier establishment of continentals on St. Croix paved the way for her arrival. She came to the island to visit a good friend (who had moved to the island from the states some time before), and from there, decided to move there herself.

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[75] VICORP was the only major sugar producer on-island at the time, and pay there would have much better than most elsewhere in the Caribbean, and the American government was facilitating immigration to fill these vacancies.This was apparently due to it being difficult to recruit workers from St. Croix who, after the wartime construction boom, were less in less interested in working in agriculture (Boyer 2010: 267-268).

Approaching Self-Sufficiency?

The U.S.V.I.'s booming economy in the 1960s-1970s thus gave shape to the territory's population for decades to come. While there was a complex set of factors accounting for this massive growth and these demographic shifts, the territory's growing prosperity was a large causal factor. By 1961, the territory already had the highest per capita income in the Caribbean (Boyer 2010: 258). By 1970, the per capita income in the territory was twice that of its neighboring American territory Puerto Rico, and five times that of the Caribbean region as a whole (Boyer 2010: 299). By 1977, the territory still boasted the highest per capita income in the Caribbean. While it seems that this prosperity should have easily achieved the self-sufficiency predicted during the relatively minor tourism boom of the late 1950s, self-sufficiency was never achieved: at the level of local government level, revenues never became equal to local expenditures.

The reasons for why this unprecedented economic prosperity did not lead to financial self-sufficiency of the territory are many and complex. However, two main reasons, which would continue to have repercussions through the time of my fieldwork, were the expansion of the local government and the disadvantageous tax system in the territory. Between 1960 and 1970 the budget of the local government had increased from $12 million to $124 million, and by 1970 30% of the labor force worked for the local government. This was in part due to the rapid inflation of the population which called for an equally inflated response in terms of government services. The advent of welfare in Washington had required the creation of several new federal governmental departments (such as Health and Human Services, Department of Labor, Department of Education, etc.) and these departments were eventually mirrored at the local level. Additionally, starting in 1965 the local government took over many of the holdings and respnsibilities of the now defunct VICORP.[76] The local government continued to grow: during the time of my fieldwork, approximately 50% of the work force was employed by the local government.[77] At present, all of St. Croix's major institutions, including the hospital, the prison, the water and power provider, are all currently local government owned.

A second major reason for why the tourist and industry boom of the 1960-1970s did not provide enough revenue to make the local government self-sufficient was that not enough taxes were being collected.The issue of taxes is a major juncture between the U.S.V.I.'s financial reliance on the federal government and big industry on one hand, and the federal disregard on the other. The full story is far too complex to outline here, however I will mention two of the large pieces of the puzzle. One piece, has to do with the agreements made with Harvey Aluminum and Hess Oil. Designed to lure big industry to the territory, the tax incentives and subsequent contracts that defined these corporations' financial obligations to the territory were, in terms of the local government's checkbooks, too generous to the corporations. The second piece is that

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[76] VICORP was the only major sugar producer on-island at the time, and pay there would have much better than most elsewhere in the Caribbean, and the American government was facilitating immigration to fill these vacancies.This was apparently due to it being difficult to recruit workers from St. Croix who, after the wartime construction boom, were less in less interested in working in agriculture (Boyer 2010: 267-268).

[77] In an interview with a former commissioner of the Department of Human services in 2016, he gave me several reasons for the seemingly disproportionate size of the local government. The first, he said, was that you had to consider that the local government was doing the jobs of a city, county, and state government all in one. Secondly, he noted that there were strong anti-privatization sentiments on island. As self-government progressed since the 1950s, and local actors took control of local government (see discussion below), continentals continued to dominate the private sector. There is thus a feeling in the territory, he said, in which government is felt, by the majority Afro-Caribbean population to be "ours." He added that another reason was, simply: "we have a lot of poor people" (and thus a great need for governmental aid services).

there were fundamental problems with the U.S.V.I.'s tax code due directly to the federal government's imposition of a "mirror system" of taxation.[78] Changes that were made at the federal level were automatically mirrored at the territory level, with very different, and often catastrophic effects. On a number of occasions[79], this caused the local government to suffer major losses in revenue. Upon becoming aware of these problems, Congress passed appropriations to help cover the local government's deficits rather than instituting a systemic fix (Boyer 2010: 367).[80]

Political and Civil Progress

This period of unprecedented economic and demographic change in the territory was also a time in which the territory advanced substantially in terms of self-government. The first major political change of the era, however, the revised Organic Act, passed by Congress in 1954, was all in all a "severe disappointment for home-rule advocates" (Boyer 2010:283). Most of the territory's political progress during this era actually came in the wake of the passage of Revised Organic Act's and not in the Act itself.

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[78] In this system, which began in 1922 with the Naval Appropriations act, "the U.S. Internal Revenue Code was transformed into a Virgin Islands taxing statute by substituting the words 'Virgin Islands' for the words 'United States' wherever the latter appeared in the code" (Boyer 2010: 366). Due to loopholes that this mirroring created, the U.S.V.I. could be used as a tax haven—wonderful for wealthy entrepreneurs, terrible fo the local government (Boyer 2010: 366; see Danielson 1978). Furthermore, any changes in the U.S. code were thus automatically "mirrored" in the U.S.V.I. code, a serious problem as "Congress usually forgot its insular possessions when making such changes" (Boyer 2010: 366).

[79] In particular, after the passage of the Tax Reduction Act of 1975 and the Revenue Act of 1978.

[80] This is part of a much larger ongoing saga involving the federal government's suspicion of the local government's misuse of funds and general financial irresponsibility, and the local government's attempts toward financial reform (that could only be granted at the federal level) in order to achieve self-sufficiency by balancing reveneues with expenditures. See, e.g. Boyer 2010: 365-372.

The major disappointment of the Revised Organic Act was that it did not provide for an elected governor nor a territorial representative in Congress. Both of these provisions had been chosen by U.S.V.I. residents through local referendum, and the bill drafted by the territory's Organic Act Reform Committee and approved by the local Legislative Assembly had included them.[81] Besides maintaining the status quo on several issues related to home-rule, the Act also instituted new controls over local governmental processes that ensured Washington would have a considerable hand in local affairs.[82] A local senator at the time claimed, after the passage of the act, that "we enjoy considerably less self-government than we did in 1936" (Ottley 1958: 10, in Boyer 2010: 237). The most welcome provisions of the Revised Organic Act were the dissolution of the two municipal legislature in favor of a single territorial legislature (a provision which the people of the U.S.V.I. had also favored in a referendum) and a "complex fiscal formula" that provided for substantially more revenues for the local government, including a provision whereby all of the "federal" taxes paid by U.S.V.I. residents would actually be paid to the local government.[83]

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[81] In Congressional hearings in the territory, native political and civil leaders testified in support of self-government, while business leaders (largely white continentals) testified against more self-government and for more financial support from Washington (Boyer 2010: 234). The final version of the Act that was passed was thus more aligned with the will of white continentals in the territory than it was with that of native leaders.

[82] For instance, while the representatives of the legislature had been elected for decades, this Act provided that the Governor—who was still appointed by the President—could "fill vacancies in the legislature by appointment" (Boyer 2010: 236)

[83] This formula included, first,the return of internal revenues collected on articles produced in the U.S.V.I. (and imported and sold stateside), although the amount of revenue returned was not to exceed the amount of revenue raised locally by the local government. It also allowed all permanent residents of the U.S.V.I. to pay all of their "federal" taxes on all sources of revenue directly into the local treasury. There was also an additional fund to be set aside each year by the federal government for the use of the local government '"for emergency purposes and essential public projects only'" (Boyer 2010: 237).

In the decades that followed the passage of the Revised Organic Act, the U.S.V.I. did gain a number of important elements of self-rule. In 1965, the first Constitutional Convention of the Virgin Islands submitted a draft to Congress of a new Revised Organic Act. It included, among other provisions: an elected governor, a representative in Washington, and the right to vote for U.S. President and Vice President, abolition of the President's ability of veto local law (should the governor and legislature be in a deadlock) (Boyer 2010: 283).[84]

Instead of voting on the Second Revised Organic Act as a whole, and in conformance with their general behavior vis à vis the territory, Congress addressed the provisions therein "on a piecemeal, rather than a package, basis" (Boyer 2010: 284). After many hearings and resubmissions of bills, the people of the U.S.V.I. were given the right to elect their own governor. In 1971, fifty-four years after American acquisition of the territory, the first elected governor of the U.S.V.I. took office.[85] By 1972, the U.S.V.I. had a non-voting representative in Congress, which is how it remains to this day.[86] In 1976, two years after such legislation was proposed by the U.S.V.I.'s delegate to Congress, Congress passed a law allowing the U.S.V.I.. to create a constitution for itself (Boyer 2010: 379). The territory has not yet, however, adopted its own

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[84] To allay what were anticipated fears or hesitations Congress might have that passing this Act would be an implicit agreement that the territory was moving toward statehood, the Constitutional Commission simultaneously adopted a resolution that officially established the people of the U.S.V.I.'s contentment with being an unincorporated territory (Boyer 2010: 283-284). The resolution stated that the people of the territory were "unalterably opposed" to becoming a state or to gaining independence from the United States, and that they "desire to have the Virgin Islands remain an unincorporated territory" (Boyer 2010: 284). The rather odd decision to make this resolution shows an aspect of the political power relations between the U.S.V.I. and Washington: when asking for more sovereignty, these representatives of the territory thought it best to assure Washington that they were not now, would they ever, be seeking full sovereignty.

[85] Although the bill was passed in 1968, it would not be, due to the election cycle, until 1970 that the right would be exercised.

[86] The federal justification for this is that the population of the territory is too small to merit a voting representative.

constitution.[87] In fact, regarding self-determination in the territory, little has changed since the gains of the early 1970s. The territory still does not have the right to vote in federal elections, and The Revised Organic Act of 1954 remains in effect.

Healthcare in the 1950s, 1960s and 1970s

There is little written historically about healthcare in St. Croix in the twentieth century. What exists, however, paints a very bleak picture. Despite the massive economic gains in the territory in these decades, healthcare never became privatized and the local government struggled to provide adequate health care to St. Croix's residents. This challenge continues today.

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[87] The second Constitutional Convention drafted a document that was approved in local referendum but by such a small margin that it was not submitted to Congress. In 1979, a document created by the Third Constitutional Convention was voted down in local elections, and in 1981 the Fourth Constitutional Convention suffered the same fate. Efforts to pass a constitution restarted in earnest in 2004, when the legislature passed a bill creating the Fifth Constitutional Convention (St. Croix Avis 2012b). It was not until 2009 that the Convention submitted a draft to the territorial governor for him to pass on to the President of the United States (who would then pass it on to Congress for review) (St. Croix Avis 2009). There were many difficulties with this draft at different stages of the process. The territorial governor first refused to submit it to the President, claiming that it clearly did not adhere to the U.S. Constitution (St. Croix Avis 2009). Upon a district court order, the Governor did submit it to Washington, whereupon the Department of Justice created a memorandum noting places in which the document needed correction in order to be appropriate under the U.S. Constitution (St. Croix Avis 2012b). In June 2010, the Senate and the House of Representatives both reviewed the document and passed a joint resolution that was guided by the Department of Justice memorandum (St. Croix Avis 2010c and 2010b). The recommendation made by these federal bodies was for the Fifth Constitutional Convention to reconvene and address the issues in the document before putting it to a territory-wide vote. However, by 2012 no action had been taken on the document, at which point the legislature and governor passed a measure to have a five-person legal team join the Fifth Constitutional Convention in order to make the necessary changes to the document (St. Croix Avis 2012c and 2012d). After members of the Fifth Constitutional Convention filed a lawsuit charging the illegality of anyone other than the Fifth Constitutional Convention working on the draft of the constitution (St. Croix Avis 2012e), the legal team was allowed by the district court to alter the document (St. Croix Avis 2012f), and did so (St. Croix Avis 2012g). But upon reviewing the new draft and meeting with members of the Fifth Constitutional Convention, the president of the Convention assessed that they did not have the two-thirds votes needed to for the document to approve, and so he did not summon the Convention to convene (St. Croix Avis 2012h) . When the deadline passed on October 31, 2012, the Fifth Constitutional Convention was dissolved and the question of what to do about about a territorial Constitution fell back to the legislature. Since that time, no substantive progress has been made on the issue. Currently, American citizens who reside in the U.S.V.I. have all civil liberties granted in the U.S. Constitution except the right to indictment by grand jury (Boyer 2010: 429).

Because healthcare remained in the hands of the local government, that body's persistent financial precarity directly impacted possibilities for healthcare in St. Croix. For instance, in 1951, "local legislators warned in 1951 that the Virgin Islands were bordering on bankruptcy and 'if something was not done soon the three hospitals, the jails, and the mental hospital may have to be closed.'The situation was so bad that 'if our people could get off the Islands they would all leave'" (Boyer 2010: 230-231)[88]. One of the local health commissioners in the even resigned because "a 1956 budget freeze caused grievous health conditions at [St. Thomas's only hospital" (Boyer 2010: 230). This commissioner wrote directly to the federally-appointed Governor about the horrific conditions, but in a classic case of disregard,received no reply.

In the 1960s, a terrible lack of medical facilities on island was blamed on the influx of laborers from other islands; but even by the 1970s, the situation hadn't improved as "infrastructure never had caught up with population growth" of the era (Boyer 2010: 343). There was one hospital and one clinic on St. Croix, one hospital on St. Thomas, and a clinic on St. John. However, even at the time these facilities were "inadequate to meet present or projected needs" (ibid). Hospitals billings fell millions of dollars into the red as patients refused to pay their bills (ibid), a pattern which continues to greatly impact St. Croix's health care system today. A list of grievances of hospital employees from 1976 gives a picture of the state of healthcare in the territory at this time:

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[88] Indeed, by the time of my fieldwork it was extremely common for those who could afford to to leave island for all medical care.

> Our frustrations include: Inadequate food and eating utensils; inadequate supply of wash cloths, towels, bed sheets, etc.; three and four patients crowded into a two-patient room; free-roaming mental patients on the medical ward, and no hospital staff psychiatrist; major pilferage of food and supplies; frequent shortages of medicines; salary levels too low to attract and fill vacancies (Boyer 2010: 350-51, citing Virgin Islands Daily News 1976)

These squalid conditions, spurred mostly by the financial insolvency of the local government, caused two patterns that continue to this day to characterize healthcare in the territory: 1, the flight of those in seek of medical care to Puerto Rico of elsewhere (Boyer 2010: 359); 2, the perennial disaccreditation of the territory's hospitals (as happened in 1979) (Boyer 2010: 343). The way these patterns in healthcare, along with the other threads I have been tracing throughout this chapter were manifesting during the time of research will be detailed in the next chapter.

Chapter 5

Recent Developments (1980-2016)

There is very little scholarly work published on the history of the U.S.V.I.. since 1980, and none since 2010.[89] This chapter will present a discussion of key events and overarching trends from this recent period, all of which have throughlines with the historical picture I have developed up in the previous chapters. Indeed, Boyer (2010: 407) summarizes his discussion of the period from 1980-2010 as one in which "the territory experienced a plethora of *persisting* problems" (emphasis mine). I will supplement this published scholarship with three other forms of accounts: newspaper articles from local press during the years 2010-2016, which I collected at the University of the Virgin Islands library archives; testimonies filed with the Virgin Islands Legislature, also between 2010-2016; and publicly available statistics.

Two Major Disasters: Hugo and Hovensa

There are two events whose significance for life on St. Croix during the period in question can't be overestimated: Hurricane Hugo, in 1989, and the closing of the Hovensa refinery, in 2012. While very different types of event, they both absolutely devastated St. Croix, touching every domain of social life.

Hurricane Hugo

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[89] Boyer 2010: 389-430 covers the period 1980-2010.

Over the night of September 17, 1989, until the morning of September 18, Hurricane Hugo, a Category 5 hurricane, passed through the U.S.V.I.. It caused an estimated $1.5 billion in damages and 7 immediate deaths.[90] St. Croix was the island hit the hardest (as it was more directly in Hugo's path). An estimated 90% of structures on St. Croix were damaged or destroyed. Normal life came to a screeching halt and the recovery efforts extended over several years. Even today on St. Croix it is common to see damaged homes—"Hugo houses"—and other structures that were victims of the storm, abandoned and never rebuilt.

For everyone who was on St. Croix when it happened—which includes all of my focal participants—their lives were deeply impacted by Hugo. It was impossible to do a life history interview and not hear about Hugo: the personal experiences of the terrifying hours of the storm itself, the months afterward in which food and all other resources were scarce, looting was rife, and many had lost not only their homes but all of their possessions. So deep and far-reaching were the storms effects on every aspect of life on island that in, 2015-2016, life for long-time St. Croix residents was divided into "before Hugo" and "after Hugo".[91]

The territory received millions of dollars in disaster relief and other aid money from the federal government. However, this was also a time when St. Croix residents felt let down, cast aside, and criminalized by this same government. My participants told me that very soon after the storm, before much aid came to the island, the U.S. military arrived in response to the

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[90] As has been shown for Hurricane Maria (2017), hurricanes can cause far more deaths than those that occur during or shortly after the storm itself. This is due to suspension of services loss of access to resources (Christensen & Casteñeda 2014; New York Times 2018a). Extended loss of power, lack of access to medical supplies or medical personnel, attenuated access do potable water and other effects of serious storms can have fatal consequences, particularly for the elderly or medically fragile.

[91] With the devastation of Hurricane Maria in 2017 I suspect that by the time of writing (Summer 2018) this categorization has changed.

widespread looting. They told me that soldiers carrying machine guns walked the streets, trying to maintain order by frightening people out of stealing the few resources left on island for themselves and their families. One of my participants, a woman in her early fifties who works in government and has lived on St. Croix her whole life, told me that the first response from the U.S. government was to evacuate all the "Americans." By this, she meant all of the stateside tourists who were visiting the island when Hugo struck. After that, she said, the military came. While I am not claiming that these accounts match the historical facts of the federal relief effort timeline, what is important here is that for many St. Croix residents, Hugo was a time in which the federal government let them down when they most needed help. It was a time when they felt not only not helped, but shunned and actively excluded from those Americans who deserved help. The extended period of recovery did little to make these residents feel that the federal government was doing everything they could to help St. Croix get back on its feet.

The Closing of Hovensa

The next major disaster to hit St. Croix was of very different origins: the territory's largest private employer, the Hovensa (previously Hess) oil refinery, ended operations in April 2012 (St. Croix Avis 2012j). Approximately 2,000 people lost their jobs at Hovensa (and its many contractors), 80% of which were long-term U.S.V.I. residents (as in, not people who had followed the job to the territory) (St. Croix Avis 2012k, 2012l). When the refinery's shutdown was complete (a few months after the process of closing down began), the loss of these jobs had caused a doubling of St. Croix's unemployment rate to an "unprecedented 18.7%" (U.S.Virgin

Islands Bureau of Economic Research 2012). These jobs alone represented approximately $250 million in salaries (St. Croix Avis 2012k), a proportionally large amount as the average salary at the refinery was over twice the average salary territory-wide (U.S. Virgin Islands Bureau of Economic Research 2012), making these jobs particularly valuable for the territory's economy. Furthermore, estimates were that for each job at the refinery lost, it was likely that ten addition jobs in the community would be lost (St. Croix Avis 2012m).

Job-loss, however, was only one of the many ways in which the closing of the refinery devastated the territorial economy. The refinery was the second largest in the U.S. and among the top ten largest refineries in the world (St. Croix Avis 2012j, 2012n), producing about 350,000 barrels of petroleum products a day (St. Croix Avis 2012o). It was thus a giant source of activity in the relatively small territorial economy and the single most important revenue for the local government outside of funding from the federal government. The refined petroleum industry, represented solely by Hovensa, represented 20% of the territory's $4 billion economy (U.S. Virgin Islands Bureau of Economic Research, 2012). In Fiscal Year 2011, Hovensa made payments amounting to $408 million to the local government U.S.Virgin Islands Bureau of Economic Research 2012: 8).

The shockwaves that hit the territory when news of the coming closure hit in January 2012 were immense. Local press quoted St. Croix residents saying the closure "would be worse than Hugo" and that it was "like mourning a death" (St. Croix Avis 2012p). On-island psychologists reported an uptick in anxiety and depression among St. Croix residents (ibid). Employees who lost their jobs, and others seeking a way out of what seemed like an inevitably hopeless economy, packed their bags and migrated stateside in search of work. This out-migration became in itself a significant source of further economic downturn and made it even more difficult for St. Croix's economy to recover. In 2015-2016, the island was still reeling from the refinery's shutdown just over three short years earlier. In everyday conversation it was the single most important reckoning point by which people oriented to the current conditions. It seemed that everything had changed, and none of it for the better.

With these two monumental events as orienting anchors, I'll now turn to discussing more general trends taking place on St. Croix during the last few decades.

Financial instability, Poverty, Unemployment and Crime

One of the most important overarching trends is the continuing financial instability of the local government. Because so little in the U.S.V.I. is privatized, the government's financial difficulties have direct effects across a wide variety of domains in the territory. The local government's continuing and severe financial instability in these decades is thus a primary context for the other ongoing developments of this era. Between 1980-2010, the local government's expenditures continued to outpace its revenues (Boyer 2010: 420)[92]. By 1987, just before Hugo, there was an $80 million deficit (for a population of approximately 106,000 [The World Bank 2018]).[93] By 2003 the local government deficit had reached $742.7 million[94] (Boyer

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[92] As inter-fund transfers became insufficient, the local government began selling bonds, and it was not long before borrowed money was being used to pay off previous debt (Boyer 2010: 421).

[93] While cost-cutting measures and an improving economy put the local government back into the red by the end of the 1987 fiscal year, Hurricane Hugo, in 1989, turned progress upside-down.

[94] The population of the territory grew only slight during these years, up to approximately 109,000 in 1996 and 108,000 in 2004 (The World Bank 2018).

2010: 422). Fiscal crisis has been the modus operandi of the local government up until the present (ibid).

As I've discussed above, the closing of Hovensa in, in 2012, had deeply devastating effects on the local government's finances. In 2011, before the closing of the refinery was announced, the local government was already in deep financial trouble. There had been 500 recent layoffs, and the budget shortfall was threatening the need for 2000 more (St. Croix Avis 2012q). The closure of the Hovensa refinery caused a whole new level of financial instability and required drastic changes to be made at the level of government spending (e.g. U.S. Virgin Islands Bureau of Economic Research 2012. The closure of the refinery affected all sectors of society both through its unprecedented effect on the economy of the territory, but also the changes it forced in the local government—an institution that is responsible for an extremely wide array of institutions and services on St. Croix.

Poverty levels in the territory also remained high during these years. By 2002, 28.9% of Virgin Islands residents lived below the federal poverty line (Central Intelligence Agency: 2018), That same year, 10.9%—almost three times less—of residents living stateside lived below the federal poverty line (United States Census Bureau: 2018a).[95] By 2017, the poverty rate in the territory was 22% compared to 14% in the rest of the country (The Henry J. Kaiser Family Foundation 2017). There is of course not a simple or direct relationship between the financial state of a government and the economic wellbeing of a people, but the lack of substantial

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[95] Furthermore, no state came close to that poverty level. The closest in 2002 was Arkansas, at 19.8% (United States Census Bureau: 2018b).

privatization means that this link is quite strong in the U.S.V.I.. I will highlight two other important aspects of this relationship here.

The first connection is that the more low-income residents of the territory there are, the more need there is for government aid services. Ever since the advent of modern American welfare, low-income St. Croix residents have been the beneficiary of federal programs.[96] In 1977 (slightly before the era we're considering here) U.S.V.I. residents "received federal grants-in-aid (for purposes such as public housing, child nutrition, and medicaid, to mention three of the largest) amounting (...) to $652 per capita, (...) 51 percent above the per capita grant to all states and local governments" (Boyer 2010: 367). Today there remains a high use of public aid in the territory, and the public aid system does not only "mirror" but is in fact a direct offshoot of the federal welfare programs (like is the case for states). Unlike states, however, it has always been the case that not every aspect of each program is available to residents of the territory (and not all programs are available in the territories).

The other connection between the local government's financial status and the economy of the island more broadly is that both are tethered to the U.S. economy. Dips in the national economy have significant effects in the territory, as governmental programs suffer cuts from a federal government that needs to tighten its belt. With approximately 50% of the labor force working for the local government, government funding cuts can mean upticks in unemployment territory-wide. For instance, after the beginning of the Global Recession in 2008, cuts were made quarterly across government for several years. Between 2008-2011, the territory lost

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[96] This is the case even though Virgin Islands residents do not, as of the Organic Act of 1954, contribute to the federal treasury.

approximately 2,000 jobs—the same number that were to be lost in 2012 with Hovensa's closure and a drastic reduction in the territory's labor force (St. Croix Avis 2012r). By 2011, the government once again found itself in a "financial crisis," as revenues had dropped to 70% of pre-Global Recession levels (St. Croix Avis 2011r). Then came the closing of Hovensa in 2012, and then the federal Government Sequester of 2013, through which many of the territory's public aid programs were cut along with those across the rest of the country.

Another important aspect of the economy since the 1980s is that it still "overwhelmingly" depends on tourism, deriving 80% of its GDP from the industry in 2009 (Boyer 2010: 423).[97] This means that a slower economy stateside means fewer vacationers in the territory, a consequence of which can also be a rise in unemployment.[98] St. Croix is both less dependent on tourism (i.e. less profitable as a tourist destination, see Boyer 2010: 424) and is also prone to significantly higher levels of unemployment that the territory overall. Tourism never developed on St. Croix the way it did on St. Thomas, as the commercial past of St. Thomas during the colonial era set it up for a more cosmopolitan and commercial present.[99] For instance, while 535 cruise ships docked on St. Thomas during 2016, only 45 came to St. Croix (U.S. Virgin Islands Bureau of Economic Research 2018). It is likely that the asymmetrical distribution of the tourist industry between the two islands accounts somewhat for the perpetually higher unemployment rates, higher poverty rates, and lower incomes that St. Croix residents experienced even before

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[97] In 2005, 2.6 million visitors came to the U.S.V.I. as tourists (Boyer 2010: 423).

[98] This industry is also extremely reactive to natural disasters such as hurricanes, which can have severe consequences for the economy (as it was in 1989 with Hurricane Hugo, in 1995 with Hurricane Marilyn and in 2017 with Hurricanes Irma and Maria).

[99] During the early 2000s, when the Caribbean region began to dominate the cruising market, St. Thomas was one of the busiest ports of call (Boyer 2010: 423).

Hovensa’s closing (see U.S. Virgin Islands Bureau of Economic Research 2009: 16, 19; U.S. Virgin Islands Bureau of Economic Research 2015: 17).

Poverty and unemployment in St. Croix are made no easier by a continually high cost of living. This is due primarily to the expense of relying for nearly all the essentials of daily life on imports that must be transported by boat. For instance, due to its history of land ownership primarily by elites paired with the dominance of the sugar industry (that is, due to the ongoing legacy of colonialism), St. Croix never developed a well-rounded agricultural base, and the territory imports over 97% of its food (The Virgin Islands Consortium 2017e). Grocery store prices average 30% higher than stateside (Avis 2011c), and Hawai’i is the only state or territory in the country whose grocery prices are higher than in the U.S.V.I. (Avis 2012a). Often, the high cost of living and doing business in the territory is overlooked by federal bureaucracies. For instance as I will discuss in Chapter 7, Medicare reimbursement rates in the territory are low enough as to dissuade the establishment of Durable Medical Equipment suppliers in the territory, a fact that has had dire consequences for St. Croix’s aging population.

As is common in communities with high poverty rates, violent crime has over the last few decades become part of everyday life in the territory. Boyer (2010: 408) writes that, since the early 1980s, “[u]nchecked crime became a horrendous reality on all three islands.” Beginning in the early 1970s, the islands experienced a “crescendo of crime” (Boyer 2010: 328), including deadly shootings. This was a time when, as we saw in the previous chapter, the island was in the midst of great societal change. The massive surge in tourism, along with the opening of Harvey Aluminum and Hess Oil was not only shifting the economy but was bringing new communities to the island while disenfranchising others. Political economies on the island were changing and inequalities growing. By the 2000s, murder rates in the territory had become staggering.[100]

In 2015, the year that I began fieldwork, the territory had the highest murder rate of any state of territory in the nation (Virgin Islands Daily News 2016).[101] During 2015 and 2016, articles written in local newspapers reporting on (and counting) each murder made it clear that the majority of killings in the territory are young men of color killing young men of color, and many of the killings are gang-related. The territory also had, in 2015, a higher average of other serious crimes than the country overall, including rape and burglary (ibid).

Contemporary Communities

From a demographic point of view, there are three main ethnic groups represented in St. Croix's contemporary population: Afro-Caribbean, Puerto Rican, and continental (mostly white).[102] However, this neat categorization belies what is, on the ground, a far more complex state of affairs. First of all, it's important that in St. Croix, the ethnic categorizations that are dominant in public discourse stateside do not cleanly apply. The history of the Caribbean, and of

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[100] In 2009,the territory had recorded 32 murders by July, giving it a murder rate of five times the national average (Boyer 2010: 409). By September of that year, the territory had surpassed, with 47 murders, its previous record for murders in an entire year (ibid). While these figures may seem low in terms of total number of lives lost, the small population of the territory means that these rates ranked the territory "'as one of the most murder-ridden communities in the world'" (Boyer 2010: 409, citing the FBI's *Uniform Crime Report*).

[101] With 42.5 murders per 100,000 people (the standard measurement is per 100,000, hence the strange "half" person murdered), the U.S.V.I. was far ahead of the second most murderous territory or state: Puerto Rico, at 16.8 per 100,000 (Virgin Islands Daily News 2016).The territory's murder rate was higher than the murder rates of the cities of Chicago, Los Angeles, and New York combined (ibid).

[102] There are small but significant groups of other ethnic groups in the territory as well, however for purposes of clarity I do not discuss them here.

the islands now known as the U.S.V.I.. in particular, created different ethnic distinctions and race ideologies than are common stateside.[103] So, while the results of a 2010 U.S. Virgin Islands Community Survey in which 81.4% of respondents self-identified as "black or African American" only, and 8.97% as white only, tells us something about ethnic identity on St. Croix, it is still a very aspectual glimpse of which groups people identify with and how they themselves characterize those groups.

One of the more important inter-group dynamics on island are significant and long-standing divisions between "native" Virgin Islanders and immigrants from other Caribbean islands, particularly the Eastern Caribbean (many of whom, on demographic surveys, would simply be counted as "black").[104] In 1982, Congress passed a law giving all H-4 residents (i.e. previously temporary workers and their family) permanent residence in the territory (Boyer 2010: 390-392). This made it possible for these thousands of immigrants to apply for green cards

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[103] Furthermore, as a white woman from the states, I was not privy to many of the understandings, distinctions, and ideologies that inform inter-group dynamics on island.

[104] While of course attitudes vary greatly between individuals, there is a substantial amount of local discourse about the tension between native Virgin Islanders and those from Eastern Caribbean islands (locally called "down islanders"), and between native Virgin Islanders and the Puerto Rican community (many of whom have been living on St. Croix for several generations). As a white woman from the states whose research participants were largely made up of white statesiders and Afro-Caribbean U.S.V.I. residents, I was most attuned to the tensions between—and the separation of—the Afro-Caribbean community and the white community. However, even this is not simple: there are, for instance, whites whose families have been living in the territory for several generations (some who even claim residents since the Danish period) and thus consider themselves to be "native" Virgin Islanders. I was told many times (although usually by continentals, white and black, who had been living on St. Croix for some time) that what matters on St. Croix is not what color your skin is but where you're from: whether or not you were "bahn ya" ("born here"). My observations suggest that it is much more complicated than that (despite a significant local public discourse about being bahn ya). Suffice it to say that ethnic dynamics are extremely complex on St. Croix, as I suspect, given St. Croix's history of ethnic heterogenity they always have been. One important, although of course not perfectly clean contemporary distinction, was highlighted for me in a 2016 interview with a white, long-time resident of St. Croix who had worked in the public sphere on-island for decades. He pointed out that in the territory one group (Afro-Caribbeans) hold the political power while another (whites) hold the economic power. There is an implicit understanding on-island that whites hold the majority of wealth on St. Croix and that whites dominate the business and financial sectors (see Navarro 2010). And, all branches of government have been, since the 1970s when federal appointment of politicians ended, dominated by Afro-Caribbeans. For the year that I was doing fieldwork, for instance, thirteen of the territorial legislature's fifteen senators were Afro-Caribbean (with origins in the territory and elsewhere).

and then for U.S. citizenship. Eastern Caribbean immigrants and their descendents thus have a large presence on-island today, as immigration from this region continues. According to the U.S. Virgin Islands Community Survey of 2005, approximately 34% of U.S.V.I. residents were born elsewhere in the Caribbean (not including Puerto Rico), and just over half were born in the V.I. Boyer (2010: 340) argues that "[t]he contributions of the Eastern Caribbean to the social, economic, and political culture of the Virgin Islands" through this community of immigrants "cannot be overestimated." The importance of this population was clear when considering the backgrounds of my ten focal participants: five of the nine individuals were born in the Eastern Caribbean, and only one was born in the U.S.V.I..[105]

Today's Healthcare

Finally, the ongoing financial instability of the territory has kept healthcare for the majority of St. Croix residents very precarious. In 1982, a new hospital was built on St. Croix, paid for by a federal grant (Boyer 2010: 411).[106] This hospital, now named the Governor Juan F. Luis Hospital and Medical Center (commonly known as "JFL") is the only hospital on-island and is owned by the U.S.V.I. government and operated through the V.I. Hospital and Health Facilities Corporation. The facility has gone through ongoing financial, infrastructural, accreditation and

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[105] Of the remaining four, two were born stateside, one in Puerto Rico. My group of focal participants is not a representative sample of the place of origin of most people living in the U.S.V.I.. In 2000 (the most recent year for which this data is published), 48% of U.S.V.I. residents were born in the U.S.V.I., 14.5 % were born in the continental United States, 4% were born in Puerto Rico or another U.S. territory, and 30.8% were born elsewhere in the Caribbean (U.S.V.I. Bureau of Economic Research 2009:11). Nine people is a very small sample compared to the St. Croix population, and it is thus not surprising that it is not representative.

[106] This grant also paid for the construction of a new hospital on St. Thomas and a new clinic on St. John).

personnel difficulties since its establishment—all of which affect the quality, reliability and indeed sometimes the very material possibilities of healthcare for St. Croix residents. For example, in 1988, "structural, equipment, and staff problems caused St. Croix's hospital (as well as the hospital on St. Thomas) to "close temporarily (...) except for emergency cases (Boyer 2010: 412). A report by the new health commissioner at the end of that year found that the hospital was "crumbling, overworked nurses were threatening to strike, and supplies and equipment were non-existent or not working" (ibid). Hurricane Hugo caused severe damage to the hospital, causing it to shut down and not re-open until 1994.[107] Earlier in 1989, before Hurricane Hugo struck, the hospital had lost its U.S. Center for Medicare and Medicaid (CMS) certification. It did not regain CMS certification until 1995, and during this time the territory lost between $3-$4 million each year in Medicare reimbursements (Boyer 2010: 412). In recent years, JFL's CMS certification has been very unstable, a sign of its struggle with financial instability. However, because the hospital relies on CMS reimbursements for such a large proportion of its revenue, decertification puts it in even more desperate straits and even less able to bring its facility and care practices up to the standard. In 2011, for instance, 40% of JFL's revenue came from CMS reimbursements (St. Croix Avis 2011d).

JFL's continuing financial instability in recent years has become dire. The hospital is not financially soluble, and this affects its possibilities for even minimal infrastructural maintenance and staff training (St. Croix Avis 2011d) not to mention care and medical treatment. For example, at one point in 2011, JFL owed over $76 million to its vendors and to the territorial government,

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[107] In the intervening years, first hospital tents and then an interim, 85-bed facility was constructed.

but only had $12 million in assets. Part of this financial difficulty can be attributed to the need to meet federal standards. For instance, in 2011, JFL ended the fiscal year $3.55 million in the red. But, a large part of this deficit was due to the fact that the hospital had once again been threatened with CMS decertification, and it had cost $3 million to bring the hospital up to specifications (St. Croix Avis 2011e) In the next year, 2012, that loss mounted to $5.8 million (St. Croix Avis 2012i). These are large numbers for an institution that drew in approximately $54 million in revenue in 2011 ("JFL Hosts the 30th Legislature of the Virgin Islands" 2016).

JFL's continuing financial instability is due primarily to uncompensated care. For instance, in 2011, JFL provided nearly $28 million in uncompensated care (an amount that would have taken it out of a deficit and put it strongly into the black) ("JFL Hosts the 30th Legislature of the Virgin Islands" 2016).[108] This was five times the national average (Avis 2011f). There are a few main reasons for the level of this uncompensated care. The most significant reason is that many patients who are cared for at JFL are un- or under-insured. In 2012, 29.7% of U.S.V.I. residents were uninsured (Morgan and Lasowski 2013) (compared to 14.7% nationwide [Cohen and Martinez 2013]).

While it might be assumed that during the period of my fieldwork from 2015-2016 these figures would have dropped significantly due to the 2014 implementation of the Affordable Care Act's (ACA) individual mandate, in fact the individual mandate did not apply in the territories (National Association of Insurance Commissioners 2013: 1; Lasowski and Morgan 2013: 30). Due both to explicit lack of parity between states and territories in the laws as well as unintended

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[108] Between 2008-2012, the most lost in uncompensated care was $31.5 million annually, and the least was $26.2 million.

ambiguity in the language in which the laws were written, the U.S.V.I., as a U.S. territory was ineligible for many of the ACA's programs and reforms (National Association of Insurance Commissioners 2013). The U.S.V.I.. was also unable to take advantage of many aspects of the law—such as the implementation of an insurance exchange—that they were eligible for on paper but, given the unequal federal support granted to them in the law, could not possibly afford. One of the many unintended consequences of the ACA was that when the marketplace reforms took effect in 2010 (such as the prohibition of denials of coverage for pre-existing conditions), the one insurance company that had been offering individual health insurance plans in the territory ceased selling new policies, choosing to simply opt out of the market rather than adhere to the new policies (National Association of Insurance Commissioners 2013: 5). It is thus no longer possible for residents of the U.S.V.I.. to purchase individual health insurance plans.

This did not have a large direct affect on the older adult population who for the most part relies on Medicare for their health coverage. However, there is a substantial indirect effect in that in maintaining high levels of uninsured patients, the hospital is continuing to fully cover the costs of their care, using funds that could otherwise expand care services and increase the quality of care provided for all patients, including older adults. The U.S.V.I. was able to initiate a Medicaid expansion, enabled by the Affordable Care Act, that beginning in 2013 both increased Medicaid reimbursement rates to 100% of Medicare reimbursement rates and extended Medicaid coverage to previously ineligible groups. One of the main aims of the way the expansion was designed was to significantly reduce uncompensated care. The four-phase Medicaid expansion plan was set to be complete in June 2015 (however the process was behind schedule). During my fieldwork year, the hospital was still struggling with high rates of uncompensated care. It remains to be seen whether the Medicaid expansion will succeed in reducing these deficits.

In addition to high rates of uninsured individuals, there was, even before the beginning of the Medicaid expansion, a significant uptick in those who rely on public aid for medical coverage. Between 2009 and 2012, the percentage of VI residents covered by Medicaid or Medicare increased from approximately 22% to approximately 34% (Morgan and Lasowski 2013: 10). This increase went hand in hand with a decrease in those who were covered by group plans from approximately 44% to approximately 32% (ibid). This switch matches the timing of the Hovensa closure, when over 2000 people lost their jobs and with it their private group health insurance. Newly unemployed and uninsured, some of these employees would have been eligible for Medicaid. Furthermore, many of these employees moved off-island, which would have also increased the overall percentage of those on-island covered by public assistance (even if there had been no increase in the number of individuals signed up for public aid plans). What this change in ratio of private-insured patients to public-insured patients means for the hospitals is lower reimbursement rates and overall lower revenue.This is one way in which Hovensa's closure impacted possibilities for healthcare on island.

Another important cause of the high rates of uncompensated care at JFL is that there is a heavily reliance on Emergency Department care on-island, with many using the ED in place of a primary care physician ("JFL Hosts the 30th Legislature of the Virgin Islands" 2016). Statistics gathered by Medicare showed that only 15% of Medicare beneficiaries (those 65+ years of age) have a primary care physician.[109] Using the ED as primary care was thus a practice that every healthcare practitioner I spoke to on St. Croix was very familiar with, and it is a pattern that I observed and participated in with some of my focal participants. Another non-negligible reason is that it is fairly common for (at least low-income) St. Croix residents to simply not pay their medical bills. When I spoke to some of my participants about this (after they told me that they were not going to pay their hospital bill), they usually told me that it was way too expensive for them to pay. Sometimes they said that the hospital must have been charging them incorrectly (and so of course they would not pay), or otherwise they simply accepted that it was outside of their ability to pay, and threw the bill away.

The hospital's ongoing financial precarity has the effect of causing healthcare on island to itself remain precarious, especially for those who cannot afford—or are too weak or medically fragile— to go off-island to seek care, as was the case with many of my focal participants. This precarity seems to be part of the territorial condition. A 2011 study showed that between 2005-2008, hospitals in the America's territories had "significantly higher mortality rates and lower performance ratings than hospitals on the U.S. mainland" (St. Croix Avis 2011g:1).

In the next chapter, I will continue this discussion by focusing in on the state of senior care and services on island in during the period of my fieldwork (2015-2016) and in the years leading up to it. In doing so, I will revisit major themes and events discussed in this chapter to show precisely what impact they had for the state of senior care in the territory during the study.

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[109] This was a statistic that was shared by Helios, the Medicare-contracted Quality Improvement organization in a meeting of the Community Care Coalition whose activities I document in Chapter 8.

SECTION III

Bureaucratic Disregard

Prologue

This section provides an examination of how American (post)colonial bureaucratic disregard shapes possibilities for care for older adults on St. Croix. In doing so, the three chapters that follow ethnographically bear out the connections between the historical picture presented in Section II with the theoretical framework presented in Chapter 2. I have suggested in the theoretical framework I presented that the dynamic of disregard is only possible within forms of relationship in which attention is somehow owed, claimed, or expected. In Section II, I traced the ways in which St. Croix had historically been constructed and treated as an object of sovereign disregard, across both the Danish and American eras. This section I present now ethnographically elaborates the ways that possibilities for care and services for older adults on St. Croix are defined by the tension between federal regulation on one hand, and sovereign disregard, on the other. It does so through focusing specifically on the workings of *bureaucratic* disregard as a particular mode of American (post)colonial disregard, and more specifically still by examining the bureaucratic workings of the agency that controls much of healthcare for older adults in the United States: the Centers for Medicare and Medicaid (CMS).

In the current moment, the bureaucratic logics of the Centers for Medicare and Medicaid (CMS), the governmental entity that runs Medicare, have a decidedly capitalist, neoliberal, late modern bent. Healthcare in the U.S. has become commodified through and through (Reich 2014) and Medicare beneficiaries (the pool of possible ‘patients’) are positioned as “active and responsible consumers of medical services" (Rose 2007: 4). However, as the case studies in this section will suggest, these logics, and the regulatory structures that disclose them and carry them out, exist within and recreate a dynamic of inclusion and exclusion that positions some Americans as legible, participatory actors (Scott 1998), and others—like residents of St. Croix—as illegible and thus outside the scope of the bureaucratic attention

My use of 'bureaucratic disregard' insists that American bureaucratic systems—like the Medicare regulatory structure—were not intended *not* to work in places like St. Croix. Rather, they simply never took the situation of St. Croix residents into account and continue to proceed in maintaining this population as illegible, and the consequence that affect them as unconsidered, within existing logics. Within these logics, *it just so happens* that places "like" St. Croix emerge as exceptions to the otherwise normal functioning of regulatory processes. That is, regulatory infrastructures designed to standardize American healthcare did not take into account places that are islands away from the mainland, that have territorial and not state status, that are populated mostly by people with black and brown bodies considered to be culturally and ethnically other, and that have never had voting representation at the federal level. People in these places are outside of its scope; they are the objects of disregard. However, they are nonetheless still regulated by these bureaucracies through which they are disregarded.

Chapter 6 presents the landscape of care and services for older adults that were available during the yearlong portion of my research period (September 2015-September 2016). This chapter is meant as something of a map, a backdrop for both the case studies to follow in Chapters 7 and 8 and for the other chapters to come. It explains what was available by way of care and services, how these were funded, what kind of impact they were having and to what extent my research engaged with each, either by way of focal participants or otherwise. The chapter begins by presenting five Orienting Conditions that are the conditions under which care and services for older adults on St. Croix existed during the period of fieldwork, and help explain the form that they have, the limits that are placed on them, and how they are interconnected. These Orienting Conditions tie strongly to the main themes identified in the recent history of St. Croix presented in the previous section, and frame the presentation of the landscape of care to follow.

Chapter 7 presents a case study comparing the trajectories of hospice care and Durable Medicare Equipment providers (DME) on island. This can be thought of as a zooming in to one particular area in the map presented in Chapter 6. For both hospice care and DME providers, federal CMS regulations wholly define their possibilities for coming into existence and for the operations that sustain that existence. Furthermore, the presence or absence of either one of these forms of care has direct consequences for the kinds of possibilities open to older St. Croix residents experiencing ill-health or disability. And indeed, while hospices continue to provide care on St. Croix, there is no longer any purveyor of Medicare-certified Durable Medical Equipment on-island. I argue that what these two trajectories show us is that within the CMS system it is seems it is more profitable to put St. Croix residents on hospice care—palliative care oriented toward providing a comfortable death— than it is to provide them access to Durable Medical Equipment—such as oxygen concentrators, wheelchairs, and hospital beds—that could help support their continuing life. In tracing the mechanisms that created this situation, particularly Medicare-reimbursement policies, I show how they disclose a logic of disregard that is definitively shaping possibilities and trajectories for older adults on St. Croix.

Chapter 8 turns to more deeply investigating the absence of DME providers on St. Croix through the activities of a “DME workgroup” that came into existence during the research period. This workgroup was created and facilitated by a Medicare-contracted Quality Improvement Organization (QIO) who had a federal mandate to improve healthcare for Medicare beneficiaries in the U.S.V.I.. Examining the activities of this workgroup, especially its engagements with other Medicare-contracted entities, I show how mechanisms of *illegibility* were maintaining St. Croix’s residents as objects of disregard within the CMS bureaucracy. I argue that illegibility is a primary mechanism through which (post)colonial disregard operates by making certain populations, and certain problems more difficult, and sometimes impossible, to pay attention to.

Chapter 6

Landscape of Care and Services for Older Adults on St. Croix, 2015-2016

Now that I have discussed the historical context from which care and services for older adults on St. Croix emerged, I turn in this chapter to presenting the state of senior care and services during the yearlong phase of my fieldwork, and to adumbrating both my own and my focal participant's engagements with these institutions and programs. This is thus the first ethnographic chapter of the dissertation.

The chapter proceeds in three main parts. First, I discuss five conditions around which of all senior care and services on St. Croix are oriented. These are meant as grounding signposts through which to interpret the existent landscape of older adult care and services. It will be evident that these conditions connect to the major themes discussed in the last section, and especially the last chapter: they echo thematic throughlines, but here specified for their concrete effects on possibilities for care and services for older adults on island. Second, I provide a snapshot, or map, of the full array of care programs and service that were available to older adults during my fieldwork. I present this through the lens of *providers*, so that it is evident what kinds of entities are responsible for these care and services. I also discuss my research engagements with these providers (more details on which can be found in Appendix D). Third, I re-focus on more specifically describing the care and services available for older adults with serious illness or disability (a subset of the broader landscape). Throughout this part of the discussion, I include the extent of my participants' engagement with these programs.

Senior Care on St. Croix: Five Orienting Conditions

My interviews with and shadowing of healthcare and social services providers and administrators, participation with seniors in need of care throughout their everyday lives, and review of locally produced literatures on senior care and services[110] lead me to conclude that the conditions shaping senior care on island during the year of my fieldwork can be summarized in five major claims. These claims serve as orienting conditions, providing the context in which care and services for older adults on St. Croix takes place and delineating its space of possibility and of impediment. These five orienting conditions are:

1. Senior care and services are highly dependent on local government programs, and thus on local government revenues.
2. Because much of the care and services for older adults provided by the local government is at least partially paid for by federal dollars, the existence of that care and those services are dependent on adhering to federal standards and regulations.
3. There is a severe death of long-term beds for older adults.
4. There is a high proportion older adults living in or near poverty.
5. There is perpetual out-migration of working-age adults to the mainland U.S.

I will discuss each of these in turn.

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[110] This included research in popular media, in testimonies given to the legislature, and in official training and promotional materials.

Dependence on Territorial Government Programs/Revenues

Many of the services and care facilities available on island receive a large amount of their funding from the local government, and many programs are operating directly through this body. A brief run-through of the main healthcare institutions on island will show this to be the case. As discussed in Chapter 5, the island's only hospital, the Governor Juan. F. Luis Hospital (JFL), is owned by the government, as is the other main public clinic on island, Charles Harwood Complex (operated through the local Department of Health). The Charles Harwood Complex is one of two clinics at the frontlines of healthcare in the territory as it serves as a primary care center for all Medical Assistance Program (the local Medicaid program, MAP) patients.[111] Many senior programs and services are run through the local Department of Human Services (DHS). For instance, DHS operates the island's only nursing home (Herbert Grigg Home for the Aged), a low-income independent living residential facility (Whim Gardens) and the Medical Assistance Program. Additionally, DHS is the hub of local government funding for the non-profit organizations that provide care and services to the islands seniors (by far the largest of which is Lutheran Social Services).

The upshot of this is that a large majority of senior care and services on island are made possible, and also impeded, by the local government's financial status. When major cuts were made during the Global Recession (2008-2011), after the closing of Hovensa (2012), and during

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[111] The second of these clinics, the Frederiksted Health Care (discussed below), is now a privately run organization, but began as an offshoot of the Department of Health.

the federal Government Sequester (2013) many of these cuts were to the Department of Human Services, forcing reductions in already insufficient senior programs and facilities.

Federal Dollars and Federal Regulatory Standards

Federal funds are significantly involved in every aspect of care and services for older adults on St. Croix. During the two fiscal years that my fieldwork overlapped, over half of DHS's budget was supplied by federal grants (U.S. Virgin Islands Department of Human Services 2014, 2015). Medicare reimbursements, from the federal Centers for Medicaid and Medicare (CMS) make up 40% of the hospital's revenue. And, non-profits such as Lutheran Social Services depend on federal grant opportunities.

In addition to meaning that care and social services for older adults on island are directly tied not just to the financial status of the local government but to that federal government as well, this means that the continuance of certain programs is tethered to adherence to federal regulatory standards. For instance, as discussed in Chapter 5, the Gov. Juan F. Luis Hospital can lose millions of dollars in much-needed revenue when they lose certification from the U.S. Centers for Medicare and Medicaid (CMS).[112] Thus, hospital care is oriented toward meeting CMS standards, and millions can be spent to bring the care and facilities up to specifications when a CMS survey threatens potential decertification. Herbert Grigg Home for the Aged, the only nursing home on St. Croix, has not been able to attain CMS certification, which means they are

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[112] This is because they must continue to care for Medicare patients but without receiving the reimbursement for such care.

currently missing out on substantial financial support via Medicaid reimbursements.[113] The improvements that the administration is aiming to make for the facility are all directed specifically toward obtaining CMS certification.

CMS reimbursements are just one way in which programs through which federal dollars are made available significantly affects the landscape of senior care and services on-island. I have already mentioned that federal government cuts directly affect senior services, particularly through DHS. However, this works in other ways as well. For instance, in an interview with a long-time director of Lutheran Social Services (LSS), the main purveyor of low-income senior residences on island, he described the projects that their organization took on in relation to senior services as directly related to what federal grants happened to be available, and whether or not they won such grants. When federal policies change, this can have extremely significant consequences for the services LSS and other non-profits are able to provide.[114]

In sum, federal dollars shape what programs, care, and services are available to older adults and how many older adults they can serve, and they also shape standards— and thus how resources and time are spent within this programs. This is especially the case in the domain of healthcare for older adults. In a these and other ways, senior care on island is oriented toward maintaining federal funding.

Severe Dearth of Long Term Beds Territory-Wide

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[113] Medicare does not cover long-term care, however Herbert Grigg would be eligible for reimbursements for its Medicaid patients.

[114] For instance, in 2011 the U.S. Department of Housing and Urban Development (HUD) implemented new standards for determining how many units of low-income senior housing they will fund in a given municipality, which brought LSS's construction of such facilities to a halt.

The U.S.V.I. does not have enough long-term beds for its seniors, and this greatly impacts the entire system of older adult care. As I've mentioned, there is only one nursing home on St. Croix, and that facility has 40 residential beds. Along with the two nursing homes on St. Thomas[115], a number of small, uncertified "homes" that private citizens were running out of their houses[116], and "everything that may even be considered a de facto assisted living bed," the territory has about 200 beds (U.S. Virgin Islands Department of Human Services 2014: 26).[117] CMS's recommendation for a community of the size of the U.S.V.I. (as cited in DHS's FY2014 Budget Presentation and DHS's FY2015 Budget Testimony) is 596 if the community has a "relatively robust system of home-based services,"[118] and 834 if such a system is not present (which in the U.S.V.I.., it is not).[119]

As stated in DHS testimony to the local Legislature (Department of Human Services 2014), and repeated to me by people all over the senior care system on St. Croix, this dearth of long term beds "leads to boarders at the hospitals, overwhelmed family caregivers and seniors

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[115] At the time of my fieldwork there were also two nursing homes on St. Thomas: one privately owned and one owned by the local government (and run by DHS). However, the privately owned facility was decertified by CMS during my year of fieldwork, and the fate of the facility and its residents was up in the air.

[116] I was told homes of this kind were mostly being run on St. Thomas. No one I spoke to could point me to any of them on St. Croix.

[117] In an interview with the author of this report in 2016, he told me that the number of existent residential beds in the territory was closer to 120.

[118] This quote is from an interview I conducted in 2016 with the DHS Commissioner who oversaw the writing of the two budget presentations cited above.

[119] The official recommendation is that a community has long-term senior beds equal to 5% of their total population of adults 65 years of age or older and the community has a relatively robust system of home care. This figure changes to 7% if such a system were not present. I made these calculations for the U.S.V.I. based on 2012 figures (the most recently available) that listed 11,918 people in the U.S.V.I. as being 65 years of age or older (U.S. Virgin Islands Bureau of Economic Research 2015: 14).

living alone who should not be." All of these consequences were evident during my year of field research.

While I did not include any hospital "boarders" in my study, it was a common topic among those I spoke to about senior care on island. It was often used by healthcare practitioners, administrators, and politicians as an example of how poorly "we" treat our seniors "here."[120] In late 2015, I was told that there were currently 6 boarders at the hospital. This abandonment of family members in need of medical care at a facility that cannot turn them away or discharge them without someone to bring them home shows the desperation of families who feel they cannot go on caring for an older loved one with (sometimes complex) medical needs. It is also a further drain on the already strained finances of the hospital that is responsible for tending to the acute care needs of the rest of the island's population, including the island's seniors.

This is not to say that long term care beds are the answer for every senior in need of some level of daily medical care. Surely, they are not. However, the point is that on St. Croix, families do not have that option. Indeed, I found that this did lead to many "overwhelmed" family caregivers and to many medically fragile or seriously physically disabled seniors living alone. The dearth of long-term care beds in the territory also significantly shapes the other programs and services that in one way or another need to try to make up for the fact that many seniors with high levels of medical need are living in the community without professional care.

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[120] A 2010 article in the local press, entitled "JLH: Patient Abandonment Draining Hospital Resources," alerted the public to the deleterious impact boarders have on the finances and functioning of the hospital and asked families to please come pick up their family members (St. Croix Avis 2010c). Another article later that year noted that at that time there were 13 boarders in the 105 bed facility (St. Croix Avis 2010d).

High Proportion of Older Adults in or Near Poverty

Older adults in the U.S.V.I. are twice as likely to be living in poverty than those in the continental United States (U.S. Virgin Islands Bureau of Economic Research).[121] While this is already quite drastic, the Federal Poverty Level on which this is based is much lower than the income needed to sustain the basis of everyday life in most communities, including in St. Croix (see Center for Women's Welfare 2018).[122] Far more older adults in the U.SV.I live below the Self-Sufficiency Standard for the territory (an figure meant to accurately reflect the most basic costs of everyday life), meaning that it is not uncommon for seniors in the territory to struggle to make ends meet.

One of the reasons that so many of St. Croix's older adults are living in or near poverty is that none of them receive Supplemental Security Income (SSI), the federal government's "safety net" program to help seniors, the blind, and the disabled stay out of poverty (Social Security Administration 2011).[123] Established in 1974, SSI is the current incarnation of what was previously three separate programs, including Old Age Assistance (OAA), that were part of the

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[121] In 2012, 19.4% of adults 65 years of age or older in the U.S.V.I. were living at or below the federal poverty level (U.S. Virgin Islands Bureau of Economic Research 2015). This is compared to 9.1% nationwide (ibid). The federal poverty level for a single adult in 2012 was $11,170; for a two-person household it was $15,130 (U.S. Department of Health and Human Services 2012). Those levels, as of writing (summer 2018) have increased to $12,140 and $16,460 respectively (U.S. Department of Health and Human Services 2018).

[122] The Self-Sufficiency Standard for the U.S.V.I.. in 2016 was $22,645 for a single adult and $34,488 for a two-adult household (U.S. Virgin Islands Bureau of Economic Research 2016: 1).

[123] SSI is potentially available to all citizens (or those otherwise qualified, such as certain refugees) 65 years or over who live in the continental United States or the Northern Mariana Islands, however individuals must be low-income to qualify (Social Security Administration 2003).

original Social Security Act of 1935 (Social Security Administration 2011).[124] However, participation in SSI was was never extended to the U.S.V.I., and so the territory still functions with the (elsewhere defunct) OAA. This is extremely disadvantageous for older adults living in the U.S.V.I.. While through SSI seniors receive a minimum federal payment that can be supplemented by their state, through the OAA program there is no minimum payment, and the federal government matches only what territories are able (Blake 1994: 6).[125] This means that in the U.S.V.I., OAA payments are determined solely by the local government who must set payment levels at what they can afford to pay. Given the perpetual financial difficulties faced by the local government, OAA payments in the U.S.V.I. are much less than the minimum federal payments made through SSI. As of the time of writing, monthly payments to individual OAA recipients is $170 (U.S. Virgin Islands Department of Human Services 2018), whereas the *minimum* federal payment to individual SSI recipients is $750 per month.[126] This lack of parity in federal aid is a significant reason for the relatively higher rate of poverty in the U.S.V.I. than in the United States as a whole.

The consequences of high levels of poverty among seniors on St. Croix for the system of senior care and service are many. One is that there is a high reliance on public aid, with governmental care and services playing an important role in the lives of many older adults on

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[124] The other two programs were Aid to the Blind, and Aid to the Permanently and Totally Disabled.

[125] Federal payments match territorial payments exactly, so that the money received by the senior is a 50/50 federal/territorial split (Blake 1994: 6).

[126] Many states supplement this basic payment; for instance in California the payment to individual SSI recipients who qualify due to old age and low income is $910.72 per month (Social Security Administration 2018: 2).

island.[127] This high poverty level of seniors on-island strains this public aid system, as they are a group who need to be served and cared for but who do very little to financially contribute into the system itself. This is true in general for seniors who have left the workforce in the United States, but a larger proportion of people in this category as well as an extremely financially precarious local government greatly intensify the problem.

Out-Migration of Working-Age Adults to the U.S. Mainland

As discussed in Section II, significant migration to and from St. Croix has been occurring for centuries. Migration is indeed one of the fundamental practices of post-emancipation Caribbean peoples (Chamberlain 1998: 1; Olwig 2007: 27-31), and St. Croix is no exception. As also discussed Section II, since the American purchase of the islands in 1917 there has been a strong stream of migrants leaving the territory to re-settle stateside. Over the decades a variety of push/pull factors have hastened or slowed the rate of migration, but the path from the islands to the continent is by now an extremely well-established one. It is currently estimated that approximately ¾ of Virgin Islanders live outside of the territory, with the vast majority living in the continental United States.[128]

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[127] This is the converse point to that made in the first point of this section (Number One of the “Five Orienting Conditions”): it is both the case that the system itself is dominated by public aid (as opposed to private enterprise) and that many seniors rely on public aid (they do not have the option of going off-island for care or for drawing on the small amount of private services that are available).

[128] As far as I could tell, most migrants from St. Croix re-settle in Florida (in cities like Orlando or Jacksonville) or in New York. Southeastern states, like South Carolina and Maryland were also common, with only a few people I spoke to having family who migrated from the territory living on the West Coast.

During the time of my fieldwork, St. Croix was still in the wake of the 2012 shut-down of the island's largest second-largest employer, the Hovensa oil refinery (see Chapter 5). The direct loss of 2000 jobs was only a part of the massive effect this closure had on the territorial economy. As business slowed, working age adults moved to the states to escape what was felt to be, at least in the short term, a hopeless job market. This exodus continued a trend St. Croix had already been experiencing for at least a decade: the "graying" of the population.[129] As many more working adults than older adults migrate off-island, often bringing their young children with them, the population of those who remain on St. Croix is growing older. As of the period of research, the territory was now close to becoming a "super aging society."[130]

In recent years an upsurge of work across disciplines has arisen delineating the myriad strains that becoming a super aging society puts on societies whose public policies and economic structures assume a much different demographic pattern. In my research, I found that the strain on public aid is irrefutable. It has been made even worse in the face of major cuts brought on by the Global Recession (beginning in 2008) and the U.S. Government Sequester (in 2013), calling for a difficult balancing act between responding to a growing segment of the population while having less resources with which to provide care and services (U.S. Virgin Islands Department of Human Services 2015).

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[129] Between 2000-2010, the proportion of residents in the territory 65 years of age or older more than doubled, from 6.4% to 13.1% (U.S. Virgin Islands Department of Human Services 2015).

[130] By 2017, those 65 years or older made up 18% of the population (The Henry J. Kaiser Family Foundation 2017). A super aging society is usually defined as having 20% of the population 65 years of age or older. Unlike the standard model of population aging (based on societies of the global North) in which this is caused by low fertility rates paired with relatively large previous generations reaching old age, the aging of St. Croix society is explained by patterns of out-migration.

Another concomitant effect of the aging of St. Croix's population is that there are less working-age adults on-island to care for older family members. This fact became a fundamental element of my research as I was time and time again introduced to older adults who were sick, disabled, and even bed-bound, but who lived alone and did not have a caregiver who provided sufficient levels of support.[131] This is not strictly due to the fact that *all* potential family caregivers had migrated, but rather that the pool of possible family caregivers for many older adults is substantially shrunken due to migration stateside. This means that it is less likely in any given family that there will be enough willing family members to provide care over the long term.

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All five of these orienting conditions are intertwined, each affecting the others. For instance, out-migration of younger generations (#5) would not be so problematic if there were more long-term senior care beds in the territory (#3). If older adults were in general more affluent (#4), there would not be as much reliance on public aid (#1). The connections are extensive and the five conditions are better thought of as components of one unified system rather than as five separate logics.

Having established the main orienting conditions in which care and services for older adults in St. Croix operate, I now present, in the next two sections, a catalog of the care and services that were available during the period of research

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[131] In Section V, I discuss the complex dynamics within families between those who are on-island providing some level of care, those who have migrated, and older family members who rely on daily caregiving to survive. A common pattern is for one family member to be providing all of the care, which means both that the caregiver is often overwhelmed and that the quality of the care is not what it could be if more than one family member was involved. In many cases, having only one family caregiver meant that older bed-bound adults were spending most of their waking lives alone.

Care and Service Providers for Older Adults on St. Croix 2015-2016[132]

In the first section of this discussion, I will introduce the main providers of care and services and will briefly summarize my ethnographic engagement with them. (Further details on my research activities with most of these entities can be found in Appendix D.) In the second section of this discussion, I will focus on a closer look at the types of care and services available to older adults like my focal participants—those who are ill or disabled. I will briefly summarize my focal participants' engagements with these services. This second part of the discussion will exclude programs and services that are geared toward the senior community but which require extensive mobility or other forms of wellness.

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[132] There are two kinds of organization I do not discuss here: small local non-profits and churches. There are a disproportionately large number of small non-profit organizations in the U.S.V.I.., due to a regulatory climate that makes it extremely easy to establish them. However, despite my research activities across a wide variety of milieus relating to senior care and services on St. Croix, I did not cross paths with any that were dedicated to this population. One non-profit, Catholic Charities, did provide care to older adults through their numerous homeless aid programs. However, none of my focal participants were involved with Catholic Charities, and as they were a fairly small organization not focused on senior care I did not attempt to recruit anyone from the organization into my research. I focused instead on Lutheran Social Services who ran a number of residential facilities for older adults and who were otherwise more involved in senior care issues on island.

Another provider of care for seniors on St. Croix that I do not discuss here is churches. There is a very high rate of church affiliation on St. Croix, and there is much talk (e.g. among hospice workers and public officials) about the role of congregants and church officiants in caring for the sick in the community. In my experience, however, the amount that this is talked about does not match the amount of impact it actually has in the lives of seniors who are disabled or in poor health. A few of my focal (and non-focal but older adult) participants occasionally had members of their church come to visit them. However, such visits were rare. (Especially, I would note, after it had been a long time since older adults were well enough or able-bodies enough to attend services.) In general, churches often provide meals after service, which can be an important source of food for low-income seniors. And, there is also definitely some "looking after" older members in church by younger members—asking how they are, making sure they have a ride home, etc. Thus, which churches provided caring and supportive presences in the lives of seniors on St. Croix, they generally were not looked to for substantive support when it was needed. The one exception I was familiar with amongst my participants was Angelica (who I do not discuss at in this dissertation, but see Appendix C for a brief profile). Angelica was extremely involved in her church and had created a veritable second family out of her co-congregants. This group supported Angelica and her family extensively when she got very sick.

Care and Service Providers

The main providers of care and services for older adults on St. Croix are the Department of Human Services, the Department of Health, AARP and Lutheran Social Services.[133] In addition to this, there are a large number of small non-profit entities and some private enterprises.

Department of Human Services (DHS)

The U.S.V.I. Department of Human Services (DHS) is a very large department with over 800 employees[134] and 60-80 individual programs[135]. Here is an outline of DHS's role in care and services of seniors on-island.[136] DHS operates:

- A variety of **aid programs**, including meals on wheels, "food stamps", homemaker services etc.
- **Herbert Grigg Home for the Aged**, the one nursing home on St. Croix.

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[133] All of these entities also operate on St. Thomas and St. John. Here I discuss only what was available on St. Croix.

[134] This was down, due to budget cuts, from over 1000 just a few years before my research (U.S. Virgin Islands Department of Human Services 2014:19).

[135] This depends both on how you categorize them and which programs are operational at a given time.

[136] The care and services DHS provides to older adults on St. Croix is done through the Division of Senior Citizens' Affairs and Family Assistance Programs.

- **Adult Protective Services (APS)** which investigates alleged cases of senior abuse and neglect
- **Whim Gardens**, an apartment complex for low-income seniors
- Two **Senior Centers**, which operate for a few hours a day and provide lunch and activities to seniors
- **Volunteer Program Services**, which provides opportunities for seniors to volunteer in the Community
- The **Medical Assistance Program** (MAP), the territory's Medicaid program

DHS is also the entity that provides funding for burials or cremations for low-income families who cannot afford to pay for them on their own.

All of my focal participants were receiving services or care in some from the Department of Human Services. I thus became quite familiar with a number of their programs through participant observation in the lives of my participants. This participant observation often led to further research in the form of interviews with the providers themselves or with administrators, and/or archival research into the program. I also familiarized myself more broadly with the current state and history of DHS's engagement in the care of St. Croix's older adults through regular engagement in public forums and archival research (see Appendix D for more details).

Department of Health (DOH)

The Department of Health (DOH) is the state regulatory agency and the territorial public health agency. They thus have a role in all institutional healthcare and public health on island. In general, however the Department of Health plays a much more backgrounded role in the care of seniors on St. Croix than does the Department of Human Services.

DOH runs a community health clinic that is one of two primary care facilities under the Medical Assistance Program, The Charles Harwood Medical Complex. DOH is also responsible for the quality of care at St. Croix's only hospital: The Governor Juan F. Luis Hospital (JFL). Additionally, DOH operates the island's Emergency Medical Services, responding to emergency calls through 911 and transporting patients to the hospital in ambulances. They are also responsible for keeping all vital statistics in the territory (death records, rates of disease, etc.)

. However, the Charles Harwood Medical complex is an important healthcare center on island. At both Charles Harwood and JFL, all patients are seen irrespective of whether or not they are insured or whether or not they are able to pay. Unlike JFL, Charles Harwood offers a sliding scale based on income. Furthermore, for older adults who are dual Medicare-Medicaid eligible, and who sign up for the Medical Assistance Program, the Charles Harwood Medical Complex would be one of two possible sites for them to receive primary care.

My engagement with the Department of Health was for the most part in two domains: participant observation at JFL, and research into health data collection in the territory (see Appendix D for details).[137] Most of my research at JFL was accompanying my focal participants to the Emergency Department or visiting while they were in the hospital, both of which

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[137] In general, my focal participants did not visit the Charles Harwood Complex. This may be because of their nearness to end of life, in some cases, and because they were bed-bound, in others, and sometimes both.

happened on a regular basis. My research with other organizations (such as Shepherd Hospice and the Community Care Coordination Coalition [Chapters 7 and 8]) also brought me into frequent contact with JFL.

Lutheran Social Services

The other major player in senior care and services on island is Lutheran Social Services (LSS). LSS is a non-profit organization that is affiliated with the national Lutheran Church.[138] It is the largest non-profit human services organization in the territory. LSS has offered many programs over the years, but currently it primarily serves the senior population through residential services, operating two residential complexes for low-income seniors on St. Croix: Flamboyant Gardens and Genep Gardens.[139] While these are officially independent living residences, LSS supplements the housing with a number of supportive services, which I describe in the next section of this chapter.

My research activities with LSS included participant observation, interviews, and filming with staff and residents at Flamboyant Gardens and interviews with past and current LSS administrators. I also regularly attended public forums that LSS was involved in and conducted archival research into their role in senior care and services 2010-2016.

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[138] LSS has its origins in the territory in the early 20th century, during the end of the Danish era.

[139] LSS serves a much wider swath of the territory's population. Some of the organization's main programs are Head Start, residential services for disabled adults, and St. Croix's youth foster home.

AARP[140]

The AARP State Office (so-called even though the U.S.V.I. is not a state) has a significant presence on island, providing workshops, disseminating information, and playing for a major role in advocating for seniors in the territory. 51% of residents of the territory over 50 years of age are AARP members.[141] However, as my research was focused more on older adults in poor health or near the end of life, the (large) group of people who participated in AARP were generally much more "active," and more affluent, than the older adults I worked with.

I conducted participant observation at a wide variety of AARP sponsored events (which I filmed and photographed) and at AARP meetings. I also interviewed the State Director and other administrators. Through my engagement with AARP I learned about a different side of aging on St. Croix than the one I saw in the lives of my focal participants and those around them, whose lives were distinctly shaped by debilitating illness.[142] A large part of this is due to the fact that AARP membership begins at 50; many participants at these events were still living out middle age, and their place in the life course just didn't fit with my research focus. Thus while the data I collected at AARP events certainly has much to say about aging on St. Croix, I do not integrate any of it here as it is truly outside the research focus of this dissertation.

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[140] AARP used to be an acronym that stood for "American Association of Retired Persons," but that is no longer the case. The group is now simply called "AARP."

[141] This figure was conveyed to me in an interview with an AARP state office administrator.

[142] This is not to say that the people who attended AARP events didn't have their share of illness or suffering or family obligation in their lives.

Private Enterprises/Small Non-Profits/Etc.

There is a relatively small but significant presence of private facilities and services that serve older adults on St. Croix. There are many small doctors' offices; one major clinic; two hospices services; two home-health services (one of which went out of business during the fieldwork period); an independent living facility; and an assisted living facility.

Small doctors' offices dot the island of St. Croix. While these facilities certainly do provide care for older adults on island, they were not central in the lives of any of my focal participants, and none of my other strands of research led me to investigate their operations or their impact on senior care. These private offices thus play a very small role in my study (see Appendix D for details).

Of the private entities in healthcare and social services on St. Croix, the one with the largest presence on island is Frederiksted Health Care (FHC). FHC is the second public clinic on St. Croix alongside The Charles Harwood Complex.[143] Originally a part of the Department of Health, it is now a not-for-profit entity funded largely through the federal government through its' status as a Federally Qualified Health Center. Like the Charles Harwood Complex, FHC is a relatively large, multi-story facility. It is a major figure in healthcare and public health on-island.

My research engagement with FHC was fairly limited (see Appendix D for details). I conducted interviews with several administrators there and toured the grounds on several

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[143] As its name implies, FHC is located in Frederiksted, the town on St. Croix's west coast. The Charles Harwood Medical Complex is located in Christiansted, the town on St. Croix's northern coast, about halfway between the eastern and western tips of the island. Each clinic thus generally serves the population in their respective parts of the island.

occasions. Two of my focal participants went to FHC for their primary care, however I was never able to accompany them on their visits.

The two home-hospice services are Shepherd Hospice and Caring Heart Hospice. Both were privately owned, for-profit companies. I conducted extensive research with Shepherd Hospice, and discuss the hospice's history and role on St. Croix extensively in Chapter 7. I spent one month in 2014 (July), and four consecutive months from October 2015-February 2016 with Shepherd as my main fieldsite (see Appendices A and D for details). I was unable to gain any access to Caring Heart Hospice, despite attempts to do so.[144]

There were two home-healthcare services[145] that were operational during part of the time of my fieldwork: Clear Waters Home Health and Shepherd Home Health. Home-healthcare is a largely rehabilitative service that helps patients transition from operations or other major medical events back into normal life. It is an integral part of a functioning healthcare system, and hospital discharge procedures and timelines in the U.S. assume the presence of home-healthcare services.

Both Clear Waters and Shepherd were privately owned, for-profit companies. Shepherd Home Health was owned by the same married couple as Shepherd Hospice and was run out of the same administrative offices with the same staff. However, unlike Shepherd Hospice, Shepherd Home Health was not CMS certified, which meant that patients had to pay 100% out

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[144] All I know about Caring Heart I heard from Shepherd, their direct competitor, and I was not able to verify any of the information. I thus do not include any information about them here or elsewhere.

[145] It provides only part-time, and never around the clock, nursing care at home. Unlike hospice care, the goal is to help patients improve and get back to being able to live independently. There is normally a limited time (around 8 weeks, depending on the case) that insurance will reimburse for home-healthcare, and a limited number of services that it provides.

of pocket. Shepherd Home Health usually only had one or two patients at a time, those who could afford to pay a nurse an hourly wage.

Clear Waters, owned by a doctor living in the territory, ceased operations in March 2016. This left St. Croix with no home-healthcare service (outside of hospice care) that was covered by insurance. This was a major blow to the landscape of care on island, especially for homebound older adults.

My research engagements with Clear Waters Home Health and Shepherd Home Health were extremely limited (see Appendix D for details). Both had very small footprints in the senior care and services landscape during the period of research.

There was one privately owned independent living facility on St. Croix, called Sunset Palms. Sunset Palms was a small apartment complex that had been opened on land a family had donated for the purpose of helping seniors on-island. Sunset Palms provided subsidized rent to its residents through a federal program (operated through the U.S. Department of Housing and Development, details below) which had also paid the facility's construction costs.

My research at Sunset Palms took place over the course of a few weeks. I toured the facility, interviewed the manager, spent time conducting participant observation in public spaces, and spent 8-10 hours with one resident in her apartment. Unfortunately, this resident decided to halt participation in my study, so she is not included here.

In summer of 2016, near the end of the research period, the island's first private assisted living home opened: Loving Home Assisted Living. Loving Home is run by a husband and wife team out of their beautiful home that they have converted into a group living facility. I spent an afternoon there, taking a tour of the facility and interviewing the co-owner (the wife part of the team). At the time that I visited, only three residents were living at the home, but the owners were hopeful that as word got around more people would move in.

Care and Services for Older Adult Facing Illness or Disability, 2015-2016

Now that we have toured the landscape of senior care and services, I am going to focus on those available and used by older adults with illness or other disabilities—older adults like my focal participants. Having introduced the care and services providers, I now turn to discussing the programs and institutions themselves in more detail. I will include brief summaries of my focal participants' engagement with these services, institutions, and forms of care.

Public Aid/Welfare Programs

As I mentioned above, all of my focal participants were receiving some form of public assistance (in addition to Medicare). In some instances, these programs played major roles in these individuals lives, and in others they were more peripheral. Below, I describe the programs and outline the roles they played in my focal participants' lives. Importantly, non-participation in these programs was not always intentional. Often, individuals were not aware that certain programs existed, or they were not aware that they were eligible. Contact with certain healthcare or social services institutions, such as Shepherd Hospice or Frederiksted Health Care, would often catalyze participation as individuals would learn about and be encouraged to sign up for welfare programs. And, as I became more and more familiar with the existing public aid programs, I would talk to participants about them and help them get signed up (when they were interested) in order to help support them.

Medical Assistance Program (MAP) - The U.S.V.I.'s Medicaid program

The Medical Assistance Program (MAP), like state Medicaid programs, operates through a combination of local and federal funds to provide low-income individuals with health insurance. When I arrived in St. Croix in late summer 2015, the Medical Assistance Program was in the final stages of a major transition: Medicaid Expansion. With a large amount of federal funds made available through the Affordable Care Act (ACA), the territory was able to expand the Medicaid program in three directions: 1, expand eligibility requirements so that more U.S.V.I. residents than ever could be covered; 2, increase Medicaid reimbursement rates; 3, enroll many more providers in the program (which was helped by higher reimbursement rates).[146] This was going to make thousands of new seniors in the territory eligible for Medicaid, and was going to drastically increase the number of providers available to them.[147]

Despite this pending improvement in healthcare for low-income seniors, the change did not represent anywhere near same kind of possibilities that the ACA opened to states. One of the

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[146] MAP eligibility had, until Medicaid expansion, been extremely restricted due to the local government's perpetual financial troubles. The maximum income level was extremely low, as it had to be in order to effectively restrict the number of enrollees in a population with such high poverty rates. In expanding eligibility, estimates were that recipients of Medicaid in the territory would rise from between 9,000-10,000 in 2012 to up to 38,000 by the final phase of the expansion (scheduled for 2015). 38,000 people is over one third of the residents of the U.S.V.I..

[147] There was one phase of this expansion of eligibility requirements, scheduled for February 2015, that would have made MAP available to more seniors in the territory. This phase consisted in the raising of maximum income for eligibility so that individuals who had previously made too much money to be covered were now eligible for coverage. In more than doubling this maximum income from $5,500/year for a head of household to the Federal Poverty Level of $11,670 a year.

many ways in which territories did not receive parity with states in the ACA was in the calculation of Medicaid matching rates—the ratio between the reimbursement dollars the federal government pitches in and those the local government pitches in. While state matching rates were based on state income (so that poorer states would get more federal support), territories all received the minimum matching rate, the one reserved for the richest states.[148] Had the U.S.V.I. had its matching rate calculated like that of the states, it would have received the maximum matching rate, which would have made a difference of hundreds of millions of dollars (Morgan and Lasowski 2013). This means, among other things limiting the effects of the ACA in the territories, that the U.S.V.I.. could not expand Medicaid coverage to as many people as they could have had they been given "state-like" treatment.

Most seniors in the U.S.V.I. are covered by Medicare,[149] but for those who are also eligible for MAP due to their low income, the program adds supplemental coverage that helps them afford the costs of medical care. It thus serves as a 'safety net' for seniors who cannot afford the co-pays and other costs associated with Medicare coverage. Expanding Medicaid to more seniors was thus seen to be filling a gap between those who previously could not afford the costs associated with Medicare, but whose income was still too high to qualify them for Medicaid.

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[148] In terms of routine coverage of those covered under Medicaid, the federal government pays a 55% of the cost, and the local government pays 45%#. This is the minimum level of federal matching available. For states, matching rates are determined based on income rates, so that low-income states receive higher matching levels. All the territories, however, received a 55% matching rate, irrespective of income rates. Had the U.S.V.I.'s matching rate been calculated on the same basis used for calculating state matching rates, it would have received an 83% federal matching rate (Morgan and Lasowski 2013: 26). This rate would have saved the territory $257 million over the seven-year roll-out of Medicaid Expansion (ibid).

[149] Broadly, Medicare covers U.S. citizens 65 years or older who have worked and filed taxes for a minimum of 10 years in the United States.

Despite Medicaid expansion, MAP was at the time of research not playing a large role in the healthcare of my focal participants. It may be that Medicaid Expansion had yet to saturate newly eligible older adult populations. Of my nine focal participants, only three of them had any involvement with MAP, one of whom has been signed up for some time and two of whom signed up during my fieldwork year.[150] I believe there are two main reasons that more of my participants did not rely on Medicaid for medical care, despite the fact that most of them (perhaps not all) were eligible under the expanded income requirements. The first is that a significant proportion of them (six out of nine) were on hospice care when I met them. Unlike other care and services covered by Medicare, hospice care is covered at 100%, which means it has absolutely zero associated costs for the patient. Additionally, because hospice is meant to be the final phase of medical care in one's life, and Medicare does not cover any other forms of care while a patient is on hospice, these participants were not seeking out other forms of care that would entail costs.[151] Indeed, it was the three participants not on hospice care who were signed up for MAP by the end of the research period.

The other reason, however, which I think is equally important, is that the care at main healthcare providers on St. Croix (FHC, the Charles Harwood Clinic, JFL Hospital) care is provided irrespective of one's ability to pay. Only private doctors' offices require insurance

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[150] In Appendix C, the focal participant profiles include a list of what programs that participated in.

[151] The problematic consequences of the free but palliative-only nature of hospice care under Medicare in St. Croix is a primary context of Chapters 7, 8, 9, and 10.

coverage or the ability to pay out of pocket.This means, for that there is no clear financial benefit in most cases to signing up for the program.[152]

The two participants who signed up without my intervention (one years before I arrived and one during the fieldwork year), they were both a) not on hospice care, b) had complex medical needs that required both specialized and ongoing treatment, and c) had sought care at FHC, where staff actively encourage patients to enroll). The third participant who signed up did so with my help and encouragement. Thus, even though my focal participants were generally income (and some in poverty), MAP did not play a decisive role in most of their care.

Meals on Wheels ("Elderly Nutrition Services")

Meals on Wheels is a program intended to supplement the nutrition of those who have trouble reliably procuring healthy meals for themselves. In the U.S.V.I., the program cooks and delivers hot lunches to seniors across the territory Monday-Friday. Meals on Wheels not income-based, but rather disability based: in order to receive a meal, you must be a senior who has difficulty leaving the house or cooking meals for yourself. During my research, about 5% of the

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[152] In an interview with me, a longtime Commissioner of DHS that had played a leadership role in designing Medicaid Expansion for the territory told me that one of the major challenges they faced in the early phases of the expansion was getting people interested in signing up. Because they weren't paying for the care they were receiving anyway, it did not save them any money to be covered by MAP.

seniors of the territory were participating in the program, receiving five hot meals delivered to their home every week.[153] Meals on Wheels is funded by local revenues and federal block grants.

Four of my focal participants received Meals on Wheels services (including Mr. Parker [Chapter 12] and Ruth [Chapters 9-10]). However, the dependence on this service varied significantly. For some, it was absolutely crucial, making it possible to get through the day and make ends meet. For others, it was treated like just one option out of many things that could be eaten, and alternatives were often procured. In general, it was relied on as a proxy for caregiving: rather than needing someone to be there in the middle of the day to either cook or otherwise obtain a meal, the older adult could be left on their own.

There were certainty focal participants in my study who were eligible but did not participate in the program (for reasons I'm not aware of). In some of these cases, it's possible that the convenience of a cooked meal midday could have lessened the strain on caretakers. However, based on the different uptake of the service amongst even just the few focal participants who used it, it is difficult to predict how this service would have impacted the daily lives of my other focal participants and their caregivers.

Food Stamps/SNAP (The Supplemental Nutrition Assistance Program)

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[153] Based on population figures from the U.S. Virgin Islands Bureau of Economic Research (2015). In 2015, approximately 653 seniors across the U.S.V.I.. had lunch delivered to their homes through this service (Department of Human Services 2016). (While this figure for each island does not exist, St. Croix should represent approximately half of this number, or 327 seniors.)

The Supplemental Nutrition Assistance program (SNAP, more commonly known as "Food Stamps") provides funds directly to low-income individuals and families to buy groceries.[154] 100% of these funds are provided by the Federal Government. Allotments are quite variable, and are determined by income and household size. In FY2014 approximately one third[155] of St. Croix's population received assistance through the SNAP program.

At least two of my focal participants received SNAP benefits. I do not know how much they received, however I do have a sense of the relative significance of these benefits in their lives. Mr. Parker (Chapter 12) and Ms. Hanks (Chapters 13-14) relied heavily on food stamps to keep groceries in their homes. It was a major source of support for them. For Mr. Parker, it was a main way through which his son and caregiver Robby was able to make ends meet, as he did not have to worry about putting aside money for his dad's groceries. Ms. Hanks's food stamps were a source of support for herself, her ex-husband (and full-time caregiver), her developmentally disabled daughter and at least one of her other daughters who lived nearby. I discuss the turmoil around the use of these food stamps in Chapters 13-14. In both Mr. Parker and Ms. Hanks's cases, I don't know how many people they had reported as living in their household, and thus how many they're food stamps were "supposed" to be feeding.

Homemaker Services

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[154] Currently, these funds are supplied via electronic transfer onto a debit card that individuals can use at most stores that sell food. Funds are renewed monthly.

[155] A total of 18,135 individuals (Department of Human Services 2014).

DHS's Homemaker program provides helpers who come into seniors' homes a limited number of hours per week to help with everyday tasks. This is a program intended to help make up for the lack of long-term senior care beds in the territory, by helping seniors "age in place," or be able to stay in their homes for as long as possible. These include household tasks such as cooking and cleaning, that must be done regularly but are difficult for disabled or medically fragile seniors to do on their own. In certain cases, the homemaker is also a Certified Nursing Assistant, in which case they also attend to personal care needs of the senior, such as bathing and grooming. In FY2014 two-thirds of those that Homemaker Services served were 80 years old or older (U.S. Virgin Islands Department of Human Services 2015).[156] From what I could tell, the maximum amount of help available to a senior was a 2-hour visit, five times per week. It was also possible, on the lower end, to only have someone come by once each week for a couple of hours. The Homemaker program is funded by local revenues which can be supplemented with federal block grants. However, the program was underfunded and understaffed and most program enrollees received far less care than they needed. The program was stretched extremely thin, and there was far more need than they were able to meet.

Only one of my focal participants, Mr. Parker, was enrolled in the Homemaker Program, and a CNA came to his apartment five days a week for 2-3 hours. Because he was bed-bound and lived alone, it was truly crucial service for him, as I further at length in Chapter 12.

Direct Financial Assistance: Social Security and Old Age Assistance

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[156] This was a total of 342 seniors, about 2.5% of seniors in the territory. However, the program served approximately 9.5% of individuals over 80 years old or above in the territory.

Social security is paid directly by the Federal Government as the main form of state financial support for retirees.[157] Monthly social security benefits vary depending on how much an individual earned while working (higher income leads to higher Social Security benefits). As discussed above, while in American states Social security benefits are supplement by Supplemental Security Income (SSI), in the U.S.V.I. the older Old Age Assistance program (OAA) is still in place. OAA pays out very small benefits at rates that are set by the territory, with Federal Funds matching at 50% (local funds pay half, federal funds pay half).

I cannot overemphasize the importance of Social Security benefits to my focal participants, for most of whom it was the main source of income. Providing them hundreds of dollars each month, this Social Security payments were what enabled them to pay for the basics of daily life, whether rent, groceries, the phone bill, the power bill, etc. Old Age Assistance, on the other hand, contributed substantially less to their income and was thus not nearly as crucial. Eight of my ten participants were reliant on Social Security benefits, and the other two had not yet reached the age at which it is standard to begin receiving these payments and thus I am not certain whether or not they were receiving them.[158]

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[157] In order to be eligible for social security benefits, individuals must have paid taxes on earnings for forty quarters, or ten years. Individuals do not need to be U.S. citizens in order to qualify for benefits.

[158] These participants, Angelica and Ms. Hanks, were both under the age of 66, which is considered by the Social Security Administration to be the standard retirement age. While individuals are eligible for benefits starting at age 62, taking benefits starting before age 66 reduces your benefits in perpetuity. Both Angelica and Ms. Hanks had situations that made it difficult to know whether they're lives were being financially supported through early Social Security benefits.For instance, Angelica owned her own house, had been working in a white color position up until close to the time she got very sick and had a large group of very supportive friends. Ms. Hanks was living in government-supported housing with her disabled adult daughter and was being cared for by her ex-husband who was receiving Social Security. These are just some of the factors that made it unclear how much additional direct financial assistance would have been needed such that they may have taken to receive their Social Security benefits early.

Pharmaceutical Assistance Program (PAP)

This program helps enrolled seniors pay for their part of the cost of prescription medications. In 2014, about 6% of seniors in the territory were enrolled in this program.[159] PAP is currently funded exclusively through Video Lottery Terminal revenues in the U.S.V.I.. During the fiscal crisis of the early 2010s, the Department of Human Services was forced to stop enrolling seniors in the program and to cut certain benefits for those in the program. However by 2015 full benefits were restored. With Medicaid Expansion, less seniors should be needing to rely on PAP, as more will be covered by both Medicare and Medicaid. (PAP as a service largely directed to seniors who had been in that 'gap' between Medicaid eligibility and adequate income.) Unlike inpatient care, obtaining prescriptions does always require payment, which means that for many seniors it simply is not possible to obtain prescription mediations without this form of assistance.

I do not know how many of my focal participants were enrolled in PAP. Once again, a significant cause of this is because so many of my participants were on hospice care, in which all prescription medications are fully covered and were obtained through Shepherd hospice. I think it is very likely that at least some of my participants were unaware of the program entirely (such as those who weren't aware of MAP before the research period).

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[159] This is about 800 people (percentage calculated based on figures published U.S. Virgin Islands Bureau of Economic Research 2015).

ECAP/Energy Crisis Assistance Program

ECAP is a program for in which the Department of Human Services helps pay the energy bills of low-income seniors and people with disabilities. For those enrolled, DHS pays their energy bill every other month.[160] In FY2014 there were 1054 recipients of ECAP on St. Croix (about 2% of the population) (Department of Human Services 2015). The majority of recipients were seniors. Electricity is very expensive on St. Croix, and it is not uncommon for gas and electric bills to run into the hundreds of dollars per month. For low-income seniors, then, this aid was substantial: in FY2014 DHS paid out an average of $877 per enrollee. This program was funded partially through the federal LIHEAP (Low Income Home Energy Assistance) program, and partially through local revenues.

Only one of my participants that I knew of was enrolled in ECAP (Ms. Donovan, who is not discussed in the chapters to follow). However, because paying the energy bill is not an everyday activity, and I did not specifically ask all of my participants about their enrollment in ECAP, there many have been others who were enrolled in the program without my knowledge. ECAP has a higher income maximum than many of the other aid programs, which is why Ms. Donovan, who had a higher income than most of my other focal participants, was eligible.[161]

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[160] In FY2015, this amounted to payouts of $1.5 million annually (Department of Human Services 2015).

[161] One of the unintended consequences of this program's design of paying the bill every other month was that Ms. Donovan would often forget which months were hers to pay and assume that DHS was going to pay the bill. Ms. Donovan had fluctuating memory problems. At least twice during the year that I was conducting fieldwork, her power was shut off because she did not pay her bill, believing that it was DHS's turn. This always made her at least annoyed, and sometimes angry, as she still swore that it was DHS's turn to pay and that the power company had made a mistake. While she may have been correct, it was the power company's policy, through an agreement with DHS, not to shut off power to homes that DHS was late paying the bill on.

Adult Protective Services (APS)

Adult Protective Services (APS) offers a very different kind of care to older adults. In addition to being the program that investigates and manages cases of elder neglect and abuse, APS also provides counseling, screens for needs, and makes referrals, connecting seniors to specialized services as well as placing them in residential facilities when appropriate. While these are much-needed services on St. Croix, at the time of my fieldwork this department was barely functional, with a total staff of only two social workers for the entire island and an enormous backlog of cases.

For the most part, APS was in the background in many of the institutional contexts of my research. For instance, it was very common in my research with Shepherd Hospice for hospice caregivers to mention that they were considering alerting APS to the situations of their patients, due to commonly finding their patients in situations of neglect. My one concrete engagement with APS was via Mr. Parker (Chapter 12). Years before I met him, someone had called APS to report that Mr. Parker was being neglected by Robby, his son and caregiver. (Robby fiercely disputes this allegation; he had been out of town and had given the responsibilities of taking care of his dad to an willing and trusted friend). Mr. Parker's assigned social worker remained in the background of Robby and Mr. Parker's life, mostly in the role of a resource who could potentially connect them to services but who usually didn't come through.[162] I conducted a

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[162] During the negotiations over Mr. Parker's living situation for instance (see Chapter 12), his social worker played a role, albeit a small one.The perpetual narrative Robby expressed when it came to this social worker was that he was a good person, but that he just wasn't getting him and his dad what they needed.

person-centered interview with this social worker, was present for his visits with Mr. Parker, and became involved in helping him try to connect Mr. Parker with relevant services (such as MAP).

Residential Facilities

There were limited residential facilities dedicated to seniors on St. Croix. As previously stated, there was one nursing home, Herbert Grigg Home for the Aged. Herbert Grigg is a public facility. There were four public independent living facilities, Flamboyant Gardens, Genep Gardens, Whim Gardens, and Sunset Palms. Independent living facilities are essentially residential complexes whose units are set aside for seniors As of Summer 2016, there was one private assisted living facility, Loving Home Assisted Living. Assisted living is a facility whose services fall between those of independent living and those of a Skilled Nursing Facility ("nursing home").

Herbert Grigg is run like a Skilled Nursing Facility (SNF), however it was unaccredited and uncertified under the Centers for Medicaid and Medicare (CMS). The facility has 40 long-term beds available for seniors over the age of 60, and 1 respite bed for temporary stays. In 2015, there was a waitlist of 35 people. Residents live two to a room, and rooms are much like hospital rooms with a few additional pieces of furniture. Residents are seen to daily by CNAs, and nurses when their conditions require it. They are taken to JFL Hospital for any acute health issues. The facility has one public room with a large tv tables and chairs in a large U-shape. There is also extensive outdoor, grassy space with some benches.

In the two weeks of participant observation I conducted at Herbert Grigg, I learned that there are very few activities or programs for residents, with most of the energy and time of staff going into medical care, bathing and grooming, and feeding. Most of the residents have advanced stages of dementia or Alzheimer's, and many are permanently bed-bound. The facility is extremely underfunded, and is reminiscent of public nursing homes stateside.

Flamboyant Gardens, Genep Gardens, Whim Gardens, and Sunset Palms are all independent living facilities that provide single apartments for low-income seniors. Whim Gardens is by far the largest, with 100 apartments; Flamboyant Gardens has 56 apartments; Genep Gardens has 20 apartments (but some are reserved for adults with disabilities); Sunset Palms has 14 apartments. During my fieldwork, all of these facilities were full. To the best of my knowledge they all had waiting lists.

These facilities were all constructed and continue to be operated with U.S. Department of Housing and Urban Development (HUD) funds. This means that the construction of each facility was based on HUD building codes and other standards. The funds allocated for projects like these stipulate that residences are reserved for low-income individuals 62 and older.[163] HUD funds subsidize residents' rent, which makes these apartments substantially more affordable than non-HUD residences on island, providing the opportunity for very low-income seniors to live in their own well maintained apartment. HUD funds also pay for the everyday operation of the facilities (such as maintenance).

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[163] The Assistant Manager at Whim Gardens told me that recently a combination of new HUD regulations and the local pressures of the Governor's campaign against homelessness meant that they could no longer "discriminate" based on age, and so now had 40% of their residents in the 50-62 age range. She was not able to provide me further details, and none of the other HUD-funded senior housing seemed to have experienced this change.

Figure A: Apartments on the grounds of Whim Gardens.

The agencies running Flamboyant Gardens and Whim Gardens, and the manager of Sunset Palms, have implemented a number of additional supports to make the facilities, to different extents, approach assisted living. Whim Gardens (run by the Department of Human Services) serves as a congregate location for hot lunches served through the Elderly Nutrition Assistance Program.[164] While they had previously had nursing staff as well as homemaker and transportation services at the facility, during the period of research these services had been greatly reduced due to budget cuts at DHS. There was one nurse coming three times each week (for all 100 residents), and there were no longer any homemaker or transportation services.

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[164] The other congregate locations are St. Croix's two senior centers.

At Sunset Palms (independently run), the manager, who was fairly new to the job, had been attempting to connect residents with existing public aid and social services (such as ECAP) that they were eligible for but not participating in. She had also been attempting to hold group activities (like group meals with games, or exercise classes) to keep the residents "active," however it seemed there was less engagement with these activities than she had hoped.

Figure B: The kitchen of a recently vacated apartment at Sunset Palms.

At Flamboyant Gardens (run by Lutheran Social Services), the services are significantly more extensive. The full-time services coordinator worked to make sure that every resident was enrolled in every public aid program that they were eligible for.[165] Transportation services were

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[165] Approximately 90% of residents had ECAP, 90% were receiving SNAP benefits (food stamps) and 7 residents (out of 56) were receiving Meals on Wheels.

available both through a regularly scheduled shuttle and through reservations placed ahead of time. Nurses ato the facility for three hours, three times each week to provide basic check-ups and to provide some medical case management services for the residents (such as helping them keep track of their prescriptions). Additionally, LSS has, for many years, won federal AmeriCorps grants to bring volunteers to Flamboyant Gardens. This volunteer staff does daily rounds checking on all residents and helping them with everyday tasks. They are also available to accompany residents on errands.

Figure C: Apartments on the grounds of Flamboyant Gardens.

The implementation of these support services was explicitly done to help make up for the dearth of long term beds in the territory by turning Flamboyant Gardens into a place where seniors could continue to reside even after they could no longer do so “independently.”

While none of my focal participants lived in any of these facilities, a resident of Flamboyant Gardens did participate in the study.[166] He was a 62-year old Afro-Caribbean man born on St. Croix, who I call Mr. Judd. Mr. Judd was in relatively good health, although he had poorly controlled diabetes.[167] I learned from Mr. Judd that a substantial reason why he had wanted to live at Flamboyant was the sense of security it brought him as an older adult living alone. He told me that he liked having the Americorps volunteer check on him everyday, and that he liked knowing about all the services available to him, even though he didn't need them yet. He told me about a neighbor who had fallen down in her apartment and who an Americorps volunteer had found and helped while in their daily rounds. Mr. Judd contrasted this to the situation of many seniors, who are living alone—were something to happen to them, he told me, no one would find them for a long time. He counted himself lucky, as if it weren't for Flamboyant he saw himself as one of those people.

Loving Home Assisted Living was the one true assisted living facility on St. Croix. It opened in July 2016, and could house eight residents. Like Herbert Grigg, Loving Home provides 24-hour nursing staff and provides residents with all of their meals. In September 2016, when I visited the facility, they had three residents, all of whom had advanced dementia. The facility is a beautiful, one-story Crucian house, with renovated interiors and two acres of lawn and fruit trees surrounding it. Home-cooked meals are provided by licensed dietician, there are planned activities every day, and family members can visit 24-hours per day. It is owned by a

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[166] A number of circumstances influenced the fact that Mr. Judd did not become a focal participant. I met him late in the research period, he was relatively young (62) and was not undergoing serious illness or disability.

[167] Additionally, an onset of debilitating sun-sensitivity in his fifties had forced him to retire early from his job as a landscaper.

husband and wife who live in the renovated basement underneath the facility and strive to make the residence feel like a family home.

Figure D: A shot of Loving Home from the expansive backyard.

In addition to the three tiers of care it provides for residents (based on medical need), Loving Home also offers day-care and respite services. Unfortunately, the price to live at Loving Home is far higher than most families on St. Croix can afford. For the lowest tier of care, the cost is $3,600/mo.[168]

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[168] Cindy, the Director of Loving Home, told me that she had found after opening that there seemed to be more of a need for daycare rather than residential care. She knew there was a dearth of long-term care beds in the territory, and initially she and her husband had wanted to open a 100-bed facility on-island. However, after those plans fell through, they chose to move forward with this smaller facility. While Cindy was from St. Croix, and was very familiar with the island,she was coming to see now that the facility was open that the price-point for daycare might be more in line with what is possible for families on island. Daycare from 7:30am-5:30pm was $75, or $17/hour for part of the day. 24-hour respite care was $150.

Figure E: A bedroom at Loving Home

One of the striking features of all of these residences is that seniors at all of them were living alone. I talked to each of these facility administrators about how much families participated in the lives of the residents. Generally they were vague, but gestured to there being some family involvement. However, these answers were belied by other observations that indicated that these seniors were more alone, such as Mr. Judd's comment about the lack of anyone save the Americorps volunteers to find him should he hurt himself, or the response of the

Service Coordinator at Flamboyant when I asked her what the hardest part of her job was: “How lonely people are,” she told me. “Feeling bad about how people’s families are too busy.”[169]

Acute Care

The major acute care facilities available to seniors on St. Croix are the Gov. Juan F. Luis Hospital and Medical Center (JFL), the Frederiksted Health Care, and the Charles Harwood Medical Center. JFL was by far the central hub of acute care on St. Croix.

Figure F: The Charles Harwood Medical Center

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[169] This is not to say that families never visit: during my one visit to Loving Home, one of the only three residents had a family member visiting who was clearly very familiar with the staff form having visited in the past.

All of the residential facilities brought residents to the hospital when acute care was needed, and Shepherd got many of their new patients from hospital referrals. It was the acute care facility most used by my focal participants.

JFL has 105 inpatient beds and has between 4,000-5,000 admissions annually. It is a full service hospital, but does not have the staff and technology available for many kinds of complex of serious procedures, for which patients must either go to a private clinic, or more often travel to St. Thomas, Puerto Rico, or stateside.[170] As I discussed in Chapter 5, JFL is perpetually suffering financial difficulties, which leads to understaffing, staff burnout, and lack of supplies.

Figure G: The Governor Juan F. Luis Hospital ("JFL")

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[170] As an example, during my pilot fieldwork in summer 2014, there was no working MRI machine on-island. Additionally, JFL's psychiatry unit has been closed for years.

My most common experiences at JFL were with focal participants, either in the Emergency Department or once they were admitted as patients. Some of my focal participants went to the ED relatively often, and I spent approximately 40 hours there over the course of fieldwork. When my focal participants were admitted as inpatients in the hospital, which was not uncommon I would visit them frequently. The quality of care that I observed at JFL was often poor, both in the ED and in inpatient departments.[171] My repeated assessments are matched in the CMS Statement of Deficiencies and

Plan of Correction issues to the hospital in August 2014 (just one of many issued in recent years). The 112-page document is the official write-up of a facility-wide survey conducted by CMS in order to determine JFL's ongoing qualification for CMS certification. It includes all of the breaches of CMS guidelines found during the survey, with narratives of particular examples provided as evidence. Some examples of breaches and the consequences include:

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[171] In the ED, focal participants would often sit for hours in the extremely cold room without a pillow, sheet, or blanket to cover themselves (for some reason, JFL was chronically over-air conditioned). When I would ask for these amenities, they would sometimes (after a long wait) be forthcoming. Otherwise I would be told they didn't have any right now. Waits to see be seen by doctors were extremely long, and waits to be seen by nurses or CNAs were only marginally better. My notes for the nights I spent in the ED with my participants list the sporadic moments in which they got some kind of care or attention in between the long periods while they waited in pain and discomfort. My visits to the inpatient wards to visit my participants also revealed poor standards of care. When I got there, I would find my participants often needing help, for instance overdue for their pain medication or their breathing treatment. Tracking down someone to administer the medications that the doctor had prescribed often took several trips to the nursing station and a number of desperate requests. For instance, on oneone particularly upsetting visit to Ms. Hanks (see Section 6) , she was crying out at the top of her lungs for someone to help her for several minutes while I rushed back and forth from the nursing station back to her side to attempt to comfort her. When the nurse finally did arrive, her attitude was blasé: she said she had just been here five minutes ago, and she seemed fine then. This is not to say that the professional caregivers at JFL are not working very hard. Indeed, I believe that most of them are almost all of the time, and that they do truly care about their patients. However, the hospital is chronically understaffed and underfunded, making it a highly stressful work environment and one where providing consistently good care is difficult. It is also the case that I did witness instances of healthcare workers at JFL being kind to my participants, or making sure to take good care of them. However, these instances were definitely the exception to the rule.

- "The Governing Body failed to ensure that the Medical Staff provided quality care to patients in that numerous cases that lead to patient harm were not brought to the attention of the Governing Board (...) This practice poses a high potential for harm to patients admitted to this hospital."
- "The hospital failed to ensure that patients were able to make informed decisions regarding their care."
- "The hospital failed to provide care in a safe environment."
- "Review of hospital documents revealed that there is no mechanism in place to track medical errors and adverse events, and no preventative measures implemented to reduce medical errors. This failure poses a high potential of harm to patients admitted to this hospital."

Each breach cited is followed by examples of poor, sometime atrocious, instances of patient treatment, in which patients were neglected or harmed, and sometimes died because of it. Many of these patients were older adults. Overall, the document indicates the continuing difficulties of running a hospital within the structural conditions of (post)colonial disregard.

End of Life Care

Shepherd Hospice and Caring Heart Hospice are the only two institutions on St. Croix dedicated to end-of-life care. They treat a minority of those who die on-island, and many St. Croix residents die either in the hospital or at their home without being enrolled in hospice care.

There is, however, growing knowledge of these two services among healthcare providers on St. Croix: one of the three residents at Loving Home was a hospice patient, and during my fieldwork Shepherd had begun attempts to once again, as they had in the past, care for certain patients at Herbert Grigg. Thus hospice is slowly becoming more integrated into the system of older adult care and services there. However, as I discuss in the next chapter, the role hospice is playing on St. Croix is a frought one in the context of the inadequate care options.

Conclusion

This chapter has provided an overview of the orienting conditions in which care and services for St. Croix operate and of the specific forms of care and services available for older adults on St. Croix during the time of my fieldwork. It is intended to be as comprehensive as possible so as to make clear what is shaping possibilities for older adults on island as well as what the bounds of these possibilities are for seniors without the means to go off-island for care. The orienting conditions indicate direct continuities with themes discussed in the previous chapter, thus demonstrating how contemporary services and care for older adults on St. Croix are outgrowths of the broader history of the island.

My fieldwork did not include in-depth research at every institution mentioned here and thus further research could construct an even more complete knowledge base of care possibilities for older adults on St. Croix. Furthermore, because of the effects of Hurricane Maria in September 2017, a year after the end of my fieldwork, this chapter does not present an up-to-date account of care institutions and services, many of which are still as of writing in various states of recovery and some of which have surely shut down permanently.

The rest of the dissertation provides ethnographic accounts of different aspects of care, illness, and end of life on St. Croix, all of which unfolds within the context of the care and services possibilities discussed here. Many of these institutions and services will be revisited in the context of my focal participants' unfolding lives and experiences. In the remaining two chapters of this section, however, I focus on bureaucratic processes shaping this landscape of care and their self-disclosure as constituting a mode of (post)colonial disregard.

Chapter 7

Hospice, Durable Medical Equipment, and Bureaucratic Disregard

In this chapter, I examine federal bureaucracy as a particular channel through (post)colonial disregard discloses itself. In particular, I consider the bureaucratic functioning of the Centers for Medicaid and Medicare (CMS) through comparative case studies of two forms of care under their jurisdiction: hospice care and Durable Medical Equipment Provision. These case studies are illustrative because the presence or absence of either one of these forms of care has direct consequences for older St. Croix residents experiencing ill-health or disability, and because they are both entirely dependent on CMS's bureaucracy. For both hospice care and Durable Medical Equipment (DME) provision, CMS regulations wholly define their possibilities for coming into existence and for the operations that sustain that existence. I argue that this case study reveals a logic of disregard to be operational in the functioning of CMS's bureaucracy on St. Croix in a way that has critical consequences for older adults needing care on island.

Within the American healthcare system, DME provision and hospice care are normative pieces within the structure of care in any community.[172] DME includes a wide variety of equipment, some of the most familiar of which are items like canes, wheelchairs, hospital beds and concentrated oxygen. Having access to this equipment in an outpatient setting is crucial for the functioning of the healthcare system and is essential for patients with illness or disability. Without it, a variety of medical conditions are far less manageable, at times catastrophically so. Hospice care is meant to provide in-home palliative care for patients near the end of life who no longer wish to pursue curative treatment, and itself relies on DME in its practice. Both of these forms of care are covered by Medicare, which means that they are regulated by CMS. Without the CMS certification that comes with adherence to CMS regulations, this care is not covered by Medicare and becomes unaffordable to many individuals.

While hospices continue to provide care on St. Croix, there is no longer any purveyor of Medicare-certified (i.e. Medicare-covered) Durable Medical Equipment on island. Indeed, what the recent history of healthcare on St. Croix shows, and what I investigate in this chapter, is that within the Medicare system it is seems that it is more profitable to put St. Croix residents on hospice care—palliative care oriented toward providing a comfortable death— than it is to provide them access to Durable Medical Equipment—such as oxygen concentrators, wheelchairs, and hospital beds—that could help support their continuing life.

To understand how this came to be, we will plunge into the history, logics, and functioning of Medicare as they articulate within hospice care and DME provision. This will first

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[172] It is certainly not the case that all communities in the United States have access to these two forms of care. However, the CMS bureaucracy assumes their presence as part of the 'normal' healthcare infrastructure.

require me to take a step back and provide a history and description of hospice care in the United States, and importantly its inclusion within the Medicare system. This is necessary background for understanding the role that hospice is playing on St. Croix today. I will then recount the local histories of the arrival of hospice care on St. Croix, and the attempts of a DME provider who tried and eventually failed to provide Medicare-covered medical equipment to St. Croix residents.

The Medicare Hospice Benefit

In order to understand the role federally regulated hospice care is playing on St. Croix in shaping the end of life of many older adults there, it's important to understand the history of hospice in the United States more broadly. In this section, I discuss hospice's origins, ideological tenets and care practices, and how it came to be included in CMS's bureaucratic scope.

A Brief History of Hospice Care

The first modern hospice[173], St. Christopher's, opened in 1967 in London. It was founded by Dame Cicely Saunders who headed the inpatient institution and created the philosophy that continues to guide hospice care today. Hospice care arose in a particular historical moment in which it was positioned as an 'alternative' to mainstream forms of end-of-

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[173] As many others have pointed out, "hospices," rest houses for travelers and the sick, have existed for millennia. The singling out of St. Christopher's as the first "modern" hospice signifies that it was the first institution in which modern palliative care measures came together with a holistic approach to treating the patient.

life care. The fate of dying patients in hospitals in the United States and the United Kingdom in the middle of the 20th century was most often to be neglected, ignored, and kept in the dark about their terminal condition (see Doka 1997; Glaser and Strauss 1965; Kastenbaum 1986, 1997; Lawton 2000).[174] As public awareness about this kind of treatment grew in the late 1950s and 1960s, it fed into other growing anxieties about death in the public sphere, anxieties that historians have linked to the growing awareness of cancer (Abel 2013; Doka 1997). Alongside this was a growing faith in biomedicine (James and Field 1996; Kastenbaum 1986; Long 2005), that left people feeling helpless and anxious in the face of death, which seemed now unapproachable by the untrained and best left to biomedical experts.

However, this was also an era when alternative social movements were rising up to unsettle normative, conventional perspectives on the social world. The civil rights movement, feminism, the "return to nature" movement and others, opened up new possibilities for envisioning and enacting life in common. In this climate, the hospice movement arose as one of several social movements aimed at disrupting contemporary normative ways of thinking about and approaching death.[175] The rise and maintenance of hospice care as a movement was further supported in this historical moment by the growth of consumerism that was fostering attitudes and practices directed toward personal control over everything in one's life, including the conditions of one's death (Doka 1997). A growing sense of public responsibility and

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[174] See Abel 2013 for a historic account of the treatment of the dying were in the United States 1880-1965.

[175] The two other main movements were the euthanasia movement and the death awareness movement. The death awareness movement that brought us such texts as *The Meaning of Death* (1959, Herman Fiefel, Ed.), *On Death and Dying* (1969, Elisabeth Kübler-Ross) and *Death, the Final Stage of Growth* (1975, Elisabeth Kübler-Ross).

volunteerism among the American middle class also helped support the fledgling hospice movement that largely relied on volunteers to carry out its work (Clark 2010).

When St. Christopher's Hospice opened, it "almost immediately became the beacon and model for hospice programs worldwide" (Kastenbaum 1997: 104-105). Even in the decade or so before it opened "a nascent hospice movement was emerging" due to Saunders's international travels, talks, and publications (Clark 2010: 44). The emergence of this movement was particularly strong in the United States. Seven years after the opening of St. Christopher's, in 1974, the first American hospice opened in New Haven, Connecticut. It was directly modeled on Saunders's institution and philosophy of care (Doka 1997). Hospice care grew rapidly in the U.S., with approximately 2000 hospice services in the country by 1997 (Kastenbaum 1997) and 4,199 by 2015,[176] serving all 50 American states and all 5 American territories (National Hospice and Palliative Care Organization 2017). Unlike St. Christopher's, today the vast majority of hospices[177] function using a home-healthcare model, with patients continuing to live in their homes or place of residence (such as an assisted living facility), and caregivers coming to them.

It's important to emphasize that despite's hospice's success as a model for end of life care

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[176] These figures represent the number of agencies certified by Medicare to provide hospice services. There are other (but many fewer) hospice programs in the country that provide care that is not monitored by, nor reimbursable by, medical insurance. However, because they are not registered with any kind of centralized entity, their numbers are unknown.

[177] Because of the way that the National Hospice and Palliative Care Organization (NHPCO) and the Center for Disease Control (CDC) collect and present their data, it is not possible for me to say what percentage of hospices in the U.S. today function out of an in-patient facility versus what percentage operate using a home-healthcare model. However, it is by far the most common method of hospice care 'delivery' in the United States today. To give an idea (with the statistics available), 96.7% of the days of routine hospice care (RHC) provided by Medicare certified providers in 2015 took place either in a private residence or in a nursing facility. Only 1.1% of the days of RHC provided occurred in an inpatient *hospice* facility. Importantly, 97.8% of the total days of hospice care were Routine Hospice Care. This shows the hospice care in the U.S. today is largely a caregiving practice that takes place wherever the patient is living when they begin hospice care.

today[178] it remains an 'alternative' form of care in many ways. Medical anthropologists such as Helen Stanton Chapple (2010) and Sharon R. Kaufman (2006) have shown the extent to which hospital care to this day orients toward patient death as failure. In this paradigm, curative efforts are the only logical course of action, and any acknowledgement that a patient is dying are indefinitely postponed.[179] Choosing hospice care near the end of life thus presents an opting out of this normative curative trajectory. However, while the hospital care model continues to dominate acute and end of life care, hospice care in the United States is now decades into a process of bureaucratization that has included it more and more within the mainstream healthcare model. It has thus become less and less a radical break and has become more incorporated as a normative stage of medical treatment.

The bureaucratization of hospice care in the United States began in in 1982, when it became integrated into the Medicare program.[180] This happened by way of a vote of Congress, through which it became law that a "hospice benefit" was included in Medicare coverage. Available to all American citizens and permanent residents[181] 65 years or older[182] who have

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[178] See Saunders and Kastenbaum (1997) for a collection of essays attesting to hospice's international spread in addition to its extensive spread in the U.S.

[179] As Kaufman (2006) shows, there are several different trajectories that hospital patients with potentially fatal conditions are pragmatically placed into by healthcare workers. Each of these trajectories has different consequences for the way that the patient's death is positioned and related to. In none of these trajectories, however is the patient's death accepted months before it occurs, as in hospice care.

[180] See James and Field (1992) for a theoretically rich discussion of the 'routinization' of hospice care in the United Kingdom that is applicable in many ways to the American hospice situation. See Saunders and Kastenbaum (1997) for accounts of the variable degrees of regimentation and bureaucratization of hospice in many countries around the world.

[181] Permanent residents must have lived in the U.S. for 5 years or more in order to be eligible.

[182] Medicare is also available to individuals under 65 with certain disabilities.

worked and filed taxes[183] for at least 40 quarters (10 years), Medicare is the assumed basic health insurance for seniors across the country. As the three footnotes in the last sentence may have signaled, Medicare is a complex program whose various regulations are not easily summarized. Most importantly for our purposes here, however, is that Medicare is divided into four "Parts" (A, B, C, D), and those four Parts each cover different kinds of medical services (prescriptions, hospitalizations, primary care appointments, etc.) and have different payment and eligibility requirements. Hospice care is within Medicare Part A. Individuals who fit the above requirements are automatically enrolled in Medicare Part A near the time of their 65th birthday and do not pay anything for Medicare Part A coverage. Part A also covers hospital, skilled nursing facility, and home health care as medically necessary, with different payment schemes for these different forms of care. For hospice care, Medicare beneficiaries deemed eligible according to Medicare guidelines pay nothing. Since the hospice Medicare legislation in 1982, most private health insurance providers have included a hospice benefit into their coverage with the same basic eligibility requirements.[184] This bureaucratization has greatly expanded hospice care in the United States. In 2015, 38% of people whose deaths were recorded in the United States died on hospice care.[185] However, despite this prevalence, it is nonetheless extremely

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[183] Medicare is paid for by through the Federal Insurance Contributions Act (FICA) that imposes a tax on all employees (except for particular categories who are exempt). Medicare is also available for purchase to individuals who have not met this requirement, details of which I will not discuss here.

[184] However, the possibilities for hospice care in private insurance plans is outside the scope of this study. This is both because almost every older adult I worked with on St. Croix was enrolled in Medicare and because (as discussed in Chapter 5) there is no private medical insurance available in the U.S. Virgin Islands except through certain large employers (such as the territorial government).

[185] This figure includes *all* deaths, including those of younger people and those not caused by illness. Of those enrolled in Medicare at the time of their deaths, 46% of people died while on hospice care (National Hospice and Palliative Care Organization 2017). As 84% of the Medicare population is 65 years of age of over, this second figure provides a better sense of the prevalence of hospice care in the deaths of older adults in the United States.

important to keep in mind that hospice care in most of the United States remains an *option* for end of life care within a paradigm and an infrastructure still dominated by biomedicine's imperative to maintain and extend life.

When hospice care became part of the Medicare program through federal legislation, the regulations that defined it and structured its place in the American healthcare system were substantially based on existent hospice philosophy and practices. Thus to understand the state of hospice care as part of Medicare, we need to look at its original philosophy, aims, and methods.

Hospice Philosophy

Since its beginnings, hospice has always been strongly oriented to providing a "good death" for their patients—it is the mission of hospice care. Hospice philosophy approaches this "good death" in a few different ways. First, it strives to understand and treat patients suffering in terms of "total pain" (Clark et al. 2005; Lawton 2000; Saunders 1997). This means addressing each patient's "physical, mental, social, and spiritual pain" that comes not just from their physical ailment, but from the experience of being terminally ill (and likely having already been very sick for a good deal of time) (Saunders 1997: 5). In American hospice today, this philosophy translates into a caregiving team composed of a doctor, nurse, social worker, chaplain, and companionship volunteer—the idea being that with all of these disciplines represented, there will be a caregiver available who can deal with each aspect of the patient's "total pain," and thus help the patient die a good death.[186]

A second part of how hospice philosophy and care envisions the "good death" for their patients is by attempting to bring their "social death" in line with their "biological death," so that those two forms of death correspond in time (Chapple 2010; Lawton 2000). This is encapsulated by hospice's unofficial motto: "Live until you die" (Lawton 2000). The following is a pledge written by Cicely Saunders herself, intended to speak for the hospice movement as a whole:

"You matter because you are you,
You matter to the last moment of your life,
and we will do all we can
not only to help you die peacefully
but to *live until you die"*
(Saunders, cited in Twycoss [1986: 19], in Lawton 2000:14 [emphasis in Lawton])

While part of this is a promise that you will be cared for until the moment of your death (and not neglected as was common in some hospitals of the era when hospice emerged) another aspect of it is that you will be helped to *be yourself* until the moment of your death. This translates into the care goal of keeping patients clear-headed through exemplary pain control. The idea is "to allow dying persons to live as fully as possible, free from debilitating pain and incapacitating symptoms" (Doka 1997: 20). Of course, pain control itself is a goal of hospice care, but it is pain control for the sake of being able to live as fully as possible the weeks and days before your death.

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[186] According to U.S. Medicare guidelines, patients in the U.S. who sign onto hospice may opt out of the services of the chaplain, social worker, and volunteer, but may not deny the services of the nurse or the doctor.

Hospice philosophy has a vision for what living during that last period will look like. As written by Cicely Saunders, being free from pain allows patients “to explore meaning, reconcile and heal relationships and complete important personal tasks (Saunders 1997: 6, from St. Christopher’s Mission Statement). The idea is that this kind of life before death is simply not possible without excellent pain control.[187] Palliative care science thus comes together with particular social goals in hospice care. In this picture, “once a dying person is freed from pain that person retains the human potential to grow and the possibility to use his or her remaining time to express love, finish significant and meaningful tasks, and reconcile with others” (Doka 1997: 25).

The possibilities for this time of life are further framed by another key tenet of hospice philosophy: that no one should die alone. This was a key ideal in the founding of St. Christopher’s hospice, that was meant to create a veritable community in a “’home-like’ atmosphere” (Doka 1997: 20), where not only would people not die alone, but they would die in a loving group that they knew cared about them (Clark 2010; Saunders and Kastenbaum 1997). Once again, this model of care arose in a time when the awareness of cancer was growing and family were feeling less and less empowered to take care of the loved ones at home, leading to the risk of relative isolation of patients in their final stages of illness, whether at home or in the hospital. When a patient was brought into hospice, then, one of the hopes and intentional

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[187] The foundational approach to pain control in hospice care is the “3-stepladder” approach, in which patient’s physical pain is ideally treated starting with non-opioids (step 1), then (when the pain worsens or the non-opioids stop working) up to weak opioids (step 2) and then, if needed, up to strong opioids (step 3) (Saunders 1997). These painkillers are ideally given on a regular schedule in order to anticipate, rather than react to, the incidence of pain (ibid). It’s important, however, that in my observations of hospice care, this process was often short circuited or circumvented. It serves as an ideal model, rather than a true description of practice, at least in the hospice agencies I have studied in Southern California and St. Croix. Furthermore pain control itself was an everyday struggle in the case of many hospice patients I worked with. Living a comfortable existence near the end of life was a promise largely unfulfilled, despite the attempts of hospice caregivers.

purposes was that the family (or loved ones) too could be cared for, as they too were in the midst of undergoing an enormous and difficult transition. The "family as the unit of care" remains a primary tenet of hospice care today.

Another critical and complementary aspect of how the "good death" is envisioned in hospice care philosophy and practice is that patients will be fully aware—and "accepting"—of their terminal prognosis. This aspect of the good death similarly reaches back to the very origins of the modern hospice movement: unlike common practice in hospitals of the time, "[h]ospice pioneers advocated a model in which patients were informed frankly and openly of their condition, and were actively encouraged to participate in all the decisions surrounding treatment and care" (Lawton 2000: 13).[188] Of course, however, "acceptance" of one's prognosis also necessarily implies a very high level of trust and certainty in prognostic accuracy. This is an issue that is not a part of hospice philosophy discourse, but that raises questions about the possibilities for hospice care to engage with communities that tend either not to trust biomedical prediction or who have beliefs that supersede such trust (for example, as is the case for many individuals in St. Croix, the firm belief in an omnipotent Christian god who can save anyone's life at any time, no matter how close to death they may seem). However, because the importance of "accepting" one's death in hospice care developed within a discourse that framed anything besides acceptance as "denial," (a phenomenon etched into the American cultural psyche by Elisabeth Kübler Ross's [1969] famous 5 stages of grief) there is a problematic assumption built into the heart of contemporary hospice practice: either patients and their loved ones accept that death is

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[188] However, this aspect of the good death has been excluded from hospice care in cultural contexts in which patients are normally never or only rarely told of their terminal prognosis. For example, see Gongal et al.'s (2006) discussion of the practices of Hospice Nepal.

nearby, or they are in denial. If they are "in denial," it is the job of their hospice caregivers to convince them that death is in fact on its way very soon. This is a phenomenon I explore ethnographically in Section IV.

While individual hospice care workers in the U.S. today show various degrees of explicit knowledge of our alignment with these original principles, my observations of hospice care on St. Croix and previously in Southern California (in 2013[189]) indicate that these principles are alive and well in the everyday practice of hospice care. I believe that a significant component of why this is case is that in order to induct hospice into the Medicare program in 1982, these goals and ideologies of care needed to be codified into a set of regulations, regulations which guide the actions, decisions, and attitudes of hospice caregivers.

Hospice Philosophy—Bureaucratized

The codification of hospice philosophy into regulatory standards was crucial for enabling the monitoring and reimbursement of the costs generated by hospice agencies by the federal government. That is, in agreeing to cover the costs of hospice care at 100% for all eligible Medicare beneficiaries, the U.S. government needed to extend their centralized system for regulating and surveilling healthcare providers all over the country to hospice agencies. To this day, everyday hospice patient care is shaped in every way by regulations put into law at the federal level. And, these regulations are themselves based in hospice's original philosophy and

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[189] I conducted a two-month pilot study researching hospice volunteers and hospice volunteer programs in two home-hospice agencies in Southern California.

aims.[190] Two of the most consequential of these regulations for older adults in need of care on St. Croix. is the suite of eligibility requirements and the orientation toward the "good death."

As hospice was originally designed as a form of care meant to tend to people who were dying and could thus no longer be treated within mainstream biomedicine, contemporary American hospice regulations ensure that hospice care is *only* extended to those who are taken to in fact be dying. While there is of course an understanding among hospice practitioners that the timing of death is never *fully* predictable, in order to begin receiving hospice care under Medicare, a beneficiary must have a physician-certified prognosis of six months of less should their disease follow its normal course. And, once again, because hospice was meant to provide comfort and the possibility of a "good death" to those in great pain near the end of their life, contemporary Medicare beneficiaries must sign away their right to have any curative treatment covered by Medicare while they are receiving hospice care, legally opting for palliative care only.

While I will further discuss the complexities of this requirement in my case study of Ruth in Section IV, I'll briefly mention here that it is a the requirement to legally sign away one's rights to curative care is a multivalent act whose meanings are overdetermined within the system

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[190] One particularly interesting remnant of this process can be found in the regulation of hospice volunteers. As hospices were originally non-profit entities staffed entirely by volunteers, Congress codified volunteer participation into hospice legislation. Now, it is federally required that all hospices who participate in Medicare record 5% of their total caretaking hours per month as volunteer hours. That is, if they recorded 95 direct patient care hours in one month, then they must, by law, also have recorded 5 volunteer hours that month. While this is a regulation that ends up affecting patient care relatively little, it is interesting as an artefact of the process of bureaucratization. Additionally, as an interesting note in the logics of Medicare, regulation 418.78(d) identifies "Cost Savings" as one of five "Standards" regarding hospice volunteers. It reads thus: "The hospice must document the cost savings achieved through the use of volunteers." It then proceeds to identify three required aspects of documenting that cost savings. A bit of research into internal hospice training and education documents shows that it is the "cost savings" that is identified as being the crucial part of volunteer hour documentation.

of care.For example, not only does the signing of this form pragmatically indicate a willingness on the part of the patient (or their legal representative/caregiver) to cooperate with the palliative, non-curative care plan that will be put in place by the hospice caregivers, it also, in what might otherwise seem like an entirely separate domain, secure the legal authority for Medicare to not cover any curative treatments while the patient is signed on to hospice care. As mentioned above, hospice care is covered by Part A of Medicare, the same part that covers hospital care, home-health care, and primary care visits. When a patient is using Part A to cover hospice care, she cannot then also use Part A to cover anything else. By signing this form, the Medicare beneficiary legally indicates her understanding and acceptance of this aspect of the terms of her Medicare coverage.

Through examining eligibility requirements and the requirement to cease all curative care, we get a glimpse how the original purpose of hospice care when it emerged in the middle of the last century has been adapted and transformed in order to becoming a functioning part of the United States national health insurance system. These examples also suggest how hospice care's inclusion in this system both creates and limits possibilities for those nearing the end of their life. While there is much more to be said about the everyday functioning of hospice care and its role in shaping end of life experiences in the United States, some of which will come out in the ethnographic sections to come, this section has provided an adequate backdrop for understanding the role that hospice care is playing in St. Croix today.

Two Medicare Certification Stories

This section will extend the discussion of hospice onto St. Croix, and then compare it with the role and fate of Durable Medical Equipment suppliers on-island. Both of these forms of healthcare support are within the regulatory purview of Medicare (under the umbrella of CMS), and as we will see, this regulatory infrastructure plays a deciding role in the conditions of possibility of them both. In the paradigm of contemporary American healthcare, both are run as for-profit enterprises, and their existence thus depends entirely on their ability to remain profitable. In comparing these two types of healthcare provider that are regulated by the same bureaucratic logics, a picture emerges of how these logics operate through a mode of disregard on St. Croix.

These two case studies are recounted largely through the trajectories and perspective of two women who participated in my study: Gloria, the owner and administrator of Shepherd Hospice, and Christina, the administrator of Apex Durable Medical Equipment and Supplies. While “DME provision” and “hospice care” might seem like generic entities whose historical trajectories supersede individual lives, the local histories of DME and Hospice Care on St. Croix are very much embedded in the lives of specific individuals. While Medicare bureaucracy is certainly a macro-level entity that functions at the level of social structure, it is also one that shapes possibilities for individual life trajectories. This is very much true for older adults on St. Croix in need of care; it is also true, though, for care providers who have sought to work within this bureaucracy. With the size of community on St. Croix, the lives of single individuals can make the difference between whether or not a given institution, product, or form of care exists on-island or not. Thus the details of the operations of (post)colonial bureaucratic disregard on St. Croix, as broad and seemingly abstract as these processes are, can be disclosed in part through the trajectories of particular individuals.

Hospice in St. Croix: the founding of Shepherd Hospice

There are two hospice agencies operating in the U.S. Virgin Islands, each serving the three main islands of St. Croix, St. Thomas, and St. John.[191] Both are home-hospice agencies. One is a company owned and primarily operated in Puerto Rico[192], and the other is Shepherd Hospice. "Shepherd" for short, was St. Croix's first hospice, opened in 2001 on St. Croix by a nurse and healthcare administrator from the States, whom I call Gloria. Gloria is a white, highly educated woman in her mid-to-late fifties who was born and spent most of her life stateside. She is deeply involved in every aspect Shepherd's operations. She runs the office, supervises all of the employees (administrative and healthcare), heads patient care, and sometimes even takes on patients herself, when the other nurses' schedules are stretched too thin. She is the public face of the hospice and is extremely well-known in the healthcare community on St. Croix.

Gloria started her nursing career early in life, getting her RN, her Masters in Nursing, and becoming the Director of Nursing at a large hospital in a major metropolitan area in the mainland U.S. by the time she was 25. In the early 1990s, after some extended travel with her husband took her away from her previous job, Gloria decided to go into home-healthcare. It was just happenstance that Gloria learned about hospice care. It happened when one of her home-

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[191] They both also serve Water Island, the fourth largest island in the territory (approximate population: 128 [U.S. Census Bureau, 2010a]), located just off the southern coast of St. Thomas, in the Charlotte Amalie harbor.

[192] Unfortunately, my attempts to recruit any employees from this hospice into the study, even for a single interview, were unsuccessful. I thus know very little about this hospice.

healthcare patients told Gloria that she no longer wanted to be a burden on her family, and that she was tired of the constant returns to the hospital. When Gloria spoke to her nurse supervisor about it, her supervisor introduced Gloria to the idea of hospice care. Gloria was able to stay on taking care of this patient when she switched onto hospice care.[193] It was witnessing the end of this woman's life as a hospice patient that turned Gloria toward a career in hospice care. As Gloria recounted it: "I was with her when she passed. It was my first hospice patient, it was beautiful. I mean here the family and the daught-they're all crying, but they said: she's here at home with us when she passed. As opposed to being in the hospital and they wouldn't have been there. And that's when I thought this is what I wanna do."

Gloria stayed working for this company for some time, before she and her husband moved to Tampa and she took a job saving a home-health and hospice care agency from immanent Medicare decertification. After getting them "back on track", she partnered with the husband and wife owners of the company, eventually becoming a Vice President and COO and growing the company to be the largest home-health company in Tampa. As we'll see, the skillset needed to save a healthcare agency from Medicare decertification would prove extremely useful to Gloria when she began setting up her own company in St. Croix a few years later.

At some point during these years, in the mid-1990s, Gloria and her husband moved to St. Croix. They had traveled around the Caribbean in the past and liked it there. Both she and her husband had jobs based stateside that they were able to do mostly remotely, and Gloria flew to Tampa every few weeks. Eventually Gloria resigned from her position at the company in Tampa

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[193] While it's not clear from Gloria's narrative exactly how this worked, it's likely that the homecare agency she was working with also had a hospice branch (which is fairly common).

and moved full-time to St. Croix, while still working as a regulatory consultant for the company for the next year or so, working to make sure their satellite offices were in regulatory compliance. Gloria thus had a very long-term, in-depth engagement with CMS's bureaucracy.

On St. Croix, with her skillset, Gloria quickly got a job working at the territory's Medicare Quality Improvement Organization (QIO), a locally owned and operated entity called the Virgin Islands Medical Institute (VIMI).[194] VIMI was an important hub for healthcare on St. Croix, and many of the administrators who participated in my study had spent time working at VIMI. It was through working in this position, reviewing charts and working on quality improvement initiatives for Medicare Beneficiaries, that, as she says "I realized I that I was living in a really vulnerable community of the haves and the have-nots." This is when she began to think about the need for better healthcare on St. Croix. Then, at a Medicare conference in Washington D.C. that Gloria was attending for work, she struck up a conversation with a woman at lunch who turned out to be the Medicare Surveyor for the U.S.V.I.. A Medicare Surveyor conducts in-person "surveys" to determine organizations' level of compliance with the Medicare Conditions of Participation. It is these surveys that determine Medicare certification. Gloria spoke to this woman about how motivated she was to try to fill some of the holes in the healthcare system on St. Croix, and particularly about how she was dreaming about starting a hospice there. This woman, as Gloria recounts it, became a mentor for her, not only motivating her to pursue this ambition but guiding her along the way.

Over the next couple of years, Gloria worked to build what would become Shepherd

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[194] VIMI's contract as the Medicare QIO for the U.S.VI eventually expired, and in the next bidding cycle Helios (discussed in Chapter 8) won the contract.

Hospice. As she put it, “I'd work from eight to five, go home eat, and then I’d sit down at this computer that I have and start building a hospice.” It was extremely hard work, but she was dedicated. Because CMS won’t even survey hospice for certification until they have been in operation for one year and have a minimum number of patients, Gloria needed to get a hospice up and running to Medicare standards without the financial support of any Medicare reimbursement.

To help get her fledgling project off the ground, Gloria networked with other established individuals and providers important to the territory’s healthcare system. Gloria’s job at VIMI—she was eventually promoted to the Director of Clinical Practice— was significant in enabling these connections and this position helped her become deeply acquainted with the healthcare goings on in the territory. She was able to make one-on-one meetings with the Commissioner of the Department of Health, who brainstormed with her and supported her endeavor. At some point, the local rehabilitation and physical therapy facility, owned and operated by stateside doctors, was facing Medicare decertification, and turned to Gloria to help. In addition to paying her, they offered her help with her hospice certification, providing her with a temporary “office,” a room at their facility to put in her Medicare application as her company’s physical address. She had made friends the woman (a British ex-pat) who had co-founded the territory’s branch of AARP and who, now 96, decided she would both be Gloria’s pro bono business consultant and her very first patient. Sometimes, it was Another one of her first patients, a wealthy Panamanian ex-pat, gave Gloria $10,000 the second time they met, allowing her to buy a second car so that she could have more flexibility in traveling to patients’ homes (she had been sharing one car with her husband). Throughout all of this time, Gloria also remained close with the Medicare

Surveyor she had met in D.C., who was extremely knowledgeable about the process and supported her throughout.

As things started to get up and running, Gloria hired a few staff members. She hired a nurse who would serve as the social worker, and a few home healthcare aides, paying them out of her earnings from her ongoing full-time job and at some points digging into her savings. During this time, her husband, a licensed physician, served as the hospice's Medical Director. The final hurdle for Medicare certification came down to patient count: while CMS requires five patients minimum for initial hospice surveys, Gloria only had three—and one had just passed away, bringing her to two patients currently under her care. In the face of this problem, Gloria spoke to the Medicare Surveyor she was friends with, who told her about a waiver available for hospices in underserved medical areas like the U.S.V.I.. This waiver officially lowered the minimum patient threshold to two. Shepherd was thus allowed to undergo Shepherd to undergo the Medicare Survey. The small new company passed, becoming Medicare Certified in 2001.

This was of course not the last obstacle for Gloria and Shepherd Hospice. Gloria says one of the biggest difficulties in those first years was trying to educate the local population. She often spoke of how hospice had been a totally unknown form of care that even many of the doctors in the U.S.V.I. were unaware of. Those first years were full of more material difficulties, too: there was the several month delay in Medicare payments when 9/11 happened weeks after their initial survey (after over a year of caring for patients with no reimbursements); there was the time when all of their office supplies, including their only computer, was robbed; and the opening of the second hospice to the territory, a few years after Shepherd opened, did not make business any easier. Gloria also struggled with Medicare's hospice reimbursement rates, that, while adjusted by geographic area in order to ostensibly account for labor and supply costs in local markets, was lower than in many places in the continental U.S..[195] But, despite all of these difficulties, Shepherd has remained Medicare certified and operational for over 15 years .

Apex Attempts Medicare Certification

Unlike the story of Shepherd Hospice who tried for and achieved Medicare certification and has been able for 15 years to serve the Medicare beneficiaries of the territory at a profit, the story of Apex Durable Medical Equipment and Supplies ("Apex" here for short) is less successful. Indeed, their story helps show just how difficult it can be to obtain Medicare certification, but it also shows that obtaining Medicare certification can, in the U.S.V.I., actually lead to financial inviability.

Apex opened in 1998, and was the first supplier of DME and other medical equipment and supplies in the U.S.V.I..[196] At the time, they were not Medicare certified, so they were selling medical equipment and supplies to customers who were paying out of pocket. While their

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[195] Hospice reimbursement rates, while relatively straightforward in comparison to other types of Medicare billing, are still a very complex matter. Broadly speaking, what Gloria was referring to when she mentioned the inequity of reimbursements in the U.S.V.I. was that generally speaking, hospices are paid a daily rate per patient in their care. The standard daily rate is updated every year. Alongside the amount of that standard rate, it is determined what portion of that rate will make up the "labor" and the "non-labor" portion. Then, based on that standard rate and those given percentages of how the rate will be split up, the actual dollar amount of the labor portion of the reimbursement for a given area is determined by multiplying their local Hospice Wage Index by that labor portion of the standard rate. Different Hospice Wage Indexes are applied to different areas (based on data gathered by the Bureau of Labor Statistics) that are defined by the Federal Statistical Area Delineations created by the Office of Management and Budget. In 2016, St. Croix's Wage Index was 0.7864, meaning Shepherd received 78.64% of the standard rate for the labor portion of the reimbursement. The other "non-labor" portion is based on CMS's hospital "market basket" a tool used to approximate costs of supplies and other expenditures within a given geographic area (areas determined by the same process as above). I was unable to find any specifics regarding the U.S. Virgin Islands' CMS hospital market basket, however Gloria indicated that it did not reflect the high prices found in the U.S.V.I..

[196] Only some forms of supplies and equipment are categorized as "Durable Medical Equipment" within CMS.

administrative office was on St. Thomas, they were selling equipment to customers on St. Croix and St. John, as well as to those on other islands in the Eastern Caribbean. Christina, the Administrator at Apex, was from stateside and had been working for Apex for many years. She had worked for the company for several years when they first opened, and then returned working for them in 2008 after having moved back stateside for a few years. By the time Christina was back working for Apex, there were two other DME suppliers in the territory, both of whom were Medicare certified. However, neither one of these businesses was able to stay afloat for very long. One closed when Medicare's Medical Improvement for Patients and Providers Act of 2008 required a number of changes in processes and procedures that proved too difficult for the small business to accommodate while staying profitable. The second company "hung on" (in Christina's words) until 2014, when they too were no longer able to stay profitable under the new regulations.

Meanwhile, Apex began the process of attempting to become Medicare certified. Apex was a small company with just a five employees, and Christina was entirely responsible for getting the company certified. However, Christina was self-taught, with a college degree in art and no other healthcare experience, and so took a few wrong turns along the way. For example, CMS requires that you purchase your own host software (to process Medicare billing), and Christina purchased software that was on the more expensive end, but seemed the most user friendly. The software cost about $25,000, plus $750/month after that to host. Plus, it took her—the only person at the company how to do medical coding—4 months to train on it. She also had to choose which Medicare-contracted entity to certify with, and as she puts it, " in my infinite wisdom of not knowing what the hell I was doing," she chose to become accredited by the Joint

Commission, which is both the most expensive and the most rigorous accreditation entity Medicare contracts with. The certification process required that they supply records for a sizeable number of beneficiaries and, analogous to the process that occurs in hospice certification, they would not be reimbursed for the supplies and equipment provided to those beneficiaries.[197] And, the process cost between $50,000 and $75,000 from start to finish. For a small company like Apex, that's a lot of money.

The process of getting certified took Apex at least a couple of years. By 2012, they were receiving Medicare reimbursements. By the middle of 2015, however, the company had reached a financial breaking point. While the costs of becoming Medicare certified had been large—larger then they needed to be, given Christina's inexperience—the real problem had turned out to be CMS's Medicare reimbursement policies. Christina detailed precisely what the problems were in a document she circulated in Summer 2015 among local politicians and health care administrators, including the Representative to Congress (whom she met with on the issue three times), the Commissioner of the Department of Human Services, and several territorial Senators. Overall, the document argued that Medicare DME regulations (including reimbursement rates and other policies) were conditions that made DME provision in the territory financially unsustainable. The main aims of the document are to draw attention to a) ways in which the U.S.V.I.. is subject to excess, unreimbursable costs, b) other practices within CMS's DME billing structure that put a financial burden on all DME providers, and that could potentially be altered to off-set these extra expenses.

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[197] Christina cited different figures at different times, once mentioning that the minimum number of beneficiaries was 12, and another time citing it as 25. As one of many details of an extremely complex process, it's pretty normal that she did not remember for certain.

The document draws attention to the added expense and logistics providing DME within the U.S.V.I.. in two main domains. First, because Apex's office and warehouse is in St. Thomas, supplying individuals on St. Croix (30 sea miles away) and St. John (5 sea miles away) incurs considerable costs that are both not figured into Medicare's DME reimbursement schemes, and are simply not reimbursable by any means. Medicare reimbursement rates from the mainland are based on estimates that assume a logistics and transportation across a landmass, and do not take into account the costs of ocean freight, barge fees, and the extra employee time required to coordinate equipment shipments in between islands. Secondly, the higher costs required to transport DME to St. Thomas are also not figured into Medicare reimbursement schemes and also not reimbursable in anyway. These costs include the ocean freight costs of shipping equipment the 1,200 miles from the closest U.S. port (Miami) to St. Thomas, plus the 4% excise tax and the 6% duty on the import of foreign made goods.

In terms of the CMS DME billing procedures that strain all DME providers, but that are even more problematic for Apex, the document focuses on two main practices. First, the document claims that almost 50% of all Medicare DME claims (the documents submitted by providers like Apex to Medicare in order to receive payment) are automatically returned to the DME provider for more information. These claims must then be reviewed and re-submitted in full, by mail, by the DME provider. This required Apex to hire another full- time employee just to processes these claims (and thus pay another full-time salary). Additionally, this process substantially slows down reimbursement rates to Apex, drastically affecting their cash flow.

Second, the document takes issue with CMS's billing schema for Apex's two top-selling items: hospital beds and wheelchairs. CMS categorizes these sales as year-long rentals, which requires that providers like Apex fill out the same paperwork 13 times (once each month). This requires employees to track and monitor the claims, as well as manage the beneficiaries' copay literally 13 times more than with other items. Furthermore, with 13 times more claims on these items than on others, this greatly grows the number of claims that will be returned to them for audit. Christina also mentioned to me in an interview that in this reimbursement scheme, Medicare is able to review every month whether or not the piece of equipment is still "medically necessary." If for some reason it was deemed not to be, Medicare would stop reimbursing for it immediately, and Medicare policy (federal law) prohibits Apex from requesting that the beneficiary make up the cost. CMS expects that in those cases the supplier would requisition the equipment from the beneficiary (and sell it to another as used equipment), but Christina told me that they had never taken a piece of equipment away, nor would they ever dream of doing it. This is because, as Christina put it, "9 times out of 10 when Medicare thinks there's no longer a need, somebody's still bedridden."

The document that Christina created suggested solutions to each of the problems it raised. A few (like requesting an exemption from the excise tax) were directed to the local government, but most of them were directed to CMS. The solutions go point by point, addressing how each problem could be solved by making exceptions within CMS legislation for the U.S. territories (all of which are islands). Indeed, in an interview, Christina told me that she spent about six months contacting DME suppliers in other American territories including Guam and American Samoa, "because they have the same situations that we have here" (i.e. islands far away from mainland, territories rather than states, no voting federal representation).[198] "And basically," she found, "nobody in Guam or in American Samoa are billing Medicare."[199] If CMS would just make a few changes to their policies and regulations in the territories, went Christina's argument, Apex could stay in business, and DME suppliers in other territories could afford to bill Medicare.

However, despite her repeated attempts over several months to present her case to various entities in the territorial government and to the territory's federal representative, nothing changed. The Representative to Congress told her that there was nothing she could really do: changing things would require an act of Congress. Unspoken in this response was that representatives like her, without a vote, simply don't have the power to get change like that made. On March 1, 2016, Apex gave up their Medicare certification. They are still in business, selling DME and other medical supplies to customers in the U.S.V.I. who pay out of pocket. Christina, when I interviewed her about six weeks later, remained incredibly frustrated. She had worked so hard to try to bring Medicare-certified equipment to people of the territory, and she felt like all of her calls had fallen on deaf ears. "Just because this is happening in the Virgin Islands," Christina told me, "doesn't mean this is happening in the United States."

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[198] Puerto Rico is an exception here. With a population of about 3.4 million, and an area of 3,515 square miles, Puerto Rico is by far the largest and the most populous of the American territories. At this scale, it seems that Medicare certified DME providers are generally able to stay profitable. There are many reasons why this might be, including the need for only ground transportation once equipment reaches Puerto Rico. While the precise reasons for this were outside the scope of my study, I was told on separate occasions from representative of Helios, the Medicare-contracted QIO working in the territory during my fieldwork (to be discussed in detail in Chapter 8), that Puerto Rico "couldn't make it work" in terms of DME, and on another occasion that they had a large number of functioning, profitable DME suppliers. It seems likely that the economy of scale makes it much easier for DME suppliers in Puerto Rico to remain financially viable, but that the policies and reimbursement rate that negatively impacted Apex's chances at success are in play there was well.

[199] Christina was quick to tell me that while her research had been as extensive as possible, many of the companies she found were impossible to reach or simply did not want to speak with her. So while she was not certain about her conclusion, it was certainly what followed from the DME suppliers she was able to have conversations with.

Some Conclusions on Medicare certification in the U.S.V.I.

What do these two stories tell us about Medicare's governance of healthcare in the U.S.V.I.? There are a number of factors involved in Shepherd's success and Apex's failure. One was a matter of capital—financial and social— and knowledge: while Gloria was professionally trained and very experienced in Medicare certification, Christina was self-taught, without a background in any of the healthcare professions. Gloria used her knowledge and experience, and the opportunities they provided her to reach out to other powerful people in positions to help her. Throughout, Gloria's success was enabled by her financial security and social mobility. Nonetheless, both Gloria and Christina's stories show us how difficult it is, and how much money and labor it takes for tiny companies to obtain Medicare certification. The process was designed with a much larger scale in mind—a mainland scale—that doesn't match that of small communities surrounded by ocean. The fact those small communities—the nation's territories—don't have federal voting representation ensured this fact.

However, all of the factors that helped Gloria found Shepherd Hospice only get us that far: they don't explain how Shepherd was able to stay in business and stay Medicare certified for over 15 years. Medicare hospice reimbursement rates are very different from those for DME suppliers, paying the hospice a fixed rate for each day that a patient is in their care. And while I don't know that precise business practices of either entity, and what other expenses they had, it is clear that based on these two sets of reimbursement rates, three DME suppliers within eight years tried and failed to remain profitable, while one hospice succeeded.[200] And, it is clear that from the point of view of Christina, the person directly managing Apex's finances during this time, that it was Medicare policies and reimbursement rates that were directly to blame for their financial instability. The likely conclusion is that within the current Medicare regulations, it is close to impossible to stay in business providing older adults in the U.S.V.I. with DME covered by Medicare, while it is easier, and indeed more profitable, to provide them with hospice care.

To lend further credence to my argument that is is Medicare reimbursement policies and other billing regulations that are the main reason that DME suppliers are likely to fail in St. Croix, where it is easier for hospices to succeed, I want to briefly draw attention to two points about the operations of Apex versus Shepherd. First, when Apex became Medicare certified, they did so for *only five pieces of equipment*. The items they became certified to bill Medicare for were hospital beds, wheelchairs, walkers (which includes all kinds of ambulatory aids, e.g. crutches, etc.), bedside commodes, and pressure mattresses (which go on the hospital beds). Everything else that Apex was selling, customers were paying them out of pocket. Even then, with the profit they were making from all of the other equipment and supplies they were selling, the Medicare policies and reimbursement rates were so disadvantageous that they could not have afforded to stay in business if they continued to bill Medicare. Secondly, it's worth remembering that while Shepherd did not have to engage in the same kind of coding and billing that Apex did, they too had to purchase and import a large quantity of DME (almost every hospice patient, for example, is provided with a hospital bed), do all of their own coding, and of course pay for all of

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[200] I do not include the other hospice operating in St. Croix in my calculations here because it was part of a larger company whose base of operations was in Puerto Rico and whose financial viability was thus not based entirely on its possibilities for operation in the U.S.V.I..

the other costs associated with running a business that takes care of patients in their homes (e.g. the salaries of all of their caretakers and administrative workers, rent for their office building etc.). The fact that given these conditions Apex was unable to stay financially viable and Shepherd was able to do so, point to a significant difference in the possibilities for running a Medicare-reimbursed healthcare business as a DME supplier on one hand, or a hospice on the other.

I have argued that this landscape of care, in which DME providers cannot manage to stay in business, and hospices can thrive, has consequences for older adults in need of care on St. Croix. To flesh out this claim somewhat, in the next section I discuss an example of one specific piece of DME, to show how its unavailability impacts older adults who need it on St. Croix. This is concentrated oxygen.

The Case of Concentrated Oxygen

During my time in St. Croix, I learned how different kinds of DME can be vital for preserving human life and attenuating suffering. For instance, for an older adult who can no longer walk on his own, a wheelchair can be the difference between being able to get his own food and water, and relying on others to remember, be able and be willing to bring it to him. A pressure mattress can be the difference between bed sores being kept at bay and the sores turning into larger wounds that become infected, threatening sepsis. Concentrated oxygen[201] can be the

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[201] It is not the oxygen itself that is the equipment, but rather the oxygen concentrator, tanks, tubing, and other equipment needed to provide a steady stream of concentration into an individual's body. I use "oxygen" and "concentrated oxygen" interchangeably throughout the rest of the chapter.

difference between breathing and suffocating. Even for those who do not use it continuously, not having concentrated oxygen in the moment when you need it can cause untold distress and physical suffering, and can be life threatening.

During the period of research there was a growing awareness within certain parts of the healthcare community on St. Croix that the lack of available oxygen was a burgeoning problem. In an interview in early 2016, Gloria told me a story she had heard from a discharge planner at the hospital. The story was about a patient who had died just a few weeks earlier because he hadn't had the oxygen he needed at home. The patient had previously been sent home from the hospital and his family, who was on a "fixed income," as Gloria put it, had purchased oxygen tanks from the standard local vendor.[202] "Towards the middle of the month there's no money," Gloria continued, "and the oxygen tank goes empty." The family brought this man, now in desperate need of oxygen, to the hospital, where he died of low blood oxygen (hypoxia) before anyone at the hospital was able to help him. The man suffocated to death.

Gloria recounted talking to this discharge planner about how "heartbreaking" a story like that is, that someone should die "cuz they didn't have oxygen. And that's basic human-they should." Stories like this were circulating between healthcare institutions, as Shepherd, JFL, DHS and others continuously scrambled to try to figure out how they could help individuals secure the oxygen they needed. It was a continuous problem, as not only did people run out of oxygen (like the man in the story above), but patients presented all the time who were newly in need of it.

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[202] As far as I am aware, there was only this one company on St. Croix where individuals could buy concentrated oxygen.

There were thus two main aspects to the problem of an absence of a Medicare-certified oxygen. provider in the territory. It was a pressing concern both because of the sheer danger to human life and the potential degree of suffering made possible by an absence of accessible concentrated oxygen, and because the effects this absence had on care coordination and the functioning of the healthcare system. For instance, case workers at the hospital knew that patients otherwise ready to be discharged were staying in the hospital for extended periods of time because they did not have concentrated oxygen waiting for them at home. These "delayed discharges" were hugely problematic for the hospital as these beds were no longer available for incoming patients. This caused a back up in care throughout the whole healthcare system. It was also a major financial problem, since in slowing the patient turnover rate the unavailability of oxygen was also slowing the hospital's cash flow.[203] A financially tenuous institution already, funded entirely by the impoverished territorial government, this added cut into the hospital's cash flow could have been greatly straining the hospital's financial solvency and thus its ability to keep its doors open.

In the midst of this absence of Medicare-certified oxygen suppliers on island, Shepherd was, as Gloria was well aware, the only healthcare provider that was Medicare-certified to provide oxygen to patients in their home.[204] Like the rest of the care and services hospice under

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[203] It is also possible that the hospital would not have been being reimbursed by CMS for any of the care provided to these patients once the patients were ready for discharge—that is, once their stay in the hospital was no longer a "medical necessity." Gloria speculated, based on her understanding of Medicare hospital billing, that this might be the case

[204] The Medical Assistance Program (MAP, the territory's Medicaid program) could also provide oxygen to individuals who were eligible. However, many people do not qualify for MAP. Additionally, there was a substantial back-up of oxygen claims at MAP, such that new requests were being processed very slowly. For instance, case workers at JFL complained that even when patients had MAP, their discharges would still be lengthily delayed because their request was stuck in the MAP system.

Medicare provides, the oxygen and all of the equipment needed to use it is completely free of charge. In order to access this oxygen, however, individuals needed to sign on for hospice care. This meant meeting Medicare's hospice eligibility requirements, including having a physician providing a certified prognosis that you have six months or less to live should the condition follow its normal course and signing a number of forms agreeing to the halting of any and all curative attempts to improve your condition. While it might seem that these requirements would stymie any possibilities for individuals attempting to access concentrated oxygen by signing up for hospice care, in reality hospice did present itself as a possibility[205] for many individuals in this situation.

The possibility that in this context individuals might try to get onto hospice care for the sole purpose of obtaining the DME they needed was one Gloria was aware of. She was deeply upset by the fact that she had access to concentrated oxygen, but that she couldn't give it to everyone who needed it. In an interview in early 2016, Gloria told me that she had had a few inquiries from patients or families who were explicit about just looking for DME, and oxygen in particular. She told me about one woman who called Shepherd and told Gloria over the phone that she was looking for oxygen. Gloria asked about her medical condition and it became obvious that the woman was not hospice appropriate. As Gloria told it: "So she called me and said 'well I'm gonna die one day so can't you get me oxygen.' I said no I cannot." Doing so, signing people up for hospice when they did not meet eligibility requirements, constituted Medicare fraud. It was not that Gloria didn't want to help women like the one who called that

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[205] Many individuals on island were not aware of Shepherd Hospice at the time of my fieldwork, but it was fairly well-known in the public sphere.

day, but that doing so would be committing Medicare fraud, thus making Shepherd vulnerable to being shut down.

The unconsidered consequences of the CMS policies that regulated Hospice and DME care nationwide put those living on St. Croix and in need of concentrated oxygen into a situation in which signing up for hospice care was their only chance to obtain that oxygen. This pushed the fact that hospice was strictly palliative care, aimed at helping create comfortable and peaceful deaths, completely out of the realm of consideration. In the face of a need for oxygen, it simply doesn't matter. Like the woman on the phone that day, whose need for oxygen trumped any concerns she might have about enforced limits on her care should she become a hospice patient, the need for concentrated oxygen can push residents of St. Croix into hospice care before they are ready for end-of-life care.

Unlike the woman who called Shepherd that day, some individuals who come into contact with Shepherd are in the midst of physiological states that do make them eligible for hospice care. Often times, these individuals become hospice patients and do receive the oxygen and other DME their conditions call for. However, this is a situation in which hospice is not a 'choice' that patients come to, but rather a trajectory patients follow through a logic of need. This is a trajectory that then forecloses possibilities for healing and recuperation by legally limiting care to palliative modes. The regulatory structure enforces these limits through billing restrictions that make it impossible for patients to access other kinds of care while maintaining any of the care they are receiving from hospice, including the oxygen and other forms of DME. These same regulatory logics that push older adults in need of care on St. Croix onto hospice care in the first place serve to ensure that these individuals only receive palliative care. In obtaining the care they need, they have no choice but to assume the trajectory of the ‘dying’ patient.

Conclusion

The aspects of CMS’s regulatory structure that I have been examining here have concrete, traceable consequences for older adults in need of care on St. Croix. Returning to the claim I made in the Prologue to this section, my argument is not that these circumstances are an intentional consequence of Medicare legislation. Rather, it is a consequence of the utter disregard of Medicare legislation, and of the U.S. Government that enacted it and continues to maintain it, of the circumstances of the U.S.V.I. and of the effects particular legislation may have given those circumstances. The document that Christina created in an attempt to bring attention to this mismatch to local and federal government officials brings to light how particular policies that simply would not be a problem elsewhere become problematic in circumstances presented by many of the nation’s territories: small communities on small islands with very limited infrastructures and very limited resource pools. Medicare regulations were not made for communities like these. But nonetheless, the territories can do nothing to adapt the regulations to their circumstances because they simply do not have the legal authority to do so under U.S. sovereignty.

What we see here, then, is not the power to oversee, to manage, to measure; but instead the power to ignore. For while this regulatory system was not intended to have the consequences it does in St. Croix, that does not mean the disregard that brought these conditions into being is itself accidental or external to the American system of statecraft. As demonstrated in Section II (particularly for the American era in Chapter 5), it is not happenstance that this disregard falls on a majority poor, Afro-Caribbean community. Rather, this disregard was built into the very origins of St. Croix's inclusion into the United States: it is a condition of possibility of its existence as part of the nation. This is a disregard that has been sedimented through a century of habits of attention in a system in which the U.S.V.I. does not appear as a place worth of regard. It is thus often forgotten about, unconsidered and unseen, by virtue of legislative, material, and psychological patterns that have emerged in response to its existence as an object that does not draw attention.

The question of which communities get attention paid to them and which do not—which communities the state makes legible to itself and which the state allows to remain outside of its own purview—is itself an integral part of contemporary forms of statecraft. In the next chapter, I consider what happens when a small group of people on St. Croix attempt to make the consequences of CMS regulations seen within the very system through which they have been made invisible.

Chapter 8

Illegibility as a Mechanism of Bureaucratic Disregard:

Efforts to Solve the "DME Crisis"

During fieldwork, as I was beginning to piece together the effects that the absence of a DME provider in the territory was having for older adults on St. Croix, this problem was also coming to the foreground for healthcare providers and administrators on island. This was largely through the activities of Helios, a Medicare-contracted Quality Improvement Organization (QIO), who had recently begun their activities in the U.S.V.I...The activities of Helios brought together healthcare 'stakeholders' (their terminology) in meetings and workgroups to collaboratively address some of the problems the QIO had identified as being crucial to the healthcare delivery of Medicare beneficiaries. The absence of any DME provider in the territory became one Helios's main foci.

In this chapter, I explore the activities of the DME workgroup that Helios assembled, examining how their attempts to fix the "DME crisis" disclosed St. Croix's illegibility within the CMS regulatory system. In particular, I analyze the DME workgroup's interactions with other Medicare-contracted entities who were responsible for different pieces of the DME provision process. By bringing some of the underlying logics of Medicare's DME regulatory scheme to light, these interactions show the particular mechanisms through which St. Croix is maintained as an object of disregard. I suggest that illegibility is a key phenomenon through which this disregard manifests: as I will show, St. Croix is illegibile within CMS's DME regulatory system precisely because it is a system that was built in order to not be able to see it.

Introduction to Helios

It's mid-morning on a weekday in mid-November 2015, and Gloria and I are finding our way up to a fluorescent-lit, air- conditioned classroom at JFL hospital. We are some of the first to arrive, but there is a small group assembled. At the front of the room, a white, middle-aged woman is setting up a powerpoint presentation on a laptop. Gloria immediately starts saying her hellos and doing the kind of upbeat, energetic networking that I often observed her doing at any kind of meeting or public event. I settle in to my seat to observe; it's fairly early in my fieldwork, and none of these faces are familiar to me yet. We're at the first meeting of the St. Croix Community Care Coordination Coalition, a group organized and facilitated by Helios. I wasn't sure what to expect, or who Helios even was at this point, but I knew from Gloria that the meeting was going to be a gathering of many of St. Croix's most important healthcare "stakeholders," (as they're called by Helios), and that the facilitator of the meeting, Kathy Davis —the stateside woman who was currently setting up the presentation at the front of the room— was serious about making changes to improve healthcare delivery in the territory.

By the time the meeting started the room was practically full, with 32 of us there.[206] I learned through introductions going around the room that in addition to representatives from Helios, Shepherd (and the anthropologist), we had representatives from the administration and clinical arms of the St. Croix hospital, AARP Virgin Islands, Clear Waters Home-Healthcare (that in November was still operational), the Representative to Congress's office, Herbert Grigg (the

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[206] There were 31 women and 1 man present.

nursing home), a local non-profit working in the sector of public health, the Frederiksted Health Center, and the Virgin Islands' independent PPO Organization. In many cases, as I learned from their titles these representatives were very high up in the organization. It was indeed a seemingly powerful group.

During the 90-minute meeting, I came to learn that Helios had a federal mandate to improve healthcare delivery for Medicare beneficiaries of the territory. Helios is an organization that had long contracted with CMS, but had just won contract to serve as Medicare's QIO in the U.S. Virgin Islands beginning August 1, 2014.[207] The improvement Helios was tasked with was to take place within the scope of terms laid out in CMS National Quality Strategy. The National Quality Strategy is a document pitched at the level of national implementation and is meant to work in concert with other similar regulatory documents in setting the agenda for improving healthcare in the United States. The document claims that CMS, "in collaboration with public and private partners, is transforming how we conduct business and operations, connect providers, and empower consumers and beneficiaries" (CMS 2016: 1). The document itself is a roadmap for all agencies working to effect this "transformation." The central aims of this plan are the "CMS Quality Strategy Goals:"

- Goal 1: Make care safer by reducing harm caused in the delivery of care.
- Goal 2: Strengthen person and family engagement as partners in their care.

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[207] In addition to the U.S. Virgin Islands, Helios had the contract for a few large states, but no other U.S. territories (Puerto Rico, for example, was assigned a different organization to perform the same functions Helios was performing in the U.S.V.I.).

- Goal 3: Promote effective communication and coordination of care.
- Goal 4: Promote effective prevention and treatment of chronic disease.
- Goal 5: Work with communities to promote best practices of healthy living.
- Goal 6: Make care affordable.

(CMS Quality Strategy 2016: 5)

QIOs like Helios had a number of mandated activities in order to carry out their part of achieving these nationwide goals. One of these activities was to organize and facilitate a “Community Care Coordination Coalition,” and this meeting was the first in their efforts to do so on St. Croix.[208]

The meeting was divided roughly into three parts. In the first, Kathy introduced herself, Helios, and the purpose of the Coalition. In the second, Kathy encouraged group discussion on certain topics that followed from the broad goals of the formation of the Coalition. Finally, Kathy moved from the concerns that had emerged in the group into a discussion of how coalitions worked and what it would mean for this group to behave as a coalition. She emphasized the importance of trust, teamwork, and agreement on shared goals (her slides included images like geese flying together in a V, and one dog standing on top of another in order to reach a pile of hamburgers), and then circled back to the specific initiatives Helios was already engaging in in cooperation with providers in the territory order to improve some of the barriers to care coordination discussed in the group.

In her Powerpoint, Kathy presented the “key roles” of Helios in the territory thus: “Champion local-level, results-oriented change; Facilitate learning and action networks (LANs);

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[208] The first Coalition meeting on St. Thomas had taken place some weeks earlier.

Teach and advise as technical experts; Communicate effectively." All of these roles are direct ways of carrying out the CMS Quality Strategy and applied to Helios's overall activities in the territory, of which the Coalition was only a part. Some of these other activities included helping both St. Croix and St. Thomas's hospital to implement processes for more accurate, systemized data collection and analysis on patient admissions; providing these hospitals with Medicare's own data on admissions at their hospitals and helping them understand how to use the data to implement better care processes; organizing a large "Learning Action Network" (a conference-style event) on St. Thomas with invited speakers from the states; attempting to have all providers in the territory adopt a single tool with which to educate their patients with chronic heart failure; supporting the continued facilitation of and attendance of "Diabetes First" classes in the territory; and supporting the implementation of a pilot "Med to Bed" program in St. Croix's hospital, in which certain patients were, for the first time, offered the option of receiving their prescribed medications before they were discharged from the hospital.[209] While these activities are diverse, I hope they give an idea of the role that Helios was playing on St. Croix at this time.

As its name implies, the role of the St. Croix Care Coordination Coalition was to bring together as many stakeholders as possible to form a cooperative group to improve "care coordination" on island. The general idea behind "care coordination" is the smooth flow of patients within the healthcare system. The main rubric by which care coordination was being judged within CMS, and thus within Helios, was hospital readmission rates. A "readmission" is when a patient returns to the hospital within a 30-day period after their discharge. The higher the readmission rates, the poorer the care coordination. Within this model, if a patient is discharged

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[209] This was based on a program Helios had worked to implement in another state.

within well-coordinated system of care, she will easily have access to the correct prescriptions, any equipment or supplies she needs and any follow-up doctor's appointments required in order to avoid another medical crisis requiring a return trip to the hospital. In a fully functional care coordination system, the model goes, hospital readmission rates will be very low.

In her presentation, Kathy told us that the national average of hospital readmission rates for Medicare beneficiaries was 17.86%. That's high, Kathy told us. On St. Croix, the rate was 16.8%: lower, but still high. Kathy was explicit in letting us know that this was not just a problem on St. Croix: hospital readmission rates were a problem everywhere in the country. She then proceeded to flesh out, based on Medicare data, some of what "we" knew about hospital readmission rates on St. Croix: chronic heart failure was the leading cause of hospitalization and re-hospitalization on island; 20.7% of beneficiaries with diabetes are readmitted to the hospital within 30 days; only a quarter of beneficiaries who are readmitted have seen a physician between admissions; and only 39% of beneficiaries report understanding their plan of care when they were discharged from the hospital. The purpose of this exposition was both to begin to set an agenda around as well as generate energy for the core projects of the coalition (notice how these statistics connect to the projects Helios was working in the territory, above), but also to get everyone in the room on the same page. Kathy needed to form a group that would be working collectively to achieve the same goals.

Perhaps most importantly, the presentation of these data gave numbers to problems that almost everyone in the room was aware of, focusing the group's attention to certain issues that they already had experience with and were at times struggling with in their work every day. From here, Kathy asked the group "what else do we know?" about the problem of hospital readmission rates and care coordination on-island. A group discussion ensued, which Kathy then built on to present more concretely the idea of working together as a coalition. This included signing a charter agreeing to shared goals as well as certain forms of intra-agency cooperation. It also included going into more depth about some of the initiatives that Helios was already engaged in on island, asking certain key individuals in the group to share some initial results of those projects. This generated the feeling that leaders in the community were already on board with and invested in Helios's project.

In the group discussion, no one brought up the problem the lack of DME availability was posing for healthcare providers and patients on island. However in closing the meeting, Kathy informally summarized some of the main issues that had come up in the group discussion, mirroring the group's concerns back to us. She said that a lot of people had mentioned "resources" (a lack of resources). "There are certain resources that just don't exist," she said. She then continued by expanding one particular kind of resources: "We found that there is not a certified [DME] provider for Medicare anywhere in the territory." Kathy then informed the group that they had looked into the situations in Guam and in Puerto Rico—other U.S. island territories that she said also "can't make it work". "We called Medicare," Kathy said, "and said in the territories we can't make this work, that people on Medicare don't get the same level of service, and this is going to have to be worked on a big level, a long period of time. But just be aware that this is already starting. So the resource issue is starting to be worked on." Just a few moments after this, the meeting was drawn to a close.

The 'Resource Issue': the DME Working Group

This “resource issue” of the lack of Medicare-certified DME providers in the territory was worked on with the support and direction of Helios in many ways in the coming months. One of the main focal points of this work was in the “DME Workgroup,” one of several smaller break-out working groups from the larger coalition, all of which were facilitated by Kathy.[210] There were three meetings of the working group during my fieldwork, all conference calls, and Kathy also worked extensively with working group members (or other ‘stakeholders’ she was attempting to bring into the working group) on a one-on-one basis within their institutional roles. From Helios’s perspective, getting affordable (i.e. Medicare-certified) DME on island was a crucial part of ensuring better coordination of care, as it could be a potential driver of hospital re-admissions (for example, when beneficiaries would come to the hospital just to have access to concentrated oxygen). It was also a major bottleneck in the system of primary care, as I discussed in Chapter 7. Kathy told me, however, in an interview a few months into the formation of the working group, that the lack of Medicare-certified DME was an issue that no other group that she knew of (as in, none that Helios had data on or that she had worked with in her previous jobs at similar companies) had raised as being an obstacle to care coordination. It was thus uncharted territory for Kathy and her team.

In the two DME Working group conference calls that I participated in[211] the groups were fairly small: 10 on the first call and 12 on the second (including myself). The calls included

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[210] The DME working group spanned the St. Thomas and St. Croix branches of the Coalition, and so included participants from both islands.

[211] I was left out of the scheduling for one call.

local representatives from Helios, Gloria, and representatives in healthcare and administration from the St. Thomas and St. Croix hospitals. Kathy, who often called in from her home-base stateside, always facilitated the calls. Additionally, Kathy invited representatives of three other entities who held contracts with Medicare related to DME. One of these companies was contracted to process all DME Medicare claims for the U.S.V.I. (and some other states and territories), including payments, audits, and appeals. That is, when a Medicare-certified provider sells a piece of DME to a beneficiary, it's this company that then gets a claim from the provider that needs to be processed and either paid or denied—and they also do all of the reporting and auditing associated with that.[212] The second company was contracted to review appeals and complaints from Medicare beneficiaries. Officially known as a "Beneficiary and Family Centered Care Quality Improvement Organization" (BFCC-QIO), this company was playing the role of Medicare customer service for patients. The third company had won the contract to serve as the National Supplier Clearinghouse, which is the single entity responsible for managing (issuing/revoking) Medicare certification ("billing privileges") for DME suppliers. Just like Helios, these three companies had won a contract with Medicare to perform this role for a certain amount of time.

Kathy never gave specific reasons for putting the group in contact with these companies, or with the particular representatives from these companies that ended up being regulars on these calls. She emphasized the importance of having "points of contact" at these companies, and the phone numbers and email addresses of the representatives of these companies who joined us on

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[212] This auditing and returning was one of the major complaints in the document created and circulated by Apex DME's administrator, Christina (Chapter 7).

the phone were repeated several times during the course of each call. It seemed to make sense to the group at the time that these would be the companies that we would need to speak to in order to help solve the "DME crisis" in the territory. After having gone through the calls however, the presence of these representatives ended up being mostly ineffectual, if our goal was to progress toward change. Instead, what was made clear was the different forms of illegibility shaping the way that these Medicare-contracted companies could and could not see the DME situation in the U.S.V.I..

Geography and Distance

The first kind of illegibility that was revealed through the DME workgroup's activities with other Medicare-contracted entities was bound up with the U.S.V.I.'s particular geographical existence, and with the fact that these entities did not have anyone on the ground in the territory. Being a collection of small islands far away from the U.S. mainland meant that many of the normal 'readings' that CMS and CMS-contracted entities rely on to determine the DME status in any location were scrambled. What these activities disclosed was how hard it was, as one of these entities, to see the DME crisis in the U.S.V.I. for what it was.

For example, one of the main problems that Helios was encountering in having other Medicare-contracted entities 'understand' that there were no Medicare-certified DME suppliers in the territory was related to the Medicare-database's geographical search function. Accessible to the public at medicare.gov, using this tool to search for suppliers within a 50-mile radius of U.S.V.I.. revealed a long list of eligible DME providers. These were the many suppliers in Puerto

Rico. However, unlike in the continental United States where 50 miles of land means that a supplier is well accessible to residents within that range, the 40 miles of ocean in between Puerto Rico and St. Thomas does not afford that possibility. Kathy presented the results of this search on the Medicare website as a true obstacle to our efforts to have Medicare understand that lack of DME suppliers in the territory. She presented it as a reflection of what Medicare as an entity "knew," as if from the perspective of Medicare these search results provided was evidence that there were in fact Medicare-certified DME suppliers 'in' the territory after all.

The DME workgroup's first conference call revealed how not having anyone from these entities "on the ground" in the territory made its DME situation illegible within the CMS bureaucracy. This is both because the actual geographical distance made representatives from these entities unfamiliar with the U.S.V.I. and because they were working within a system that assumed a continental perspective. On the first call, in mid-March, Kathy had arranged for representatives from two other Medicare-contracted entities involved in Medicare-certified DME supply to be on the call. Some were from the company contracted to process all DME Medicare claims for the U.S.V.I. There were also some representatives from the company that I have described as responsible for Medicare 'customer service.' Calling in from the U.S.V.I.., we had Gloria, two case managers and one high-up administrator from JFL hospital, and a few clinicians and administrators from the St. Thomas hospital. Kathy facilitated the conversation from her location stateside, and two of her Helios colleagues working at the St. Croix and St. Thomas offices were also on the call.

The call consisted mainly of conversation with the representatives from the company contracted to process DME Medicare claims for the territory. This was the first time the workgroup had had contact with this company, although Kathy had been in communication with them. From these interactions, two things became clear: first, this company was not aware of the fact that there were no DME providers in the U.S.V.I.; second, they were not aware of this because of particular bureaucratic mechanisms that controlled what a company with their role in the bureaucracy was able to 'see,' and thus was able to pay attention to.

The representatives of this company knew the broad purposes of the DME workgroup, and understood that they were on the call to help this group make DME more easily available to Medicare beneficiaries in the U.S.V.I.. However, early on in the call it became clear that they did not understand the extent of how unavailable DME currently was in the territory. After Kathy had introduced these representatives to the group she asked them, by way of handing over the floor, if they had familiarized themselves with the issues surrounding DME in the U.S.V.I., and what suggestions they had for the group regarding how they could best address these issues. At this point, I was actually excited, as I believe many other members of the group were, to see what this company had to say. It seemed like the moment we had been waiting for: expert advice from people who knew the Medicare system inside and out. The suggestion they presented, however, was strangely out of sync with the aims of the workgroup and indeed with the level of crisis in the territory. The suggestion was that we, as healthcare providers in the territory, work to get all DME documentation to the territory's DME providers in a more timely and accurate fashion. This was documentation, for instance, of proof of medical necessity that justified a certain piece of DME for a particular patient. This would directly support the DME providers, the argument went, by making sure that the providers could adequately respond to all of the claim audits that their company routinely sent them. They explained to the group that this auditing processing can add up to extra costs for DME providers if they do not have access to the appropriate documentation in a timely fashion, and so my providing them with this documentation the territory's healthcare providers could support DME providers and help them stay in business.

This response disclosed a number of things. First, it disclosed that from this company's perspective, the exact issue that Apex DME had identified as a problem within Medicare bureaucracy that was pushing them out of business, was instead a problem with the healthcare infrastucture in the territory itself. From this perspective, it was not the rate of auditing that was problematic, but it was the slow and inaccurate documentation flow in the islands that was to blame. While I will not go into this issue in depth here, this implicit engagement with discourses of 'island time' that portray islanders as slow, lazy and lackadaisical is revelatory of a common discriminatory stance in stateside/U.S.V.I. relations. It is certainly not coincidental that a stateside company's first line of response to problems they see as being isolated in the territory was to suggest conducting operations in a more 'timely' way.

Most importantly, however, this suggestion disclosed the fact that from this company's perspective, there *were* DME suppliers operating in the U.S.V.I.. I asked the representatives if they could clarify for the group which DME suppliers they were talking about, since as far as this group knew there was nowhere to purchase Medicare-certified DME in the territory. The conversation to follow disclosed a number of the different ways that it appeared, from the point of view of this billing and auditing company, that there were DME providers doing business in the U.S.V.I.. They mentioned that they had been "working with" Apex (see Chapter 7), although they knew that Apex had recently given up their Medicare certification. They also mentioned that there had been claims filed from the U.S.V.I. from at least one physician's office that has billed them for orthotics/prosthetics, walkers and canes, and some pharmacies that have billed for urological supplies. They also mentioned that many people in the U.S.V.I. were purchasing DME from Medicare-certified DME providers stateside.

In this picture, the practice of obtaining DME that is covered my Medicare was actually taking place for residents of the U.S.V.I.. However, this picture was constructed from the view of what we might think of as "bureaucratic blinders," mechanisms that were limiting this company's possibilities for seeing what the DME situation in the U.S.V.I. really was. The first of these mechanisms has to do with the way that DME is categorized, and thus billed, within CMS. Within CMS typologies, "DME" does refer to a specific category of medical equipment, however, for the purposes of billing DME is combined with three other types of material medical support items: prosthetics (e.g. artificial limbs), orthotics (e.g. corrective insoles and ankle braces), and supplies (e.g. bandages and other wound care supplies). Thus, for this company, that processed billing, it was Durable Medical Equipment, Prosthetics, Orthotics and Supplies (DMEPOS) that was the salient category. These orthotics, prosthetics, and urological supplies claims that were being submitted to them alerted the company that DMEPOS was being sold within the Medicare system in the U.S.V.I.., while distracting from the fact that DME itself—like oxygen equipment, which was a major concern of the workgroup—was not a part of these transactions. And, while one physician's office had apparently billed for "walkers and canes" this does not mean that these claims were successful and that this DME was actually covered by Medicare. It just meant that their company had seen DMEPOS claims coming out of the U.S.V.I., which hid the fact that there was actually no Medicare-certified DME provider there. Yes, one of the major DME providers (Apex) has recently given up their certification, but this was not, in this picture, a decisive blow to DME territory-wide.

The final piece of evidence that these representatives provided for Medicare-certified DME being available within the territory was that they had processed claims from DME providers located stateside who had apparently sold DME to beneficiaries in the U.S.V.I.. On the claims that came into the company, this would have shown up as a stateside location for the DME provider and a U.S.V.I. location for the beneficiary. However, Medicare's Conditions of Participation[213] require that DME suppliers are able to replace or repair equipment within a 24-hour period, which means Medicare-Certified DME providers do not sell equipment to beneficiaries outside a certain radius from where the provider themselves is located. This was a fact that the workgroup was now well-familiar with. Indeed, one of the first, hopeful, initiatives of the project was to try to connect individuals in the U.S.V.I..with Medicare-certified DME providers in Puerto Rico or stateside. This failed across the board because no DME supplier would agree to sell to beneficiaries that were out of the range they could easily access within a 24-hour period. It thus seemed very strange that some people in the territory had managed to get stateside DME companies to do this on their own. Later in the call, however, one of the representatives re-interpreted what these claims might be indicating: instead of showing that people in the U.S.V.I. were obtaining DME from Medicare-certified companies stateside, they said it was actually more likely that these claims showed DME being sold to beneficiaries with U.S.V.I.. addresses, but who resided most of the year somewhere in the states (people

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[213] Medicare Conditions of Participation are the requirements that organizational must meet in order to become and remain certified by Medicare that is, eligible to receive Medicare reimbursement. They differ based on type of organization (hospital, DME supplier, etc.)

colloquially called ‘snowbirds’).

All of these things together—the fact that Apex only recently stopped billing Medicare and so many of their claims have recently been in the system, that there are at least a few offices in the territory who do bill for certain items that fall into the DMEPOS category, and that there were items of DME being sold to beneficiaries with U.S.V.I. addresses—paint a very different picture than that on the ground: that there is not a single Medicare-certified DME supplier in the territory. It is possible to trace, however, at least some of the specific dimensions of the bureaucratic blinders that limited this company’s view of what was really going on in the U.S.V.I.. With access only to DMEPOS billing claims, the category of ‘DME’ gets lost, as does the actual location—as opposed to the documented address—of those using the DME. This particular form of seeing, which is a constitutive element of the CMS bureaucracy, does not make the reality on the ground legible.

“The Only Way to Be Heard”

The second major issue that the DME workgroup faced in trying to alert CMS entities to the “DME crisis” in the U.S.V.I.. was that there was not “adequate documentation” of the problem. Of course, what constitutes ‘documentation’ and what constitutes ‘adequate’ is limited by the bounds of what is made visible within the logic of CMS’s bureaucracy. This problem centered on what was positioned as the failure of Medicare beneficiaries in the territory to call into CMS’s helpline, run by the company contracted to conduct ‘customer service’ for CMS, to report that there was no way for them to obtain the DME they needed. This was the official way of ‘documenting’ a complaint with Medicare. Without this documentation, the workgroup was told, CMS entities could take no action to solve the problem. Without this documentation, the problem did not, as far was CMS was concerned, even exist.

This lack of calls into the company’s helpline from residents of the territory was raised by Kathy at the very first meeting of the St. Croix Community Care Coordination Coalition. It was a problem that Helios foregrounded within the activities of the Coalition and of the DME workgroup. The importance of encouraging beneficiaries to call the company’s helpline indeed felt like something of a campaign. At every meeting of the coalition and of the other workgroups (including the DME workgroup) Kathy would distribute flyers advertising the helpline, encouraging healthcare providers to give the flyers directly to their patients. The helpline phone number was mentioned at all meetings and was included in all meeting minutes—as Kathy said at one point, they had been “kind of blanketing everyone with it.” The logic was that having beneficiaries call this phone number was a key way for effecting change, that this would help open the path to a future in which there was a Medicare-certified DME supplier in the territory. However the actual causal chain inherent in this logic was never stated, nor was it ever questioned. Within the groups’ (the Coalition and the working groups) practice and discourse, getting more beneficiaries to call this helpline took on the status of a good in itself.

This logic was on display in the DME workgroup’s direct interactions with the Medicare-contracted ‘customer service’ company. On the DME workgroup’s second conference call, about a month after the first, some of the company’s representatives were on the phone with us. The rest of the group consisted of a few clinicians and administrators from both St. Croix and St. Thomas hospitals, some representatives from the Medicare-certified billing company who had been on the previous call, a few Helios staff members, including Kathy who was facilitating the call, Gloria and myself. The representatives from the ‘customer service’ company were there to provide us with updates on how the campaign to get more beneficiaries to call in DME complaints to the helpline had been going, and to answer any questions the group might have. On this call, they reported that there had been a definite “upswing” in total calls to the helpine, with 2 “appeal” calls and 2 “quality cases” called in from the U.S.V.I. in the last month. They compared this to the only 6 total calls that had been documented in the previous 18 months. Because this helpline is for all Medicare-related complaints, however, these calls may not have been specific to DME, and this was not information that was discussed on the call, or that was necessarily even available to the company’s representatives. It was sheer number of calls documented that was treated as significant.

The company representatives’ responses to the group’s questions proved equally unidimensional. For instance, about 40 minutes in to the call, a case manager from one of the territory’s hospitals brought up the problem that they are currently unable to discharge many patients from the hospital because the families cannot pay for the medical equipment needed to care for the patient at home. This constitutes what is known as an “unsafe discharge” under Medicare guidelines, and it is prohibited according to the Medicare Conditions of Participation. The case manager explained that this was a huge problem at the hospital right now, and asked if they had any suggestions about what could be done. They suggested that the only way they thought attention could be brought to this situation, the “only way to be heard” was to document the problem. Without documentation, the representatives told the group, there was no way for CMS to know about the problem.

While formulated in the language of hearing, rather than seeing, we have here another representation of a particular logic of legibility—or perhaps, audibility— within the CMS bureaucracy. Instead of knowing the situation in the U.S.V.I. through filed billing claims like the company from the first example, this company could also know the situation through documented complaint calls. Anything that was happening that did not get documented through CMS's system of complaints simply did not exist as an object within CMS's purview. It remained unconstituted as something that could draw attention.

Furthermore, within this paradigm the enduring DME situation was not caused by any problem within the CMS bureaucracy, but rather was the fault of U.S. Virgin Islands residents themselves who failed to call in and (as was so often said in Helios meetings) "make their voices heard." This was parallel to the way that the billing and claims company encouraged healthcare providers to support their local DME provider by providing them accurate documentation in a timely manner, thus locating the blame for the extra costs accrued at the local rather than the bureaucratic level. In the CMS bureaucratic discourse employed within Helios groups, U.S. Virgin Islands residents needed to be "educated" and "empowered" to "make their voices heard." If they could obtain this education and empowerment, the logic went, then they could behave the correct way within the bureaucratic system, and their complaints could be documented.

The reason why residents of the territory were not calling in to the helpline *despite* the DME crisis in the territory was actively discussed in the St. Croix Care Coordination Coalition meetings. In the first Coalition meeting back in November, Kathy brought up that "Medicare education" was one of Helios's main initiatives in the territory. She told the group that they monitor the helpline to find out if anyone is complaining and what they are complaining about.

She then told the group that the helpline didn't as yet have any complaints filed from the U.S.V.I.. "Why?" she asked, "because people in the community don't know how to complain." This caused a wave of murmurs throughout the group, with my neighbor (an Afro-Caribbean healthcare provider) saying under her breath that "they don't know how to complain in public, but they complain inside." Another person's voice rose above the rest to say "the only place they know where to complain is go to their [territorial] Senator's office." Then, out loud to the group, someone mentioned that of course complaints are an issue, but the real problem is that they are not educated about the Medicare program in general, so they don't know what to expect—what is normal and what is something deserving of a complaint. Someone else added that it's important that "we" work on helping patients understand that "there won't be any repercussions for making a complaint," and feeling a sense of trust in the system, a sense that the system actually works.

The ideas brought up in these few minutes continued to come up in future meetings and in my one-on-one conversations with Kathy and Gloria. The idea that territorial residents, particularly Afro-Caribbean residents, are *ineffectual* complainers was a common one, both among stateside whites like Kathy and Gloria, and among Afro-Caribbean healthcare providers in the Coalition. This was either glossed as an issue of "culture" or of "education;" often, it was represented as a "cultural" issue that could be remedied through "education." For instance, in an interview the same month as our second DME workgroup call, Kathy was speaking about the uniqueness of the Virgin Islands community compared to other communities she had done similar work with (stateside and internationally). She noted the lack of documented complaints as one of the first obstacles Helios had identified:

Kathy: there was no evidence
that they had reported those concerns
to anybody.
So how do I empower and educate
the providers
and then the community
to become informed
about how to notify people
about their concerns.
That's-part of it is you know
you have to work within the culture of the area,
they're not a culture where they take-
they complain to each other,
but not to the effective agency.

Here, culture is represented as a habitual way of behaving that is problematic in the context of the Medicare bureaucracy, one that can be fixed through empowerment and education. The bureaucracy itself is entirely naturalized here: it is not that the bureaucracy has invisibalized the interests of U.S.V.I. residents, but rather that U.S.V.I. residents are making *themselves* invisible by not registering their complaints in the correct fashion.

A major object of the "education" that was seen as being needed in this situation was U.S.V.I. residents' lack of trust of a federal agency like CMS, and a fear that there would be repercussions for voicing complaints (e.g. an effect on one's welfare benefits).Gloria, for instance, told me that it was obvious to her that for some of the families she worked with, calling a 1-800 number to a federal agency in Washington D.C. (in the imagination of the caller) would seem like a very daunting, intimidating proposition that could have repercussions for them personally. However, there is an alternate understanding of the character of this mistrust, one that is not due to fear of personal repercussion, but of belief that the system is one that is not built to support their interests. This was mentioned briefly by a local healthcare provider at the initial Coalition meeting (the need to give local beneficiaries a sense “that the system actually works”), but it was not taken up by the group then, nor was it integrated into the ongoing discourse of ‘education’ and ‘empowerment’. Indeed, if it was the case that CMS’s bureaucracy did not function to support the interests of residents of the U.S.V.I., then Helios’s Quality Improvement initiatives in the name of CMS would have no grounding. Kathy was explicit about the fact that documenting complaints from the U.S.V.I. would lead to better outcomes. This would prove that the CMS bureaucracy could function to help residents of the territory, if they just played by their rules.

However, on the conference call with representatives from the ‘customer service’ company, this logic unraveled. At one point, I asked the representatives something that hadn’t been directly asked before: if they documented enough complaints, what could we the workgroup, and the Medicare beneficiaries in the U.S.V.I., expect to be the result? The response given was vague and non-committal. The representatives told the group that that was something they would have to look into, because this was not a situation they had never been in before. They repeated that the only way to be “heard” was to be “documented,” and that if we ever reached a point where there was “enough” documentation, that it was possible that it would have an impact. When I inquired about what kind of an impact that might be, I was told they “wished they could tell me."

Here we see that the background assumption motivating the campaign to have Medicare beneficiaries call the helpline is, perhaps, unsubstantiated: there is no answer as to whether or not these calls will add up to influencing any change. What is revealed here is instead documentation for the sake of documentation, legibility for the sake of legibility. Furthermore, it appears that U.S. Virgin Islands residents had good reason to distrust CMS's bureaucracy. Calling the helpline to complain would have no direct effect on the state of DME provision in the territory. But from their disregarded position as residents of a territory whose DME situation did not seem to be legible by the CMS bureaucracy, this very distrust, this refusal participate, could itself be tagged as the reason for their illegibility.

Some Conclusions

In this chapter, I have continued my discussion of American (post)colonial bureaucratic disregard through a case study of a Medicare-contracted entity, Helios, tasked with helping to solve the U.S.V.I.'s "DME crisis." Continuing threads established in the previous chapter that showed the absence of a Medicare-certified DME provider in the territory to be a result of (post)colonial bureaucratic disregard, this chapter examined *illegibility* as a core mechanism for how disregard is maintained. Following the activities of the "DME workgroup" that was formed under the guidance and facilitation of Helios, I demonstrated how the illegibility of the U.S.V.I. within the CMS bureaucracy was disclosed, particularly through the workgroup's direct engagements with other Medicare-contracted entities involved in the DME supply. Through showcasing the particular ways that these different companies were unable to ‘see’ the scope of the problem the territory was facing—the absence of any Medicare-certified DME provider—I have made visible these forms of how illegibility operates.

As many have argued, legibility is a key method in the rise of modern state power (e.g. Scott 1998): in this logic, legibility directly enables and facilitates control. However, in the contemporary moment, in which new forms of power have emerged, it is not only through inclusion within the realm of the legible, but exclusion through illegibility that defines (post)colonial statecraft. The very etymology of the term dis-regard suggests the relationship between the disregarded and the illegible: that which cannot be read is not paid attention to/looked at, that which is not paid attention to/looked at cannot be read. I will not return here to the complex causal loop inherent in this relationship as it has unfolded historically through time. I will simply indicate that the history I have presented of St Croix (chapter 2) shows how St. Croix has passed through the changing slot of the ‘excluded’ within the various forms of power that have emerged from the colonial era to the present. Thus while this contemporary relationship of disregard and illegibility is in some ways novel in terms of the historical trajectory of St. Croix, it is also simply the contemporary version of how the island’s residents kept out and kept away—kept alone—by the group who claims sovereignty over them.

This demonstration of the U.S.V.I.’s illegibility in the eyes of Medicare provided a look into the background workings of how and through what logics the circumstances facing Medicare beneficiaries living on St. Croix are maintained. These examples of particular forms of illegibility are symptoms of the same politics of disregard that make it possible for hospice to remain a profitable enterprise while DME suppliers cannot afford to stay in business. In the next chapter, I pick up where this argument leaves of. The chapter is a case study of one woman, Ruth, whose healthcare at what turned out to be the end of her life was a direct consequence of the absence of Medicare-certified DME and the presence of hospice care on island.

SECTION IV

Hospice and the Embodiment of Bureaucratic Disregard

Prologue

this family here,
is probably makin it
the hardest I've ever had it. (oh,)
ever. (wow)
and I’ve been doin this a long time. (mhm)
um, I donno if it's because we're on an island
and there's such a lack in services
usually you have case workers,
and social workers, an’ aides,
an you-jus-tons of neighbors, and family (mhm)
an', you know it's like
there's always so much goin’ on,
death'll happen before you even know it (mhm,)
cuz everybody's kept you,
you know, bringin’ food,
you know how they do that? (DF: mhm)
here you are alone.
you are alone.

(Sunny, Ruth’s hospice sitter, in an interview six days before Ruth’s death)

This section examines the consequences of the healthcare landscape created by (post)colonial bureaucratic disregard for the life, and death, of one woman on St. Croix. I call this woman Ruth. Ruth was a white woman who had lived the first 40 years of her life stateside. She was 71 years old when I knew her. The chapters to follow trace Ruth's illness and care trajectory for what turned out to be the last three months of her life. The section examines how Ruth's care was shaped—from the beginning until the end—by the impossibility of her having access to the DME she needed at home without being a hospice patient.

When Ruth became a hospice patient, in late 2015, it was at the time that she had realized that she needed DME in order to survive. She had COPD (chronic obstructive pulmonary disease, what used to be called "emphysema"), and had quickly become dependent on concentrated oxygen in order to breathe. After once paying out of pocket for tanks filled with concentrated oxygen, Ruth ran out of oxygen and returned to the hospital. There, she signed onto hospice, returning home as a hospice patient to free concentrated oxygen for the rest of her life. This need for concentrated oxygen and the impossibility of obtaining it in any other way than through hospice care (or through being an inpatient at the hospital) shaped Ruth's trajectory until the end of her life a few months later. This section is thus an ethnographic demonstration, through the end of life of one woman, of how the absence of any DME Medicare provider on St. Croix, and the presence of hospice care, can powerfully shape possibilities and trajectories for older adults in need of care on island.

Within this broad context, this chapter also examines of some of the other aspects of Ruth's existence—particularly forms of aloneness and disregard—that powerfully shaped how these few months unfolded, and what kinds of possibilities were open to Ruth at crucial moments. In particular, Ruth did not have a reliable caregiver and often found herself alone. This section thus also traces how this aloneness and disregard figured into her caregiving in both evident and more subtle ways, dramatically influencing the course of the last few months of her life. The section shows in particular how this aloneness and disregard made her particularly poorly positioned within the context established by the previous section, magnifying the troubles that this healthcare context presents.

This section thus elaborates on the theoretical claims presented in Chapter 2 regarding the relationship between disregard and aloneness. I have argued there that disregard in itself constitutes particular forms of aloneness, and thus that the (post)colonial bureaucratic disregard that manifests in an absence of DME providers and a presence of hospice care on St. Croix shows how the island is separated, distanced, and made alone. In this section I explore how forms of aloneness and disregard present in Ruth's life at the interpersonal, intimate level collided with these societal circumstances. This collision brings into view both causal relationships—like the fact that there was no Medicare-certified DME on St. Croix pushed Ruth to sign up for hospice care, and of non-causal, but mutually affecting relationships—like that between the unreliability of Ruth's daughter, hospice's model of care, and Ruth's embodied experiences. Interpersonal disregard and bureaucratic disregard—and the forms of aloneness the created—were all at play in shaping the end of Ruth's life.

The chapters to follow both personalize and generalize Ruth's circumstances, showing the meanings and roles of these circumstances within the particulars of Ruth's own life and demonstrating how the situations she faced are versions of situations all too common on St. Croix. As a white woman who lived most of her life stateside, Ruth was in important ways not representative of most older adults living on St. Croix who are in need of care and DME and find that hospice is the only available way get those things. However, beginning my case studies of individuals on St. Croix with Ruth allows me to show something important about the situation for older adults in need of care on island: even people “like” Ruth—people who are white, have a somewhat higher SES, and have family connections stateside—can have their possibilities severely limited by the heathcare landscape of (post)colonial bureaucratic disregard.

It is important to keep in mind that while Ruth is not “typical” in terms of being representational of certain majority groups on St. Croix, the island itself, as I discussed in Section II, is a place that has long been characterized by ethnic diversity. In the current moment, this is a diversity perhaps most concisely explained by its geopolitical position as both inside and outside the U.S., and both inside and outside the Eastern Caribbean. Focusing on Ruth’s case highlights one important aspect of the mix of populations characteristic of this particular (American) moment in St. Croix’s history.

Thus, without by any means flattening the extremely complex differences between being a white statesider on St. Croix and being an Afro-Caribbean on St. Croix, we can see that there were important aspects of Ruth’s situation that spoke to the broader situation of older residents on St. Croix. Her financial precarity and her reliance on one family caregiver were both very common among my focal participants and among other older adults that I spent time with both within and outside the bounds of my study. Furthermore, the way the end of her life was powerfully shaped by (post)colonial bureaucratic disregard, in particular Medicare’s control over—and disregard of—healthcare possibilities on island is paradigmatic of the kinds of end of life trajectories I witnessed on St. Croix.

In Chapter 9, I discuss Ruth’s trajectory onto hospice care and the creation of her identity as a hospice patient. This chapter focuses on both the near and the more distant trajectory of how

Ruth came to be a hospice patient on St. Croix, presenting a biographical sketch of her life and discussing the circumstances that most immediately brought her to Shepherd. I then discuss her care in the first week or so of her time as a hospice patient, tracing the way that a certain identity was created for her by her hospice caregivers. I show how the picture of Ruth as a "woman who lives alone" was crucial to her becoming a hospice patient in the first place and to the unfolding of her care and sedimentation of her identity that occured in this first week. However, because Ruth did not live alone but in fact lived with her daughter Jess who was an unreliable caregiver, I discuss the forms of disregard that were at play both in Ruth's aloneness, and in the way that "aloneness" was constructed and responded to by her hospice caregivers.

In Chapter 10, I leave the first week of Ruth's hospice care to examine two crucial episodes that shaped Ruth's end of life trajectory. I focus on how these incidents unfolded in a nexus of tensions between hospice care philosophy and regulations, the healthcare landscape of (post)colonial disregard, the identity that had been created for Ruth as a patient, and Ruth and Jess's explicit wishes. I focus in particular in forms of disregard inherent to American hospice policy practice within Medicare, and how that disregard was amplified, and at times questioned, during these two crises. I show that these two health crises—which urgently raised the question of whether or not need acute, rather than palliative, care—disclose how dynamics of interpersonal disregard and the overacrching context of (post)colonial bureaucratic disregard can collide in limiting end of life possibilities for older adults on St. Croix.

Chapter 9

Becoming a Hospice Patient on St. Croix

I first heard of Ruth when I was sitting in Gloria's Shepherd Hospice office, shadowing her one day in late October 2015. We had been supposed to meet in the morning, but Gloria had gotten a call from the hospital asking if someone from Shepherd could come see about possibly admitting a patient onto hospice, and—as she would often do—Gloria went herself. Now she was back in her office at Shepherd, on and off the phone trying to coordinate the patient's discharge onto hospice care. Through listening to Gloria's side of these phone calls and through her explanations of the case to me in between, I started to learn a bit about Ruth at this moment in her life.

Gloria explained to me, hurriedly in a brief moment in between phone calls, that Ruth had been to the hospital last weekend for a urinary tract infection ("U.T.I.") and when she was there they told her that she needed to be on oxygen.[214] Because there was no Medicare-certified oxygen supplier for the hospital to refer her to, Ruth paid out of pocket for a tank full of oxygen at the local gas supplier. Including the large deposit that she had to pay for the tank itself, this initial purchase cost her $600. Using it continuously at the rate the hospital had prescribed, the amount of oxygen in the tank lasted her just a day and a half. When the oxygen ran out, Ruth returned to the hospital's ED. Gloria told me that when she had been evaluating Ruth in the hospital earlier that morning, her blood oxygen level was low even though they had already gotten her hooked up to oxygen. Monitoring the pulse oximeter attached to Ruth's finger, Gloria

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[214] While Gloria didn't specify this, this could have easily been discovered through a routine blood-oxygen check.

was able to see that it was 93% when she first got there, and dipped as low as 90% during her visit.[215] I learned later, in interviewing Shepherd's medical director about Ruth's case, that these low percentages reflected that her body's ability to bring oxygen from the lungs into her blood (and thus circulate it to the rest of her body) appeared to be seriously compromised, a symptom of her advancing COPD.[216]

Ruth's physical need for concentrated oxygen was evidenced in these percentages, and it was because of this low blood oxygen level that she was back in the ER. Indeed, Ruth presented to Gloria as one of the many casualties of the U.S.V.I.'s "DME crisis." Unable to afford to supply herself with concentrated oxygen at home due to the lack of a Medicare-certified DME provider in the territory, she was back in the hospital.

However, Gloria also saw other the reasons, besides the high cost of oxygen, that Ruth's blood oxygen level had gotten so low, and she saw these reasons as also crucial to understanding Ruth's situation and framing her as a patient. The way Gloria framed the main issue facing Ruth to me that day in her office, was that "now this woman who lives alone is going to have to find a way to get her oxygen refilled every other day." This phrase painted a picture of a woman who only had herself to rely on, and, given her ill-health, simply wasn't able to do everything necessary to take care of her worsening condition. Just over a week before, Ruth hadn't needed oxygen, but this new physical requirement now posed new logistical challenges that, it appeared, she wasn't able to take care of on her own. Gloria came to see the 'fact' that Ruth "lived alone"

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[215] In people with normal/healthy lungs, blood oxygen levels stay around 98-100%.

[216] The medical director also explained to me in this interview that in someone with COPD around the level of Ruth's, their blood oxygen level when not hooked up to oxygen might be somewhere around 85%. He told me that someone with normal lungs would not be able to get their blood oxygen this low even by holding their breath, as their hypoxic drive would force them to breathe.

as a significant part of why she needed to be admitted hospice care, and it indeed would become central not only to her admittance onto hospice care, but to the construction of her identity as a hospice patient, to the kind of care she would receive, and to her end of life trajectory.

This chapter traces the ways in which Ruth's aloneness—in both its emotional and material realities and in its imagined being and consequences— enacted a central role in her hospice care and in how her life came to an end. The interesting thing about the fact that Ruth "lived alone" was that it simply wasn't true: Ruth did not live alone. She shared a house with her grown daughter, Jess. Of all the things that "living alone" might entail, the fact that Ruth was taken to be a woman who "lived alone" had a very particular meaning for her as a patient: it meant that she did not have a competent, reliable caregiver. And this, on the other hand, was true. Jess's unreliability in taking care of her mom, and the ways that unreliability was engaged with and reacted to by her hospice caretakers deeply shaped her trajectory in the last months of her life. In what follows, I return first to a deeper look at the construction of Ruth as someone who lived alone and in what that was taken to mean during the process of her becoming a hospice patient. I then go back even further, presenting a biographical sketch of Ruth that includes a history of her relationship with Jess and an explanation of how she came to be living the end of her life on St. Croix. I then return to Ruth as a hospice patient and discuss the further sedimentation of her patient identity during her first few weeks of hospice care. This was an identity that was as much created through Ruth's aloneness as it was through the role Shepherd Hospice has had to take up in St. Croix's healthcare landscape and the extremely limited options that presented themselves both to Ruth and to her hospice caregivers.

“This Woman Who Lives Alone”

I don’t know how Gloria, through one visit in the Emergency Department with Ruth, came to think of her as someone who lived alone. It’s possible that Ruth, angry again with her continuously disappearing daughter, told Gloria this. She might have thought—in her newly vulnerable situation— that it could potentially get her better care. What I think is much more likely, however, is that Ruth living alone was a situation assumed by hospital staff. As I mentioned, Gloria was called by a nurse at the hospital to come and evaluate Ruth for hospice care. This wasn’t a common practice, which in my reckoning shows that she was seen as patient more or less on her own, who did not have family helping her out, and who thus needed the kind of at-home support that, on St. Croix, only hospice could provide. Ruth had been to the ED fairly frequently in recent weeks, and at a hospital the size of JFL patients come to be known and recognized fairly easily. I believe it is likely that due to the absence of any apparent family in Ruth’s life—that is, the fact that she was repeatedly showing up at the hospital alone—the small group of ED nurses and other staff took her to be a woman who lived alone. This would have then been one of the causal factors that led to Shepherd Hospice being called in.

The day that Gloria went to evaluate Ruth, she told me that one of the nurses in the ED, had challenged Gloria’s assessment and even her presence there, saying that Ruth wasn’t hospice appropriate (this nurse apparently used to work in hospice). Gloria, explaining the story over the phone to the hospital discharge nurse helping her coordinate the transfer of Ruth’s care, said that she told this ex-hospice nurse that hospice diagnoses are changing, and that now there is much more emphasis on “co-morbdities.”[217] While this term is usually used to refer to two or more disease processes or medical conditions affecting the same patient, Gloria went on to list several social “conditions”: “she lives alone, there are financial issues, she has an alcoholic daughter.”[218] She also mentioned, on the medical side of things, that Ruth had osteosclerosis and a fracture in her back (this was a past injury). Just as in the way that the presence of multiple medical conditions can worsen or complicated a patient’s primary diagnosis—for example, if a person with chronic heart failure also has diabetes—so Gloria was claiming, that these social conditions could complicate Ruth’s COPD.

In a curative biomedical context, co-morbidities are usually seen and acted upon as complicating treatment, making it more difficult to cure or improve any of the conditions on their own as the conditions limit what kinds of treatment is safe or effective.[219] In the hospice context there is a similarity in that the recognition of co-morbidities is important in building a patient’s care plan, as the interaction of multiple conditions in one body affects what palliative care will be the most effective and appropriate. At hospice intake assessments, however, co-morbidities also serve a different purpose: they are used as resources to help predict how much longer a patient will live. The particular multiplicity of disease processes and other ailments a patient is undergoing is important evidence for how close to death that patient might be, and can help

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[217] Gloria was referring to Medicare’s changing guidelines for hospice eligibility and billing, which are updated frequently. These include what kind of evidence is legally considered to be legitimate when documenting a patient’s hospice eligibility.

[218] This “alcoholism” was never confirmed. As I’ll discuss more further along in the chapter, Jess’s alleged alcohol and drug use—based on her speech and behavior, her physical presentation, and her social history—played a big role in Shepherd’s understanding and treatment of her. I saw Jess drink, but never to excess, and never with a frequency normally attributed to “alcoholics”.

[219] See Weaver, Barrett and Nichter (2016) for a brief critical history of the term “comorbidity.”

nurses assess if a patient is hospice appropriate. In Ruth's case, then, Gloria was claiming that in correctly predicting the course of Ruth's COPD—the primary diagnosis with which she was admitted to hospice care—these social conditions needed to be taken into account. As an argument against an ex-hospice nurse who felt that Ruth's current medical condition did not make her hospice appropriate, the claim was that her medical condition plus these social conditions *did* make her hospice appropriate. The fact that Ruth "lived alone" was here taken by Gloria as a condition that could, in combination with other factors, shorten her life.

The fact that Ruth had run out of oxygen and had needed to go to the ED in order to get some was evidence of one of the ways that not having a reliable caregiver could influence Ruth's illness. For someone with advanced COPD, not having a reliable source of concentrated oxygen could have disastrous effects on their condition, and could eventually be fatal. (A few months later, Gloria would tell me the story I recounted in Chapter 7, of a man suffocating to death upon arriving at JFL hospital because he had ran out of concentrated oxygen at home.) However, the effects of the absence of a reliable caregiver showed itself in other ways that day too. One of the reasons Gloria was on so many phone calls in her office after evaluating Ruth was that she needed to coordinate having the oxygen concentrator (and other DME, including a hospital bed) delivered to Ruth's house so that it would be there when she got home. Ruth would oxygen in her transportation from the hospital, and would need to put on the oxygen immediately when she got home. Since there was no one at her house, Ruth, from her cell phone in the ED, and Gloria from her office at Shepherd, were together trying to come up with ideas and chasing down leads for who could receive the equipment. Ruth found out by calling her neighbor's house that her neighbor's daughter was home and would be willing to receive the equipment, and then Gloria had to coordinate her delivery driver getting in touch with the daughter's neighbor. This might seem like just a small inconvenience, but the solution they ended up finding was only settled on after a number of back and forth phone calls and different attempts between Gloria, Gloria's equipment delivery driver, Ruth, various parties at the hospital, and the service that would be driving Ruth home. In the end, the effort took most of Gloria's day.

Although it could easily not have happened then, by the end of that day, Ruth was back at home and breathing concentrated oxygen through a nasal canula. The point is not just that even seemingly simple tasks like coordinating the home drop-off of medical equipment can actually be complex when multiple healthcare entities are involved, but that the complexity of tasks like these were greatly increased by the fact that Ruth "lived alone." It turned out that the complexity of this first day was a preview of what caring for Ruth was going to continue to be like for her hospice caretakers. They both were charged with taking on tasks that were not normally in their purview—like making sure Ruth had adequate access to food and water—and discovered that many of their habitual tasks—like making sure their patients took a certain medication every day—were made much more complicated by the absence of a reliable caregiver. These complications added to their workload in comparison to what they had come to expect, and forced them to try to create new solutions to care problems they had not encountered before. The complications made their jobs materially and logistically more difficult. However, these complications also grated on them—annoying them, testing their patience, and deeply shaping their attitudes toward Ruth.

Ruth: A Biographical Sketch

Ruth was born in 1944 as the first child in a lower-middle class family in Long Island. Her parents both worked, and Ruth remembered wearing hand-me down dresses and beginning to make her own money by babysitting around the age of 12. Her parents had two more daughters in the five years after Ruth was born, but she was never close to either of them growing up, and they remained distant throughout life. Ruth lived with her parents until she got married at the age of 21. She married a man who proposed to her after the two had known each other for just two weeks, and the wedding itself followed swiftly as well: “we met in May and I got married in September.” Looking back on it from our interview when she was 71, she called it a “major mistake” and said that she only married him because she wanted to get out of the house and her parents wanted her to get out of the house. She had been working at a bank after high school, but stopped at her husband’s request when they got married. She described working at the bank as a really fun time, when everyone working there were just young kids like her who would fool around and bend the rules. She remembered with glee the long, late lunches the whole staff would sometimes take, when she would split a wedge salad with her girlfriend and have one two many martinis. This kind of fun, carefree time was a real exception in Ruth’s recounting of her life. When I knew her—which was only when she was very sick—Ruth was very particular about how things were done and came off to many as being picky. She tended to orient strongly to the rules or the correct procedure in a given situation, wanting things to be done right. She did have a sense of humor, but it took a little digging to get to it, and while she certainly did have a bit of a naughty or playful streak, it was mostly discernable in her stories of her past and did not have much of a place in the way she conducted herself in the months I knew her.

Returning to her biography, Ruth gave birth to her first daughter—Jess's older sister—when she was 25, about 4 years after getting married. Fourteen months later, in 1970, she gave birth to Jess. (This made Jess 45 during the time I was spending time with her.) Ruth remained a stay-at-home wife and mother until Jess went to school. At that point, she began driving a school bus, which she did for about 5 years, and then started doing accounting, which turned out to be her true calling. She had loved accounting ever since taking an accounting class in high school. It had come easily to her, and she was really good at it, even winning an award from the National Office Managers Association. After rediscovering accounting in her late thirties, she was an accountant for the rest of her career. She worked for various companies, first working at a men's clothing store. In St. Croix, she did the accounting for a local office supply store that eventually merged with a larger store. Ruth told me that she liked working, and would have still been working had she not been diagnosed with cervical cancer 5 years before I met her, at the age of 66.

Ruth had a difficult home life, both as a child and as a spouse. She remembered waking up at night as a child with her body trembling, hearing her father "having a fit somewhere" in the house. She said he used to punch holes through plaster walls, "not sheetrock plaster, plaster." When I asked Ruth if her father ever hit her, she seemed to recall it only happening one time. As a teenager she had lied to him about where she had been going, and when he found out he hit her with a belt, giving her huge welts on her back. Ruth told me that she refused to cry, but instead just stood there, almost encouraging her father to hit her again. She said she thinks this "rearranged his thinking" on her. In retrospect, she told me, her husband was just like her father.

She said that when they first met he was a really fun guy, a great guy, but at home it was a different story. “The world loves [her husband],” Ruth said, “except the people who live him.” She described him as “emotionally abusive” to her and their two daughters, and said that he was at times physically violent with her. A career police officer, everything had to be his way: the furniture, the paint color, everything. “You can have an opinion,” Ruth said, “along as it agrees with his.” She said home life had been “overshadowed” by her husband, “what he was gonna do, what he was gonna allow what he wasn't gonna allow.” Her husband’s presence was so dominant in the home that when I asked Ruth what being a mother was like for her, she told me that it felt like she hadn’t even been there while it was happening:

Ruth: well, haha-
it's gonna sound awfully funny,
but about, about twenty years ago
I woke up and said
where have I been the last twenty years of my life (hm)
it's like I didn't remember,
it was like I didn't participate.
DF: wow, yeah
Ruth: it's weird
DF: yeah
Ruth: but.
DF: so you were, about fifty-ish?
when that happened
Ruth: ehhm no younger (yeah) forty-forty
-between thirty five and forty five

DF: yeah.
so that woulda been all the time
you got married, had your kids
and everything
Ruth: yeah.
DF: yeah,
Ruth: where have I been all these years
DF: wow
Ruth: scary too.
DF: yeah

This is Ruth at 71, recounting that between 35 and 45 she had an experience of waking up from a sort of 20-year slumber, a feeling of non-participation in her own life for the past two decades. Remembering that she got married at 21, I think it is likely that the beginning of her marriage to his emotionally abuse man marked the beginning of this period.

While she doesn't mention it here, the end of this period, the time when she "woke up" coincides with the time when she divorced her husband and moved to St. Croix. The timeline is a bit fuzzy here, but she moved to St. Croix sometime in between when she was 36 and 42. While she didn't tell me the precipitating reason for the divorce, needless to say it had been a long time coming. She said that by the end, if she hadn't of left, one of them "would have killed" the other. When I asked her why she moved to St. Croix, she said that she "had always wanted to live somewhere else." She had been to Bermuda, but it wasn't the same as living in the U.S. She came to St. Croix to visit a close girlfriend, and felt like she was at home. "I've been Crucian all my life," she told me, "it just took 42 years to get here."[220]

Ruth never bought property on St. Croix, and moved around a lot. She joked that she used to be known for moving every two years. Despite Ruth feeling like St. Croix was home, though, her stories didn't provide a lot of evidence for her finding a community for herself on island. Some of her stories mention a man who seemed to be her serious boyfriend for a period of time, and of course there was the close girlfriend she had originally visited on St. Croix, who she also lived with for a period of time. Her girlfriend died around 2005, though, and her ex-boyfriend had also died some time ago. It wasn't clear from her stories who else had been part of her life on island in the 30 or so years since she had moved there. When Shepherd came on the scene, Nancy[221] the Shepherd social worker, interviewed Ruth, at one point asking about people in her life who might be able to help her (financially or otherwise). Ruth told her that she had one friend on island. This was Patti, who she knew from church and who was her landlady. She said she "maybe" had one other friend, a retired nurse. Ruth said that she wouldn't be comfortable asking either of them for help; they were just friends.

Some of the stories Ruth told indicated that making friends and becoming part of a new community might not come easily to her. For example, Ruth was a lifetime smoker, and had only stopped during her cancer treatment in her 60s. I asked her how she had first started smoking. She told me that when she was 13, a girlfriend had come over to her house with cigarettes, asked her if she wanted to smoke, "and that was it." "Oh it was stupid," she said. She said she kept

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[220] This is an instance in which she says she was 42 when she moved to St. Croix. Elsewhere, dates and ages she and Jess told me conflict with this estimate a bit.

[221] Nancy was a white, stateside woman in her sixties. Like Ruth, she had been living in St. Croix for decades. She had come to St. Croix in the 1970s and had been working in social services ever since. She was extremely connected to St. Croix, but also maintained strong ties to the continental U.S. and would travel there several times each year.

doing it for the usual reason: because her friends were doing it. Ruth continued with the story, which turned out to be a story about the friend who gave her the cigarette, rather than about smoking itself:

> **Ruth**: but um,
> then for some reason she-
> she dumped me. (mm,)
> I haven't-haven't had very much luck with girls. (hm,)
> um, one day she called me
> uh-she asked me
> to tell her boyfriend
> she didn't wanna see him anymore, (mhm,)
> so I did,
> and the next time I saw them (chuckling)
> they were engaged
> or something like that
> **DF :** oh my gosh, wow (chuckling)
> **Ruth**: so I said uh,
> what's wrong with this picture
> **DF**: yeah, that's strange, huh.
> **Ruth**: so. I'm uh-
> I think it made me a little standoffish
> with girlfriends (chuckling)

At this moment in the interview, I kept the topic on smoking and continued to ask about smoking in her life. She told me about a funny dream she had after she had quit smoking, and then about how easy it would have been if she had "just said no" and not become a smoker in the first place.

Then, Ruth turned to again showing how her smoking was implicated in her social connections with others:

Ruth: I liked smoking,
it was my friend,
and it was a way to hide. (yeah,)
you hide behind things like that.
cuz most people around here
don't like smoking.
ya know it's v-the, the locals? (yeah.)
so they don't want anything to do with ya
if you smoke. (mm)
which is,
I don't wanna say good and bad,
got-got it's good points
got its bad points,
in my opinion um,
because, ya know
as christians you're supposed to embrace people
no matter what kinda shape they're in
and yet,
that's the biggest obstacle I ran into in the church.

Smoking cigarettes is indeed very rare on St. Croix, and so it is not surprising that being a smoker set Ruth apart from others on-island.[222] But she presents an ambivalent relationship to this distance: smoking at once was “a way to hide,” a way to keep herself away from others, but it also was the “biggest obstacle” she ran into when trying to connect with people at church. It seems, as Ruth says, that for her it had it’s “good points” and it’s “bad points,” maybe giving her a way of avoiding people or social situations she didn’t want to be involved with, but also hindering her acceptance in the community she did want to belong to. This ambivalent orientation toward being with others is in no way unique to Ruth[223] but it is nonetheless provides an important insight into her relationships. It’s important for her to be able to get away from others, but she also of course still needs human connection, caring, and love. However, the way she refers to those she sees as native to St. Croix, the “locals” discloses her perduring feeling of being an outsider even in a community she lived in for several decades.

The most central interpersonal relationship to Ruth’s life during the time I knew her was with her daughter, Jess. When Ruth moved to St. Croix, both of her daughters were still growing up. Depending on which version of the timeline is correct, she moved to St. Croix sometime between 1980 and 1986. In 1980, Jess was 10 and her sister was 11. In 1987, Jess was 17 and her sister was 18. From other stories that both Ruth and Jess told me, I estimate that Jess was between 13 and 16 (and her sister between 14 and 17) when her mom moved to St. Croix. She thus left both of her daughters to move to a far-

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[222] Health data from 2009 indicate that approximately 4% of U.S. Virgin Islands residents were daily cigarette smokers at that time, compared to 12% nationwide this same year (Centers for Disease Control and Prevention 2018).

[223] See, for instance, Jackson 1998 for a particularly eloquent investigation of the existential-anthropological dynamics between self and other.

away island when the two were still in school and in the midst of adolescence. Furthermore, she left them in the sole care of their "emotionally abusive" father. This move was a major break in family life and a major break in Jess and Ruth's relationship. Ruth said that part of the reason she went so far away when she and her husband divorced was that in their teens her daughters had gotten totally out of control. Ruth felt like she didn't know how to handle them, like she couldn't handle them, like she needed to get away from them. This opting out of everyday parenting marked her relationships with her daughters for the rest of her life. Jess's sister, all these years later, still barely talked to Ruth. And Jess had been mad at her mom for decades.

By the time I came on the scene in 2015, these family relationships had continued to develop along their own trajectories. After Ruth left for St. Croix, both Jess and her sister had come to visit her during summer vacations. I got the impression, though, that Jess's visits had continued as she got older, while her sister's hadn't (it may just have been that as the younger sister, she had more time left in school when Ruth left, and so made more summer vacation visits). When Ruth was diagnosed with cervical cancer in 2010, Jess, forty years old at that time, moved to St. Croix to be with her mom after treatment. Jess told me that while she had been really mad at her mom for a long time, after a while she started to understand that her mom had to get away from "him" (her dad) too. Jess now had a lot of affection for Ruth, and a desire to be a part of her life. She wanted to be a daughter to her again, and had moved to St. Croix to do just that.

When I met them, Ruth and Jess both had an ongoing relationship with Jess's dad. Ruth told me that they were on good terms, and they talked on the phone fairly often. Not to say that it wasn't still a complicated relationship, though. She told me that he was the same now to his current wife as he had always been with her, that he hadn't changed a bit. She also said that he controlled their daughters with money. Indeed, Jess received regular checks from her dad, and her dad called her a lot.[224] Jess told me like she feels like he gives her money in order to get her to talk about things—about their life, now—that she would rather not talk about with him.

Despite Ruth and Jess's reunification, all was not well in their relationship, either. On one hand the two knew each other intimately—from years living together just the two of them—and displayed a kind of symbiosis. But on the other, the two argued all the time, often could not see eye to eye, or even seem to be able to understand the other person at all. I remember often sitting in their living room observing Ruth and Jess talking to each other, and being astounded at the extent to which they literally could not make out what the other person was saying (while I could understand them both with no problem). They had to repeat themselves all the time just for the other person to understand the words they were saying. It was as if the words were coming through deafening with static, or like each one had earplugs in that only blocked out the other's voice.

And then, there were Jess's disappearances. Jess would usually take off on foot, walking with purpose along the side of the road for several hours to another part of the island. Her dark tan skin was evidence of these long walks under the sun in shorts and a tank top. Over time I figured out that she would usually leave to go stay with a group of her friends that lived in an

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[224] At one point, Ruth told the Shepherd social worker, Nancy, that Jess—being the one who picked the mail up from the post office—stole checks from her dad that had been intended for Ruth (or perhaps, used checks for her own expenses that had been intended for the two of them, it wasn't entirely clear). Whether or not this was true (it's hard to know for instance, how Jess would have cashed checks that were made out to her mom), it seemed that Ruth's ex-husband was regularly sending down money to both of them. While I don't know for sure, I believe that he was sending somewhere around $100 every week. I don't know how long this had been going on.

area of the island about 7 miles away. Her mom knew about these friends, but all the same it was never a sure thing that this was where Jess was when she was away. She wouldn't have a cell phone with her when she would go (Ruth and Jess only had one cell phone between them) and would usually not be in touch at all.

For Ruth, these sudden, extended disappearances were a continuation of the acting out Jess had done as a teenager and a young adult. It was this kind of acting out Ruth needed to get away from, but that Jess and her sister had reproduced on their visits to St. Croix, disappearing for days at a time even then. For Ruth, Jess had always been this way, and she had never known how to handle it. At some point in their lives (although not necessarily at the same time), both Jess and her sister became pretty heavily involved in drugs and alcohol, and Jess still drank regularly.[225] This history shaded Jess's disappearances, making them darker and more troublesome. Whether or not these disappearances were in fact extensions of past modes of behavior (drug-related or otherwise), there were aspects of Jess's periodic leaving of her mom that mimicked Ruth's leaving of her when she was a teenager. She would, in the circumstances the situation afforded her, go "far away" by making herself unreachable. She was just miles away, but performed the kind of distance, the kind of unavailability that her mom's move to St. Croix had created. Throughout the time that Jess lived with her, Ruth had varying degrees of need for Jess's help and care. However, until late 2015 when her COPD got so bad that she needed to be continually attached to an oxygen concentrator, Ruth could survive without her. This is the same position an adolescent Jess would have been in when her mom moved to St.

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[225] I generally interpreted her drinking as being a culturally sanctioned "idiom of distress"(Nichter 1981; see also Hinton and Lewis-Fernández 2010; Nichter 2010). However, I only knew Jess during this stressful time in her life, and so don't have any baseline against which I can compare her drinking during this period.

Croix: greatly in need of help and care, but able to survive without it.

The other most important relationship in Ruth's life during the time I was getting to know her was her very active engagement with the Christian god. I don't know how long she had had this kind of relationship, but it seemed from some things she said that it was a relationship that she had begun to take much more seriously later in life. She saw this god as actively engaged in her everyday life, and would pray often. She was not well enough to go to church during the time I knew her, and I don't know how regularly she had been going when her health was better. However, her TV, which was always on, was usually tuned to a church channel, and she prayed along with them and would sometimes call out in spontaneous praise of god. She would sometimes have phone calls with her friend Patti, (who she had met at church), in which the two would spend most of the call praising god together. As her health worsened, she seemed to be coming to understand this god as an unconditionally loving figure, who not only loved her and every other person on earth but wanted us all to love and care for each other. Ruth believed that when you die, your soul leaves your body and rejoins god.

Ruth's Medical Trajectory

The decline in Ruth's health had started about five years before I met her, in 2010, when, as I've mentioned, she was diagnosed with cervical cancer. She had surgery on St. Croix to remove the affected areas, followed by radiation and chemotherapy at treatment centers in the states. She had a relatively easy go of the chemotherapy, but the radiation treatment was very painful. She didn't fully regain her energy and wellbeing after treatment, and spent a lot of time on the couch. She and Jess would still go grocery shopping together and go to the beach from time to time, but it seemed like she still had a lot of recovery to do. However, from what I could gather, Ruth never really did recover, and stayed mostly on the couch for the years in between her cancer treatment and when I met her. Jess described her during this time as “sort of” sick: definitely not a normally functioning healthy person, but not requiring constant medical care either. It’s not clear when Ruth began to develop COPD. Her hospice care did not depend in any way on when her illness had began, and when I asked Shepherd’s medical director if he could estimate based on her current condition, he simply told me he didn’t know. However, it’s likely that the decreasing function of Ruth’s lungs during this period, leading up to her need for continuous concentrated oxygen in 2015, greatly impeded her healing and kept her this “sort of” sick state.

In addition to this, Ruth had serious and painful back problems. She had several herniated discs as well as osteoarthritis (also called degenerative joint disease) and compression fractures in her spine. This degeneration of her spine had caused her to lose 2 inches off her height. When Ruth came onto hospice care, she was managing her back pain with daily use of tramadol, a narcotic painkiller. Her initial hospice assessments show that her back pain was mild during this time. However, this was when the painkillers were active: if she wasn’t on painkillers or had to stay in a particular position for too long, her back pain would easily get quite severe. Throughout the time I knew Ruth, her back pain was one of her main sources of discomfort, and on many occasions caused her a great deal of suffering.

Alongside her back hurting her, Ruth also experienced bouts of what is medically known as ‘shortness of breath’, or difficulty feeling like she was getting enough oxygen. Although she was on concentrated oxygen continuously through a nasal canula, a certain amount of talking or movement caused her to become winded and need to catch her breath. However, because Ruth's lungs had lost much of their elasticity as well as their ability to transfer oxygen into her blood stream, catching her breath was not as easy as it is for people with healthy lungs. Sometimes it could cause her to feel panicky, like she was suffocating. This feeling, while not always present, was always a close possibility for Ruth during the time I knew her. The continuous potential for its appearance definitely shaped her feelings about what was possible for her in terms of activities and conversation, causing a good deal of anxiety as she very much wanted to avoid the feeling of not being able to breathe.[226]

It was this, the need for oxygen and her body's declining ability to adequately extract oxygen from the air around her, that put Ruth on a path to hospice care. In the rest of this chapter, I discuss how Ruth's patient identity formed within the Shepherd care team during the first week or so that she was a hospice patient. During this short period of time, the Shepherd nurses co-constructed a narrative in which Ruth's aloneness and her attitudes and behaviors regarding that aloneness made her a particularly problematic patient. As time went on, this narrative affected the kind of care they provided her, including what they had the energy and will to do and what they felt her medical condition warranted.

The Construction of an Problem Patient

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[226] This physiological trigger of anxiety played an important role in the narrative that arose surrounding Ruth's anxiety, discussed below.

The first week after a patient is admitted at Shepherd is usually a relatively busy one in terms of activities surrounding that patient's care. A number of different assessments need to be done, prescriptions have to be decided on and be ordered, and family caregivers need to be engaged in the care plan. Nurses often visit the patient's home several times in that first week to help patients and families come to understand and start to get used what hospice care is going to be like, and what their role in that is. With Ruth, though, the first week went beyond this normal flurry, marking Ruth out as an exceptionally difficult patient and branding her with a particular patient identity.

This identity was organized around three main components. As was clear from the day she signed onto hospice care, the fact that Ruth "lived alone" made her care more complicated, and it did so in unexpected ways, adding to the work the Shepherd nurses had to do to take care of her. On top of this, she was seen as "non-compliant," refusing some of the care that Shepherd thought was best for her, in a stance that was interpreted as being contrarian and difficult to work with. And, she was labeled as being a very anxious patient, which was problematic in that it was seen as causing much of the behavior and stances that were problematic for her care team. In this section, I'll show how these perspectives on Ruth emerged through the practice of taking care of her within a home hospice model of care. Doing so will draw attention to the modes of disregard playing a role in this first week of Ruth's care, which I will attend to explicitly in the chapter's conclusion.

The work of taking care of Ruth in this first period of time fell largely to Nicole, Ruth's

RN (Registered Nurse) Case Manager, who was in charge of Ruth's care.[227] Nicole was both the person who made regular visits to take care of Ruth and as the leader on her care interdisciplinary team. Nicole was a young nurse, in her mid-twenties, who had grown up and lived her whole life stateside before moving to St. Croix earlier that year. She had some "ex-pat" family on island, loved it there during her visits as a kid, and had been looking for a change. Like most of the nurses Shepherd employed during the length of my fieldwork, Nicole was white, had been educated in the states, and had no previous experience in hospice care. Still getting used to her new job as a home-hospice nurse, Nicole consulted Gloria regularly for both advice and executive decisions regarding Ruth's care.

In addition to Nicole and Gloria, the other main figure playing a role in how Ruth's care unfolded in the first week or so was Jess. This was because during this time, Jess was in and out of the house. She was gone when Ruth was in the ED signing up for hospice care, and then she was back for a few days after that, and then she was gone again for a few days after that. It was hard to tell when she was leaving; or, really, it was hard to tell when she was coming back. Jess's stays away from home may not all have been marked this way, but usually she would go out to run errands—to the grocery store or the post office— and then just not come home for days. Other times, though, she would leave to run errands or hang out with her friends, and be back a few hours later, before the sun went down. It seemed that the most problematic thing about Jess's

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[227] At this point in her care, Ruth also had a Certified Nurse Assistant (CNA), a social worker, and a chaplain assigned to her. The social worker and chaplain had yet to visit Ruth (they normally visited patients 1-2/month), and so were not yet playing big roles in Ruth's care (although they were familiar with her case). Her CNA came for two hours Monday-Friday to bathe Ruth and help with other grooming and cleaning tasks—providing the most caretaking hours of anyone on the team—but did not have any say in decisions about Ruth's care and was not authorized to take part in team meetings. Thus here I focus on the work of Nicole, Gloria, and the on-call nurses (a role that all the Shepherd nurses rotated through, responding to patient needs outside of normal business hours) who were managing Ruth's care during this time.

disappearances from Shepherd's perspective was not that she was gone, but that she was sometimes gone and sometimes there, and that both states were unpredictable.

This stuttering presence in the house—and hence stuttering ability to help take care of her mom—was mirrored in Shepherd's responses to Jess, the way they tried to account for her. Early on, Gloria explicitly told Nicole not to include Jess in the care plan. This means not giving Jess any responsibilities at all when it comes to her mom's care, and building a care plan that treated Ruth as if she lived alone. Indeed, Jess's name was absent from Ruth's official patient profile in her hospice medical record. In hospice records like this, there is a space to list any family or friends who are involved in caring for the patient, but Jess had intentionally been left out. However, because Jess was home sometimes and did play a role in Ruth's life and care, her name *can* be found in Ruth's chart, in the narrative notes the nurses and other caretakers are mandated to write at the end of each visit. In the official record of the last few months of Ruth's life, she is at once there, and not there.

For her part, Nicole, in an interview after one of our visits to Ruth that first week, told me that she was having a hard time knowing "how to handle" Jess. Jess had been there during our visit, and Nicole had shown Ruth and Jess together her how to dose out the correct amount of liquid laxative using one of their kitchen glasses. In the interview, Nicole told me that our upcoming visit later that day would be a good test to see if what she had shown them had sunk in, and either one of them had remembered to do it. Her plan, as she was tentatively envisioning it during our conversation, was to give Jess some very specific, delimited responsibilities. For example, Nicole said, one day she might ask Jess to go to the store to get orange jello (her mom's favorite), and that would be it.

But Nicole also struggled with how to talk to Jess, not knowing "what answers" to give her, because she didn't want "to give her too much responsibility." From early on, Jess's sometimes erratic behavior had caused a rumor among the Shepherd caretakers that Jess was using drugs, and this was certainly at play in Nicole's assessments and interpretations of Jess. This had been foregrounded for her during a conversation she and I had with Jess during our last visit. Jess had wandered out to the front stoop to smoke a cigarette, and I had followed her, followed then by Nicole who was giving Ruth some time alone to use her bedside commode. Sitting out there on the steps together, staring out at the blue ocean from our vantage on the hillside, Jess had expressed feelings of deep frustration and helplessness at feeling like she didn't know how to help her mom. In our interview the next day, Nicole told me that those kinds of moments happen with patient's family members a lot, and "normally" she had "all these answers to give them like you could try this or this or this." But, because she couldn't rely on Jess, and didn't know "how much she could handle," Nicole had felt at a loss for what to tell her.

This ambivalence about Jess's role—as someone who should not be involved in her mom's care at all, to someone who could perhaps be given small jobs to do but could not handle normal amounts of responsibility, to someone who, after all, lived with, loved, and wanted to help Ruth—intermingled with Jess's stuttering presence during this first week or so of Ruth's hospice care, playing a big part in the way things unfolded.

"Making Sure She Has Food and Water"

A few days after Ruth was admitted onto hospice care, Nicole went over her case in the weekly Shepherd team meeting (attended by nurses, the social worker, the chaplain, the medical director, and the anthropologist). These weekly team meetings, which are mandated by Medicare and thus standard across hospices in the U.S., are called InterDisciplinary Group meetings, or just "IDG". IDG meetings are a crucial incubator for collective narratives within the hospice care team.[228] During these meetings, the official business of re-familiarizing the team with the patient's case and updating them on any changes in the patient's condition or circumstances intermingles with exchanges of stories, thoughts, impressions, and theories about patients and their families. In some moments, the conversation can dip into the genre of gossip, while in others it is much more clinical. Often, it is somewhere in between, or bouncing back and forth between one and the other. In this meeting, only Gloria and Nicole had met Ruth, and so this conversation, along with the information in Ruth's chart, was the rest of the team's introduction to her. Many of the issues that arose as problematic in Ruth's care in the next week (and continued in the time after that) were introduced by Nicole and Ruth in this initial IDG.

One of these issues raised was that Ruth did not have reliable access to food and drink. Nicole mentioned this as somewhat of a temporary or short-term issue, saying that "she had had trouble getting food the other day," while, Gloria positioned it as more of an enduring facet of Ruth's condition, saying that she "gets very dehydrated" and has "poor nutrition." Nicole said that they were "working on getting her some more support" to try to help with the food issue, while Gloria took a different tack, presenting it as an issue that could be solved through social services, reminding Nicole to ask Ruth if she would sign up for Meals on Wheels. Gloria

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[228] It is required by Medicare that every hospice patient have their case reviewed once every 14 days, and so half of the patient census is reviewed every week.

contained the issue as a medical one described in medical terms that could be solved through a resource the hospice used often; in Nicole's presentation, the issue was more difficult to pin down, involving the lack of whatever "support" was needed so that Ruth wouldn't occasionally end up not getting enough to eat. What is strange in both of these presentations is that what the actual problem is remains opaque: what was causing Ruth to not get enough to eat? Clearly, it was a bad thing that a patient didn't have access to food or water, but it seemed that the possibilities open to hospice for trying to solve the problem depended a lot on what was causing the problem in the first place.

It took me some time—a couple of visits to see Ruth in her home—before I put together how it was that she wasn't getting enough to eat. And the only reason I was able to put it together is because it continued to be a problem—a big problem. The reason that Ruth sometimes wasn't able to get enough to eat is that she was at home alone a lot, and her oxygen tubing didn't reach to the kitchen. Now that Ruth had to be on oxygen continuously, she could only travel as far as the oxygen concentrator's power cord and the oxygen tubing would let her. It happened that the outlets in her house were such that there was no outlet that her oxygen concentrator could plug into that allowed her to reach both the couch and the kitchen. If there had been someone there to feed her every day, this wouldn't have been a problem. But, since Jess was unpredictably there and then not there, since Ruth "lived alone," Ruth was sometimes unable to eat.

This IDG meeting happened at the end of the week, and that next Monday I stood in Gloria's office with Nicole, getting an update on Ruth. One of Ruth's acquaintances, a retired nurse—the person she would later identify to Nancy as "maybe" her second friend on island—had called the hospice helpline several times over the weekend. She was panicking, saying that

Ruth was suffering dehydration from not having eaten or drank, needed intravenous fluids, and that there was no food in the house. Miriam, the on-call nurse who had fielded all these calls, had, on Gloria's advice, gone out and bought Ensure (a meal-replacement beverage) and bottles of water and brought them over to Ruth's house. Gloria had told Miriam to just pay for the stuff, and that she would pay her back out of her own money. There was no procedure for what to do when a patient doesn't have any food or water, so they improvised. And there was no procedure for what to do when a nurse needs to buy a patient food, because, in hospice care, nurses don't buy patients food: that's something the family and other loved ones are supposed to take care of. This was over and above the work Shepherd's nurses normally had to do, and over and above the kind of responsibility to their patients they normally had.

When Nicole and I got to Ruth's house later that Monday, after talking to Gloria, there was plenty of food in the fridge and in the cabinets. The problem had been that Ruth couldn't reach it, and there hadn't been anyone there to bring it to her. Jess was back at home now, through, so it seemed like the crisis was over. Nicole talked to the mother and daughter about food, asking what the plan was moving forward. Ruth said that Jess was going to go grocery shopping tomorrow. Nicole took out a piece of paper and started a list of groceries, asking Ruth what sounded good to eat, trying to do what she could to make sure this grocery shopping actually happened. Ruth was feeling nauseous and said that nothing sounded good, and Jess intervened saying that her mom would make the list later. It was one of those moments were it felt like Jess was defending the pair's independence, and indeed their existence as a pair: the two of them did things a certain way, and they were going to keep doing things that way.

The next day, though, Jess left in the car and didn't come home. When Ruth eventually called the hospice helpline, about 24 hours after Jess left home, Nicole was again left with the responsibility of making sure Ruth had enough food. On that first day, she asked the CNA to make sure Ruth got some Ensure and water when she was there, and made an extra trip herself to Ruth's house later in the day to make sure she still had access to these things. On the second day, she told the team in IDG, before the meeting officially started, that Jess still hadn't come home and that between her and the CNA they were making sure Ruth had enough food and water. Later in the meeting, however, Nicole got a call from the CNA summoning her to Ruth's house, and a new kind of crisis began. That crisis, Ruth's bowel obstruction, dramatically shifted her care and will be a focus of the next chapter. For now through, Ruth had already become a patient who in the eyes of the Shepherd caretakers required an inordinate amount of extra work (compared to other patients). It wasn't just that making extra visits and calls to make sure Ruth had food and water added to Nicole's (and Miriam's) workload, but that having the responsibility for whether or not Ruth had enough to eat and drink was much more than they were usually responsible for and was a source of significant stress.

"Just Mark Her as Noncompliant"

Alongside the extra work and stress that Ruth's food insecurity was causing Nicole, Miriam, and others, there were other issues that arose in Ruth's care during this time that also contributed to her being seen as a particularly problematic patient. One of these issues is that Ruth did not agree with all aspects of her care plan, and so was labeled a "non-compliant" patient. Ruth did not want to sleep in the hospital bed that Shepherd had provided for her, preferring instead to stay sleeping on the couch, where she had been sleeping for about 5 years (ever since she returned to St. Croix from her cancer treatment). She said that the hospital bed was "hard as a rock," and she didn't see any reason why sleeping on the hospital bed would help her. She thought it would cause even more pain in her back, and that she likely wouldn't be able to sleep well on such an uncomfortable surface. Shepherd preferred patients to be in hospital beds, as it was easier to deliver proper care in them—easier to do bed baths, to turn patients, to access their whole body, to change the sheets and keep the area sanitary—and it was seen as much safer for the patient, as it has side bars to prevent falls in the night and was electrically adjustable, making it possible for patients whose movement was limited to sit up and lay down on their own. Gloria was thus strongly encouraging Nicole to get Ruth to sleep on the hospital bed. However, Nicole wasn't giving Ruth any reasons that convinced her that it would actually improved her care, mainly telling her it was "just safer."

In the meantime, as an additional source of Ruth's "non-compliance," Nicole reported to Gloria that Ruth had stopped taking the antibiotics she had been prescribed upon discharge from the hospital to treat her urinary tract infection (UTI). Nicole told Gloria that Ruth thought that they were making her sick to her stomach, which they both judged to be extremely unlikely. Gloria, seemingly already a bit annoyed with Ruth, told Nicole to "just mark her [in her chart] as non-compliant for the day."

Ruth was seen to be pushing back against medical advice on different fronts, refusing the help that Shepherd was trying to provide. Meanwhile, her growing nausea—which also came up in Nicole's conversation with Ruth and Jess about groceries, above—was backgrounded throughout this first week of care. It was by far Ruth's most persistent complaint, but was mostly sidelined[229] by Nicole and Gloria (and others) who were more wrapped in other aspects of Ruth's care, like her "refusal" to comply with medical advice and her ongoing food insecurity.

"It's Making Her Sick how Anxious She is"

The third issue that arose as prominent during this first week of hospice care was Ruth's anxiety. Gloria interpreted her as an anxious person from the first day she met her in the hospital ED, and transmitted this impression to the hospice team during that first IDG meeting. In her comments to the group, she explained: "she was like a deer in the headlights when I met her, they [the hospital] said 'hospice' and she was so anxious, I told her it's not like hospice is putting you out to pasture, and we just leave you and then you die." She related this "deer in the headlights" look especially to Ruth's reaction to signing a DNR (which she did not end up signing at this time). Nicole also mentioned 'anxiety' several times during her presentation of Ruth to the group. This interpretation of Ruth as an anxious person came to dominate her care in that first week and beyond. The nurses found evidence for this theory in different places, putting it together to create a sound understanding of who Ruth was and what she was going through and thus how best to care for her. For instance, Gloria told me in a moment alone in her office that she thought Ruth was "really scared," and that she had "bladder cancer that she didn't like to talk about." In this casual conversation, Gloria had actually confused Ruth's condition with another patient who had signed on around the same time, but this slip-up it showed how she was building

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[229] Nicole did supply Ruth with an anti-nausea drug to help with the discomfort.

a narrative for about Ruth as a scared, anxious patient.[230] While taking Ruth's vitals during her second home visit, Nicole found that her heart was beating at 92 beats/minute, which is quite high for someone at rest. Finding physical evidence for her theory, Nicole told Ruth, "our heart can beat fast when we're anxious." She offered to start her on Ativan (an anti-anxiety medication[231]), which Ruth accepted. Nicole brought the Ativan to Ruth the next day, and Ruth started taking it regularly.[232] Reporting this visit to the team in this same pre-IDG chat, Nicole said she thought "it's making her sick how anxious she is." Here, Ruth's nausea, too, becomes evidence for the theory that Ruth is incredibly anxious.

In the first week of Ruth's care, the object "Ruth's anxiety," came to functionally stand in for what in theory could have been a variety of different problems. Solving the anxiety thus became a way of taking care of things in one fell swoop. If Ruth was incredibly anxious, that might explain why she is nauseous, Nicole suggested. It might also be the reason she is placing so many calls to the hospice helpline, and asking for so much assistance (like obtaining food) that is normally outside of the bounds of hospice work. In the IDG that took place a little over a week after Ruth became a hospice patient, Gloria asked Nicole, per routine, how often she was visiting Ruth. This allowed Gloria to set Ruth's official care plan to a certain number of visits per week (a matter of Medicare compliance). "Already twice this week," Nicole replied, adding that

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[230] This confusion about bladder cancer was just a momentary slip and did not itself endure in Gloria's assessment of Ruth's medical condition or in Ruth's her treatment.

[231] Ativan is a brand name of the drug lorazepam, which is a kind of benzodiazepine, a class of drugs that acts on the central nervous system.

[232] Shepherd Hospice, like all hospices, has a standing order for certain prescription drugs. For Shepherd, this list included Ativan, several painkillers, laxatives, and others. The Medical Director does thus not need to be consulted every time a patient is issued a new prescription for these drugs, instead just signing off on the change to the patient's plan of care during the weekly IDG meeting.

she thought Ruth "might need three visits a week...unless the Ativan works!" Nicole was making a direct connection between Ruth's need for nurse visits (and hence Nicole's workload), Ruth's anxiety, and the hope that her anxiety would start to be relieved—and thus her need for visits lessened—by the anti-anxiety medication. Solving her anxiety could, in this thinking, potentially solve the problem of Ruth needing so much "extra" care.

Ruth being an anxious person could also explain what Gloria described as her fear when she first heard about hospice care, and what Gloria continued to experience as Ruth's instability as a hospice patient. In this first week, Gloria demonstrated some extra sensitivity to the possibility of Ruth discharging herself from hospice care in order to return to the hospital for acute care. For example, after telling Nicole and I about the calls the hospice helpline had received over the weekend from Ruth's acquaintance, Gloria was clearly unsettled about this acquaintance's urgent advice that Ruth needed to go to the hospital and receive intravenous fluids for what was. "She's on hospice," Gloria said, "we're not taking her to the hospital." Then in IDG, when Nicole was reporting her visit frequency as based on whether or not the Ativan worked (above), Gloria replied immediately: "I think 3 times a week is great, because unless she feels really secure, someone's going to call 911." In these instances, it seemed like Gloria interpreted Ruth's anxiety as being a risk to Ruth's continued possibilities for hospice care. If "someone" did call 911, and Ruth decided to receive care at the hospital, she would have to come off of hospice care. And because Gloria saw Ruth's condition as chronic and terminal (not to mention the fact that Ruth needed continuous concentrated oxygen), it was hospice that she saw as her best chance for appropriate care.

However, what this perspective doesn't include is the fact that, perhaps, Ruth was not fully ready for hospice care. Perhaps she had signed on because she needed continuous oxygen and so no other way of getting it, and the fact that she didn't feel "really secure" was that she was not ready to be on an end-of-life trajectory. This would be a problem without a ready solution on St. Croix, within the hospice paradigm or outside of it. If she wasn't ready for hospice care, Ruth didn't have any other options. This was not a possibility that was voiced at Shepherd, however. Instead, the situation was constructed as one with a solution: Ruth was being this was because she had anxiety, and there was a pharmaceutical solution for that anxiety. By calming Ruth down, it was thought both that she would both be much more comfortable (and thus better taken care of, in the hospice paradigm), and that she would not be as volatile and likely to seek out emergency care, which itself threatened her continued care.

Conclusion

How was Ruth's 'aloneness' shaping the care she received, and the kind of patient identity that was constructed for her during her first week in hospice care? How was this aloneness interwoven with disregard? In the case of her unreliable access to food or water, it was Ruth's literal, physical aloneness—Jess's absence from the home for extended periods, her disregard for her mom's need for care—that shifted the care Ruth needed and the perceptions that the nurses built up of her. This put the responsibility for feeding Ruth onto her Shepherd caretakers, which in turn made them feel burdened by the "extra" care that Ruth needed. Ruth's 'non-compliance,' too, was made more problematic because of the ways in which she was alone. In most homes in which Shepherd works, there is usually one (sometimes more than one) caretaker who makes most decisions for the patient, interfacing with the Shepherd care team as a kind of authorized representative. Most often, this is because the patient is too sick or weak to have involved conversations or to make their needs known to anyone who isn't intimately familiar with them. It is more common for Shepherd nurses to negotiate the details of a patient's care with this caretaker, rather than with the patient themselves. With Ruth, however, her nurses had no one else to help them carry out her care plan in the home. There was no one to give her the antibiotics at regular intervals, for instance, or to encourage her to sleep in the hospital bed. This made the work of taking care of her feel more burdensome.

There was also a sense that Ruth's anxiety was tied in with the aloneness created and the disregard disclosed by Jess's unreliable presence. It was not that the Shepherd caretakers thought that Jess necessarily had a calming influence on her mom—indeed, from the beginning they saw Jess as a troublesome influence on Ruth, stressing her out and making her upset and anxious. There was an air of "who knows what she might do" that the Shepherd caretakers created around Jess, often linking her unreliability to the highs and lows of imagined drug-induced states of being. Nonetheless, there was a concrete sense that a lot of the visits that the nurses made to Ruth's home, and a lot of calls they received from her home, would have been avoided if *someone* had been there to take care of her. Because the caretakers were used to working in homes with a patient and a caregiver, not having a reliable caregiver in Ruth's home upended the normal flow of their work in lots of small ways that contributed to an overall sense of difficulty and overwhelm. There wasn't an easy solution to this problem, though, as they tended to feel—and would at times express to me and to each other in conversation—that they didn't know if it was better when Jess was gone, or when she was home. Both states of affairs brought problems, as far as they were concerned.

In this first week then, a patient identity was created for Ruth that painted her as anxious and needy—with needs that went above and beyond what hospice normally offers—but also as noncompliant, only cooperating with the parts of her care that she wanted to. This combination of perceived traits often seemed to add up to more of the sum of their parts, becoming overwhelming for Nicole and abnormally troublesome for Gloria.

There are many vectors of disregard that were playing a role in this situation. I want to draw attention back to the role of American (post)colonial bureaucratic disregard in setting up, as discussed in the previous section, a situation in which Ruth signed up for hospice care when she found herself in need of continuous concentrated oxygen. This is a mode of disregard that at the end of Ruth's life also shaped and was itself refracted by modes of interpersonal disregard. Perhaps most obviously, there was the way in which Jess seemed to unpredictably enter into modes of disregard toward her mom. This was particularly problematic in this situation because it existed in a position that Ruth's hospice caretakers and expected to be occupied by care. Without having a reliable caregiver who was paying attention to Ruth's ongoing needs being there in the home with her, Shepherd caregivers struggled to care for Ruth. As I've suggested, however, this disregard was itself part of what we could think of as an intergenerational cycle of disregard between Jess and her Mom, one that reached back to when Ruth moved to St. Croix decades before. In Jess's unreliable caregiving, we see one of the ways in which disregard travels intersubjectively throughout the life course.

Secondly, there was the forms of interpersonal disregard that Shepherd's nurses were disclosing in their care for Ruth. In defining her as anxious and needy person, their view of Ruth disgrarded much of what might have been going on for Ruth doing this stage of her life. In orienting to anxiety as disorder in itself, rather than as an expression of fear or distress whose origins warranted attention, they closed off possibilities for understanding what she was going through, and thus what kind of care she might have really needed. This was a form of disregard offered easily within the framework of American hospice care, in which anxiety is generally seen as discomfort that can be palliated. Furthermore, Ruth's nurses were stressed and exhausted, and had their own families to care for at home—families whose care they explicitly spoke of as being put at risk by the long hours they were putting in caring for Ruth.

In the next chapter, I pick up where this chapter leaves off by discussing how particular modes and objects of disregard came to shape two critical health episodes that Ruth endured in her final months of life. These episodes were definitive in Ruth's end of life trajectory and her experience in the final months of her life. The patient identity and the patterns of disregard that were in play in this first week—all connected with Ruth's aloneness—continued to strongly influence Ruth's hospice care, including how these health crises were handled. However, new forms of interpersonal disregard also revealed themselves, building both on these pre-established patterns and connecting more materially to the limits of care in a landscape of (post)colonial bureaucratic disregard.

Chapter 10

Health Crises in Hospice Care

Jess is standing over the washer and dryer, angrily flipping clothes inside. She's infuriated, frustrated, and confused. "It's politics, it's politics! I just! We got on hospice, for the oxygen right, and now we can't take her to the hospital because then we can't afford the oxygen, soo, what—I mean what are we supposed to do?" Earlier that morning, as Jess was turning around to bring her mom, Ruth, the scrambled eggs she had made her for breakfast, she saw her mom's eyes roll back in her head. Jess, panicking, called 911 and Shepherd Hospice. An EMT, (the 911 responder) and the on-call hospice nurse, Miriam, had now come and gone. They had decided that Ruth didn't need to go to the hospital and told Jess to just let her mom rest. Jess was furious with them, and clearly wanted her mom to be taken to the hospital for care. Unlike just hours before, and every other day of her life up until this point, Ruth wasn't reliably responding to her name, couldn't follow a conversation, seemed completely disoriented in time and space, and couldn't swallow well enough to eat or drink. She never was taken to the hospital, and never regained enough of her faculties to have another conversation or even reliably respond to simple questions. Eleven days later, Ruth died in her home.

This episode occurred a few months after Ruth became a hospice patient (and thus a few months after the events described in the previous chapter). I skip forward to it here because it introduces the cluster of tensions that will be thematic in this chapter. Here we have Ruth in the midst of some kind of major change in condition. We have Jess, her daughter and only family caregiver, asserting Ruth's need for immediate, curative (i.e. hospital) care, despite the fact that she has legally agreed to palliative, end of life (i.e. hospice) care. We have the professional caregivers denying that need and deciding that Ruth does not need acute, curative care, and that she should stay on hospice care. But we also have Jess claiming that her mom didn't sign on to hospice care because she was accepting palliative, end-of-life-only care, but simply because she needed continual access to concentrated oxygen—a claim that would seem to undermine the logic of the professional caregivers' decision. In this chapter, I elaborate the complexities of this problematic within the very specific context of the St. Croix's healthcare landscape of (post)colonial bureaucratic disregard in which contentrated oxygen (and other DME) is a good that for most people is only obtainable through hospice care.[233]

Ruth had two serious health episodes during her time as a hospice patient, and both of these episodes disclosed the work of these tensions in structuring her possibilities for care also for life. In both, Ruth's "choice" of hospice care worked to keep her in a palliative care trajectory, even when it seemed that she or Jess wanted a curative intervention. The ways that both of these events transpired are disclosive of the important role of forms of both aloneness and disregard in shaping Ruth's care. These are forms of aloneness and disregard that both emerge out of and surpass those I described as central to shaping Ruth's care in her first week as a hospice patient. They disclose both the ways that certain attitudes and habits of attention and disregard had become an integral part of Ruth's care while also magnifying their underlying logics. These underlying logics themselves had to do both with hospice policy in the context of St. Croix—and thus the role Shepherd took on in the community— and with the interpersonal

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[233] As mentioned previously, individuals who are eligible for MAP, the territory's medicaid program, can also obtain concentrated oxygen for home use at affordable rates.

relationships, expectations and assumptions that had developed in the specific context of Ruth's time as a hospice patient.

Hospice vs. Hospital

Key to the way that care and decision-making around Ruth's two health crises transpired is the way that Medicare's bureaucracy handles hospice care versus hospital care billing. While I discussed this issue in Section III, I return to it here in order to bring it into the specific context of Ruth's situation.

There are many facets of the relationship between hospital care and hospice care under Medicare that related to Ruth's situation. The most significant one is that in order to receive treatment at the hospital, Ruth would have needed to be discharged from hospice care. Legally and bureaucratically speaking, this is because hospital care and hospice care belong to the same billing cluster within Medicare, "Part A." And beneficiaries can only be using one if their Part A benefits at one time. Medicare will not reimburse a facility for a patient's hospital care at the same time that it is paying for their hospice care. Rather than solely an issue of bureaucratic red tape, however, this billing schema is based on the exclusive roles these forms of care are taken to play. In this model, hospice care is a mode of care that is chosen *instead* of acute care in the hospital, and "choosing" hospice care is understood to signal a decision to halt all curative interventions. The hospital and hospice are the sites of two mutually exclusive, care trajectories and life choices. Thus, the reasoning goes, if a patient is on hospice care, then there is no reason that their medical insurance should also cover hospice care.

As I discussed in the last chapter, however, the circumstances in which Ruth signed onto hospice care do not match the ideal model of how a patient “chooses” hospice care instead of continuing curative interventions. She could not both receive curative care and have access to continuous concentrated oxygen at home. Faced with that “choice,” Ruth signed up for hospice care. And while this perspective on the situation certainly puts into question Ruth’s commitment to palliative-only care and to preparing for death, it doesn’t change these are the only forms of care hospice is legally able to provide. It also doesn’t change the fact that Ruth’s condition was serious enough for her to be eligible for hospice care, and that COPD is not curable. But prognoses are unreliable, and there was no certainty that Ruth going to die within six months. Furthermore, when Ruth experienced these two health crises, it wasn’t necessarily clear how they were related to her condition. Were these separate, acute episodes that called for curative care, despite Ruth’s more long-term palliative care trajectory? Did Ruth’s legal commitment to hospice care precede and therefore override any and all future changes in her health?

Ruth’s two health crises urgently raised the questions of what Ruth’s real wishes might be, how best to care for her given Medicare’s hospice policies, and what the nature of her actual existential condition was—whether or not she was really dying. However, they did so in very different ways to the situation’s differentially positioned actors. Examining the different perspectives that were taken up when Ruth experienced these sudden changes in her condition disclose the ways in which forms of disregard were at play in these episodes and show which forms of disregard ended up shaping what turned out to be her end of life trajectory.

Crisis One: The Bowel Obstruction

Nausea

In the last chapter, I traced how a certain narrative about the kind of patient Ruth was emerged in her first week or so on hospice care with Shepherd Hospice. According to this story that framed the nurse's interactions with and understanding Ruth, she was anxious, she was needy, and the fact that she "lived alone" made that she was a lot of extra work to take care of. Throughout this period of time, however, there was also another sort of story unfolding. This was a story that remained backgrounded for the Shepherd nurses, until one day it forced itself into the foreground. This was the story of Ruth's nausea.

To say that the Shepherd nurses had disregard Ruth's nausea would not be entirely accurate, but it also wouldn't be far from the truth. They had noticed it, and had brought her prescription-strength anti-nausea medication, but they didn't believe that it warranted much attention. Ruth brought it up often, but it was only a peripheral part of what Nicole and Gloria saw to be going on with her. They certainly disregarded her experience of how central it was to what she was going through. For instance, after the weekend when the Shepherd helpline had received several calls from Ruth's acquaintance saying that she didn't have any food or water and needed to go to the hospital to be treated for dehydration, Gloria's main concern was that this kind of panic-driven atmosphere was going to eventually end up causing Ruth to return to the hospital. In the conversation Gloria had with Nicole and I in which she told us about these calls, she only mentioned Ruth's nausea as an afterthought. It was when Nicole had just walked out of her office, but I was still there to hear it: "I guess she felt like she was going to throw up all weekend." Vomiting can easily lead to dehydration, and could have been an important contributing cause to what Ruth had been going through over the weekend. It was, however, not taken up in this way by her hospice caretakers.

One of the main reasons Ruth's nausea was not focused on by Gloria and Nicole during these early days was that, as I discussed in the previous chapter, they believed that it was a symptom caused by her anxiety. It thus did not appear as a problem in itself, only as an expression of a broader problem. And it was that broader problem, the anxiety, on which they focused their attentions. The day after after Gloria had told us about the weekend of helpline calls, Nicole and I went to visit Ruth. During the visit, Ruth told Nicole that she had been throwing up all night and had barely slept. When Nicole repeated her suggestion to drink more water, Ruth replied (obviously at her wit's end) that it's hard to drink water when you're throwing up. This was the first visit that Nicole had brought Ativan, the anti-anxiety medication, after Ruth had said she would be interested in trying it. She gave some to Ruth with the idea that through helping her anxiety, it would help her nausea too.

As it turned out, though, Ruth's nausea was central to what was going on with her during that first week. It was a symptom of something much more serious. Two days after her first dose of Ativan[234], Ruth's CNA found her extremely sick, and Nicole and others on the Shepherd team had to change their care immediately, shifting into a period of even more intensive caregiving.

The Crisis Begins

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[234] Ativan is a brand name of the drug lorazepam, which is a kind of benzodiazepine, a class of drugs that acts on the central nervous system

We were in the middle of IDG (InterDisciplinary Group meeting) when Nicole got a text from Ruth's CNA. The CNA told her that when she had gotten there for her routine morning visit, Ruth was throwing up green vomit, had chills, was feeling extremely weak, and was breathing very quickly. She also reported that Ruth was asking to go to the hospital. Nicole got on the phone with Ruth to see if she wanted her to come to her house, but Ruth was so weak that she could barely talk on the phone. Nicole, with Gloria's go-ahead, left the meeting right away to drive out to Ruth's house. I went with her, as did the hospice's chaplain for spiritual and emotional support.[235]

In the car on the way out to Ruth's house, Nicole said that it sounded like Ruth might have a small bowel obstruction. A bowel obstruction can have many causes, but in general terms it is the presence of a blockage in the intestines that prevents the normal flow of solid waste production, inhibiting excretion. While some resolve on their own, some require medical intervention (such as surgery or other treatments) and can be fatal if such interventions are not made in a timely way. Ruth had mentioned to Nicole during one of her recent visits—in the context of her unrelenting nausea—that at the hospital she had been told that she was "close" to having a bowel obstruction, so she needed to make sure that she didn't get constipated, as this would precipitate the formation of an obstruction. When Ruth had told her this, Nicole had quickly found something to write with and had scribbled this information down with a focused

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[235] It was rare for the chaplain to come to urgent visits like these. She spends little time at the office and otherwise does her (usually monthly) visits to patients alone. In this instance, it was only because the urgent text happened to come through during IDT, when all the caregiving staff were gathered together. The chaplain played a small role in the visit (she and Ruth never formed much of a relationship) and so I don't document that aspect of the visit here.

intensity—this wasn't in her medical chart, and was new information to Nicole. Now, the CNA had reported that Ruth's vomit was green, indicating that she was throwing up bile, and that she hadn't been had recent a bowel movement, both symptoms of a bowel obstruction.

When we got to the house, Ruth was doing terribly. She seemed so weak that she was barely conscious, her eyes mostly closed, rolling back in her head. She was pale—the blood drained from her face—and looked sweaty. She was having pain in her abdomen that seemed to suddenly get very severe and then recede again.[236] She could barely talk. She had a small trashcan next to her that she had been vomiting into, apparently all night, and it contained a green, foul-smelling liquid (bile). Nicole and the CNA worked together to clean Ruth up a bit and move her from the couch onto the hospital bed. There, the CNA gave Ruth a bed bath, and combed her hair. Once the two were done, they agreed that Ruth looked much better, and the CNA left to go see her other patients.

Nicole and I stayed a little while longer as she continued to work to stabilize Ruth. She helped her take an anti-nausea pill Ruth had been clutching in her hand when we arrived, and that seemed to help. As Nicole was working on taking her vital signs from one side of her hospital bed, I was standing on the other. Her respirations per minute were still quite high, indicating physiological stress. At one point during this period, Ruth said to us: "I'm afraid of you all going." I assured her that I would come back soon, but that we had come in the same car, so I would need to leave with Nicole when she went. She seemed to understand and make an effort to contain her desperation.

Around this time, Nicole left the room to take a call from Gloria on her cell phone. She

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[236] This severe, periodic abdominal cramping is also symptomatic of a bowel obstruction.

came back in a few minutes later, with the call on speakerphone, and Gloria and Shepherd's medical director both on the other end of the line. For a few minutes, the two of them went back and forth asking questions about Ruth's current condition and medical history. The doctor asked about past abdominal surgeries (which can cause the development of certain kinds of bowel obstructions) and Gloria responded that Ruth had had a hysterectomy[237], while Nicole quickly searched Ruth's belly for scars. After a few minutes, having collected enough information to make a decision, the medical director ordered intravenous fluids, two blood labs (to check for dehydration and infection), and that Ruth be put on "NPO" (nothing by mouth) status for 24 hours. I learned that the intravenous fluids were to counteract the dehydration Ruth was almost certainly experiencing due to all of the vomiting, and that halting any food or drink by mouth was to put her on an a period of "bowel rest." As Gloria explained it, this was the way they would treat a bowel obstruction at the hospital, but there was no reason for Ruth to go to the hospital because they could do all the same things for her while keeping her at home on hospice care. As Nicole and I got ready to leave to retrieve the supplies needed to carry out Ruth's new treatment plan, we told Ruth we would be back soon. "Hurry," she pleaded.

Over the next two days, the Shepherd nurses scrambled to carry out an urgent care plan that involved treatments they were not used to giving and that Shepherd was not well-equipped to provide. This involved not only extra hours of work, many of them at night, but also an atmosphere of stress and overwhelm that they did not usually encounter with hospice patients. Early in the process, Nicole started to show some misgivings, in the midst of her exhaustion, about whether keeping Ruth on hospice care was the right thing to do. It stayed with Nicole that

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[237] As part of the surgery entailed in her cancer treatment.

Ruth had told her CNA should wanted to go to the hospital that first morning when her CNA had found her so sick. While this utterance was being interpreted in the framework of her ongoing care as a panicked, thoughtless cry for help, Nicole saw it as a request that should be honored. This perspective was further supported, for Nicole, by the fact that Ruth had told her in earlier visits that she had no plans on dying soon. Ruth had told her she planned on getting better. For Nicole, this deeply put in question the logic of keeping her on hospice care.

Ruth's care situation continued to get more aggravated and complex. That afternoon, we came back to set up an I.V. line in Ruth's arm and to draw some blood to bring to the lab for testing. Setting up an I.V. was outside the scope of Shepherd's usual caregiving, and ended up being a fairly complicated endeavor. After we had left Ruth's house earlier in the day, Nicole had had to rummage through drawers of medical supplies at the Shepherd office to find the needles, tubing equipment, and pole required to hook Ruth up to an I.V. line. And, because Nicole "couldn't do a stick"—as in, she was very out of practice putting needles into patients' blood vessels—she had to coordinate with another Shepherd nurse, Mike[238], to meet us at Ruth's house to collect her blood for testing at the lab and get the I.V. line going. Because Ruth was so dehydrated, it was hard for even a seasoned nurse like Mike to get the line going, requiring many attempts of sticking a needle through Ruth's inner arm, pushing it around under the skin to find a vein. Then, that night, the I.V. site in Ruth's arm got infiltrated—the fluid infused into the tissue surrounding the puncture site—and Nicole had to rush to Ruth's house to discontinue the fluid

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[238] Mike was in his forties, white, and from the states. He had been living on St. Croix for a few years with his wife and children, deciding after decades of hard work to finally do something to make him and his wife happy and move to a tropical island. He had no previous experience in hospice care, and had been working for Shepherd for less than a year.

drip before the infiltration got more severe. While we were there at the house that night, Ruth asked us when she was going to the hospital. Nicole explained to her, sticking to the care plan that had been decided, that everything they would do for her at the hospital, Shepherd was doing for her at home: blood labs, I.V. fluids, and bowel rest.

After the first night of attempting to treat Ruth with I.V. fluids, there was a brief period of calm that spanned the next morning and early afternoon. I was there with Ruth for several hours in the middle of the day, and while she was still sick and weak, she seemed to be more herself and spent much of the time peacefully resting. But a few hours later, by late afternoon, things had again reached a fevered pitch. The results from Ruth's blood draws came back, showing that she had an infection and needed to be treated with antibiotics. By late that afternoon, Nicole was again running around picking up supplies and coordinating with Mike. By the evening, things were chaotic at Ruth's as Nicole, Mike, Miriam, and now Sunny—a hospice sitter that Gloria had hired that day specifically to stay with Ruth—were all scrambling to follow the new care plan in the midst of Ruth's escalating illness.

In a private discussion that night, the nurses talked just outside the house about what to do about the predicament they felt themselves, and Ruth, to be in. Jess was still gone, so she didn't have any family there with her. Was this chaotic care better or worse than just having her go to the hospital? Was keeping her on hospice care the right thing to do, given her new condition? If she wants to go to the hospital, should we just let her? They also talked about what the possible upsides of keeping her on hospice care might be: given her chronic ill health in past years, she might have run out of Medicare-compensated hospital days. In that case, sending her to the hospital might be throwing her immediately into thousands of dollars of debt that she would never be able to pay down. They were all frustrated in their own ways, with some feeling like Ruth absolutely should have gone to the hospital a long time ago, and others seeing keeping her at home as potentially the best way to care for her.

During this conversation, with the four of us gathered outside in the dark, an S.U.V. started crawling up the long driveway from the road. We were all surprised, and speculated about who it might be: our guess was someone dropping Jess off. As the car pulled up near the house, we could see into the cab, and it was just one person, and not one any of us recognized. When she stepped out, it was a black woman in her late 50s or early 60s. She looked just as confused about our presence as we were about hers. She just said "hello" and asked if Ruth was alright. Nicole stepped forward and introduced herself, and the woman introduced herself as Patti. Nicole was immediately relieved: she knew Patti as Ruth's closest friend who she had given as her contact person when she had signed on for hospice care. Nicole had been trying to get in touch with Patti ever since she had started taking care of Ruth, but hadn't yet been table to get a hold of her. It was extremely good news, and felt like remarkable luck, that Patti was now here standing in front of her. As Nicole and Patti started talking the other nurses dispersed Mike gave me a hug and quietly went home, while Miriam went back inside.

Over the next hour or so, Nicole brought Patti up to speed with Ruth's condition. The three of us sat in a room next to the one Ruth was in. While we talked, she seemed to be resting. At this point, Ruth could still barely talk and didn't look like herself. She had been throwing up for hours and hours. Patti was shocked to see how poorly Ruth was doing, and was also very surprised that Ruth had signed up for hospice care. She told us she knew that Ruth didn't want to die. Eventually, after having come to terms with what was going on, Patti decided that she needed to ask Ruth if she wanted to go to the hospital. She gently approached Ruth, said hello to her friend, and asked her what she wanted to do. Ruth said she wanted to go wherever she could get the best care. Patti called the hospice hotline to inform them that she was calling an ambulance to come and get Ruth, and then she called 911.

About two hours later, I rode in my car behind Ruth's ambulance, and she was admitted to the hospital that night. Before we left the house, I asked Ruth if she wanted me to leave a note for Jess. She just shrugged.

The Bowel Obstruction Crisis: Some Conclusions

What does this episode tell us about home hospice care on St. Croix? I have suggested that the absence of a Medicare-certified DME provider on St. Croix powerfully shapes the role of hospice care on-island. With this example, I have shown how Ruth's "choice" to sign onto hospice care soon after she began needing to continuously breathe concentrated oxygen shaped the possibilities for her care—and thus also for her experience—at a moment of increased medical acuity, and also of increased acuity of her suffering. What happened to Ruth in the couple of days that I have been describing here was certainly not a necessary consequence of her having signed on to hospice care. It was one of the possibilities that became open once she became a hospice patient. Importantly, it was a possibility that opened up in the particular context of home hospice care in the healthcare landscape of St. Croix—and in the particular circumstances of her life at that time.

When the symptoms of her bowel obstruction worsened, and Ruth said she wanted to go to the hospital. One aspect of Nicole's uneasiness in providing the kind of care they were to Ruth during this time was that she saw this statement as possibly being interpreted as a straightforward revocation of her hospice benefit, a legal decision based in Ruth's rights as a Medicare beneficiary. However, it could also be interpreted as something said in a panic, without thinking, and without a full understanding, or acceptance, of her ongoing. Within the hospice paradigm, it is normal for patients to have trouble accepting their death, to be unsure about their condition, and to perhaps have second thoughts. It is the hospice caregivers' job to help hospice patients come to peace with the fact that their life is coming to an end.

Furthermore, within the contemporary Medicare bureaucracy, there are many material and legally binding ways in which hospice patients indicate their desire to cease curative treatments and to remain on a palliative care treatment regimen for the rest of the lives. As is required for all hospice patients, Ruth had very recently signed several forms expressing in various ways her desire to halt curative treatment and receive only palliative care in her home. This creates a kind of weighty precedent against any decisions or desires that arise contrary to what was legally understood, acknowledged, and even desired in the many signed forms.

This precedent is especially convincing because the subject around which the decisions are being made is death. There is a pervasive cultural narrative in the United States about individuals' fear in the face of their own death, and especially their "denial" that their death will ever come, or at least, that it is coming now—that it can't be stopped, that there truly isn't anything more to be done. Shepherd Hospice caretakers spoke often about the "denial" that patients and their families were exhibiting (Flaherty 2014, 2015a, 2015b) when they would ask about potential treatments or talk about getting better.

Seen cynically, this could be just a self-serving narrative to keep patients on hospice care, and keep hospices in business. However, there is also truth to the idea that it can be hard for individuals and families to face death, and that some don't ever want to "accept" that there may be nothing to do to stall its arrival. In the paradigmatic model of hospice care, patients choose hospice when they are ready to begin the process of accepting that they are dying. On St. Croix, however, there is a dual problem. Individuals with all different *attitudes* toward their own death find themselves signing on to hospice care in order to get medical help. But also, individuals with all different levels of *actual closeness* to their own death sign onto hospice care. These important differences are covered over by the Medicare policies that prohibit, in an over-determined way, the extension of hospice care to anyone who does not express, with their signature, their desire to halt curative efforts that might extend their life. These are policies that encourage and provide material and legal canalization of disregard for any possibility that exceeds hospice's framework. The possibility that the patient is not in denial, but that she wants curative treatment; the possibility that the patient is not dying—these are possibilities that are the objects of disregard in the everyday practice of hospice care.

The fact that Ruth, by this time in her care, had been identified as an "anxious" patient contributed to the potential for ambiguity in her claims that she wanted to go to the hospital. From beginning the of her care, her two primary hospice caregivers, Gloria and Nicole, agreed that anxiety was a major aspect of what was going on with Ruth. Ruth's constructed identity as an "anxious" patient dovetailed with the broader understanding of hospice patients in general who often have trouble facing the reality of their death. However, the anxiety itself, within this framework, is taken to be something to be treated within the paradigm of palliative care, not taken to be a legitimate desire to escape that very care. Seeing her in this limited way allowed her fears and some of her decisions to be disregard as mere symptoms, a magnification of the habitual disregard described above.

The medicating of "anxious" hospice patients with anti-anxiety pharmaceuticals (usually Ativan) was an extremely common practice at Shepherd. While this is common in U.S. hospices more broadly, there is a possibility that the extent of anti-anxiety use at Shepherd was related to the absence of other forms of home-care available on St. Croix. At Shepherd, prescribing Ativan was taken to be a way or reducing patients' suffering in the name of palliative care. To the extent to which it does so, I am sure it is a welcome blessing to many. However, pushed to its extreme, as I believe it was in Ruth's case, this medicalization of anxiety delegitimizes and disregards patient voices that push back against hospice care, expressing their desire to attempt to keep living and claiming their right to curative treatment.

All of this unfolded in a moment in Ruth's life when she did not have a loved one at her side. Jess was nearby, probably just a few miles away, but for the purposes of her mom's care, she was completely absent. Ruth's trajectory and experience during these few days was strongly shaped by this disregard, as well. Some of the nurses had Ruth's aloneness on their minds, and it came up in their debates about how best to do right by her. For instance, at a moment of peak frustration, one of the nurses suggested to me that if Ruth had had a family member there to advocate for her, she would have gone to the hospital right away. In the nurses' private discussion the night Ruth ended up going to the hospital, it came up that one of the problematic aspects of keeping her on hospice care was that, since Jess was still nowhere to be found, it also meant keeping her alone.

In this next episode, though Ruth wasn't alone. Jess was by her side. However, other forms of disregard were still in play. In addition to the general modes of disregard through which hospice patients are seen as resisting or denying their death, both Ruth and Jess's past "anxiety," their construction as "anxious" people, shaped how they were interpreted by hospice caregivers and thus also shaped the form that Ruth's care took.

Crisis Two: The "Stroke"

We've now returned to the episode with which I opened this chapter: the morning when Jess called 911 because she had turned around, a plate of scrambled eggs in her hand, to find her mom's eyes rolled back in her head. Jess had screamed her name, she said later, and Ruth still wouldn't answer her. That was when she called 911. This was mid-January, about seven weeks since Ruth was hospitalized with a bowel obstruction. When the EMT got there, he did a quick evaluation of Ruth, including taking her vitals, and concluded that there was no reason to hospitalize her. But, since Ruth was a hospice patient he said he would wait until the hospice nurse got there to let her weigh in on Ruth's treatment. When Miriam got there a little while later —as usual, the nurse on weekend call—she also did a brief evaluation of her, and took her vitals again. She too didn't see any reason to hospitalize Ruth. The EMT asked her if this is how Ruth "normally is" and Miriam said it was. The EMT left, and Miriam did too, shortly after. She told Jess just to let her mom rest.

Here, we have another instance of a marked rise in the acuity of Ruth's condition, and the possibility of her going to the hospital to receive treatment. This time, however, it was Jess asking for her mom to go to the hospital. And, also unlike the last incident I recounted, this time she didn't end up going at all. Miriam's decision to not send Ruth to the hospital catalyzed a lot of upset—on the part of Jess, Patti, and in some ways Miriam herself—and a lot of strong opinions among Ruth's care team. It was an extremely chaotic day for Ruth's care, with people's differing opinions and emotions flying in all directions. Here, I focus on how this incident can be seen to have arisen following logics that were disclosed in the bowel obstruction incident. Instead of giving a play-by-play chronological account, I focus on certain key moments in which the logics informing Miriam's decision came to light.

Jess was extremely upset when her mom wasn't taken to the hospital. After Miriam left, she was absolutely fuming. She was of course very distraught by the state her mom was in, and this distress was magnified by the fact that no one seemed interested in helping her. There were a few key parts of what had happened when Miriam and the EMT were at the house that Jess kept returning to, talking half to herself in angry rants, pacing around the house. The first was the basic fact that she had called an ambulance and the ambulance hadn't taken her mom, despite—in her eyes—something clearly being very wrong with her. Not only had her mom not been taken to receive medical treatment, but, per Jess's account, Miriam had told her that she was going to tell the 911 dispatcher to re-route calls from Jess to the hospice, instead of to the EMT (Miriam denied ever having said this, claiming that Jess misunderstood her).[239] On top of this, she was very upset and confused about the fact that Miriam had told the EMT that this is how her mom "normally is." Indeed, alongside what she took to be this verbal assessment of her mom's

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[239] When the incident was discussed in IDG 5 days later, the story had made its way to Gloria, who reported it to the rest of the team. In this version. It was the EMT who had told Jess he was blocking calls from her number and re-routing them to hospice. Gloria made it clear to the team that the EMT doesn't have the authority to do that.

condition lay a significantly changed Ruth. Her face looked completely different than it had the day before, her mouth drooping precipitously to one side, her eyes empty, gazing into nowhere. She seemed to have lost control of one of her hands, clenching it continuously. She could barely speak. She sometimes responded to her name, but other times didn't respond to any stimuli for several minutes. Having her mom in this state—so different than the perky, "with it" Ruth that had been there just hours before—and having a nurse tell an EMT that this is how her mom "normally is" was driving Jess crazy. She just couldn't believe what was happening. She was aware that going to the hospital would mean coming off of hospice, and that this would be problematic due to her mom's need for continuous concentrated oxygen, but she still felt her mom deserved some kind of intervention. She felt completely helpless and frustrated.

Adding to the confusion and the upset were the mixed messages Jess was getting about what was actually happening to her mom. In her initial panic, Jess called lots of people for help: 911, Patti, me, Sunny[240] (the hospice sitter who had been hired during Ruth's bowel incident episode, and who bothRuth and Jess had become very close with), and then finally the hospice helpline. We each ended up arriving at different times, and so Jess experienced many first impressions of her mom's condition. When the EMT and the Miriam got there, they both established that there was no reason to hospitalize Ruth, but they didn't say anything else that might explain to Jess what was going on with her mom. Then, when Sunny got there, she

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[240] Sunny was in her early fifties and had lived her whole life stateside until earlier in the year. She was "bi-racial" (in her words) with one black parent and one white parent. She and her husband decided to move to St. Croix because Sunny had wanted to retire, and had wanted her husband, who was over a decade older than she was, to experience the benefits of year-round warm weather on some of his chronic health difficulties. Sunny began working again after two weeks of "retirement." She had joined the staff of Shepherd a couple of weeks after Ruth became a patient. While she did not have palliative care experience, she had worked in nursing homes and thus had a lot of experience providing healthcare for older adults.

immediately went over to Miriam to have a private discussion with her, saying that Ruth had had a stroke. Sunny, who had just recently moved to St. Croix from the states, had been an RN for over 30 years and had just recently transitioned into being a “sitter” (a non-medical companion) at Shepherd. Miriam treated her suggestion as just that—a suggestion that was plausible, but certainly not definitive. What Sunny wanted to know is what they were supposed to do, as hospice caretakers, when a patient had a stroke. Miriam told her that since it’s hospice, and since Ruth had a DNR (Do Not Resuscitate form) that they weren’t supposed to do anything.

In separate, private conversations with Sunny and Miriam just a little while later, it became clear how divided their opinions on Ruth’s state were: Sunny said she would put all three decades of her nursing career on the fact that Ruth had suffered a stroke. Miriam was enraged that Sunny had even mentioned the word “stroke,” saying not only was it obvious that that was not what was going on with Ruth, but even if it had been, she would never have mentioned it in front of the family. She seemed to think that naming a diagnosis like that both made things more dramatic (causing more upset) and would incite the feeling that something ought to be done about it. I wasn’t there when Sunny had spoken about a stroke in front of Jess, but Miriam apparently had been. And, starting after Sunny arrived, Jess seemed inclined believe that her mom had had a stroke. She didn’t understand, though—if that was the truth—why Miriam wasn’t telling her that and why she was acting like there was nothing wrong with her. A stroke diagnosis also didn’t explain to Jess what that meant in terms of her mom’s health and what needed to be done to take care of her. Was this permanent? Was there anything anyone could do to help her recover? Was it making it worse that we weren’t doing anything right now?

Another very important part of Jess’s anger and confusion was that she had not, until that very morning, been aware that her mom had signed a DNR. While Miriam, in her conversation with Sunny, drew on the presence of a signed DNR to justify not taking Ruth to the hospital, Jess did not have things explained to her in this way. And she did not, in those long moments of experiencing her mom as newly unresponsive, have the knowledge that her mom had signed a DNR. It was only after Miriam and Sunny, in the midst of their discussion of the possible stroke, had gone over to Ruth's care folder together to take a look at her DNR—to confirm that it was there as they thought—that Jess learned of the DNR. After looking the form over with Sunny, Miriam had left it out on the table for Jess to see. Indeed, Jess came upon it not long after this, and was completely shocked and very distressed. Having been intentionally left out of much of her mom's hospice caretaking, she had no idea that her mom had signed a DNR. Not only did Jess not think that the presence of the DNR justified not taking her mom to the hospital, but she refused to believe that those were her mom's wishes at all. She was extremely angry, shouting and making calls to Shepherd threatening to take them to court if they didn't rescind the DNR.

What was going on from Miriam's perspective? How to explain why she acted the way she did? From Miriam's point of view (as she expressed in private interviews that day), all that was going on with Ruth was a bad case of anxiety. While she admitted that she wasn't totally certain, what she thought was that Jess had gotten in a big tizzy over something, and this had made Ruth panic to the point of putting her in the state she was in now. Importantly, Miriam genuinely didn't think that Ruth had changed very much. As the nurse who was on call most weekends, Miriam was familiar with Ruth but didn't see her very often, and definitely didn't have sustained encounters with her. When asked what might have been happening with Ruth to make Jess call 911 in the first place, Miriam said that perhaps her eyes were rolling back in her head for a moment or something like that, but that itself had likely been some kind of a reaction to Jess's anxiety. Miriam thought that all Ruth needed was to calm down, sleep it off, and that she would wake up feeling better.

Here we once again a narrative of anxiety coming in to explain an acute shift in medical condition. Over the past couple of months, as Jess began spending more time at the house and the Shepherd team got to observe her more, their dominant narrative continued to be that Jess and Ruth upset each other. Ruth had remained a troublesome patient, still being interpreted as uncooperative and needy. Her calls to the helpline and her other requests were discussed as if they were truly over and above what she actually "needed". This perceived neediness that had built up among the Shepherd caregivers definitely played a role in Miriam's interpretation that anxiety was the main culprit behind Ruth's sudden shift. For instance, Jess didn't know why Miriam had told the EMT that this was how her mom "normally was," and she confronted her about it later in the day. Miriam had come back to the house on Jess's request (that she made by calling the helpline—another instance of "neediness" coming from this household). During this visit, still very upset, Jess asked Miriam why she had told the EMT that, since it wasn't true. This wasn't how her mom normally was. Miriam explained to Jess that what the EMT had actually been asking her wasn't about Ruth's condition, but whether she was the kind of patient who habitually ("normally") called 911 when it wasn't an emergency. By telling him "yes," Miriam was confirming that this was standard behavior for this patient, simultaneously confirming that there was not any medical action that needed to be taken. In a classic "boy who cried wolf," scenario, the characterization of Ruth as an excessively needy and overly sensitive patient among the Shepherd's nurses—and the way that the extra work that neediness required had worn them down— foreclosed the possibility of Jess's call being taken seriously and acted upon.

On the day of the incident I'm discussing here, Jess's panicked, dramatic, behavior only reinforced the idea that she was an overly anxious person. She was becoming extremely anxious about being alone with her mom in the state she was now in, and didn't know how to take care of her. As Jess quickly learned, Ruth now needed to be coached through how to eat and drink (e.g. "open your mouth, wider, chew, chew, okay swallow") and sometimes it seemed that her swallowing reflex simply wouldn't kick in at all. She also was so out of it that she couldn't be easily moved to have her adult diaper changed (when the day before she could have changed it herself), and Jess struggled with how to do this on her own. Furthermore, her mom often wouldn't respond to basic questions (e.g. "are you hungry?") and wouldn't respond at all to things that were right in front of her (like a spoon with food on it), which made Jess worry about how well she would be able to take care of her. She worried especially about her mom starving to death. She kept exclaiming, as she paced around the house, things like "what am I supposed to do? Just sit here and watch her deteriorate?".

Her anxiety around her mom's potential "decline" (as it is called in hospice) reinforced not only the idea that she was an excessively anxious caregiver, but that she was "in denial" about her mom's condition. For instance, there was some doubt among Shepherd's caregivers that she had truly not known about the DNR, and that she was just being dramatic about it now that her mom's condition was worsening and her death seemingly closing in. From my point of view as a relative outsider, it was all too easy to see that it was Jess's intentional exclusion from her mom's care that had kept her relatively insulated from the realities of hospice care—that, ultimately, it was aimed toward her mom's death. She wasn't just supposed to "sit here and watch her deteriorate," but she wasn't supposed to be calling 911 to save her, either. Instead of seeing Jess as a caring daughter who had not been brought into conversations around her mom's care decisions, and who was now having to face them all at once, Miriam saw Jess as bowing out of responsibility for understanding what hospice care was for, and causing trouble for everyone by doing so.

As I discussed during my account of the bowel obstruction incident, however, it wasn't at all clear that Ruth was "on board" with the purposes of hospice care. When Jess was shouting out from the laundry room that they had "gotten on hospice for the oxygen," and now were stuck on it, this was a much more accurate assessment of the situation as I understood it from Ruth's perspective. But now, Ruth was too weak and sick to talk, and too disoriented to understand what was going on. Throughout the day, small things happened to let us know that Ruth was no longer fully in our shared world with us. For example, at one point she was asking repeatedly for the remote for the T.V. One of us would pick it up from her side and pass it to her, holding it where she could see it, but she would just keep asking for it. Once, Ruth was holding her hand above her body, making a repeated gesture. When asked what she was doing, she just said "sewing". At other times Ruth seemed to be more aware of her situation, but in a way that made it clear she didn't have full use of her faculties. For example, at one point, Ruth said of that she couldn't tell anyone what was wrong with her, and that when she drinks water it spills out of her mouth (which was new). Her voice was weak and child-like. When I first got there that day and immediately went over to her to ask her how she was, she just said "scared." Hours later, she had forgotten that I was there, and was surprised to see me, grabbing my hand tightly and not letting go until I had to unwrap her hand from mine some time later. There was no way, in this state, for

Ruth to make her wishes known, or perhaps even to formulate wishes that would have a bearing on her medical treatment.

Of the people who could speak on her behalf, Jess's identity among the Shepherd caregivers—of a hyper-anxious, irresponsible, substance abuser —denied her a legitimate, authoritative voice. And, as I've mentioned, she was not, as far as Shepherd was concerned, actually allowed to speak on her mom's behalf. Patti, on the other hand, who had did have at least some authority to speak for Ruth, came to the house at Jess's urgent request. She showed up very concerned about Ruth, and upset to see how changed she was. Immediately upon seeing Ruth's face, she believed that she had had a stroke. However, while's Jess's concerns in reaction to her mom's state had seemed so dramatic, overblown, and chaotic to Miriam, Patti had some experience with hospice care and expressed her concerns to Miriam within a hospice framework. While she, like Jess, was also shocked and upset to see Ruth's DNR, she more quickly adjusted to trying to understand what was going on with Ruth that day in terms of her trajectory as a hospice patient. This enabled a discussion between Patti and Miriam in which Miriam explained her decisions that day through the logics of hospice care.

After Patti arrived at the house and took some time to process the situation, she asked Miriam if she could speak to her outside. I came with them. Patti told Miriam that she had been close to two people on hospice care before, but in both cases it had been for cancer, so it was a bit different than Ruth's situation. She told her that she was trying to understand what was going on, why Ruth hadn't been brought to the hospital despite this sudden and major change in her condition. What she wanted to know was whether or not what was happening now was "to be expected" as part of Ruth's ongoing condition. Miriam and Patti went in circles around this question for a while—they were both somewhat emotionally flustered, although for the most part they were speaking calmly to each other. Miriam was working to re-frame the issue not in terms of what could be expected but in terms of "decline." She kept saying, in various ways, that this new change was part of Ruth's decline. At the same time, Patti felt like she wasn't getting an answer to her question, and was re-wording and repeating it. She was clear that this was a decline in Ruth's condition—she was definitely much worse off now than she had been. Patti wanted to know whether or not this change followed from her COPD, which was her certifying hospice diagnosis, or whether this was something new. Patti kept saying that if what was happening to Ruth had been expected, if it was a consequence of Ruth's COPD, then she could be okay with that. She even said that if that were the case, she could help Jess calm down and to accept what was going on. If this was something new, however, something unrelated to her COPD, then Patti didn't understand why Ruth wasn't being taken to the hospital.

Miriam never answered Patti's her question directly. After going around and around for quite a while, Miriam put forward a statement that sounded conclusive: "she's at the end of her life and so this is part of her decline. She wouldn't be on hospice care if she wasn't declining." Miriam than briefly tried to paint a picture of Ruth as a patient who had been declining in lots of ways, attempting to fit this new change into a broader pattern of decline. She kept saying that she had "all these co-morbids," and "all this other stuff going on." She said that even if she went to the hospital, they might put a (metaphorical) band-aid on it, but probably they would just have her rest, which she could do better at home (the same type of reasoning that had been employed during the bowel obstruction episode). Plus, Miriam said, even if she went to the hospital now, she had so much else going on that she would just keep declining. Eventually Patti challenged

Miriam on this claim, saying that she didn’t understand what “other things” she was talking about: what else was going on with her besides the COPD? To this, Miriam said that she didn’t know, she was only the on-call nurse. But, she said, “if she didn’t have co-morbids she wouldn’t be on hospice care.”That’s how the conversation ended. The message that Patti seemed to get was that there was apparently a lot more wrong with Ruth than she had known, and that she was actually approaching the end of her life.

The logic employed by Miriam here—that Ruth’s very presence on hospice care means she is “declining” and that she has “co-morbids”—shows why she was unable to see the change in Ruth’s condition as urgent or dangerous to Ruth’s health. The very fact of Ruth being a hospice patient meant, within this framework, that Ruth was going to be getting worse over time. And, because being a hospice patient meant she had “co-morbids,” that worsening could take various forms. It is the very definition of a hospice patient that these things are going to happen, and thus when they do, hospice care should proceed as usual. This is the same logic that supports the understanding of patients as “in denial” once they are on hospice care and are still interested in getting better, and of their anxiety as being a medical condition rather than a legitimate desire to continue curative efforts. These frameworks define the very things that might cause a patient to leave hospice care (acute new medical conditions, fear of immanent death) as part of the reason they are on hospice care in the first place.

Along with the signed forms that attest to patients’ (and often family members’) desire to pursue hospice care and their understanding of what that entails, the DNR form can also serve, as it did in Ruth’s case, as a powerful piece of evidence supporting this kind of reasoning. Patients don’t need to sign a DNR in order to become a patient with Shepherd, although it is much preferred. Like the hospice admittance forms, once signed, the DNR takes on a life of its own, completely divorced from the context of its signing. I was there when Ruth signed that DNR. It was the day she got home from the hospital after the bowel obstruction, in mid-November. Nicole and I were at the house when Ruth got there.[241] Jess was there too, but she wasn't in the room when Nicole started the admission paperwork, and neither Nicole nor Ruth asked her to come in. Now that Ruth was coming back onto hospice care, Gloria had told Nicole that it was important to try to get Ruth to sign a DNR—whatever other reasons Gloria may have had for this, it seemed to me to be one more further safeguard against Ruth's anxiety making her true wishes ambiguous. With this form signed, things would be clear.

When it was time to do the paperwork, Nicole told Ruth that "this should be easy" since she had already done it once before. Ruth actually hadn't signed a DNR before, but she had done all of the other paperwork before, and Nicole didn't mark out the change (perhaps trying to allay some of the stress or anxiety that can come from signing important documents of this kind). When they got through the other paperwork and to the DNR, Ruth had lots of questions. Nicole was asking her yes or no questions, like "if we get here in the morning, and you're not breathing, do you want us to bring you back?" Ruth didn't answer yes or no. Instead, she said "there had to be circumstances."[242] Ruth was concerned that the form didn't capture all of the subtleties of any given life or death situation, and thus that it wasn't easy to make a yes or no decision as the form demanded, at least not without further conversation to clarify the circumstances delimited by the

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[241] She was driven by a service that charges to give patients with medical equipment rides home from the hospital.

[242] Recall the "deer in the headlights" look that Ruth had purportedly had on her face when Gloria had introduced the idea of signing a DNR to her in the ED some months earlier.

form. However, the nature of the form forces yes or no choices, and doesn't have room for subtleties. Nicole then switched gears to try to present Ruth with more straightforward decisions. Nicole returned to her same question, but this time going through the list of medical procedures listed on the form. "You're not breathing, do you want us to...." do CPR, intubation, break your ribs (as is possible in CPR), put you on a ventilator. Ruth shook her head to all of these things, as Nicole checked the "no" box on the form. Then she passed it to Ruth, who signed it.

How this form got signed—hesitantly, with questions that lingered—completely disappeared once the form was signed. On the day that Ruth had this episode, it was employed as a genuine, unquestionable expression of Ruth's "true" wishes.

The last 11 days of Ruth's life (Coda)

Ruth died 11 days after the stroke-like event, three months and one day after she signed up for hospice care. She spent those 11 days floating in and out of consciousness. She slept a lot, and when she was awake seemed to be in a dreamy, drowsy state. Sometimes when she was awake, she seemed to be feeling fine, where other times it was clear that she was very uncomfortable: confused, disoriented, in pain. No one, including Jess, was ever able to have a conversation with her again.

Jess didn't disappear at all during this time. She would go out for a few hours during the day sometimes, but mostly she would stay at home. When she did go out, she always made sure there would be someone there with her mom the whole time—usually me or a CNA. It was a very emotional time for her. For the first few days, she was extremely anxious, calling the hospice helpline a lot. Then, Gloria and the social worker, Nancy, came to the house and had a long talk with her. They explained how C.O.P.D. affects the body, and how what had happened to her mom could have been caused by not enough oxygen getting to her brain. They spoke to her more about hospice and about her mom's trajectory and her mom's wishes. A little while after that talk, Jess started to feel a lot better. She shifted into being really sad about her mom dying, and really torn up inside that she hadn't been there for her mom in her early days as a hospice patient. She told me that she wanted to be alone with her mom and just talk to her mom, and didn't want anyone else to be there, but that she was also really afraid to be alone with her. She started sleeping out in the living room with her mom every night, on the couch that her mom had spent so many nights on. Sometimes Ruth knew who was there with her, other times she didn't. But I don't think she was alone for more than a few minutes for the rest of her life.

The struggles between Shepherd and Jess continued. After Gloria and Nancy's talk with her things went well for a while, but Ruth's new R.N. caseworker Beth[243] and Jess had a really hard time getting along, and conflicts erupted often. Gloria and Nancy had found out, during their long talk with Jess, that she had Multiple Sclerosis (M.S.). For Gloria, it all of a sudden made sense: her erratic behavior and mood swings, her anxiety, her physical clumsiness and lack of balance, the slur that was sometimes in her words. She felt really guilty for having pegged Jess has a drug-user when really she was just dealing with an illness of her own. The compassion she felt toward Jess and the heavy guilt she felt for how she had treated her, though, didn't spread much to the other members of the care team. Nancy asserted that she was still definitely doing

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[243] Ruth had been re-assigned to Beth when she came back on hospice care after the hospital. Beth was a white nurse from the states, in her early 50s. Like Nicole, she had no previous experience in palliative care, and was fairly new to Shepherd.

drugs, whether or not she had M.S. And Beth seemed to think that nothing really excused how irresponsible Jess had been at times, how upset she made her mom, and how much she was asking of Shepherd.

Now that Jess was around so much more, the Shepherd team relied on her for a lot of her mom's caregiving, and often assumed things about her knowledge and abilities as if she had been taking care of her mom for months, blaming her when she came up short. They had a lot of conflicts over her mom's medication. Shepherd was pushing the Ativan around the clock, but Jess thought it made her mom drowsy and wanted to see if she was able to talk and be more herself if she wasn't on it. This caused a number of stern talking-tos about being "compliant" with her mom's care plan. Jess was also instructed to giver her mom morphine, in addition to the fentanyl she was getting through a transdermal patch. It wasn't clear to me how much of the state Ruth was in was due to the medications she was on, and Jess definitely struggled between wanting her mom to be comfortable and wanting to make sure she wasn't smothering whatever consciousness she had left.

Ruth died in the afternoon, with just Jess there with her. Beth and I arrived at the house soon after, once Jess called the hospice helpline. Jess was okay. She put on her sneakers, threw her purse of her shoulder, and headed out for a long walk. She kissed her mom on the forehead before she left and told her that she loved her.

There was no funeral, as there was no money for one and no family—not her dad, not her sister, not either of Ruth's sisters—offered to help Jess out. Nancy, the Shepherd social worker, helped Jess file the paperwork to have the Department of Human Services pay for the cremation. As far as I know, Jess was alone with her mom's body as it was being cremated. She texted me soon afterward, saying she was “just hanging out with ma”—she had her ashes with her on the long bus ride across island back to the house. We stayed in loose touch after that, but Jess became harder and harder to reach, until she basically disappeared. The only help her dad had offered her was to pay for a one-way ticket “home,” back to New York. Weeks after I had seen Jess, when I had assumed she had taken her dad up on his offer, I saw her walking along the side of the road as I was driving by. I pulled over and gave her a ride. In the car, she told me that her dad was getting impatient; no one understood why she wouldn’t just come home already, and she was late on the rent and had no idea what to do with the house full of her mom’s stuff. She would leave sometime soon, she said. She just wasn’t ready yet.

Conclusion

Ruth’s story is just one example of how the role hospice care plays on St. Croix can shape the end-of-life experiences, trajectories, and possibilities for older adults there. Building on the discussion of (post)colonial bureaucratic disregard in Section III, I have shown in the past two chapters how lack of a Medicare-certified Durable Medical Equipment provider in the territory can turn individuals, who might not otherwise elect palliative end of life care, to hospice, and I have shown the impact this “choice” can have for their care, experiences, and trajectory. Following Ruth throughout what turned out to be the last three months of her life shows what consequences the lack of any option besides hospice for older adults in need of DME can have on a life and a death, and on those who are left behind.

There were two main framing premises for this chapter’s ethnography. The first premise was that older St. Croix residents finding themselves in need of medical care sign up for hospice without aligning with the intentions of palliative, end-of-life care. This, briefly, is the suggestion that for older St. Croix residents within a certain range of ill-health, it is easier to obtain care aimed at helping them die a comfortable death than it is to obtain care aimed at helping them live a longer life. The second premise was that it is often a need for Durable Medical Equipment is often what pushes these residents to sign up for hospice care. These claims motivated the telling of Ruth's story in particular (and which parts of her story I told here). But, telling her story was also a way of providing evidence for these claims—for showing that these claims matter.

I have argued that within the context of (post)colonial bureaucratic disregard, forms of interpersonal disregard also greatly shaped Ruth's experience, care and trajectory near what turned out to be the end of her life. In both of the health crises that I discussed in this chapter, Ruth's trajectory was determined in part by a form of disregard that I have suggested is endemic to American hospice practice and thus is deeply connected to the landscape of (post)colonial bureaucratic disregard in which hospice is the only option for some in need of care. This disregard of the possibility that a patient ought to be taken off of hospice care, that they need, want, or deserve curative treatment is in many ways pushed into the realm of disregard by hospice bureaucracy, policy and practice.

The way that identities were constructed for Ruth and Jess also brought into being certain forms of disregard for their possibilities. These were identities—primarily, being "anxious" people—that dovetailed with hospice ideology, policy and practice around patients' and caregivers' attitudes toward death, and thus served to enhance the impact of these forms of disregard. But seeing Ruth and Jess in this way was also its own form of interpersonal disregard, one that at certain moments, certain members of her care team resisted.

Lastly, there are many ways in which Ruth's end of life trajectory was shaped by Jess's intermittent disregard for her. I have sketched some of them here: the extra burden it put on Ruth's hospice caregivers, how that enhanced their perceptions of her as a "needy" and "anxious" patient, how it shaped the caregivers' impressions of Jess, pushed Jess out of the circle of her mom's hospice caregiving and defined how she was seen—and thus the power she had to help her mom—in the midst of Ruth's second medical crisis. It also meant, however, that Ruth was alone a lot of the time during her last few months of life.

In the next section, I focus on interpersonal disregard. Specifically, I take as central the phenomenon of older adults in need of care on St. Croix finding themselves alone for much of their waking lives, due to the fact that they only have one family caregiver. I embark on a discussion of interpersonal disregard as it is situated within particular familial configurations that, like that between Jess and Ruth, developed over a lifetime.

SECTION V

Caregiving and Disregard:

Sole Family Member Caregivers on St. Croix

Prologue

Global migration is shaping family-based care in areas all over the world. Generations are separated from their kin network, requiring the development of new forms of care for those who cannot care for themselves, such as those at the early and late stages of the life course. Migration is extremely common in St. Croix, as it is across the Caribbean and has been since the end of slavery (Chamberlain 1998: 1; Olwig 2007: 27-31). Every family I was familiar with on St. Croix (whether or not they participated in my study) was spread at least between St. Croix and the mainland, if not between several other islands as well, such as Puerto Rico, St. Thomas, the British Virgin Islands, and the many islands of the Lesser Antilles. As has been documented elsewhere in the Caribbean, migration to the metropole is a normative trajectory open to those growing up on St. Croix, and for those who stay, it is just part of everyday life that much of one's family lives stateside. This (post)colonial pattern is an indication of the continued monopoly held by the U.S. on opportunities for living well, including economic, educational, and medical options simply not available on island. Since 2012, the closing of Hovensa's oil refinery (see Chapters 5 and 6) has only exacerbated the "push/pull" migration dynamic between the island and the states, sending thousands of working-age adults and their families to the continent in search of steady employment.

Recently, migration scholars have turned away from a paradigm that paints migration as causing a lack, loss, or deficit of care and have instead sought to build perspectives that emphasize the creative, constructive solutions that families enact to take care of the kin despite being separated by great distance (Ahlin 2017; Dossa and Coe 2017; Lamb 2009; Madianou 2016; Nedelcu and Wyss 2017; Yarris 2017; cf. Hochschild 2000). In St. Croix, though, many working in healthcare, politics, and social services feel that there is a serious lack in family care for older adults. This was borne out in my research. Most of my focal participants—older adults near their end of life in need of daily care— had only one person from their family taking care of them on a regular basis, a pattern that was very familiar to professionals I spoke to. Because of this, and the concurrent need for these caregivers to work to make ends meet, many of my focal participants spent most of their waking lives alone. Without exception, this aloneness had a deleterious effect on their care and their quality of life.

This is not to say, however, that these families are not still configuring themselves within a space of shared meanings, expectations, and understanding to create the care that is taking place. While from a certain perspective we can see the aloneness these older adults go through as displaying the disregard of their family members, we can, at the same time, see this disregard as enabling these family members to care for other things. Taking the human being as always in a mode of care (Heidegger 2010), we can conceptualize disregard as care, directed elsewhere. While one family member is attending to the elder in need of care, the others can attend more to their children, to their own wellbeing, and to building possibilities for generations to come.

In this section, I discuss the familial organization of care for older members near the end of life as being organized through social expectations for attention and disregard over the life course. These expectations, while they can be and are contested by individuals, are locally rendered in the sense of being constituted from publically shared orientations that shape the space in which practice and sense-making around this form of care unfold. Migration plays a large role in these familial caregiving configurations, as it is one of the main reasons why potential caretakers are not nearby when older family members begin needing care. This is not the only reason that caregiving is limited to one family member, but it play a significant role and is dominant in the discourse. One of the aims of this section is to probe how the distance created by migration is made sense of and oriented to in the domain of family caregiving for older adults on St. Croix. In particular, I will discuss how this sense-making is intertwined with local understandings of attention and disregard over the life course, and how both of these are undergirded by a particular logic of distance and proximity.

It is important before embarking on a discussion of family caregiving for older adults on St. Croix to account for forms of care that may have been taking place remotely. In particular, these would be the sending of remittances, and communication and virtual co-presence via information connection technology (ICT). However, neither one of these played a role in the lives of my focal participants. In my research experience, there is no system of remittances on island. To the best of my knowledge, in none of the families in which I worked were family members sending remittances to help caregiving efforts. Furthermore, there was extremely low use of ICT among my focal participants. While most (although not all) of them had use of a cell phone, none of these phones were smart phones, and in certain instances the older adult was sharing the phone with their family caregiver (as was the case with Ruth and with Ms. Hanks).

Only one of my focal participants had access to the internet in his home.[244] Thus, recent arguments about the possibilities for "ambient co-presence" (Madianou 2016; see Baldassar et al. 2016, Baldassar 2016, Baldassar 2017; c.f. Ahlin 2017) and other forms of togetherness and care supposedly made possible by ICT simply were not at play among my focal participants.

This section is organized around the narratives and experiences of two groups of people, each group consisting of one older adult, their sole family member caregiver, and the professional caregiver providing them nearly daily homecare. In Chapter 11, I investigate local understandings of how familal care for older adults is organized with an emphasis on understanding how situations in which there is only one family caregiver come about. This will be explored primarily through the narratives of the two professional caregivers, Coraline and Ms. Ramirez, although informed by accounts by and my observations of others. Both of these women worked as in-home CNAs (Certified Nursing Assistants) for older adults on St. Croix, and had been working in that job for at least five years. They were thus familiar with a large number of caregiving situations for older adults on-island, both those involving sole family member caregivers and those with multiple caregivers. My discussion of Coraline and Ms. Ramirez's accounts will emphasize what is shared between them and what I can confirm from my experiences with others as a shared local understanding. I preface this discussion with short biographies of Coraline and Ms. Ramirez that are meant to provide some grounds for seeing how their positionality and life histories may be coming to bear on the accounts they present.

In Chapter 12, I turn to the experiences of the two older adults and their family caregivers. These are Mr. Edwards and his grandson Eli, and Mr. Parker and his son Robby. In

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[244] This was Mr. Landry, a stateside hospice patient who participated in the pilot phase of my study.

this chapter, I discuss how Eli and Robby’s situations, and their own interpretations of their own situation, both conform to and break from the locally shared understandings established in the previous chapter. Both Eli and Robby, in different ways, show an awareness of the typified understandings of the caregiving arrangement that their family has come into, in which they are the family’s main (and it could be said, only) caregiver for the older relative member in question, while other potential caregivers turn their attention elsewhere. Through their expressions of this awareness, they show their own aspectual understandings of the patterns of disregard and attention over the life course that have shaped their situations.

Chapter 11:

Local Understandings of Sole Family Member Caregiving

Among the human services and healthcare workers that I spent time with on St. Croix, it was well known that many older adults in need of daily caregiving only had one family member (or sometimes close friend) taking care of them. As my research progressed and I started going inside more and more homes, and hearing about more and more caregiving situations, this was a pattern that was impossible to ignore. Eventually, I would also come to understand what these professionals knew very well: that most of these older adults were a part of large families, and thus that there were many individuals who could have been, but were not, taking care of them.

The main reason that this pattern of sole family member caregiving is known to individuals working within the healthcare and social services systems is that it often has repercussions for the kind of care that these older adults receive at home. In only one[245] of the many families that I was familiar with did a caregiver stay at home full-time to tend to an older loved one. Usually, these caregivers worked long hours to make ends meet[246] (i.e. keep groceries in the pantry, lights on in the house, and cable on the TV) in St. Croix's perpetually depressed economy. Given these caregivers' need to be out of the house for most of the day on most days of the week, older adults with sole family member caregivers end up spending much of their

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[245] The one family was the Landry's, a stateside husband and wife who participated in the pilot phase of my study. Mr. Landry was a hospice patient, and Mrs. Landry stayed home with him full-time.

[246] This was not always the case, as not all of the caregivers in my study were employed. However, in the case of the two focal participants' whose caregivers who were not employed, they also were not family members and did not live in the same house as the older adult. Providing caregiving in these cases was just one of the many responsibilities they were committed to. In any case, no participant in my study had a full-time caregiver at home with them.

waking life alone. These long stints of being alone, for people who have various degrees of illness and immobility, can sometimes lead to serious or even disastrous scenarios. More often, there is the perpetual build-up of inconveniences and discomforts that come from being ill and not being able to care for yourself, and not having someone nearby. People who work in the healthcare and social services systems are familiar with these situations because family members will at times turn to these institutions in order to help, usually at times of acute health crises or more gradual downturns in health that cannot be managed by a single caregiver. Those professionals therefore talk about single family member caregiving as an unfortunate state of affairs that they end up having to try to make up for.

In this chapter, I explore familial organizations of caregiving for older adults, and specifically the particular configuration of single family member caregiving, from the perspective of professional caregivers on St. Croix. I focus on the narratives of two Certified Nursing Assistants (CNAs), Coraline and Ms. Ramirez, who had both been working as CNAs for older adults on St. Croix for over five years.[247] When I met them, these caregivers were each taking care of one of my focal participants: Coraline was helping take care of Mr. Edwards and Ms. Ramirez was helping take care of Mr. Parker. They both were caring for other patients as well. Coraline and Ms. Ramirez are not only very familiar with familial patterns of caregiving, but also have something at stake in it, as they both felt that the degree and quality of the work they have to do in patients' homes was inversely related to how much care the older adult is getting from their family. In considering the patterns that Coraline and Ms. Ramirez pick out in

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[247] I chose to focus on the accounts of these two caregivers both because they has extensive experience caring for older adults in their homes and because they were the two people that I who had spoken to me the most directly and the most expansively about patterns of familial caregiving.

their narratives, I focus on how these patterns provide accounts of the regular workings of attention and disregard not just in the contemporary state of affairs in which caregiving is taking place, but along the life course.

As in many places in the world throughout time, it is taken for granted on St. Croix that children have the primary responsibility for taking care of their parents when their parents can no longer take care of themselves (see Kreager and Schröder-Butterfill 2004). While in reality different kinds of relatives end up being caregivers (spouses, nieces, grandchildren, etc), the normative case on St. Croix is of a parent being taken care of by their children. This common pattern seems to be founded on a sense of basic reciprocity over the life course (Kostakiotis 2010; van der Geest 2002; c.f, Kreager [2004: 34]). This is a model for reciprocity of attention organized over the life course. Just as a parent attends to their children when they are young—turning away from other things they could be paying attention to—so those same children attend to their parents when they are old. Coraline and Ms. Ramirez's narratives riff off of these normative patterns, suggesting patterns of attention over the life course that are modulated in orientation to two main variables: gendered cultural expectations of parental attention and disregard (matrifocality), and locally shared conceptualizations of physical distance, primarily rendered in the binary distinction of on island/off island.

Coraline and Ms. Ramirez's narratives demonstrate much about locally shared understandings and typifications of familial organization around caring for older relatives, but they also emerge out of particular life trajectories and experiences. These include their own childhoods and histories of parental (and other familial) attention and disregard, and also the particular caregiving experiences that have shaped their perspectives on how families organize individuals' attention and disregard vis a vis the caregiving of an older relative. Thus, I turn first to abridged biographies of these two women.

Coraline

Coraline is an ethnically Afro-Caribbean woman who was 37 years old at the time of my research. She is the mother of two daughters, one who was a toddler and one who was about 11. She is legally married to and lives with the father of her two daughters. The family of four share a very nice, newly built mid-size track home in a rare area of new residential development on St. Croix. At the time of research, Coraline had been working for Shepherd Hospice as a CNA for about 8 years, with some time in the middle spent as the office's administrative assistant.

Coraline was born on the eastern Caribbean island of St. Martin. She was the only child between her parents, and by Coraline's account it seems that their relationship was a fairly casual one (an instance of one of the more casual "extra-residential" unions [see Barrow 1996]). Coraline was raised almost exclusively by relatives who were not her parents. She lived on St. Martin with her mother until she was about a year old, at which point her mother, who was in her twenties, decided she wanted to "move on with her life and to do what she have to do." She called on Coraline's father, who had not until then been involved in her life, to take care of her where he was living on St. Kitts. Coraline's father, who was 19 when she was born, told her mother to send her instead to live with her maternal grandmother (Coraline's mother's mother). However, as her grandmother was already taking care of 13 grandchildren, her mother told her father to ask his mother (Coraline's paternal grandmother) instead. His mother said she wouldn't take her, so her father asked his sister, who was living in this same household with their mother. Coraline's paternal aunt said yes and snuck infant Coraline into the house. And, as Coraline put it, her grandmother "had no choice but to love her". Coraline spent most of her childhood being raised by her grandmother in this house.

Coraline was her mother's fourth child of five, and the oldest of four on her father's side (some of her siblings on her father's side weren't born until she was a young adult). Her mother's five children had four different fathers, and her father's four children had three different mothers. However, none of these half-siblings[248] lived with Coraline's mom or dad, nor in the household she was raised in. However, for each of them she can recount who in their family they were raised by and whether or not they ever moved in between households.

Coraline remembers a pleasant childhood in which, as the only child in the house during that time, she was very well-cared for and lacked for nothing. She described her neighborhood, on the outskirts of the island's capital, as filled with multi-generational family homes, in which every family on her street "had a senior or soon to be." It was a very tight community, and Coraline can still remember the composition of every household on her block. Everyone she described to me either consisted of a mother-daughter, or of a grandmother-daughter-grandkids. None of them, according to her description, had fathers in the household. She described this household make-up as common across her whole village, making her household, in which her grandmother lived with her daughter and her granddaughter, a very typical one.

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[248] No one I spoke to on St. Croix, including Coraline, called siblings with whom they only shared one parent their "half-sibling." They were familiar with the term, and when I would probe for clarity they would sometimes use it in order to help me understand their family, but then they would return to referring them as "sibling," "brother" or "sister."

Coraline had opportunities to travel much more than her peers, visiting her father on St. Kitts every summer and taking trips to Canada to visit the aunt that had snuck her into the house, who had moved there when Coraline was 8 years old. In general, her parents weren't around, and Coraline didn't really know them, and still doesn't. She described them as "kinda standoffish." It was only during one of these trips to Canada to visit her aunt that Coraline saw her mom (who had come from New York to visit) for the first time since she was an infant. When Coraline was 13 or 14, her mom came down to bring her and her older half-sister back to New York to live with her. However, her sister's paperwork wasn't completed in time, and so both girls stayed behind. During this time, her mother and father got into a series of disputes over Coraline's last name. When Coraline was born, she was given her mother's last name, but then when she was about 12, her mother had secretly changed it to be that of her current husband. When her father found out a couple of years later, he was extremely angry and changed Coraline's last name to his own, which in turn infuriated her mother and led to her not speaking to Coraline for several years. This conflict shows that even though her parents did not participate in her everyday life, there was still something at stake for them in having her belong to their respective families.

When Coraline turned 18 and graduated high school, she moved to Miami to live with her mother. However, the two women barely knew each other and didn't get along well, and so Coraline soon moved out. She first went to stay with her aunt in Canada for a few months, and then returned to her grandmother's house in St. Kitts. The next few years of Coraline's life are filled with a series of moves to different islands around the Caribbean (including a long stint in St. Thomas, U.S.V.I.) while she worked hourly retail jobs at companies like JC Penney and Foot Locker. She eventually moved back to Miami to live with her mom, but the situation was again interpersonally difficult. She heard about Job Corps[249] from a friend in Boston, and after going there for the weekend to check it out, decided to move there to participate in the program (instead of applying to participate in the program in Florida, which was also available). She took the Business-Clerical track but, despite many opportunities after she completed the program, never landed a clerical job, instead working at a coffee shop and eventually, through a friend's connections, in the dietary department of Massachusetts General Hospital. In the meantime, an old friend from St. Kitts reconnected with her through her network of friends from back home, and the two hit it off. He was living in St. Croix at the time, and Coraline moved there to be with him. The two got married in 2003, when Coraline was 25, and have lived together ever since.

After spending a few years working in retail at stores like Payless and Kmart, Coraline decided to go back to school and "get something done." She chose the CNA program because it felt most familiar to her: her aunt that she grew up with was a nurse, and she lived very close to the hospital on St. Kitts and had worked in a hospital in Boston for some time. She took evening classes, obtained her certification, and then began working for Shepherd Hospice in 2008.

Ms. Ramirez

Ms. Ramirez was born and raised on St. Croix, and was 34 at the time of my research. She is ethnically Hispanic. She grew up living in the projects, but never thought of her family as poor, as she and her siblings always had all of their needs met. She, along with her three brothers

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[249] Job Corps is a residential work training program for individuals 16-24 years of age. It is run by the U.S. Department of Labor.

and four sisters (which may have been half-siblings), were raised by their mother. Her father was not really a part of her life, although she did see him from time to time. She went to public school, graduating high school after having her “high school baby” at age 17, a daughter who herself was 17 at the time of my research. Ms. Ramirez maintained a romantic partnership with her daughter’s father, her high school boyfriend, having another son with him who was about ten at the time of my research. The two were still together and had gotten legally married about two years earlier. Ms. Ramirez was currently living with her husband and their two children.

When I started our first interview by asking her how she had gotten started as a CNA, Ms. Ramirez told me that when she was a teenager, her grandmother had become very sick (as a result of kidney failure combined with diabetes), and that she had watched her mother (her grandmother’s daughter) take care of her. She said that even though her grandmother had twelve kids, it was her mother alone who took care of her. Ms. Ramirez and her sisters “had no choice” but to help out with the caregiving, as “the burden sorta kinda fall on” their mom. She said it was up to the girls to do it, as boys didn’t really participate in “hands-on” caregiving. “So,” Ms. Ramirez explained to me “that’s sorta how I start to kinda get into this field.”

At age nineteen, Ms. Ramirez was looking for a change, and so moved to Miami with her daughter, who was a little over one year old at the time. Her older sister was living there, and Ms. Ramirez came to join her. Her husband stayed on St. Croix, as he had a stable job working for the local government. At this point, Ms Ramirez was not yet a medical professional, and worked in Miami as a cashier at a gas station. However, one year after moving, Ms. Ramirez’s mother died unexpectedly of meningitis, and she and her sister returned to St. Croix to mourn with family, help get all of their mothers’ affairs in order, and care for their two younger sisters who were in middle school. Her mother's death was completely devastating for Ms. Ramirez. When her mom would come up in the course of an interview, almost 15 years after her death, Ms. Ramirez would get noticeably sad and introspective. She told me that it was still strange, after over 5 years, to be back on St. Croix without her mom there. She said she still missed her a lot.

A few months after her mom's death, Ms. Ramirez and her daughter returned to Florida, this time to a new city. She began going to school part time in order to obtain her CNA certification, and also got her Home Health Aide and phlebotomy certifications. All in all obtaining these certifications only took a few months. During this time, she got fired from the gas station where she had resumed working and started working at another gas station part time.

After obtaining her certifications, Ms. Ramirez got a job at the nursing home where she had done her clinical training. However, she was uncomfortable with the way the institutional setting made her treat the patients, for instance having to start waking them and getting them bathed and dressed at 4:00 a.m., just so that she would have everyone done by the time the next shift came on at 7:00 a.m. She attributed these deficiencies in care, that her job forced her to be a part of, to the fact that it was a facility for low-income patients that was funded primarily by Medicaid. She noted that families of the patients were often completely absent, re-appearing only when the patient was about to die. Uncomfortable in her job, she moved back to St. Croix to be with her boyfriend, as the two had been managing a long-distance relationship. After a few months of fruitlessly applying for jobs on St. Croix, however, and finding the island "limited" and "boring" she moved back to Florida (where some of her sisters were still living) with her daughter. This was in 2006. At this point, she began working at a large regional trauma hospital, where she stayed for five years. She enjoyed the work very much, as it was challenging and varied from day to day. During this time, her boyfriend moved up to live with them for two years. However, her boyfriend didn't like life in Florida and missed island life, and so in 2010 the family—which now included a young son— moved back to St. Croix.

Ms. Ramirez had applied to the territory's Department of Human Services Homemakers Program before leaving Florida, but it took over a year in order to her application to get processed and for her to be hired. When I met her, she had been working in the job for about five years. During this time, Ms. Ramirez also took on the task of caring for some of her older family members on island in addition to the older adults she was taking care of professionally. Within the first year of being back on St. Croix, she was asked to begin taking care of her maternal uncle, who she had never been close with, but had become severely ill with kidney failure, blindness, and other ailments brought on by years of heavy alcohol intake. His sister, who had been taking care of him, was "burned out," and so Ms. Ramirez stepped in after the social worker at Adult Protective Services requested that she do so. As Ms. Ramirez put it, "I felt like, I'm working in human services, and a family member need help and nobody is helping him what kinda shit is that, this is what I'm saying to myself." While the care that she provided for her uncle varied over the years, at the time of my research she was bathing him every other Saturday —normally one of her two days off—while his sister took the alternating Saturdays. During this same period of time, Ms. Ramirez's began helping her paternal grandmother, who was in her eighties, to take care of her aunt (her grandmother's daughter) who was in her fifties and had a life-long disability. Because of her grandmother's own growing limitations, Ms. Ramirez would come to feed and otherwise help her take care of her aunt. Her aunt had since been accepted into Herbert Grigg (the island's only nursing home) and Ms. Ramirez had begun taking care of her grandmother instead. However, her grandmother was steadfast about wanting to live as independently as possible, which limited how much caregiving Ms. Ramirez provided her, only helping her when she asked for help.

During the time of my research, Ms. Ramirez had reached a point of exhaustion with her caregiving duties—both family and professional. She described herself as "overwhelmed" and "burned out." In talking about the caregiving she had been providing family members, specifically her uncle, whose care seemed to be the most extensive and burdensome for her, Ms. Ramirez said she felt like she was afflicted with a "generational curse." Because her mother had been the only child to care for her grandmother, Ms. Ramirez felt that out of everyone who could have been caring for her uncle, including his many children, it was her that had ended up doing it for years. Employing a different frame, she said that it was partially because she had seen her mother take on the caregiving duties that could have been distributed among many others that she felt compelled to be the one to do the caregiving. From Ms. Ramirez's point of view, despite the many relatives that lived on St. Croix, it was Ms. Ramirez who took on most of the responsibility for caring for older family members.

Narratives of Sole Family Member Caregiving: Experiences and Explanations

I now turn to Ms. Ramirez and Coraline's narratives about the organization of familial caregiving, particularly how and why sole family member caregiving situations come about. There are two general questions that need to be answered in order to explain any particular familial caregiving configuration, including the common sole family member caregiving situations that were taking place among many of my participants. The first is why there is only one family member providing the caregiving, and not more than one. The second is why the particular family member who is providing caregiving is the one in this role. There is also a third area of explanation that speaks to the process of this family member becoming *sole* family caregiver. That is, why they are sole family caregiver *now.* Is this how things began? What is keeping them in this role? Is anyone going to be coming to help them in the future? Other questions, too, could be relevant in this area. Coraline and Ms. Ramirez's narratives speak to all three of these explanatory domains. However, as we'll see, aspects of their explanations often speak to one or more of these aspects of the situation at once.

These narratives draw on experiences within the homes of other families, as well as, in Ms. Ramirez's case, experiences within her own family. As we will see, the theories of these long-term professional caregivers about how and why configurations of familiar caregiving end up the way it do are largely focused on feelings of responsibility, obligation, or care (or the lack thereof). For Coraline and Ms. Ramirez, important frames for understanding the patterning of these feelings is whether a potential caregiver is on island or off island, and also what kind of relationship the potential caregiver has had with the older adult through the life course. Intertwined with both of these frames is, I will suggest, a locally shared conceptualization of physical proximity and distance. What I will be highlighting is how these feelings of obligation, responsibility, and care themselves serve to direct attention, as people or situations we feel responsible for, obligated to, or care about strongly pull or attention. The lack of such feelings allows attention to go elsewhere, to other objects of concern.

The Narratives

I will start with a narrative excerpt from Ms. Ramirez that provides a good introduction, or road map, to the points we will be exploring. Just before Ms. Ramirez's turn at speech below, I had commented that I knew Mr. Parker had other children besides Robby, but that I had never met any of them. Ms. Ramirez replied (my utterances in parentheses):

Ms. Ramirez: they're in the states or whatever
DF: yeah, as far as the-
Ms. Ramirez: it seems like Robby is left with the burden.
DF: yeah,
yeah I donno what to make of it really
you know I-
Ms. Ramirez: I really donno.
But it look like
he's the only one who they just left,
like he lived there,
okay let him deal with that,
that's not my responsibility (mhm)
cuz you know sometimes when you growin up,
an', you're not raised in the same household
with your mom and your dad (mhm)
and probably your dad
hasn't been there for you all the time (mhm),
and he hasn't been
a real good lovin' supportin' father to you (mhm)

so, if he been there for the last one
the first second middle won'tsoever,
some people feel,
okay, you should take care of him
you should deal with it (mhm)
you know? (mhm, mhm)
so I donno if that's his situation
due to the fact he's here (yeah)
I think he's the last one,
the last child

Ms. Ramirez's first few words here point to an important conception that was common in discussing caregiving for older adults on island narrative. This is the equivalence between living stateside and being gone. Indeed, this is one of the most common explanations for why family members aren't participating in caregiving. Often enough, in explaining why a family member was the only one providing care (for instance, in team meetings at Shepherd Hospice, as well as in my conversations with Coraline, Ms. Ramirez and others), the answer would simply be that they were the only one on-island. Of course, it is most often true that at least some potential caregivers are living in the states, and is not rare for only one child to be living on-island in a parent's older age. However, this explanation was also simply the go-to, immediate explanation when it is discovered that an older adult is being taken care of by only one family member.

Ms. Ramirez phrase "in the states or whatever" indexes the way that living in the states functions as both a reality and a placeholder for absence in local understandings and discourse. She then articulates the notion that these absent children do not feel like it's their responsibility to care for their dad, which frames her following points as reasons that they do not feel this responsibility. The implicit general explanation here is that children do not come to help—whether because they are living stateside or are otherwise absent—largely in relationship to their understandings of the responsibilities of the child who is in some way or another "there." Thus, the meanings of being 'gone' is constituted by the meanings of being 'there'. Having never met Mr. Parker's other children, nor spoken to Mr. Parker or to Robby about them, all of these reasons are generic reasons that emerge from shared, typified understandings of potential motivations of people in their situation (Schutz 1967).

Ms. Ramirez then elaborates upon general reasons why children might not take it to be their responsibility to take care of their parent in a situation where they are off island and there is a child left on-island. More precisely, she presents reasons why kids in general might not feel responsible for taking care of their fathers, and also links these reasons to what their understandings might be of the responsibilities held by the child who is still on island. The reasons she cites here are ones I found were some of the most common for explaining why children might not be taking care of their parent.

The explanation presented in this narrative is made up of what we might think of 'negative' and 'positive' motivations (that are nonetheless strongly related): the negative reasons are the reasons that the children in this account do not feel that they themselves are responsible for taking care of their father. The 'positive' reasons are the reasons that the children feel that someone else in particular ought to be taking care of their father. The negative reason that Ms. Ramirez offers explains here is that the children may not have had their father in their lives when they were growing up. Speaking in the general case ("you know sometimes when you growin' up") she evokes both the fact that children may grow up without their father in their home, and that children may grow up without their father providing love and support. While these two states of affairs could be separate, in Ms. Ramirez's reasoning if your dad is not living in the same household with you then "probably" he "hasn't been there for you."

The 'positive' reason that Ms. Ramirez evokes here for children not feeling responsible for taking care of their parent is connected to why they themselves don't feel responsible. It is the fact that there is a "last child" who they feel "should deal with it." One possible interpretation of "last child" is that because this child was the youngest, while the older siblings grew up and left for the states, the "last child" was still too young to leave. This last child will necessarily have been born when their parents were oldest (compared to when the other children were born) and thus they will be more likely, in general, to still be living on island at whatever point their parent(s) begin needing care. Another possible interpretation of this, in the Caribbean context, is based on a model in which a father has many children, but lives with, or is closest to the last. It is well-established in studies of Caribbean kinship (Barrow 1996, 2010; Roberts and Sinclair 1978; Rubenstein 1980; M.G. Smith 1962, 1970) that "extra-residential unions" are a common type of partnership for having children, and that individuals will often engage in several of these unions over the course of a lifetime. In these situations, it is normative that the child will live with her mother or her mother's kin (although of course there is variation in practice, as shown, for example, by the fact that Coraline was raised by her paternal grandmother and paternal aunt). Men will thus often have children living in many different households—one of the processes that can lead to the situation evoked by Ms. Ramirez, in which children are not being raised in the same household as their father. However, co-residential unions generally become more common later in the life course (Barrow 1996; R.T Smith 1957) and thus it seems generally more likely for the last child a man has to be raised in a household he has established with the child's mother.

The tenuous relationship between children and their fathers, and the unlikelihood of children feeling responsible for taking care of their fathers (as opposed to their mothers) was a common theme in both Ms. Ramirez and Coraline's narratives. When Ms. Ramirez's uncle, who she had been taking care of for several years, passed away, she told me that none of his children came to the funeral. However, their names were listed in the funeral booklet, and it turned out that there were about eight of them. She said that a lot of the family had been surprised at how many kids were listed, implying that they weren't familiar with at least some of these children because they hadn't been involved in their father's life in any significant way. When I asked Ms. Ramirez why none of her uncle's children showed up to his funeral, this is what she said:

Ms. Ramirez: I donno. (yeah)
I donno if he been in their life or not. (yeah)
but it had to be something around that (yeah)
you know because,
how could you have so many kids
and nobody come (yeah)
how could you have so many children
and no one cares? (yeah)
You know?

She goes on to explain that she didn't have the kind of relationship with her uncle where she knew about his kids and what kind of life he used to lead. Here, Ms. Ramirez's supposition about why her uncle's children were not at his funeral is that he was not in their lives as a father. It seems to her that the same relational distance that left absent a sense of responsibility to provide caregiving while their father was alive then showed itself as lack of caring after he was dead. Here, when Ms. Ramirez asked "how could you have so many children and no one cares?", I had the feeling that she was not just speaking about not showing up for the funeral, but about the final years of her uncle's life in which he was ill and suffering and none of his children came to help take care of him.

In Coraline's narratives on this topic, her reasoning about the difference between taking care of mothers versus taking care of fathers is intertwined with a (in my experience, unique) theory about how the number of children can affect senses of responsibility for caregiving. While in both of the cases above Ms. Ramirez is speculating about the absence of children in caregiving for fathers, Coraline discusses the differences between how mothers and fathers are cared for by their children. Consider these contrasting descriptions, which she provided in response to my question about how unique or common the caregiving situation at Mr. Edwards' home was[250]:

Coraline: okay, what I realize,
most of the times,
when I goin to a home,
that the home only have one or two children? (mhm,)
they show a lotta love? (mm)
to whoever the family member is that's sick, (mhm,)
if it's, the mom especially,

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[250] I will describe these circumstances in detail in the next chapter. Here, I was referring to the fact that Mr. Edwards is alone most of the day and that he only has one family member, his grandson, Eli, taking care of him.

they go, all out. (mhm,)
cuz I had a patient last year
she died at ninety eight. (mm,)
and, she had two children,
they was from Saint Kitts also.
a son and a daughter.
Dat woman's skin was clean,
her sheets every day change, (yeah)
she-she bathe her mom twice a day
with me when I go?
she doin the bath (yeah)
I only helpin her. (...)
when I tell you her skin was baby soft,
no long fingernails, (yeah,)
every day you comb her hair,
her feet wasn't dried and cracky and ashy,
nuh, thing. (yeah,)
you coulda bathed that woman without gloves.
(yeah,) because you're shore she clean.

Here, Coraline presents the scenario of a mother of two children who is receiving impeccable care. She then contrasts this to another family caregiving scenario:

Coraline: at that same time
I had a patient now,
he was from Saint Kitts. (yeah,)
This man had, bout fourteen, or sixteen children.

and it was, opposite! (mm,)
this man lived in a house, (mhm,)
by himself, in Princesse [a St. Croix neighborhood] (mhm)
and, he had a, a white lady,
was livin there with him,
she was just livin with him
I donno if they were girlfriend or whatever (yeah)
but he wife died.
and he had all these children.
the lady got sick
went to the hospital
the guy who used to cut the yard,
stayed there, with him,
until she came back out (mhm)
unfortunately she didn't come back out (...)
His daughter, that live here
used to come and visit.
the garbage would be there,
pilin up, in front of him,
she wouldn't say she takin it out. (mhm,)
when you go to the house
from your park up outside
you could smell the inside the house,
so when you go there
you either eat before
because when you leave there
you can't eat right away (mm)
cuz that scent (mm)

> still in your memory
> just talkin about it I could still smell it (oh my gosh, yeah)
> after so much years later.

Here, Coraline makes a distinction between one home in which the older adult was impeccably cared for, and one which was "opposite." She elaborated on many points in our conversation about the squalid conditions the man in the second example was living in, for example with dead rats lying on the floor of his room, his bedside commode not being emptied for days with foul-smelling excrement in it, etc. While her distinction here turns on the number of children each parent had, with the first having only two children and the second having at least fourteen, there are other markers that this distinction is also a gendered one between mothers and fathers. After making her general claim that "most of the times" when she goes into a home with only one or two children, the parents is impeccably cared for, she specifies that this happens "if it's the mom especially," in which case "they go all out." Then, in the example of poor care for an older adult, we are in the home of a father. This is not a strict division, indeed Coraline mentions another family in which a father's only two children—two sons—were taking impeccable care of him. However, she does mention that this family "was very unique." Overall, as we will see in the narratives that follow, Coraline's reasoning does seem to posit a division between children's tendencies to care for mothers versus fathers.

Elsewhere it is even more clear that her theory is a gendered one. At one point she notes: "when most of the times you have, a bunch, a man or a woman with a buncha children, (mhm) mostly men, you have different mothers." Thus, it will usually be men who find themselves with many children in old age, and thus, according to Coraline, with worse care. Women, on the other hand, find themselves with fewer children, and thus, better care. She continued:

Coraline: and, it always seems to be like a push and a pull.
when you have a bunch of children,
one always tend to favor you,
more than the other one (...)
so when you have them amount of children,
sometimes, each of them pick a side (mhm)
but then if you have thirteen or fourteen a'them
it's only one g'on gravitate toward you
the rest may gravitate to the mom (yeah)

Here, Coraline's theory seems, until the last few words, to be applicable to either gender of parent.[251] However, it again becomes clear that she is working within an understanding in which it is fathers much more often than mothers who will have a large number of kids, and thus they that will be in a situation to perhaps only have one out of all of their children "gravitate" toward them. Here, importantly, she is talking about children "favoring" or "gravitating" toward certain parents during childhood.[252] This helps make sense out of what might seem a counter-intuitive consequences of her theory: if there were more children, wouldn't more and better care

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[251] Coraline's ideas about the number of children affecting felt responsibility for caregiving, were, as far as I could tell, fairly unique. It was not part of the common discourse about these matters that when a parent had many children it was less likely for them to get good care than it was if they had only one or two children. For Coraline, however, it seems that generally speaking it would be fathers who were in the situation of having lots (e.g. "thirteen or fourteen") of children, and nonetheless only having one caregiver as an older adult, which does align with common local understandings.

[252] This is clear because she illustrates with an example of her two young daughters, one who prefers her and one prefers her husband/their father.

theoretically be possible? A lighter load for everyone involved? What Coraline's narrative suggests, though, is that a more diachronic view of the situation is necessary: by the time an older parent with a lot of children needs care (normally a father), most of those children have already long ago "gravitated" away from him. The caregiving configuration was, according to this theory, largely shaped through childhood.

It seems that she sees affection or attachment toward a parent growing up as playing a big role in who ends up caregiving. Furthermore, it seems that for fathers who have a lot of children, it is unlikely that many of those children will feel more attached to him then they do to their mother—typically, it will be only one who does. In this model, fathers would thus be more vulnerable than mothers to ending up in sole family member caregiving situations. While Ms. Ramirez's explanation for why many of a father's children would not provide caregiving relied on the idea that those children had not had their fathers in their lives growing up, Coraline's explains this same consequences in terms of children not "gravitating" toward their father growing up. The two women's accounts, at least of caregiving for fathers, are very compatible, although they each emphasize different possible factors shaping the situation.

One way that both Coraline and Ms. Ramirez articulated the idea that ostensibly potential caregivers (primarily children) might not be providing caregiving because of previous family experiences was in terms of "issues" in the family's past. These issues might have to do with a father not having been there for his child in the way that child (or others in the family) may have wanted, but could include many other things as well. For instance, in discussing the relative dearth of her uncle's family members at his funeral (a situation which included his children's absence), she said "they have too many family issues from back in the day." A bit later in the interview, talking about her uncle's death in the context of family getting together for his funeral led her to think about her grandmother (his mother), who died at the same age of 69. This was the grandmother who was cared for mostly by Ms. Ramirez's mother while, from her perspective, the rest of the family did nothing. Speaking in generalities that made it difficult for me to know exactly what she was getting at, she again said "so, you know families have a lotta past history and you know issues that they need to deal with." I never got a glimmer of what kind of issues she was talking about, only that they were related to the absence of family support when her mother was taking care of her grandmother, and what felt like the same absence of family support when she herself was taking care of that same grandmother's son.

Coraline, on the other hand, did tell me some of the "issues" she had learned about as motivating the absence of certain potential caregivers in the lives of older loved ones. (This may have been, in part, because it was not her family we were talking about.) At one point, I began to ask her why she thought it was that in families with so many kids, parents got worse care than in families with fewer kids. (This was the question that also lead to the "gravitation" discussion above.) She said that from what she gathered, for "one of the parents," it's "a deep rooted issue from when they're a child." It seems that what she meant by indicating "one of the parents" is that it's a issue from childhood that determines either what parent you feel close to, or what parent you are distanced from. For instance, she elaborated on the background of the two children who had been taking such impeccable care of their mother in the example above:

Coraline: so, with the two
that I told you that was from Saint Kitts

and mom live, fifteen years bedridden (yeah)
was the only two
that had the same father the same mother (mhm)
the mother went to Curacao to work
left them with the grandmother
the grandmother took care of them
then the mother came here
the mother sent for them (mhm)
gave them her all (yeah)
right?
they had nobody else,

While it's not clear what relationship the children had with their father growing up, it is clear that they were both raised by only their mother, and their grandmother. Their mother left them only to go work, but as soon as she was back, began caring for them again, giving them "her all" as a mother.[253] For Coraline, this is a case in which the two children would have no reason not to feel responsible for providing their mother caregiving.

Coraline described other cases in which it became clear to her the reasons why certain children were not providing caregiving for an older parent. For instance, Coraline found out that the man with fourteen or sixteen children (in the example above) whose daughter would not even take the trash out when she came over "used to drink and was abusive." The daughter who was taking care of him was the only one on-island. She, was, though, according to Coraline, extremely bitter and unpleasant all the time, taking as little responsibility as she could for her

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[253] Barrow (2010, Chapter 5) presents narratives of Afro-Barbadian adults whose mothers migrated without them as young adults. For many of her participants, parents who had been expected to come back did not. It is thus not a given in this context that parents will always return to take care of children.

father's care. Coraline also recounted an incident she heard about from the man himself, when he and this daughter had a falling out just after she finished school (causing her to move out of the house), further demonstrating to me that the daughter herself did not want to be providing caregiving, but was doing it anyway as the only child on-island. In this case, it's not necessarily clear whether it was the "issues" in the family's past, or simply the fact that they were off-island, that was keeping his the other children from providing caregiving. For Coraline, both seemed to be at play. This is very similar to Ms. Ramirez's explanation of why children who were off island might be staying away in part because they did not feel responsible for their father's care in the context of there being another child on-island.

These family "issues" don't only exist in these accounts as binary deciders of who will be providing caregiving and who won't be later on in life. They shape the present caregiving situation in other ways, as well. For instance, just as the daughter taking care of her father was bitter because of things in their past, so past family dynamics can shape caregivers' longevity in the role. Coraline told me that Mr. Edwards had previously had one of his step-daughters coming to care for him, and she told me the details of how this caregiving ended. She said that it was back when she had first that when she had first started working in Mr. Edwards' home as his CNA. At this time, one of his step-daughters had been coming by three times a day to check on him, cook him meals, and keep the house clean. But then his other step-daughter (from the same mother) started accusing her of stealing money when she would take his card to the bank to get money out for him. This step-daughter was Mr. Edwards' power of attorney, but was not providing any regular caregiving. The step-daughter who had been providing caregiving got in touch with the bank in order to clear things up, but even after it was resolved the accusations continued, and the accusing step-daughter got other family members on her side. Eventually, the step-daughter who had been providing the caregiving had enough, and stopped coming around entirely. At this point, things became as they were when I came on the scene, with Eli as Mr. Edwards's sole family member caregiver.

As might be expected, the issue between these two sisters did not just start when one of them began taking care of their step-father. While Coraline didn't know a lot about their family history, she did know that the step-daughter who was Mr. Edwards's power of attorney was "the favorite." In his will, he had given her the piece of land he owned elsewhere on island. The other step-daughter, the one who had been taking care of him was the "not so favorite" who he had never liked and apparently had not treated as well as his other children. How this impacted their relationship is impossible for me to say, and there were certainly many other dynamics at play. However, this example gives a hint of how past "issues" might not only determine which children come to provide care, but how multiple family caregivers get whittled down to one.[254]

The question of how and why sole family member caregivers stay caregiving was only obliquely spoken to in Ms. Ramirez and Coraline's narratives, and I didn't become familiar with any common local explanations. In the following, Coraline describes what can happen after a family member began caregiving, and this speaks to a sense of the dynamics that are at play, as she sees them. This includes an alignment with Ms. Ramirez's account of the role of the "last child" in taking responsibility for caregiving:

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[254] Furthermore, it is interesting to consider what might make a child who was the "not so favorite" growing up provide such extensive caregiving for the man who raised her. It could be that, while this happens, caregiving configurations like that are less stable than those based in reciprocity of attention over the life course. Unfortunately, I simply do not have enough data on situations like these to do anything more than speculate.

Coraline: and, so that's why I realized
when there's a lotta siblings in-involve,
and the one siblin' that remain home,
always get, the burden (yeah)
of takin care of that parent (...)
and then when you ask for help from the others,
the others all will, turn their back. (mhm)
or, oh why don't you put him, or her, in Herbert Grigg [nursing home] (mhm)
or why you don't do this
or why you don't do that (mhm)
and den, you tend, to love that parent,
care for that parent,
because you know,
since they care for you,
you need to care for them (mhm)
so you get stuck

Coraline's use of "remain" here makes it ambiguous as to whether the child who ends up providing caregiving stayed home or is actually the last/youngest one. However, I would suggest that the more common local usage of "remain" is synonymous with "is left," as in "there is only one slice of pie remaining," rather than its similar connotation of "intentionally stay" as in, "she remained there for hours awaiting his return." In this interpretation, Coraline's conclusion is the same as Ms. Ramirez's: it is often the youngest child, the one still at home—in the house, or on-island—when the older siblings have left, that ends up providing caregiving.

Coraline here offers a few different scenarios of what happens after a family member, the one “that remain home” begins taking care of a parent. Other possible caregivers might “turn their back”—refusing to offer help with caregiving and perhaps even shutting down communication. Or, they might tell the caregiver to put the loved on in the nursing home. This option seems to be not only denial of their own responsibility to provide caregiving, but a denial of the responsibility of the current caregiver as well. In moving their parent to a nursing home, none of the children would have to be caregivers, and their parent would still be taken care of. Within perhaps what are other scenarios, or just additions to these already mentioned scenarios, Coraline says that the family members will tell the caregiver what to do (by way of “why don’t you” questions). It’s not clear if these would be other ways to lighten their caregiving load (like sending their parent to a nursing home), or some other kind of command/suggestion. However, they do indicate that other family members take a certain amount of distance from engaging in caregiving itself, making orders about what kinds of behaviors the caregiver should engage in, rather than becoming a caregiver themselves.

Essentially, what Coraline indicates here is that once one person takes on caregiving, other potential caregivers refuse to provide them with hands-on assistance of any kind. However, clues from other pieces of her and Ms. Ramirez’s narratives indicate that this is not a configuration of responsibility that arises de novo, but that this caregiving configuration was shaped long ago. Already engaged in caregiving, then, pulled by the felt responsibility to their parent (or other family member) sole family caregivers get “stuck,” with no one to help them. Part of this stuckness, as Coraline points out, is that “you tend to love that parent, to care for that parent” because they had cared for you (when you were a child). Coraline here articulates the common worldwide cultural logic of reciprocity and care over the life course as part of what makes the "stuckness" of sole family member caregivers situation: not only will no one help them, but they can't just stop, either. They feel obligated to provide care, and certainly that obligation is accompanied by varying levels of attachment, concern, and love.

The concept of sole family member caregiving being a "burden," that Coraline evokes above, was a very common one. Returning to the first excerpt I presented of Ms. Ramirez's speech (above), she says that "it seems like Robby is left with the burden." This was by far the most common way that caregiving for older adults on one's own was talked about. "Getting stuck with the burden" was the most typical rendition of the situation of sole family member caregivers on St. Croix.

Discussion

I would now like to suggest three main takeaways from the narratives we have just explored, points that indicate important connections between how familial caregiving for older adults near end of life is configuration on St. Croix, and modulations of attention over the life course. The first point is that these narratives suggest a kind of "paying forward" of attention and disregard between two different phases of the life course: when children are young and their parents are adults, to when children are adults and their parents are in old age. The second is that the feelings of responsibility, obligation, and care that motivate individuals to provide caregiving are modulated by the respective presence of certain family members on or off island, and also that this distribution of family members is potentially shaped itself by those feelings of responsibility, obligation and care. The third point, derived from the first two, is that there seems to be local orientations toward physical proximity and distance (being “there”) that are tied in important ways with the kind of attention that constitutes “being there” for someone.

As I’ve been tracing in the exploration of Coraline and Ms. Ramirez’s narratives, there seems to be an agreement that children who do not have their father in their lives growing up will not feel a responsibility to care for him when he is older. Conversely, it seems to be likely, in these accounts, that the child who is providing the caregiving did feel attended to and cared for by that parent growing up.[255] This recasts the question of why no other children are taking care of a parent in a sole family member caregiving situation along the timescale of the life course. The fact that this general pattern of the work of attention between parent and child over the life course is organized in this gendered split in St. Croix corresponds with classic theories of matrifocality in among Afro-Caribbean families.

Indeed, the role of fathers has long been a preoccupation of studies of Afro-Caribbean kinship (for a review, see Barrow 1996).[256] In Smith’s (1956) original discussion, matrifocality was a variable within Afro-Caribbean households that had a tendency to grow stronger over time, through locally “normal” social processes. According to the theory, this process begins when a

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[255] Again, it is interesting to consider counter-examples like that of Mr. Edwards’s “not-so-favorite” step-daughter.

[256] Much of this came out of racialized studies pathologizing Afro-Caribbean families as broken versions of the supposed “universal” norm for family life: the nuclear family. These studies sought “not to provide a theoretical explanation, but to investigate Caribbean family structure as a social problem” (Barrow 1996: 9). This kind of research identified “promiscuity” and “illegitimacy” as central characteristics of the pathological kinship patterns identified (West India Royal Commission 1945: 217-220, in Barrow 1996: 9). Smith’s concept of the “matrifocal family,” first suggested in the 1950s (Smith 1956) has unfortunately often been co-opted to support perspectives in which the Afro-Caribbean family was to some degree “lesser” version of the nuclear family. This is in large part because it does—in name at least—seem to support the notion that men are “marginal” to family life. Indeed, along with the matrifocal family, the marginal man is perhaps the most famous stereotype of Afro-Caribbean kinship studies (Barrow 1996, 2010; Brown et al. 1997).

man and a woman begin a household together, either by legal marriage or not, and either having children from previous unions with them or not (Smith 1956, 1996: 41). During this initial phase, "the woman is fully occupied with child-rearing and maximally dependent upon her spouse" (Smith 1956, 1996: 41). During this time, the man supports the family financially but does not spend much time at home nor does he participate in childcare. As the children age, a new phase begins during which time children are aging, leaving school, and beginning to help keep up the household, first by doing chores and running errands, and then by earning a wage outside of the home to contribute financially to the household. At this stage, the woman shifts from being solely the "focus of affective ties" in the household and becomes also "the center of an economic and decision-making coalition with her children" (Smith 1996: 42). In Smith's original conception, this growing matrifocal quality of the family is unrelated both to "whether the husband-father is present or not" (Smith 1996: 42), and to whether the mother is the head of the household or not (usually she is not). Rather than household heading, "by far the most important element producing a matrifocal quality in lower-class West Indian kinship is the low priority of solidary emphasis placed upon the conjugal relationship within the area of 'close family' ties" (Smith 1996: 55). In his 1973 analysis and clarification of the concept of matrifocality, Smith writes, "I specifically intended to convey that it is women *in their role as mothers* who come to be the *focus* of relationships, rather than the head of the household as such" (Smith 1996: 42, emphasis in original). Smith writes, in this same re-assessment of the concept, that matrifocality has been identified in many societies worldwide, and that found across all of the cases is "an expectation of strong male dominance in the marital relationship and as head of household, coupled with a reality in which mother-child relations are strongly solidary and groups of women, daughters, and daughters children emerge to provide a basis for continuity and security" (Smith 1996: 45).

The concept of matrifocality is primed for a discussion of the modulation of attention within family life. In this conception of matrifocality, the mother becomes the focus of attention despite the presence of the father in children's lives. However, later research, especially that of Christine Barrow (2010) has shown that the matrifocal tendency of Afro-Caribbean families extends to fathers being more or less absent from children's lives all together. Barrow (2010: 1), notes that "[g]rowing up without a mother or, more commonly, a father for at least some period of childhood is familiar throughout the Caribbean." Similar to Coraline's narratives, Barrow (2010) includes the possibility that a mother will not feature strongly in children's lives, but emphasizes that this is really a pattern that is found most commonly with fathers. Barrow also writes (2010: 152), in describing father's roles in Afro-Caribbean families, that while mothers

> continue [sic] to anchor families and hold them together (...) Not so for fathers – although they are beginning to pitch in with childcare, they are not expected to maintain continuous contact or prioritize children's needs; neither is their absence seen to have such a marked impact on the quality of childhood.

In these cases, in which a father is not around for at least some part of childhood, his physical absence directs attention more toward the mother. Interestingly, while Barrow claims that the presence of absence of a father is not thought to strongly impact the quality of childhood, the narratives of Coraline and Ms. Ramirez show that it is thought to affect felt obligations for caregiving later on in life.

Recasting matrifocality as a particular form of culturally-shaped normative modulation of attention during childhood—drawing attention away from the father, and toward the mother—we can trace the work of this modulation farther along in the life course. The lack of sustained attention between father and children is thought to lead to a lack of feelings of obligation, care, and responsibility, later in life, which in turn leads to lack of attention—to disregard—from these same children vis a vis their father. This implication is founded on the functioning of attention, specifically the way that our attention is drawn to that which we feel obligated to, responsible for, or that we care about.

As we learned from Coraline and Ms. Ramirez's narratives there is an intermingling between, on one hand, being off island and not feeling tugs of obligation to care for an older family member, and being on island and feeling those tugs, on the other. Within the frame of considering the work of attention over the life course, I want to offer an account of why this might be. First, we can consider that the lack of feelings of obligation on the part of off-island family members (especially children) seems to be directly related to there being a family member on island who is providing caregiving. Where feelings of obligation or concern—and thus attention—may have arisen, then, they can be let go, and the corresponding attention dispersed, when the duties one perhaps feels pulled to do are being taken care of by someone else.

We can also consider, as I believe Coraline and Ms. Ramirez's narratives suggest that we do, that the very configuration of some children being off island and some staying on island could be in part shaped by how these patterns of attention shaped possibility for feeling of obligation, care and responsibility. When making the decision to move off-island, likely permanently, what do individuals feel tied down by? More specifically, which of their potential obligations attract their attention, ask to be noticed and considered? It is possible that those who feel most obligated to one day care for a parent—those who have their attention most on the wellbeing of their aging parents—find reasons to stay on-island. Leaving might appear more risky to them, more frought with potential complications. For those who do not feel as connected to their older relative (often their father), such concerns might not even arise. With their attention on other things—their future, their children's education, reuniting with other family members who have migrated—they can disregard the possibility that a loved one on island may, some time in the future, need care.

Lastly, thinking through the logics of attention across the life course that I have argued Coraline's and Ms. Ramirez's narratives suggest also reveals a locally rendered orientation toward physical closeness and distance. In these accounts, if a parent was there with you, living in the same household, and thus regularly co-present, this has a large impact on your attachment or feelings of emotional closeness to that parent. Physical absence, on the other hand, leads to the opposite: feelings of distance, a relative lack of care and concern. Here, the metaphorical "closeness" that is generally taken to motivate children to feel responsible for taking care of their older parent seems to be predicated, within the logic of these explanations, on past physical closeness—regular co-presence during childhood. A similar relationship can be seen between the common idiom of a parent being "there for you" or "not there for you," and whether or not a parent was actually *there*, physically co-present with you, when you were a child[257].

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[257] While kinship itself is in many societies the basis for moral obligations, including the duty to care for in old age, it is certainly not a social universal (see Bodenhorn 2000), and anthropologists have documented the way that kinship itself is in some groups created through particular everyday practices of being together (Carsten 1995, 1997, 2000). While kinship itself is not reckoned this way in St. Croix—individuals do not become any more or less parents to a child depending on their levels of co-presence—feelings of responsibility to care for parents in old age does seem to be predicated on past physical togetherness.

Local conceptions that the ‘last child’—the one still on island—is the most likely to take on the role of sole family member caregiver[258] also align with this logic, foregrounding physical closeness in determining felt obligations to provide care. As I’ve indicated above, a father’s last child may be more likely to co-reside with him. Even if this is not the case in a given instance, the last child on island will have regular opportunities for co-presence with their father, opportunities not available to that father’s other children, who are at more of a distance. As the narratives of sole family member caregiving bore out, not being emotionally close to one’s parent—due, as I’m arguing, to a lack of physical co-presence during childhood—was understood as a reason that children who are off-island remained off-island and did not come back to engage in caregiving. And, as I’ve noted, this motivation also includes knowing that there is a child on-island who will provide caregiving (the “last child”).

It’s important, however, to remember that these constitutions of distance—what makes someone close, versus what makes someone far away—are not objective calculations of distance, but are rendered and made meaningful within local communities of practice. Not only is what meaning distance has for action and obligation, but also that very distance itself is constituted in large part through local processes. In St. Croix, as I’ve discussed, when relatives are stateside, they are generally considered to be out of the picture—“gone,”—when it comes to caregiving for older family members. However, this is just one way to make sense of and take action in

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[258] Ahlin (2017) notes that in India it is traditional for the youngest son (and his wife) to be his parents’ caregiver as they age. I am not aware of how common a pattern this may be worldwide, but it is thought-provoking to consider what local logics undergird this expectation in India, and if such logics are common in other societies in which caregiving for older parents is thus structured.

relationship to that physical distance. Indeed, distance itself is not, from a human perspective, something that is just objectively present. Within a phenomenological approach to distance,

> [w]hether something is close by or further away is not to be determined by geometrical measurement. Distance cannot be defined in absolute terms, but is relative to context, practical concerns, and interests. Likewise, that which is closest by is not necessarily that which is at the shortest 'objective' distance from one's own body. Rather, it is what which Dasein is concerned with (...) To bring something closer is to incorporate it in the context of concernful dealings and use. (Zahavi, forthcoming: 73)

Through this perspective, we can see the distance of being off-island as co-constituting disregard toward older family members in need of care. Being off-island, on-island concerns have moved largely into a space of disregard. Being on-island, on-island concerns feel close, pressing. According to Coraline and Ms. Ramirez's accounts, this is a calculus that family members both on and off island feel the force of.

This is not to discount the genuine difficulties that family members may face, once migrated off island, in coming back home. Indeed, the structural barriers to mobility St. Croix residents who have moved stateside face support the constituting of life on island as feeling far away and out of reach, allowing other, stateside concerns to take their attention. Feeling emotionally removed and not obligated to an individual's future care on island may cause one to migrate, and the felt distance between stateside and the island then further pushes any lingering feelings of responsibility out of the realm of attention.

That objective, or geographical distance is not the kind of distance through which feelings of obligation to care for a particular person are constituted is important, and I would argue often overlooked, in contemporary studies transnational care and kinship. As I discussed in the Prologue to this section, recent approaches in transnational migration studies have sought to emphasize the creative, constructive enactments of families in doing kin and providing care across distance. One thing I hope to have brought to light in this chapter is that the way that any particular family understands the distance between themselves, and what that distance means for their obligations to care for one another, are based on culturally rendered understandings of distance that surely vary across domains. They are greatly shaped, also, by cultural ideologies of kinship (such as matrifocality), and these two domains of meaning intermingle in creating local understandings of familial caregiving configurations near end of life. I have argued that examining these typified understandings reveals that both these gendered ideologies of kinship and collective renderings of distance both affect and are affected by the work of attention and disregard along the life course, work that is often catalyzed by feelings of obligation, responsibility and care.

In the next chapter, I switch to a discussion of the particular experiences of those doing and receiving familial caregiving in a sole family member caregiving configuration. I will examine how two sole family caregivers, Eli and Robby, understand themselves and their situations and how they relate them to these shared understandings and expectations. And, I will present a view on the everyday lives of Mr. Parker and M. Edwards, the men in their respective care, with the aim of showing some of the lived consequences of this familial configuration of caregiving.

Chapter 12

Experiences of Sole Family Member Caregiving

In this chapter, I discuss the stories and everyday experiences of caregivers Robby and Eli, and the family members they were caring for: Robby's father Mr. Parker and Eli's grandfather Mr. Edwards. In the last chapter I showed that professional home-caregivers for older adults have awareness and explanations of the processes of formation of familial configurations of caregiving in which only one family member is providing care. While based in particular experiences, these accounts were nonetheless typicalized and generalized: we were in the realm of what 'normally' happens, what people 'typically' do. I suggested that these accounts reveal certain locally shared understandings of the normal modulations of attention over the life course (in particular between parent and child), and how these modulations are connected both to feelings of obligation, care, and responsibility and to a locally shared orientation toward the meaning of the distribution of family members as either 'off-island' or 'on-island. I also suggested that undergirding these explanations was a logic of the meanings of distance and proximity for attention, disregard, and care. I now turn to examining the lives and experiences of individuals in the midst of sole family member caregiving. First, I portray the everyday lives of Mr. Parker and Mr. Edwards. Then, I examine Robby and Eli's accounts of their own experiences as single family member caregivers, exploring what relationship these experiences have to the narratives discussed in the previous chapter.

In bringing these two new aspects of single family member caregiving into the discussion, I hope to show two pieces of what is at stake in this process of family configuration around caregiving for older relatives. What impact do these patterns of attention described in the last chapter have, for those who end up providing caregiving, and for those who receive it? How did these general patterns play out in two actual instances? How did those going through the process experience it?

Scenes of Everyday Aloneness

It was my experience spending time with older adults like Mr. Parker and Mr. Edwards, older adults with either just one caregiver, or just one family caregiver (whose work was supplemented by a professional), that turned me toward an investigation of what was shaping their situation. This is because spending time with them revealed that they spend much of their lives alone. Ethnographic research has begun to show how contemporary forms of sociality, shaped by structural economic patterns, are leading to patterns of increasing aloneness among older adults around the world (Allison 2016; Danely 2010, 2014; Lamb 2009). While keeping in mind the important, large-scale structural factors that are shaping possibilities for both older adults and their potential and actual caregivers on St. Croix, I am interested in how these circumstances of persistent aloneness are experienced and judged and the level of the individual in his or her “local moral world” (Kleinman 1995). Upon learning, for instance, that Mr. Parker and Mr. Edwards had large families, I begun to conceive of their aloneness as a consequence of forms of interpersonal disregard, the creation and maintenance of which was the focus of the narratives explored in the last chapter. Here, I return to, what was for me, the beginning of this investigation: older adults in need of substantial care spending most of their time alone.

Mr. Edwards

When I met Mr. Edwards in the fall of 2015, he had only been seriously ill for a couple of months. He was 96, and was now bed-bound, with prostate cancer and bone pain (either from gout or from the cancer) causing him a great deal of discomfort pain and making it impossible for him to walk. Mr. Edwards was ethnically Afro-Caribbean, and had moved to St. Croix from Antigua in the 1950s. When I met him he still lived in the same house he had built when he had first moved to the island. A few months earlier his grandson, Eli, who was 25, had stopped by the house and had come upon Mr. Edwards fallen over on the ground and in pain. Eli immediately got his grandfather to the hospital. From there, through the recommendation of a family friend, Mr. Edwards became a patient with Shepherd Hospice.

Mr. Edwards had a large family by Afro-Caribbean standards. He had 16 kids (including step-kids he adopted as his own) and over 100 grandchildren and great-grandchildren. Many of these descendants, and other nieces and nephews, he had raised with his wife[259] in that very house (his wife had died about two decades earlier). As Eli told me, "he raise everybody." This "everybody" included Eli. Eli had been born stateside and his mom, Deedee (Mr. Edwards's daughter) had brought him as an infant to be raised by his grandfather and grandmother. Eli recounts he and his grandfather as always having an extremely close bond. He described himself as always being a "granpa boy," and from his stories it was clear that he was Mr. Edwards's

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[259] I never confirmed whether Mr. and Mrs. Edwards were legally married, or if they lived together in a common law union. Either way, relatives referred to her as his wife.

favorite. In terms of attention over the life course, Eli certainly received a lot of care and attention from his grandfather as a child—indeed, it seems that Mr. Edwards's attention was pulled to the young Eli, even more than it was toward other kids he had raised.

As soon as Mr. Edwards was out of the hospital, Eli moved back in with him, becoming his main caregiver. However, Eli worked as a fisherman, which kept him out of the house six days a week from morning until well after dark. When Mr. Edwards first became bedbound, right after he got out of the hospital, it seems that other family members had been involved in his care. As we learned from Coraline in the last chapter, one of Eli's "auntie's" (Mr. Edwards's step-daughter) had been coming everyday to care for Mr. Edwards. However, disputes with Eli's other auntie (her sister, Mr. Edwards's other step-daughter) led to the ceasing of her daily visits.[260] Eli also told me that a group of Mr. Edwards's kids would come every Saturday night to sing and play religious songs on instruments. Mr. Edwards was extremely religious, and as a Seventh Day Adventist, Saturday was the Sabbath. There was some talk of other relatives and acquaintances who may have been looking in on Mr. Edwards at some point after he got out of the hospital. By the time I met him though, about 2 ½ months after the initial incident, whatever help there had been from others seems to have almost entirely dissipated. Mr. Edwards was spending most of every day alone.

Bed-bound as he was, during this time Mr. Edwards lived on a hospital bed (provided by Shepherd Hospice) in a tiny bedroom in the center of the one-story house. There were 5 bedrooms in the small house, and this was the one Mr. Edwards had been occupying for some

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[260] Because this all happened before I came on the scene, however, I couldn't know for sure how regular or how long these visits were (and neither could Eli, as he was always absent for the length of them).

time. The room didn't have any doors, and the walls didn't connect up with the ceiling, giving something of an open-air feeling to the room, despite its lack of natural light and its extremely small size. The room was always hot, dim and stuffy, and mosquitos lingered. The walls were painted white and there was nothing hanging on them. From Mr. Edwards's vantage point, from one end of the narrow room, he would have had a sliver of a view out into the living room on one side and an equally narrow view into the hallway on the other side. Eli would usually leave the TV on when he left the house, which Mr. Edwards couldn't see, but could hear, as it was just in the next room over.

The event that first got me thinking about how much time Mr. Edwards may have been spending alone during this period of life was a story told to me by Mike, Mr. Edwards' hospice nurse, just before I first met Eli and Mr. Edwards. Mike, was a white stateside nurse in his early 50s who had been living in St. Croix for a few years and had started working for Shepherd several months previous. It was my first day shadowing Mike, and we had spent the day going from home to home, Before we got to Mr. Edwards' house, Mike told me the story of the last time he had come to visit Mr. Edwards. That had been his first visit to the home, as he was taking over from one of Shepherd's other RNs. When he had gotten there, he had found Mr. Edwards alone, without any food or water in reach, crying out in pain. He told me that he rushed to try to help him, first looking for bottled water[261] and not finding any, and then looking for his pain meds and not finding those either. Mike rushed out to the pharmacy, where he bought a case of bottled water and a large plastic cup with a built-in lid and straw, and picked up Mr. Edwards'

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[261] Water from the governmental water service in St. Croix is safe to drink (despite what many statesiders and tourists believe). However, many houses get their water from on-site cisterns, which makes the water non-potable. Mike wouldn't have known at this point whether or not the water coming out of the tap was from a cistern or not.

pain medications that were there waiting. He rushed back to the house where he gave Mr. Edwards some water that he guzzled down and some morphine (a very fast acting pain medication) for his pain. Now, on his second visit to this house, Mike had this incident on his mind. It had really shaken him.

Eli was there when we arrived (it was a Tuesday, his normal day off of work), so Mike got to meet him and learn that he was a very friendly and seemingly trustworthy guy. After the visit, Mike felt somewhat better about Mr. Edwards's situation. In subsequent weeks, I became Mr. Edwards's hospice volunteer, coming over for a few hours a couple of mornings each week to sit with Mr. Edwards and make sure he was alright. In this way, I became more acquainted with his everyday life, and gained some idea of how much time Mr. Edwards spent alone.

When I would arrive in the morning, around 8:30 a.m., Eli would usually still be there, getting ready to go to work. Depending on what time I got there, Coraline, his hospice CNA, would either be just finishing up his bed bath, or would have already come and gone. Eli would give him breakfast when I was there, helping him a bit to eat it, or there would be remnants of a breakfast just eaten on Mr. Edwards' tray. When he remembered, he would also give his grandfather his morning medications. When Eli was in the house, Mr. Edwards would call out to him often. Eli would come to his side, and Mr. Edwards would say something to him that—due to his dialect as well as the difficulty he sometimes had in speaking—I couldn't usually understand.[262] Eli would usually reply with a "yes, daddy." Then, Eli would leave, and Mr. Edwards and I would be alone until I left a few hours later. During these hours, Mr. Edwards would often sleep a fair amount (common in later stages of end-of-life illnesses). He didn't have very much energy. Sometimes he would call out for Eli after he left, and I would have to remind him that Eli had gone, sometimes needing to repeat myself (the difficulties in linguistic comprehension went both ways), before he understood that Eli was truly no longer nearby. If he was awake, I would normally try to engage him in conversation, but because we had trouble understanding each other, and because his speech was usually repetitive and somewhat circular, our conversations were limited. Sometimes the phone would ring, and while it was usually someone looking for Eli (often someone from Shepherd), at least once it was someone calling to talk to Mr. Edwards. I passed him the phone and the two talked for a few minutes. On one other occasion, a middle-aged man came by to check up on Mr. Edwards as well as to collect some fish that Eli had offered him. Mike would come by usually twice a week for fairly quick visits. Other than this occasional contact with the outside world, however, things inside the house were quiet, and we were alone. When I would leave mid-morning, I was always leaving him alone.

Mr. Edwards never asked me for anything to eat or drink, and as a volunteer I wasn't allowed to dispense any of his medications, so my care for him consisted solely of being nearby, being someone who he could make his needs known to should those needs arise. On one

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[262] Mr. Edwards was just one of just a few participants in my study who did not either regularly adjust their speech in my presence (as many did) or regularly use a speech variety that was easier for me to understand (for instance, Ruth, who learned the variety of English she spoke in her lower middle class, mostly white community on Long Island). I was perpetually astounded by the linguistic range of many of my participants, many of whom could speak a bassolectic English creole that I had no hope of understanding as well as a variety close to Standard American English, with an Anglophone Caribbean accent, and many varieties in between. I noticed, however, that it was generally the younger generation of participants in my study who displayed wider linguistic ranges (though of course there were exceptions).

occasion, I arrived to find Eli already out of the house and Mr. Edwards in terrible pain. I called Mike several times, but cell service was very spotty at the house[263] and it was a long time before he could understand what I needed, and then longer still before he was able to get to the house, as he was in the midst of caring for other patients. For about an hour, I variously paced and sat by Mr. Edwards as he cried out in pain, repeating his pleas to me to call the doctor, as I reminded him that I had called several times already and that he was on his way. I gathered that the pain was emanating from somewhere that felt like his bladder, which was consistent with the kind of urinary difficulties that prostate cancer can cause, especially since he was catheterized. When Mike arrived he first gave him morphine and then changed his catheter, which, although a painful procedure, seemed to fix the problem.[264]

While Mr. Edwards was not alone during these times, because I was there with him, my presence in his home was an anomaly. My research assistant and I were Shepherd Hospice's first and only volunteers, and so it is not the case that had I not been in St. Croix, the hospice would have sent someone else to sit with Mr. Edwards. At this time in his life, bedbound as he was, Mr. Edwards could only be together with someone if they came into the house, and, while Eli was there every night and every morning, and there were regular visits by others, there were long stretches of time most days that Mr. Edwards spent alone. It seems likely that there were more than just the two occasions I know of in which he was alone and in pain. During my first visits to the house, I noticed that on the hospital bed with Mr. Edwards was a telephone with large buttons

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[263] The land-line at the house could not make long-distance calls. Mike, like many statesiders who move to. St. Croix, still had a stateside area code connected to his cell phone number.

[264] I found out from Mike that Mr. Edwards had been overdue for a catheter change.

with oversized numbers printed on them (for the visually impaired). I interpreted it as being put there by Eli so that Mr. Edwards could have a way of contacting people outside the house, a lifeline should he need help. However, my observations of Mr. Edwards memory, cognitive capacities, and physical dexterity during this period of his life indicated quickly to me that he wouldn't be able to place a phone call. After a while, I stopped seeing the phone nearby.

Mr. Parker

Unlike Mr. Edwards, Mr. Parker lived alone. He was in his early 80s, and had been bed-bound for about five years due to rheumatoid arthritis and weakness that had developed over a period of extended illness that had since resolved itself. When I was spending time with Mr. Parker, all of his joints were extremely stiff, and many of them, like his knees and ankles, he could no longer articulate at all. His leg muscles appeared to have atrophied, and certainly could not have carried his weight, and his arms and back were also weak enough that he could not turn himself over on his own (although he could shift his weight to some extent).

Mr. Parker was ethnically Afro-Caribbean, and had come to St. Croix from his birthplace of St. Kitts in the 1970s, when he was in his forties. When I met him, he was living in a hospital bed[265] in a small, shack-like house that he had occupied for several decades. He was being taken care of by Robby, the youngest of his six children, and the only one of his kids living on-island.

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[265] As I discussed in Chapter 7, in-home hospital beds are extremely hard to come by on St. Croix. I asked Robby how he had gotten it, and he told me that he had bought it for several hundred dollars from Shepherd Hospice after his dad had been a patient with them for a short time. It was not Shepherd's usual practice to sell Durable Medical Equipment to families, and I never heard of this happening on any other occasion. Since they could not bill Medicare for these sales, families would have to pay out of pocket for the used equipment. I cannot explain why this transaction would have happened in Mr. Parker's case.

Robby lived about a 10-minute drive away from his dad. He worked three jobs, one of which was steady and two of which were on-again off-again. These jobs, and his dad's social security money, was how he paid for everything his dad needed. Robby came by twice a day most days to check on his dad and to sometimes drop off food of other supplies. As far as I could tell, he never stayed long.

In addition to Robby. Mr. Parker was receiving care from a Ms. Ramirez five days per week, through the territory's Department of Human Services Homemakers Program. As I discussed in Chapter 6, the very small program brought helpers (all female, some CNAs, some not) into the homes of seniors in need. Because she was a CNA, Ms. Ramirez was able to give Mr. Parker a bed bath and provide other forms of grooming care for him (such as helping him brush his teeth, putting lotion in his dry skin, etc.). She would change his clothes, make him breakfast, make him a snack for later in the day, and do some cleaning around the house. Because Mr. Parker was bed-bound and also had limited mobility in his arms (because of arthritis affecting his joints), Ms. Ramirez needed to be very careful about how she set things up for him when she left for the day. For instance, she needed to make sure to set a few water bottles within (his) reach, loosening the caps so that he could open them with his limited strength (but so they would not spill in the meantime), prepare his snack so that he could eat it on his own and package it so that it could be left out of the fridge for several hours in the hot, humid air without attracting ants or becoming unappetizing, and turn the TV to his favorite channel (because he couldn't change it himself).[266] All in all, Ms. Ramirez was there for 2-3 hours, Monday through Friday.

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[266] See Buch (2010, 2013) on labor and embodied empathy in caregiving among homecare workers in the U.S.

While there is much to say about the various forms of labor involved in Ms. Ramirez's extremely attentive caregiving, the reason I have described these things here is to give an idea of just how limited Mr. Parker's own abilities were and thus how much care he needed just in order to maintain a relatively basic level of comfort and wellness. Ms. Ramirez, however, was fairly new in Mr. Parker's life, having begun caring for him just a few months before I met him. Robby had been trying to get his dad accepted into the Homemakers Program for several years, undergoing a good deal of work and frustration in his attempts until he was finally successful. Thus, until just a few months previous, there had been a few years during which Robby was taking care of his dad in this state completely on his own. Things were much better now. Nonetheless, unless I was going to observe Ms. Ramirez's visit, almost every time I would arrive at Mr. Parker's home I would find him alone, and when I left, I would almost always be leaving him alone.

Mr. Parker had a cell phone, and he had a few friends and family members who would call him from time to time. While his significantly impaired vision made it difficult for him to place calls, he had voice activation turned on, so that he could sometimes manage to call people himself (Robby almost certainly set this up for him, although it's also possible that Ms. Ramirez did it). Whenever I came by the door to the house was unlocked, and I'm not sure if it even had a functioning lock. I never knew anyone besides me, Robby, and Ms. Ramirez to come and visit, though.[267] The TV at the foot of his bed was on all day and into the evening (turned on by Ms.

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[267] The one exception to this is my Crucian mother, who introduced me to Mr. Parker and came with me to visit him on one or two occasions. She knew him because as a local senator, her office had become involved in the dispute between Robby, Mr. Parker, and the investors who had purchased the property that Mr. Parker was living on (see below). She introduced the two of us both because of my research interests and because she strongly felt that Mr. Parker would enjoy my company and benefit from having a regular visitor.

Ramirez on the weekdays and Robby on the weekends), and every night when Robby would check on his dad before going to bed, he would turn off the TV and turn on the radio, which would be on all night. Mr. Parker's house sat on a large, otherwise empty lot in one of St. Croix's two main towns, and Mr. Parker told me that he would listen to the people walking by, down the road several yards away from the window next to his bed. In these ways, the long stretches of aloneness and silence were populated by others—through the television, radio, and voices in the street—even if those others weren't *with* Mr. Parker in terms of actually being co-present.

A few months into knowing Mr. Parker, the context of his aloneness changed significantly. A few years before I met him, developers had purchased the large, otherwise empty lot that the house sat on, and had begun refusing rent payments in order to force Mr. Parker to leave the house that he was now officially squatting in. (The developers planned on constructing a multi-level parking structure on the property to encourage commerce in town.[268]) While for some time the developers and Robby were at something of a standstill, they came to an agreement during the time that I was regularly visiting Mr. Parker (with the help of a local senator's staff who served as moderators and guarantors). The agreement stipulated that Mr. Parker would move into a new apartment, vetted by Robby, and that the developer would pay Mr. Parker's rent for six months. In the meantime, the senator's office would work on getting Mr. Parker a bed at St. Croix's only nursing home, cutting in line in front of the many other people on the waitlist. While I was skeptical, given how long the process up until that point had taken, that the terms of this agreement would be carried out during my fieldwork, Mr. Parker did end up

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[268] This sort of development is fairly rare on post-Hovensa St. Croix. However it is something that the local government is actively trying to encourage.

moving to a new apartment, leaving behind the house he had lived in for the better part of his time in St. Croix.

This move drastically changed Mr. Parker's connection to the outside world. From a certain perspective, the apartment was a massive improvement in Mr. Parker's living conditions. Unlike the dim, dirty, shack-like interior of his other house, this apartment looked new and felt clean, with white tile floors, white cabinetry, appliances and countertops, and off-white walls. Mr. Parker's hospital bed put in what was meant to be the living room space of the apartment's main room. The front door opened directly onto this room, which had a kitchen on one side and open space, where the hospital bed was put, on the other. In addition to the main room and a small bathroom, there was a furnished bedroom directly off of this room in which Robby could, and sometimes did, stay the night. However, what these putative improvements covered over were aspects of the apartment that cut off Mr. Parker's possibilities for sociality. First of all, the small apartment building was much farther from the center of town than his previous house, and his unit was set toward the back of the lot, far away from the street. There was hardly any foot traffic at all on this street, and even if there was, the one window in the main room faced away from it. This meant that Mr. Parker could no longer hear the voices of others as they passed by throughout the day.

Secondly, the door to this apartment (unlike the door to his house) had a functioning lock with keys that opened it, and so the door was sometimes accidentally left locked. While this occasionally interfered with my and Ms. Ramirez's visits, it was more than anything the possibility that it was locked, and Mr. Parker never knowing whether or not he was locked inside, that most affected him, rather than the actual blocking of people coming inside. On one occasion, I came to visit Mr. Parker in the morning and was locked out. Mr. Parker and I called to each other through the window. To my surprise, he quickly became panicked and angry that I couldn't get inside, telling me to call Robby and tell him it was an emergency.[269] What to me was just a minor inconvenience alerted me to how sensitive the otherwise mellow and laid back Mr. Parker was to this particular aspect of his new living situation.

Finally, the aspect of this new apartment that seemed to affect Mr. Parker the most was that for several weeks, he did not have any cell phone signal inside. At first it wasn't clear to Mr. Parker how long this would last, and he seemed to orient to it as something that would get sorted out right away. When I would visit, he would ask me to call people on my phone, having me search through a notebook in which many names and phone numbers were written and then dialing and passing him the phone if someone picked up. As the weeks went by, though, the lack of a working phone began severely affecting his mood and bringing him into a depressive, resigned state. At a certain point, after it had been over a month of him not being able to receive any phone calls at all, I noticed that instead of being in bed with him, set right up against his body, the phone was now sitting on the shelves next to his bed, with the battery completely dead. With a bit of probing, I learned that he had purposefully not charged it and wanted it to be out of his sight. In the both the way he told me about, and in the determined, resentful quality of his silences on the topic, it seemed that he was doing it as a form of protest against Robby's slowness in fixing the situation; like he was performing giving up on ever using his phone again in order to show how disregarded his felt his needs had been. Eventually, Robby sorted things

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[269] I did call Robby, and eventually got inside. On the rare occasions after this that I was locked out, I called Robby before letting Mr. Parker know that I was there so as not to upset him. If I wasn't able to get a hold of Robby, or he didn't call me back for some time, I would postpone my visit.

out, and Mr. Parker was able to hear his phone ring again, and to speak to and hear the voices of people who were not nearby.

I mention these aspects of Mr. Parker's living situation in order to give a sense of the kind of aloneness that characterized his everyday life during this time. The fact that he was sensitive to whether or not he could hear the voices of passersby and to the fact that at any time the door could possibly be locked, and that he was so distraught by the lack of cell reception in his apartment, highlights how important these forms of distal sociality were for his comfort in the world. His attentiveness to these things, I suggest, is indicative of the great absence of face-to-face contact Mr. Parker experienced.

Much like in Mr. Edwards's situation, there was always a risk in Mr. Parker's aloneness —a risk that he would need someone and wouldn't have anyone nearby. Because his health was relatively good, there was far less of a chance of pain being the source of this need. However, there was one incident in which some of the more terrible possibilities of his aloneness did instantiate themselves. This was when Mr. Parker experienced a blackout in his apartment for two and a half days. A quick survey of all the equipment he relied on that used electricity will show how deeply this impacted his world. His electrically controlled hospital bed was stuck in the position it was in when the power went out, keeping him in an uncomfortable, awkward position halfway between sitting up and laying down. Furthermore, the air mattress that provided a cushion between his bony frame and the hard, thin hospital bed mattress deflated entirely, as it was also electrically controlled. The TV that was on all day wouldn't turn on, nor would the radio that was on all night. He lay there, alone, unable to move himself at all from the increasingly uncomfortable position and with no distractions from the radio or TV (nor any voices passing by outside). Ms. Ramirez and Robby both came for their normal daily visits, but other than that, he was by himself, not knowing when the power would come back on.[270]

By evoking these spans of time in which Mr. Parker's and Mr. Edwards's frequent and extended aloneness allowed for particularly painful or difficult experiences, I don't at all mean to hyperbolically suggest that these were the kinds of experiences that filled their everyday lives. This was certainly not the case. However, I do think that the possibility of experiences like these arising did at times—perhaps more often than not, perhaps only in momentary glimmers—inflect these men's experiences of their daily aloneness. In Mr. Edwards' calls out for Eli long after he had gone, in Mr. Parker's panic in discovering he was locked into his apartment, I see some underlying awareness that being alone in the physical states they were in always held the potential for further forms of suffering. It was not, then, just what happened or didn't happen when they were alone, but the always present possibility that things could go wrong, and that if they did, that it would be quite a while until anyone was there to help them. Mr. Parker and Mr. Edwards, in their aloneness, were vulnerable in a way that they wouldn't have been had someone always been nearby.

This aloneness is one of the consequences of the configuration of caregiving that these men's respectives families had come into. Next, I explore, through the narratives of Eli and Robby, the trajectories of how these two families became organized in this way around caregiving. How much did the patterns of attention explored in the previous chapter—the relative attention between parent and child during childhood, the fact of being on island of off island, and

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[270] This happened to occur during a three-day period when I didn't visit Mr. Parker. I only found out about the blackout from him, and then from Ms. Ramirez, after the fact.

the feelings of distance and closeness intertwined with both of those dynamics—play a role in their understanding of events and of their feelings about their situation?

Sole Family Member Caregiver Experiences

Eli: "I Just Stay Round He"

As described in the description of Mr. Edwards' current situation, Eli had a childhood that both breaks and aligns with normative models of Afro-Caribbean kinship. Eli's mom, Deedee was born on St. Croix, but in her mid-twenties she moved to the states, and gave birth to Eli soon after. While this is quite a normative life trajectory, bringing her infant son back to be raised my his grandparents on Croix is fairly unusual. Eli didn't meet his mom again until he was 25, which is definitely rare among children raised in St. Croix, and he never knew his dad (which, on the contrary, is quite common on St. Croix). It is quite interesting that Mr. Edwards, rather than his wife (Eli's maternal grandmother) was the figure who by all accounts in the family[271] raised all the children, as it is directly opposed to normative renderings of the matrifocal family.

Eli loved his grandfather deeply, and Mr. Edwards loved Eli. During Eli's childhood, there were three other kids in this house, his brother and two male cousins. While the other kids were allowed to leave home and go play with their friends, Mr. Edwards made Eli stay at home--if his friends wanted to see him, they had to come to his "yard". Eli laughed telling me this, as if

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[271] After Mr. Edwards passed away, his family gathered on St. Croix for several days around the time of the funeral. I was able to speak to many of them, and there was a consensus that Mr. Edwards had been both the head of the household and the person who had raised all the children who passed through.

it was a symptom of his grandfather's over-the-top affection for him, never wanting him out of his sight.

During the time that Mr. Edwards was bed-bound, this physical and emotional closeness between the two men continued. Before Eli stopped by the house that day to find his grandfather helpless on the floor, he had actually moved out of the house and was staying elsewhere on island. It was this moment of finding him alone and helpless that prompted Eli's move back into the house as soon as Mr. Edwards was released from the hospital. Eli connected the moment of finding his grandfather on the ground and what he feels is his current, persistent closeness to him, to the physical closeness the two shared when he was growing up:

Eli: I just meet he,
on the floor
so it's like wow,
so like yeah (yeah)
from then I just,
just stay round he you know?
just stay around he,
I around him all the time,
I never really, (yeah) left this house
cuz really and truly
whe'i wa younger,
grandpa boy I was daddy's boy,
((DF and Eli laugh))
couldn't go nowhere (yeah)
nowhere,

all my friends used to meet me here. (yeah,)
yeah, all my friends used to b'the yard,
can't go out, stay here.
mhm.

In this account, the physical and relational closeness Mr. Edwards and Eli experienced when Eli was growing up is reproduced, its reproduction catalyzed by a moment of being co-present with his grandfather when he was in desperate need of care.

At a certain point in our interview I asked Eli, quite indelicately, why he was the only one taking care of his grandfather. His response both refutes typical assumptions of single family member caregiving and makes a claim for the connection between responsibility for taking care of his grandfather and being physically close by.

DF: so how come you're the one
taking care of your grandfather?
Eli: why
DF: yeah aren't there lots of other people ((Eli laughing))
I'm just wondering
Eli: he has sixteen kids
DF: yeah,
so where are they?
Eli: they all over like
they li-they live in like
nobody holdin no malice
but they busy
everybody busy you know

DF: oh totally I-yeah
Eli: everybody's busy and like,
who's here gon' be here for he
ya know
DF: right,
Eli: yeah
DF: right
Eli: ain't nobody really want nothin,
don't want nothin from he just,
DF: yeah
Eli: I want him to get better,
DF: yeah

Here, Eli offers two defenses against typical readings of his situation as sole family member caregiver: that there is ill-will ("malice") between his grandfather and other family members—what was glossed my Ms. Ramirez and Coraline in the previous chapter as "issues"—or that certain family members are interested in getting an inheritance from him. While I didn't focus on this in the last chapter, there is a common understanding on St. Croix that caregiving for older relatives rightfully entails an inheritance. By following "ain't nobody really want nothing, don't want nothin from he" with " just, I want him to get better," he is also counting himself as someone who is not interested in his grandfather's inheritance: *all* he wants from him is for him to get better. It is very interesting that Eli mentions these motivations unprompted—this was the beginning of our conversation and these topics certainly had not come up. In doing so, he shows his awareness of these typified assumptions, and positions his family as an exception.

In the midst of positioning his family as one whose motivations do not fit local typifications—motivations that were part of Coraline and Ms. Ramirez's accounts—Eli also makes certain claims about what motivational factors *are* at play. He claims that the family members who are not there are "busy." Eli is directly evoking the fact that the other children that Mr. Edwards raised—other potential caregivers—have their attention on other things. In being busy with certain things, one disregards others. This disregard, is not, in Eli's picture, because of a malicious, intentional turning away, but rather because of the limits of attention: we cannot pay attention to everything at once, we must disregard some things in order to pay attention to others.

Eli locates these "busy" family members, whose attention is turned elsewhere, "all over the place." While some of Mr. Edwards's children were off-island (in the states, in Antigua, etc.), many of them were on-island. Eli does not foreground this distinction in his account, attending instead to the importance of physical co-presence. In contrast the other children Mr. Edwards raised, who are "all over the place," Eli says "who's here gon' be here for he". Here, instead of explaining his presence as his grandfather's caregiver based on their emotional closeness, he bases it solely on physical co-presence, and in so doing makes a direct connection between physical co-presence and attention, and physical distance and disregard. Whoever is "here," that is, where Mr. Edwards is, is going to "here for he," that is, is going attend to his needs and care for him. Thinking about Eli's story about finding his grandfather on the ground and staying near him ever since in light of this, Eli becomes the one who was "here," in the room with him, in a crucial moment, and so he is the one taking care of Mr. Edwards—staying near him, paying attention to him, taking care of him.

Robby: "They All Say that I'm the Only one Here with Him"

Robby provides an interesting comparison to Eli. Robby grew up in a typically matrifocal family, without his dad in his life very much. He was raised by just his mom, and grew up in a house with his half-siblings, his mom's kids from other fathers. His dad lived about 6 blocks away (in the same house he lived in when I met him, decades later). Robby is Mr. Parker's youngest son; Mr. Parker was in his late forties when Robby was born. Mr. Parker, had five other kids with at least two other women—one on St. Croix, and one on his native island of St. Kitts. As far as Robby knows, he got to spend more time together with his dad than any of Mr. Parker's other kids did. Although he didn't meet most of his other kids until later in life, Robby thinks that as far as their dad goes, he "had the most loving out of all of them." Nonetheless, it was very important to Robby in our interviews that I understand that his dad was not there for him when he was growing up:

Robby: he was not a father to me. (no?)
ya understand (okay,)
so, me and him like,
you know the kids wanna go with their dad
somewhere go out,
go to the playground
whatever the hell
no,
none of that was there for Robby okay? (mkay,)
I used to come home every day?

wash his cars[272], clean his cars, clean stuff,
wanna be around dad for that?
I get to be around him for that.
okay?

Later in the same interview, Robby again repeated that he was allowed to wash his dad's cars and wait for him to get home from work, but that was the extent of their relationship. As soon as Mr. Parker got home from work, he would clean himself up, get ready to go out for the night, and then would send Robby home to his mom's.

However, despite Robby feeling strongly that his dad was not "there" for him when he was growing up, that he did not get the kind of attention he wanted and was never allowed to be around his dad as much as he wanted, Robby is now his dad's sole family member caregiver. For Robby, this was a deliberate choice he made, in spite of the fact that Mr. Parker "was not a father to him": "now my dad, I take care'a him I do all of this I take care of him cuz I got older and wiser and realize only one person can be your father in this world." These phrases "I grew older and wiser" and "only one person can be your father in this world" were refrains throughout our conversation. It seems that the claim he is making is that he recognizes that he is not obligated,

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[272] Mr. Parker owned a couple of trucks he would use for his small delivery business. He also owned a couple of nice cars. I have never been able to figure out, given everything else I know about Mr. Parker's life (including, for instance, that he lived in a small shack for decades), how he was able to afford these cars. Everything else about his life indexes a much lower SES.

given the relationship he had with his father as a child, to take care of his dad. And yet, he has come to his own decision to do so anyway.[273]

Already then, we see that Robby's trajectory into sole family member caretaking has an interesting relationship to the local explanations I examined in the last chapter. He recognizes the typified assumption that children who do not get their father's attention when they are young are not obligated to pay attention to their father when he is older and needs care, and then explains how his choices differentiate him from that trajectory. Robby's actions also unsettle the logics of attention and physical closeness I have highlighted as undergirding Ms. Ramirez's and Coraline's narratives and Eli's explanations. Indeed, Robby had tended to his dad in various, substantial ways at a distance, as well as when the two were close together.

Robby's caretaking for Mr. Parker began when he was 21 or 22 years old, and his dad began having severe prostate trouble. For several years, Robby took care of his dad on his own. At some point during this period of time, for reasons unknown to Robby at the time, it began becoming very difficult and painful for Mr. Parker to walk. This of course added significantly to Robby's caregiving labor and ended up defining the kind of care Mr. Parker needed for the rest of his life.

Eventually, Robby was able to bring him up to Florida, where Mr. Parker's daughter lived, for "better care," including a number of appointments with specialists and various kinds of diagnostic testing. Robby sent his dad up there accompanied by a close friend, and then came to

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[273] This contrasts greatly with the way Robby talked about taking care of his mom when she got sick. He was in high school at the time, and she was having chronic health problems. In describing the three years that he and his (half) brother took care of her as teenagers, he never provided any reason why he did it, he just spoke of it as a completely normal, something he did without questioning it. He says that it was due to this experiencing taking care of his mom that he had the skills and inclination to begin taking care of his dad.

visit and check in on things the second week his dad was there. Robby stayed in Florida for a week, and then returned to St. Croix, as his half-sister was taking care of his dad and they were still waiting on a number of test results. About three weeks later, Robby was at his dad's house on St. Croix, cleaning up and making sure everything was in order, when a car pulled up with his dad in the passenger seat. Robby had had no warning that his dad was coming back to St. Croix. Apparently Mr. Parker and his daughter had gotten into an argument over money, and Mr. Parker told her to send him home.[274]

Still looking for answers as to why his dad was unable to walk properly, Robby got in touch with another of Mr. Parker's daughters, a nurse living in New York. Robby made the arrangements and was able to send his dad up there and get him into a hospital in Manhattan. There, they discovered that Mr. Parker had a pinched nerve at the top of his spinal cord, which on top of his developing rheumatoid arthritis was making walking extremely difficult and painful. After treating him, the hospital moved Mr. Parker to a rehab facility elsewhere in New York. During this time, Robby spent about a month up in New York with his half-sister, making sure his dad was getting taking care of and helping make all of the arrangements. After the rehab facility, Mr. Parker was moved to a long-term care facility (a "nursing home"), where he lived for less than a year.[275] During his time in the nursing home, his kids living in the states would visit him sometimes, Robby says, but not all that often.

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[274] As Robby tells it, she had been stealing from him, from a large stash of cash Mr. Parker had brought with him and when the money ran out she realized she couldn't get any more money from him and wanted him out. Here again, we see interfamilial financial interests having a decisive role in end of life caregiving.

[275] Robby's account is that his dad was moved there because he wasn't engaging in the rehabilitation, and so the rehab facility "got tired of trying to force him to do it." He says that his dad wouldn't do it because it was uncomfortable, and that that has a lot to do why he never regained his ability to walk and became permanently bed-bound.

After some time of his dad living in the nursing home in New York, Robby started getting calls from him, saying that they "weren't treating him right." This was 2009, and Robby attributes the change in his care to government budget cuts brought on by the global recession. Robby decided he needed to get his dad out of there, so he flew up to New York and brought him home to St. Croix. In retrospect, he doesn't see this as having been the best course of action:

Robby: he made it seem like
he was gettin' treated real bad, (yeah,)
which, I shoulda just,
talked to my sister [who lives in New York]
and get her to find out what's goin on? (yeah,)
but, I ended up buyin tickets
and goin up there
and, bringin him, back home
not thinkin about what it would be for me? (mhm,)
I-ya know it's like,
he does say that they're treatin him bad
so I decided okay
let me go for him (yeah)
he wanna come home
lemmie go for him (yeah,)
not realizin' how bad it woulda been here.

By "how bad" things would be on St. Croix, Robby is referring to how difficult it would be for him to get help taking care of his dad from governmental services. Indeed, for the next two or three years, Robby was once again taking care of his bed-bound dad all on his own. He immediately attempted to get his dad into Herbert Grigg (St. Croix's nursing home), but the length of the waiting list meant that despite years of Robby's continued attempts, his dad still hadn't gotten in. He was also, for several years, unable to get his dad help through the Department of Human Services' Homemaker Program—the Program that Ms. Ramirez worked for, and which had begun serving Mr. Parker within the year before my fieldwork. During a certain period, when Mr. Parker's bed sores got particularly severe, Robby found out about Shepherd Hospice and was able to get his dad placed in their care for a short amount of time. Sometimes, when Robby would leave island, he would train a close friend, or his half brother on his mom's side, to take care of his dad while he was away. Other than that, though, Robby took care of his dad on his own every day for years.

This kind of trajectory, in which an older parent moves stateside for care on a number of occasions and one child takes on ultimate responsibility for their care throughout, was unique among my participants. While it is common among older adults of a higher SES travel to Puerto Rico or stateside for care, for most families that I heard about this was done, if done at all, because of urgent medical necessity.[276] It is thus remarkable that Robby arranged for his dad to travel to the states several times when not medically necessary (i.e. when not referred by a physician and thus when likely not covered by insurance). It is even more remarkable that he continued assuming responsibility for his dad at this distance, especially when there were other children much closer by (in Florida, or in New York).

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[276] Among my focal participants, Mr. Parker, Ruth (Section IV), and Ms. Hanks (Section VI) had travelled stateside for care as older adults. Ruth and Ms. Hanks had done so for life-saving cancer treatment (not available anywhere in the U.S.V.I.). Ms Hanks had also once travelled stateside to obtain a surgical procedure that would avoid the need to have her legs being amputated (what doctors had told her was the only option available on-island).

In line with his unsettling of locally shared logics of attention and physical closeness, Robby harbored much anger and resentment for Mr. Parker's other children for not coming to help him care for their dad in St. Croix. That is, he did not see the distance as excusing their absence. Robby repeatedly referred to the fact that none of Mr. Parker's kids had ever come to help him, even though for years he was taking care of him all by himself, without any governmental support. Here, early in our interview, he is explaining to me how he first, as I put it "ended up taking care of his dad:"

Robby: So, after he got sick uh,
he have six kids,
I'm the only one here, (yeah)
I'm the only one with my mom and him together, (mm,)
and he is um,
they're all in the states
all a them came down when he first got sick
to make sure that everything he was not dyin, (yeah, yeah yeah)
and alla that
but then, after that,
they just disappeared
like I'm tellin em that we need help
it's only me alone
I gotta bathe him clean him,
this is before human services stepped in, (yeah, yeah)
before I got help from anyone (yeah)
it was me for years
doin alla that for myself

Then, after Mr. Parker came back from the nursing home in New York, Robby describes a similar situation:

Robby: uh after gettin' him back home here
now it's all back on me alone
uh none of the other brothers and sisters
call or help (yeah)
my one brother
he was doin, a little problem
got into a little bit of trouble
we' to jail for a few years
and now he's out, (yeah)
um, he was claimin
that when he got out
he was gonna move down here
and help me
but uh things change
he got married,
an, all that
I donno how long he been talkin to this lady but.

In this last comment, Robby shows some of his resentment about his brother choosing to stay with a woman who didn't seem to be a serious part of his life over coming to help him take care of their father. This resentment, though, characterizes his stance toward his siblings (on his dad's side) overall. At the time of our interview, he had put in so much time, energy, and hard work taking care of his dad, that he was angry and resentful that others who he felt had legitimate responsibility to help were not there helping him.

His siblings, however, at least in Robby's accounts, seemed to be emobodying the typified positions of off-island children recounted in the local accounts of single family member caregiving. Robby actively refutes the logics of their position, which gets them off the hook for caregiving based on misconceptions they have about Robby's motivations:

Robby: they all say that aw-
I'm the only one here with him
and you grew up with him
like, he wa-
like I was in the house with him
an-ya know? (yeah, yeah)
whatever he has is yours
and this and that,
that's what the other three
that lives in New York was say-sayin
when they found out he was sick
and I was like,
shit I don't really give a shit
about anything he owns
all I know is
I jus' wanna help to take care of the freakin guy (yeah)

In this account, Robby refutes the typified motivations of someone in his position as ascribed to him by his siblings. In their eyes (through his eyes), it makes sense that Robby is the only one taking care of their dad, since he is “here with him” and “grew up with him.” Here, we see the logics of proximity across the life course intertwining with on-island, off-island distinctions and with obligations to care. Within this typified understanding, that close relationship growing up also means that “whatever he has” is going to Robby when he dies. However, as noted, it’s very important to Robby that he is not taking care of his dad because of growing up with him, because he does not take himself to have grown up with him. He is also clear about not being interested in “anything he owns.” Here, we can see him contrasting his siblings’ understanding with what he takes to be the reality, when he describes their position as amounting to the claim that “I was in the house with him.” In thematizing this assumption of regular co-presence that is indexed by co-residence—an assumption that is false—Robby emphasizes the extent to which he is not obligated, by local norms of attention and obligation, to be taking care of his dad. In doing so, he also supports the local logic of the meaning of co-presence to these understood obligations for caregiving.

Eli and Robby: Some Comparisons

Much like Eli, Robby claims to be caregiving for his loved one for no other reason than he “jus’ wanna help to take care of the freakin guy.” Both men refute the idea that he is hoping for an inheritance. While Eli implicitly attributes such assumptions to anonymous others who might have grounds for believing this because Eli actually was Mr. Edwards’s favorite and did grow up in the house with him, Robby evokes this attribution as being grounded in the *false* assumption that he and his dad lived together when he as a kid.

However, while we can see in what Eli says that regular co-presence is a key decider (and not just consequence) of who is taking care of his grandfather ("who's here gon'be here for he"), Robby refutes this orientation. He is not taking care of his father because of co-presence (at any point in his life) and he resents how this logic enables his siblings, who are at a distance, to feel released from what he sees as their obligation to help him take care of their dad. On a certain level, then, Robby presents himself as in somewhat the opposite position of Eli: even though Robby feels strongly that his dad did not raise him, he has chosen to take care of him nonetheless. Furthermore, unlike Eli who brushes of the absence of other family caregivers, and takes a perspective in which anyone in his family who was in his position would be doing the same thing he is doing, Robby harbors a lot of anger toward his siblings for not coming to help him.

However, in other ways, Robby and Eli are not so different. Both are the youngest child[277] (the last child) and both admit that as children they got the most attention out of anyone from the man they are now taking care of. While, then, local logics of attention within family over the life course would identify both Robby and Eli as the most likely caregivers, neither of the men see their situation from exactly that perspective. Eli takes the view that any of his family members who were "here" would be taking care of his grandfather just as he is, and he emotionally inhabits his closeness to his grandfather as a reason it feels right and normal to be staying so close to him. Robby, on the other hand, rejects typifications of him as the one "closest" to his dad, claiming that he is taking care of him because of a decision he made to care

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[277] While this is a bit complicated in Eli's case, as Mr. Edwards raised many children of different generations. However, Eli was the "last" child that Mr. Edwards raised—as far as I know he was the youngest child in the house during his childhood, and Mr. Edwards didn't raise any more children after him.

for his one and only father, despite feeling that his father didn't care of him. He is holding up his end of the reciprocity of attention, even though he feels his dad never engaged in his end. And, because it is not "closeness" that is motivating his caregiving, he doesn't believe that the distance cited by his siblings—a distance constituted partially through knowledge of Robby's closeness—dissolves his siblings obligation to care for their father.

Conclusion

When I asked Mr. Parker why he thought it was Robby, out of all of his kids, who was taking care of him, he at first had trouble understanding my question. It was a bit of a weird question after all--I had posed it with a number of hypotheticals and counterfactuals. Then, when we started to come to an understanding, he told me that Robby has "a good heart," that he was "a nice son, nice boy." Then I asked him why he thought Robby turned out so good. "I don-I really donno, but I know one time," he said, and then told me this story. It took place probably twenty years ago. One day, Mr. Parker came home from work to find Robby sitting on his front steps. Since the two didn't live together, Mr. Parker asked him "Robby what you doin here?" Robby said "Daddy," and told him that his mommy wasn't getting any money from him, and that she hadn't bought him a uniform from school, and that he needs a new uniform because he doesn't want to go to school in his old uniform. Mr. Parker gave him $200 and told him to head up to the island's main shopping center. "And he went and he buy it, Mr. Parker continued, "what he want, and he go school and he never stop from that. So I donno if I think it's that I donno. But he does treat me real good man.” A moment of surprise face-to-face contact, closeness of distance engendering closeness of care, perhaps engendering years of devoted caregiving decades later.

This section has continued my examination of how disregard and aloneness shape the domains of aging, end-of-life, and caregiving on St. Croix through a focused look at the phenomenon of single family member caregiving. In the next section, I focus on the experience of disregard itself, exploring the experiences of one woman who only had one family member taking care of her and who felt extremely alone in the final weeks of her life.

Section VI

Experiencing Disregard

Prologue

"My family is cooking and they're not bringing me any food." This was a refrain that Ms. Hanks came back to during the last three and a half weeks of life in the hospital. Sometimes she would say it word for word, other times she would speak around it, evoking its themes of exclusion, hunger, and unfulfilled reciprocity. It was her ex-husband and primary caregiver, Vincent, as well as the several grown children she had living on-island, who were the subject of this claim. Ms. Hanks's positioning of herself as excluded from the circle of those for whom food was being prepared[278] shows the extent to which she felt excluded from family life and uncared for in her final weeks by those she had spent her entire adult life taking care of.

This section presents a case study of the particular ways in which the experience of disregard was constituted for Ms. Hanks in the final weeks of her life. It thus offers a person-centered, aspectual consideration of experiencing disregard. It contributes to the aims of this dissertation by considering the workings of attention and disregard on the scale of Ms. Hanks's life course, and showing how these workings disclosed themselves through experiential registers in the final weeks of her life. By investigating the ways through which the absence of food prepared by her family was pulling Ms. Hanks's attention in these final weeks—how her

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[278] Van Esterik (2015) has called this the "commensal circle." Grignon (2001, in Tan 2015), has suggested a taxonomy that divides commensality into domestic, kin and communal, ceremonial and religious, and political types. While classic approaches to commensality (i.e. Douglas 1966, Durkheim 1981 [1894], Levi-Strauss 1963, Mauss 1954, Sahlins 1972, Smith 1889 [1957]) focused largely on the functions of what Grignon (2001) would call "ceremonial and religious"—and sometimes also "political"—commensality, in this section I explore Ms. Hanks's experiences of domestic commensality: the everyday sharing of food that occurs between members of a household.

attention was continually pulled by a particular forms of disregard—it also contributes to the exploration of the workings of attention and disregard for older adults at the end of life.

While it has been well established within social scientific approaches to commensality that eating together creates social bonds, feelings of togetherness, and group identity (Carsten 1995; Coleman 2011; Durkheim 1982[1884]; Garth 2013; Fajans 1988; Kerner and Chou 2015; Mauss 1954; Smith 1957[1889]; Tan 2015; c.f. Appadurai 1981) this section investigates how the particularities of one woman's mutli-faceted relationship to sharing food with her family shaped her experience at the end of life. Sociocultural standards of Afro-Caribbean womanhood and motherhood made likely the possibility that cooking for her family was to play a central role in Ms. Hanks's life. However it is how Ms. Hanks made meaning out of this practice, as situated in her particular experiences throughout her life course, that informs how she experienced disregard at the end of her life.

In Chapter 13, I investigate why, for Ms. Hanks, not having her family prepare food for her during her final weeks of life in the hospital became a focal orientation for her experience. After presenting a biographical sketch of Ms. Hanks, I trace some of her memories of caring and being cared for through shared food along her life course, as a daughter, mother, and wife, examining how both her adult identity and her close relationships were forged through cooking. I also discuss the role that sharing food was playing in her life during the research period, when she was largely bed-bound and unable to cook for herself. I show how Ms. Hanks saw the faults and deficiencies in her caretaker and ex-husband Vincent's provision of food as directly thwarting her hopes for recovery, and how malnutrition at times acutely threatened Ms. Hanks's health. Here, we see how her culturally shaped orientations to what foods were healthy were interwoven with her personal memories of sharing food and her embodied feelings of illness, all of which were playing a role in Ms. Hanks's mooded experiences of her own health, her relationship with her family, and her possibilities for her future.

In Chapter 14, I trace this nexus of experience into the three and a half weeks Ms. Hanks spent in the hospital before she passed away. During this period of time, in her repeated assertions that her family was cooking but not bringing her any food, in her talk of memories of cooking for her family when they were in need, and in her refusal to eat hospital food, it became clear that Ms. Hanks was feeling deeply disregarded. Through analyses of moments of time that we spent together, I discuss how her experience of disregard during this time was constituted through embodied, material, mooded and sensory modes. And, I discuss how this experience of disregard is put sharply into relief through by the dramatic changes that occured in Ms. Hanks's mood, energy, and way of being during one visit in which she and I shared a piece of fruit.

This section thus traces how a particular form of care and attention sedimented meaningfully for Ms. Hanks along her life course, how the absence of that form of care and attention created an experience of disregard near the end of her life, and how that experiences of disregard was constituted when she was in her final weeks of life.

Chapter 13

Care, Food, and Attention over the Life Course

I sat next to Ms. Hanks in her hospital room, slicing off pieces of a pear with a plastic knife. One for her, one for me. One for her, one for me. Ms. Hanks had been in the hospital for over a week, and had hardly been eating at all. During my last visit a few days earlier, she had asked if I might be able to bring a pear and some plums with me next time I came. Luckily, I was able to find the kind she wanted at the grocery store. I normally wouldn't have eaten any of the food she had specifically asked for, especially since she was so sick and had been eating so little. But she had asked me to share something with her. I had been holding a styrofoam cup full of juice for her (her hands were too weak and shaky to hold it herself). She paused her sipping out of the straw:

Ms. Hanks: have a plum or something!
DF: no no, I got 'em for you
it's okay
Ms. Hanks: well just share one
DF: okay
Ms. Hanks: share something with me
DF: okay, I will
what will I have, umm

I decided on a pear. Ms. Hanks's ill-fitting dentures, along with her general weakness, made the pear a little hard for her to chew, so I cut small pieces. It was just soft enough that she could eat it. As we sat there, eating this pear, I felt Ms. Hanks' mood change significantly. Normally very tired and uncomfortable, she suddenly became buoyant, even a bit giddy. We talked about how delicious the pear was and she gave a moan of pleasure every time she put a new piece in her mouth. I could feel how happy she was.

During a brief interruption when Ms. Hanks's caseworker and her hospital nurse came in to talk to her, her good mood and elevated energy showed. After they left, we continued working on the pear. I handed Ms. Hanks a piece, and she moved it around in her mouth for a while, savoring the flavor while breaking the flesh up enough so that she could swallow it. After about half a minute, Ms. Hanks asked me a question:

Ms. Hanks: are we eating this fruit?
DF: what do you mean?
Ms. Hanks: are we sharing?
DF: mhm!
Ms. Hanks: great.
((DF laughs))
DF: I'm cutting off
a piece for you
and a piece for me
Ms. Hanks: mhm
I'm enjoying this

A little while later, after we had finished the pear and she had told me a few stories, it was time for me to go. As I was getting up to leave, Ms. Hanks told me that she was happy (my utterances in parentheses): "I am-bum so happy I've got good nurses, good friends (mhm), and a good case worker. (mhm) It's just, things seem to be coming together." It was an unprecedented moment of hope and comfort during what had been a long stretch of illness, weakness, and decline.

How did we get to this moment? Why was sharing a pear with me in her hospital room an even that so elevated Ms. Hanks's experience? In this chapter, I explore the constitution of sharing food as a focal experience of caregiving and being cared for throughout Ms. Hanks's life course. Commensality is known, across human societies, to create interpersonal bonds and shared identities (Carsten 1995; Coleman 2011; Fajans 1988; Kerner and Chou 2015). It is thus a sociocultural practice that is open and available to being interpreted and experienced within individual lives as a site for care, togetherness, and love.[279] Here I focus on how preparing food

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[279] Despite this connection, care is not a prominent concept within the commensality literature. Indeed, major reviews on the topic to not mention "care" at all (see Dirks and Hunter 2012; Messer 1984; Mintz and Du Bois 2002; Sutton 2010). The single exception is found in Messer's (1984) discussion of obesity in her Annual Review on the Anthropology of Diet. There, she notes that in certain communities being obese can be interpreted as being "well loved and well cared for," as it is perhaps linked to "warm emotional bonds traditionally associated with feeding" (Messer 1984: 210). This is the sole mention of the word, and the author does not discuss any further why appearing as if you have eaten a lot could be interpreted as being well cared for—that is, she does not make the connection between commensality and care explicit.

Occasionally, ethnographers working in professional caretaking contexts discuss food preparation and commensality as integral to the work of caregivers (see Buch 2010, 2013; Mol 2010). For instance, Buch (2010, 2013) discusses how a significant part of the job of many homecare workers in Chicago is creating comfortable mealtimes for their clients, which often, in addition to the time and labor invested in making sure the client's particular desires are attended to, includes bringing food from home or purchasing it at the restaurant (out of pocket) so that the two can eat together. Similarly taking mealtimes as a focal site for investigating the complexities of care work, Annemarie Mol (2010) discusses how feeding in a Dutch nursing home presents a site for seeing how different goods associated with what she calls "nourishing care," (e.g. "cosiness," nutrition, dignity, choice) are in tension in the context of the institutional care setting. Important as these analyses are, these discussions do not engage with theories of commensality and so it is difficult to know how caregiving in these setting, particularly caregiving through feeding, may be related to—or put into question, or expand, or critique— the established social functions of commensality.

for others and having food prepared for her was thematized as a site of care in Ms. Hanks's memory near the end of her life.

I am here presenting the ways in which memories of care were constituted in Ms. Hanks's experience in order to lay the groundwork for explaining how experiences of disregard were constituted for her in the final weeks of her life. During this time, feelings of abandonment, shaped by senses of unfulfilled reciprocity—aspects of disregard—were foregrounded in Ms. Hanks's experience. That the phenomena of a lack of sharing food with her family became the focal vehicle through which Ms. Hanks felt disregarded emerges out of a life history through which she came to feel cared for, and that she was providing care, through sharing prepared food. This chapter is presents a biography of Ms. Hanks, followed by an account of some of her memories of sharing food throughout her life course, as a daughter, mother, and wife. In demonstrating how Ms. Hanks felt the giving and receiving of care throughout her life, this chapter sets up a discussion of how she came to experience disregard when her life was coming to an end.

Ms. Hanks: A Biographical Sketch

Ms. Hanks was born in 1951, turning 64 soon after I met her in the fall of 2015.[280] She was born in Trinidad, and was ethnically Afro-Caribbean. When I met her, sickness had rendered

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[280] Ms. Hanks was the youngest focal participant in my study, and was initially outside my intended age-range (65+). However, her life circumstances when we met—including her medical fragility, prognosis, level of disability and life stage (she was a great-grandmother)—were extremely similar to her older peers, making her an appropriate participant despite her younger age.

her extremely skinny[281], with dark skin, a large puff of black hair growing grey at the tips, and dark, serious eyes. Pictures of her when she was younger showed a robust, slightly chubby woman; she looked so different now that it was hard to believe she was the same person as the woman in the photographs.

Ms. Hanks had come to St. Croix as an older teenager, around 1970.[282] At the time, she had an infant son. The baby's father, Vincent Hanks, had recently moved from Trinidad to St. Croix. Also ethnically Afro-Caribbean, Vincent was in his early twenties at the time he migrated, several years older than Ms. Hanks. While both his ensuing life course, particularly his subsequent employment at the two largest companies then operating on St. Croix (Hess, the oil refinery, and Harvey, the aluminum plant), and the period during which he migrated suggest that he came in search of more lucrative employment possibilities than were available to him in Trinidad, his explanation in an interview of why he came was somewhat more in the spirit of exploration: "I donno," he said, "just to, ya know, come up here. I didn't know that much about St. Croix."

As was common during that period for couples migrating from the Eastern Caribbean, Vincent migrated first, established residency, and then "sent for" Ms. Hanks, who then migrated with their young son.[283] After she arrived, the two got married (at which point she took Vincent's

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[281] Ms. Hanks's own reports to me establish her heaviest during this period as being 85 pounds. However, that was after she reported having just gained 7 pounds, placing her at around 78 pounds when I first met her. I do not know Ms. Hanks's height, and it is hard for me to estimate as I never saw her standing up. However, she was not short. My estimate would be that she was between 5'4" and 5'7".

[282] I was never able to establish a firm date of migration from either Ms. Hanks or Vincent. However, other dates in their biography establish that Vincent moved to St. Croix some time in the late 1960s, and Ms. Hanks not very long after. She certainly had moved to St. Croix before the two got married, in 1971.

[283] As I discussed in Chapter 4, their residency and subsequent citizenship was likely enabled by the H-2 and H-4 visa programs.

last name and became “Ms. Hanks”). While Ms. Hanks never spoke of this aspect of their marriage, Mr. Hanks told me that they had gotten married so that Ms. Hanks could “get her papers,” i.e. become an American citizen and continue living in St. Croix permanently. This kind of marriage—partially built on intimacy and familiarity, but also done for reasons of securing citizenship and the ability to live and work in the United States, as well as have children who would be American citizens themselves, was very common among this generation of immigrants to St. Croix.

Mr. and Ms. Hanks had seven children together in total (a number well within the normal range of Afro-Caribbean families during that time) and then eventually divorced, in the mid-1990s.[284] Ms. Hanks spent most of her adult life at home raising children, and then for a time had also worked at the drug rehabilitation center on island as an administrator of some kind. When I met Ms. Hanks, all seven children were alive and grown, and she had seven grandchildren[285] (most of whom were grown, or at least adolescents) and two great-grandchildren (who were still young children). She was living in a neighborhood of small, track-houses whose construction had been subsidized by the government in order to provide housing for migrant workers of the aluminum plant and their families (see figure A). Indeed, it was Vincent’s job at that aluminum plant that had enabled him to secure three of the houses for his family in the mid-1990s. Up on a hill overlooking the now defunct aluminum plant, and the vast blue sea beyond it, this planned community had a reputation on-island for being a “bad”

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[284] Ms. Hanks told me that they separated in 1996 and got divorced in 1997. Vincent told me they got divorced in 1996.

[285] One of her grandchildren she and Vincent had raised until the age of 4, when their daughter (his mother) took him back to continue raising him in Florida.

neighborhood where shootings were known to be common (Vincent confirmed that he often heard gunshots just outside) and drug deals supposedly rampant.[286]

Figure H: Ms. Hanks's neighborhood. In the background in the far right, you can see the towers of the defunct aluminum plant whose employees these homes were originally meant to house.

Ms. Hanks lived in the single story three-bedroom, one-bathroom house with her developmentally disabled daughter, Cynthia, who was in her early forties, and one of her sons, Shawn, who was in his mid-to-late twenties. Cynthia was unable to complete basic everyday activities on her own (such as eating, bathing, and getting dressed), and thus needed semi-continual care and of supervision. With Ms. Hanks as immobile, sick, and weak as she was (see

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[286] Her neighborhood had a reputation similar to that of many inner city housing "projects" in the mainland U.S.

discussion to follow), Vincent was Cynthia's only caregiver and much of his day every day was spent caring for her.As for Shawn, the other one of Ms. Hanks's children living in the house with her, he was so rarely home and had such little involvement in family life that—despite my efforts to learn everything I could about the household—it wasn't until after Ms. Hanks died that I learned that he had been living with her. I had assumed that the bedroom, which actually belonged to her son, was Vincent's, as he was at the house nearly every time I visited. In reality, Vincent lived a two-minute walk down the road, in the same patch of track-style homes, with one of the couple's daughters, Candy. A two-minute walk in the other direction, in the same housing area, lived another one of the their daughters, Julia, her daughter, and her daughter's son who was a little over one year old.

Despite the geographical proximity of her daughters, they rarely, if ever, came to visit.[287] Ms. Hanks did not maintain good relationships with most of her family.[288] She and Vincent fought often, and it seems to have always been that way. She also got into arguments often with her children who lived on-island, particularly her two daughters who lived down the street. In certain moods, she would speak in mean, nasty terms about these daughters. In other moods, she would be sad and despondent that she didn't get along with her children better and that everything was such a mess between them.[289] From my observations and Ms. Hanks's reports,

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[287] This is an interesting state of affairs to consider in light of the local logics of proximity and caregiving discussed in the previous section.

[288] Her nineteen year-old granddaughter, who lived with Ms. Hanks;s daughter Julia down the road, was an exception. Ms. Hanks felt that she was one of the only people in her family that truly loved her and that she could truly trust.

[289] Her relationships with her sons, and with the daughter that lived in the states, were more up and down, and her difficulties with them seemed to be based more on particular incidents that would occur, rather than an overall poor relationship. That being said, she was not close to any of her children, and was actively antagonistic toward the two who were the most geographically close.

none of her children contributed to her care when she was at home. The tension and acrimony in the mother-daughter relationships was clear when Vincent told me, when I was visiting the house a couple of days after Ms. Hanks died and expecting to find her daughters there gathered there: "no no," he said, "they don't come to this house."

Ms. Hanks was the only focal participant in my study who was (known to be) HIV-positive, having gotten infected in the mid-1990s. None of her children, nor Vincent, were infected, and indeed Vincent did not know that Ms. Hanks was HIV positive until just a few years before I came on the scene, having been told by his children. While Ms. Hanks's medical records from different facilities were not in concordance about how she came into contact with the virus, my tracing of these records and my knowledge of her life story lead me to believe that she was infected with the virus through heterosexual sex.[290] Now, twenty years later, she had AIDS.

Because of her extremely low household income, Ms. Hanks was eligible for and had been receiving antiretroviral medications (ARVs), other medical support, and case management services at no cost through the Ryan White Prevention and Clinical Services Division of the Frederiksted Healthcare Center (FHC, discussed in Chapter 6). The Ryan White HIV/AIDS Program is a federal, nation-wide program originally created in 1990 to fund prevention and treatment of HIV/AIDS through cities, states, and nonprofit entities nationwide (U.S. Health

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[290] In Ms. Hanks's timeline, as related to me by her on different occasions, she separated from Vincent and moved into her current house the same year, 1996, which is also about the same time that she often said she had stopped being able to walk. This is also right around the time she acquired HIV, from a sexual partner other than Vincent. While it is interesting to think how these three events may be related to each other, I unfortunately don't have any data that speak to how they might be.

Resources and Services Administration 2016).[291] Ms. Hanks's Ryan White Program case manager visited her home often. She managed Ms. Hanks's prescriptions, delivering them to the house in person, managed her doctor and other healthcare (such as dentist) appointments including any needed follow-up, and kept her supplied with a large collection of books on tape that she picked up and then returned to the library for the blind.[292] Ms. Hanks loved books on tape, and played them loudly throughout much of the day from a large, colorful player with oversized buttons. Her favorites were *Charlotte's Web* and *The Lion, the Witch and the Wardrobe* (both of which she refused to return to the library). Many days when I would step into the doorway of her bedroom after having been greeted at the front door by Vincent, a pleasant female voice would be blaring from the player, saying something about Aslan the lion, and I would have to ask to shut it off before I started recording our conversation (she never seemed to mind).

Besides the HIV medication and related care that Ms. Hanks received through the Ryan white program, her other medical needs were covered by the Medical Assistance Program (MAP), the territory's version of state Medicaid (see Chapter 6). Ms. Hanks needed access to concentrated oxygen at home, for example, and MAP covered those costs.[293] MAP also covered

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[291] FHC had begun receiving funding from this program in 1999, a few years after Ms. Hanks was infected.

[292] While these were certainly only some of the tasks that her case worker was responsible for, they were those that were most visible to me and seemed the most consistent throughout the several months that I knew Ms. Hanks. As is the nature of case work, it is likely that in the past her caseworker had helped manage other issues that arose in Ms. Hanks's life affecting her wellbeing and that she kept tabs on an ongoing basis on issues that might at some point need her attention.

[293] This is in contrast to Ruth (Section IV), whose income and financial assets, while they were sparse, had still been too significant for her to qualify for MAP when she applied before the research period. Given MAP's expansion (the local version of Medicaid expansion made possible by the Affordable Care Act, discussed in Chapter 6) to cover single adults with higher levels of income than previously possible before the new law, it's possible that Ruth had actually become eligible for MAP after she had first applied and been deemed ineligible.

her doctors' appointments at the Frederiksted Healthcare Center. She received "food stamps" (officially known simply as "benefits") every month through the federally funded and locally run Supplemental Nutrition Assistance Program (SNAP), and her rent was subsidized by the government. Ms. Hanks was too young to receive Social Security[294], and as best I could tell did not have any income at all. Vincent, however, was receiving a monthly social security check in the amount of approximately $800, and these funds indirectly supported Ms. Hanks. Ms. Hanks was thus fully dependent on federally-funded medical and social services programs for her survival.

I met Ms. Hanks through my fieldwork with Shepherd Hospice. She had been referred to hospice care by her caseworker at the Ryan White Program. It was clear that she was referred to Shepherd Hospice because of the all of the 'extra' medical support hospice provided—daily CNA visits, weekly nursing visits, fully subsidized prescriptions, etc. This support that would, in addition to providing Ms. Hanks with more frequent and intensive (although only palliative) medical attention, relieve the other entities supporting Ms. Hanks of most of the costs associated with her care. What was not clear, however, was whether or not her caseworker referred Ms. Hanks to hospice because she believed that Ms. Hanks was in fact in her final months of life.[295] Whichever the case may be, it was clear upon my initial visit with Ms. Hanks at her home,

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[294] It was unclear to me, given my spotty knowledge of Ms. Hanks' employment history, whether she would have become eligible for the program when she turned 65. American citizens 65 years of age or older who have worked and filed income tax for 40 quarters (10 years) are eligible for Social Security. This was the main source of income for many of my focal participants, as well as many patients whose care I became familiar with but who did not participate in my study.

[295] Given my observations of healthcare and social services workers on island in a variety of settings, I believe it's plausible that her caseworker was unaware of federal hospice regulations specifying as eligible only patients with a certified prognosis of six months or less.

(shadowing Karen[296], one of Shepherd Hospice's RNs) that Ms. Hanks did not believe herself to be in the final months of her life. Upon Karen's repeated mentions of "end of life care," Ms. Hanks explicitly disputed that she was near the end of her life. She stated that she planned on living for quite a while still, and that what we didn't understand was that "this" (as in, her severe illness and disability) had been going on for twenty years already. (I came to learn that this was her typical estimate of both how long she hadn't been able to walk, and how long she had been infection with HIV.) Despite Karen's attempts to convince Ms. Hanks that hospice could help her, Ms. Hanks refused to sign on for Shepherd's care. This was the only time, out of all of my home visits to potential hospice patients and their families on St. Croix, that anyone refused hospice care.

After that first visit, I continued to visit Ms. Hanks in her home, and during her frequent trips to the hospital. As I got to know her better, I learned that the way she stood up for herself to Karen, flying in the face of the norms I had otherwise witnessed for patients referred to hospice, was just one display of how tough, resilient, and independent Ms. Hanks was. She was, it turned out, a rather fierce woman. She always spoke with great intensity in her voice (even when it was very quiet due to her physical weakness), as if every story she told me about her life was a mythic, epic tale whose twists and turns unfolded on a grand scale. Her stories were often filled with violence within her family: physical violence— such as people getting beaten up and pulling knives on each other—and also emotional violence, with hearts being broken, love being stolen, people deeply betraying one another and intentionally deceiving one another, and all sorts

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[296] Karen was a white stateside nurse in her early sixties. During the time of my fieldwork, she and her husband were living part of the year on St. Croix, part of the year in the states (the residential pattern of "snowbirds").

of other interpersonal cruelties. In these stories, Ms. Hanks was often the victim who found a way to gather her strength and carry on in the face of the otherwise unendurable. Other times, she was the one righteously threatening or perpetrating violence on someone (usually in her family) who had wronged her. In this locally exceptional mode of storytelling, it was always difficult for me to tell how much was dramatic performance of otherwise mundane, everyday human activities, and how much of her life had truly been as dramatic and violent as it was represented in her stories. Certainly, the life she portrayed was one of much suffering.

As I got to know Ms. Hanks, I learned how deeply the last two decades of her life had been defined by ill-health. As I've mentioned already, Ms. Hanks hadn't been able to walk well or reliably for about the past twenty years. This was due to pain and other difficulties with her hip, which she had surgery on in in an attempt to correct the problem. The surgery, which occurred either in 2008 or 2012 (Ms. Hanks told me both dates at different times) left her in intense pain.[297] During this period she also had femoral bypass surgery at a stateside facility, after having been told by her doctors on St. Croix that they needed to amputate her legs. While I can't be sure, the fact that both of these procedures were offered for her condition suggest that she had Peripheral Artery Disease, a syndrome that can cause great pain in the legs and that has been found to be more common among HIV-positive patients with low CD4 (T-cell) counts , especially those who have other cardiovascular risk factors (Freiberg et al. 2017), such as being a smoker (which Ms. Hanks was). She had also, during this period, been diagnosed with lung cancer, and had spent some time in Florida getting treatment, apparently making a full recovery.

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[297] It is possible that she actually had two surgeries on her hip, one in 2008 and one in 2012. Ms. Hanks indicated that she had been more severely disabled for the past 3-4 years, which, in 2016, could have been since a surgery in 2012. Either way, neither a surgery in 2008 nor in 2012 was successful in alleviating her pain in any long-term way.

By the time I met her, Ms. Hanks was in pain every day, and her ailments were many: she couldn't sleep more than a few hours each night, her knee hurt intensely almost all the time, she had a persistent, severe cough, and she was extremely skinny and frail.

While her frailty and persistent cough was very likely due to AIDS, it was her knee pain that bothered her the most, and that she saw as her main problem. Because of whatever had happened during her hip surgery years ago, the doctors she had consulted told her that she now needed to have knee surgery to correct her incessant pain. However, she would not be permitted to have surgery until she gained weight, something her body seemed simply unable to do (likely due to complications of AIDS). The troubles with her hip and the pain in her knee, along with her extreme weakness, made her entirely bedbound. There were large canisters of oxygen and a commode next to her bed, with a walker in between so she could lift herself onto it when she needed to use the bathroom. Her main goal throughout the months I knew her was to gain enough weight to have the surgery on her knee. Once she had the surgery and was able to walk again, she was sure she would be back to her normal self.

Feeding Ms. Hanks

It was up to Vincent to prepare food for Ms. Hanks everyday, as she could not make it to the kitchen, let alone stand long enough to cook. However, her relationship to Vincent's provision of food for her was extremely fraught. This was due primarily to two things: first, she felt that he took advantage of the fact that she couldn't go to the grocery store, buying whatever he wanted to eat with her food stamps, instead of buying the groceries she had asked for, components of meals that she wanted to eat to help her get stronger. Secondly, she felt that he never cooked the right things for her to eat. She said he always cooked chicken and rice over and over again[298], never cooking any greens[299] (one of the foods she often evoked as being crucial to her health), any beans, or any other meats. This repetition of this same basic meal both dulled her appetite and did not, she thought, provide the kind of nutrition she needed to gain weight, get stronger, and become eligible for knee surgery.

Ms. Hanks's feeling that Vincent was consistently not preparing her the right kind of food occasionally took an acute turn. Twice, in early 2016, she was hospitalized with symptoms that were likely connected to not eating enough food. The first time, after trying unsuccessfully to visit her at her house, I found her in the hospital's Emergency Department. At the house, Vincent had told me that the ambulance had taken her because her blood pressure had been up over 200 (systolic).[300] When I arrived at the ED, Ms. Hanks was in the initial stages of being treated for dehydration that was causing her extremely high blood pressure. As the nurses and aides struggled for several minutes to "get a stick" (put a needle) in her vein—a procedure already difficult because of her very low body weight, and now made more difficult by her dehydration—Ms. Hanks was very weak. She was having a hard time gathering enough energy to speak, and when she tried, her mouth was very dry. She lay on the hospital bed with her eyes closed most of

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[298] I noticed throughout my time on St. Croix that "chicken and rice," in addition to being a very common staple meal, is also is a local idiom for indicating the most minimal of meals, somewhat akin to what "bread and water" signifies to some communities stateside (although not as severe).

[299] Interestingly, although forms of cooked greens are a staple in many Caribbean and American Southern cuisines, they are not a part of Crucian cooking. This may be due to the strong Puerto Rican influence on the island's cuisine. However, they are an important part of Trinidadian cuisine.

[300] This is dangerously high. It means that Ms. Hanks was experiencing a "hypertensive crisis" which can require emergency treatment.

the time. Her skin was visibly ashy. Once the intravenous (I.V.) line was established (but still several minutes before it was actually connected to any fluids), Ms. Hanks told one of the aides that she was hungry, and asked if she could have something to eat. The aide said she would check with the doctor if she was allowed to eat right now—what I came to learn was standard response in this ED, as the aide wasn't sure if there was a chance Ms. Hanks would need to undergo any procedures that required fasting. When I left some time later, Ms. Hanks was resting comfortably. While she hadn't yet had anything to eat, the saline drip was rehydrating her. The large blood pressure monitor next to her bed showed that, even though it was dropping, her blood pressure was still 186/121, a reading still within the range of "hypertensive crisis." She stayed in the hospital for five days before being discharged.

Two weeks later, I again attempted to visit Ms. Hanks at her home. When nobody was there, I tried the hospital, and found that she had already been admitted for several days. This time, she had been brought to the ED because she had fainted. While the doctor assigned to her case thought it might have been due to a stroke, tests showed no sign of one. The reason for her fainting was thus left undiscovered, however given her previous hospitalization, I think there is a reasonable chance that it was related to not having had enough to eat. What role Vincent had in this and what role Ms. Hanks herself had in it was unclear.

These events, alongside an understanding of her perspective on Vincent's food provision, help to show that prepared, shared food—including its perceived insufficiency, poor quality, or absence—was an important site through which Ms. Hanks both related to the social world and through which her wellbeing and life chances were shaped during the time that I came to know her.

A Life of Sharing and Preparing Food

I have gestured toward different aspects of how food prepared by her family (in particular, by Vincent) was playing a role in Ms. Hanks's life during the period of my research. There was the connection between her incessant knee pain, the her desire to gain weight, and the hope of lasting recovery. There were strong feelings that Vincent's provision of food for her, including his refusal to purchase and the prepare certain ingredients at the store was holding her back, keeping her immobile and in pain every day. And there was the fact that, some times at least, not eating enough was causing her to undergo acute health crises. These different aspects show the intermingling of biological, cultural and personal components of Ms. Hanks's relationship with prepared, shared food during this time of her life.

I would suggest that what might be categorizable as separate from an outsider's perspective were in large part co-constituting in Ms. Hanks's experience. For instance, one component of her experience was her culturally shaped sense of what foods were healthy and unhealthy (such as greens), and thus what foods would help build up her body's strength. This was surely linked to the embodied sensations of eating food that did not feel strengthening to her (such as chicken and rice). Furthermore, the displeasure with the food she was being served was surely also linked to other embodied sensations, perhaps of weakness, or of the other sensory qualities (olfactory, gustatory, etc.) of being presented repeatedly with food that one is not interested in eating. Her experience of her enduring knee pain would also, I suspect, be constituted partially through her feeling that her continued state of discomfort was due largely to not being provided with what she considered healthy foods over a span of time. This network of co-constituting experiences (which I have only begun to explore here) was, I suggest, inflected through, and cannot be considered apart from, Ms. Hanks's personal memories, and embodied sedimentation of meaning through which sharing food became a particularly potent site of caregiving. In what follows, I discuss how this process of meaning-making disclosed itself in her memories of preparing food and having food prepared for her at different moments along her life course.

Being a Mother, Preparing Food

It is incredible how frequently preparing food for others appears in Ms. Hanks's stories, recorded on our visits in her bedroom at home. Often, in Ms. Hanks's particular way of telling stories, she would juxtapose memories whose place in time wouldn't be made clear alongside commentary about her present life. Hers was a biography permeated with cooking, and she was attuned to the practice of preparing food for others as a significant part of what made up life in common. Ms. Hanks's gender, her status as a mother, and her cultural milieu made it a likelihood that cooking would be a large part of her life, and many Afro-Caribbean women I spent time with on St. Croix did seem to orient to cooking as a crucial component of social life.[301] However, the

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[301] As Holtzman (2006) notes in his review of food and memory, "a wide body of literature emphasizes memory structured through what is construed as women's special relationship to food" (Holtzman 2006: 370). This suggests the likely importance of food preparation to many women's biographies and to their orientations to their lives, as I have suggested was the case for Ms. Hanks. See Garth (2014) for an ethnographic engagement with this topic in the life of one Cuban woman.

way that Ms. Hanks interweaved cooking throughout her narratives, and the way she used it to orient to her life in the present, was particular to her.

Ms. Hanks's stories were often set during the time when at least some of her seven children were still kids, during the many years when she was a full time stay at home mom. It was a period of life that pulled her attention. Some of these stories were joyful and nostalgic, while others were focused on the difficulties and continuous burden of raising so many children with (as she recounts it) hardly any help from their father (Vincent). In many of these stories, cooking played a part, showing up either as something she loved to do, or as a symbol of the exhaustion and relentless hard work of caregiving. For example, in one story that was set in in an era of her life that she often expressed nostalgia for, when the family lived in a house in a different area of the island, she and the kids would walk to the beach and spend the whole day at the ocean. Ms. Hanks absolutely loved the beach, and until she died loved being there more than anywhere else. She mentioned, as part of the joy that infused this era, that she "was always cooking in those days." She also told me a story that took place later on in her life, when all seven kids were born. She was working by this time, and so, she told me, didn't have time to cook for the kids. To make up for it, sometimes she would take a whole week off of work to cook for them and play with them. During this week, each of her seven kids would get one day where they would get to pick what she would cook, and she would cook exactly what they wanted. She presented this like a fun, special game, one that brought joy to her and her kids.

In other stories that took place when she was raising her kids, cooking was a relentless burden. For example, she told me once that she herself never used to have parties, but that her husband or kids would just tell her that they were having a party. This announcement meant that she would have to "cook and cook," without even being asked or thanked, while they enjoyed the party. In stories like that one, it was clear that she felt like her family took her for granted, not caring at all how much work it took to cook for seven children and two adults (not to mention a whole party), and what toll that work must have taken on her over the years.

A Sense of Self

Despite the range of tones that Ms. Hanks's stories about cooking for her family took, together they show how integral cooking was to her experiences of being a mother and primary caregiver of her children. She had spent a lot of her life cooking for her family, it was a practice that much of her attention had been devoted to over the years, something like a proxy through which she attended to her family. Cooking anchored many of her memories (see Holtzman 2006), reappearing in different forms depending on her mood and on the kind of story she was telling me. Through these kinds of stories, it became clear to me how much cooking was a part of Ms. Hanks's identity—not just something she had to do because of her position as a mother, but something she felt was a substantial component of who she was. This was the case despite the fact that by the time I met her she hadn't been well enough to cook for many years.

That cooking was integral to Ms. Hanks's adult identity was confirmed to me on a few occasions when Ms. Hanks would speak about cooking as being an integral part of her normal, everyday life. For example, on one of her many trips to the hospital, I was visiting Ms. Hanks when her attending doctor came in for her daily check-up. The doctor asked her how she was doing, and Ms. Hanks said she wasn't feeling like her regular self. The doctor then asked in what way she wasn't feeling like herself. Ms. Hanks responded (doctor's utterances in parentheses): "um, my regular self is just to run around and take control'a things (yeah), and just carry on. Cook and just...(mhm) Be me." In the subsequent few moments of talk, Ms. Hanks informed the doctor, in response to her questioning, that she hadn't been able to walk in about twenty years—a testament to how enduring her sense of self as someone who cooks was.

Being a Daughter, Feeling Cared for

In addition to cooking for those she cared for being an integral part of Ms. Hanks's life and identity as a mother, being cooked *for* strongly shaped Ms. Hanks memories of her own childhood. Ms. Hanks's parents separated when she was fairly young, at which point Ms. Hanks went with some of her siblings to live with their father.[302] Whenever Ms. Hanks spoke of her father a noticeable shift would occur in her voice: it would become warmer, softer. It was full of love. Despite Ms. Hanks's tendency for harsh words, I never heard her utter a single word against her father (who had died some years ago[303]). Her refrain, whenever she spoke about him was: "he was the very best of fathers." Often, this phrase would be surrounded by an account of how he would always cook for her and her siblings. For example, during one of our usual visits in her bedroom, Ms. Hanks had just been telling me about Vincent' ineptitude (and general

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[302] This is a non-normative family arrangement. As far as I could tell, and according to local ideologies of family and kinship (see Section V) it was very rare for a father to raise his kids on his own in St. Croix.

[303] According to Ms. Hanks, her father had died of a broken heart, although "they like to pin it up on cancer."

absence) as a father, forcing her to be their children's mother and father. She then began speaking about her own father:

> **Ms. Hanks**: My father was (?) father.
> The best father I've ever met.
> He was the best man I ever met,
> my father.
> He washed our clothes,
> he cooked our food,
> he sent us to school every day.
> Our mother didn't do that.
> Did not do that. (sigh)
> Left to my mother
> we would have never
> seen the door to school.
> My father believed in education. (?)
> Especially his daughters.
> And he believed in me (?).
> He went work for six in the morning
> you know (mm) yeah,
> but he still went to work.
> He made our breakfast and lunch.
> So we went to school with our lunch
> and we had our breakfast.

Here, the love and admiration Ms. Hanks has for her father, and the way she felt cared for by him as a child, is intertwined with and causally related to him cooking for her and her siblings. His consistent cooking for them, along with his dedication to their education, is presented as proof of what a good man and good father he was. It is presented as a testament of how well he took care of them, of how he supported them in the world.

Conclusion

The way Ms. Hanks's speech moved, in moment transcribed above, from Vincent's failings as a caregiver to her own father's excellence as a caregiver discloses a comparison between how cared for she felt as a child, and how uncared for she felt the in her present life. Another aspect of this comparison is that Vincent's lack of engagement and relative absence as a father made Ms. Hanks have to work harder as a mother. She felt very much that she had raised their children by herself. How much work she had put in raising her children, especially in always cooking food for them and for Vincent, was a substantial component of her anger and displeasure at her current situation of food provision. She felt, due to her decades of labor feeding her family, that they owed her the same care she had given them. Ms. Hanks's individual experience of locally shared expectations for reciprocity of care between parent and child over the life course was focused specifically on the provision of good, nourishing food.

This sense of unfulfilled reciprocity became particularly heightened in the last few weeks of Ms. Hanks's life. She spent these weeks in the hospital, no longer in the same house where Vincent was cooking. In the next chapter, I examine how Ms. Hanks's sense of disregard during these last few weeks of her life was constituted through many aspects of the experience of missing food made for her by her family.

Chapter 14

"My Family is Cooking and They're not Bringing me any Food:" Ms. Hanks's Experiences of Disregard at the End of Her Life

Ms. Hanks spent the last three and a half weeks of her life in the hospital in St. Croix. During this time, she continued to tell me stories of cooking for her family, and just as often spoke about how her family was not providing food for her now. Having established in the last chapter that preparing and sharing food amongst family was, for Ms. Hanks, a potent experience of caring and behind cared for along her life course, I turn in this chapter to how not being cooked for by her family in her final weeks of life made Ms. Hanks feel deeply disregarded.

Through presenting different moments, while she was in the hospital, in which Ms. Hanks spoke to me about cooking for her family and having her family not cook for her, I explore the range of modalities through which her experience of disregard was disclosed. These sensory, material, embodied, mooded and biological showings constitute the particular manifestation of disregard that shaped Ms. Hanks's experience of the end of her life. This chapter thus both aims to suggest a robust conception of experiences of disregard and to suggest that disregard manifests in individual experience in ways that are singular, albeit founded in shared conditions and meanings.

A Note on Perspectives: Disregard Here, Care There

While Ms. Hanks certainly felt disregarded by her family in the last few weeks of her life, and while this experience is the focus of this chapter, it is important that this focus not implicitly villainize her family. I do not know to what extent Vincent and her children who lived on-island were intentionally disregarding Ms. Hanks, or to what extent they were aware of her experience of abandonment.[304] However, it's important to keep in mind that when caregiving for certain intimates is lacking, it is often because caregiving is being directed elsewhere. As I suggested in Section V, in considering the possibilities that disregarding an older relative can open up for family members off island—specifically the possibilities to provide for and care for their own children or others nearby. Here the ethnography provides concrete reasons to see Ms. Hanks's family, especially Vincent, as engaged in forms of caregiving that directed their attention away from her.

Vincent had been taking care of Ms. Hanks and their adult developmentally disabled daughter, Cynthia, for at least two decades on his own. Now in his early seventies, he was utterly exhausted. Whenever I saw him (on my visits to the house or at the hospital), his affect was low, his speech mumbled (practically garbled), and it looked like he was dragging his body around. Often when I visited, he would be resting on the couch. In the times we talked before I began formally interviewing him, and in the healthcare home visits I observed, it was common for him

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[304] I did not interview any of her family members during the time she was in the hospital. Ms. Hanks was so upset with all of them, and trusted me so much as a friend (at times, as her only friend), that it felt like a betrayal to try to get closer to them and understand their side of the story while she was feeling so abandoned and unfairly treated by them. Although I did interview Vincent after Ms. Hanks died, it did not feel right to question him or any of her family, in their mourning, of their treatment of her while she alive, or to intimate that she had felt abandoned by them.

to say how tired he was.[305] He would say that he didn't think he could do it anymore, he didn't think he could keep going. Near the end of Ms. Hanks's life, then, Vincent felt that he had reached the end of what he could bear and that he did not have any energy left.

I do not know much about Ms. Hanks's other children. Of the three she had living in island in addition to Cynthia, at least one of them, Julia, lived with her teenage daughter and her infant grandson, both for whom she had to care for. As mentioned in the previous chapter, these children were not involved in Ms. Hanks's everyday caregiving when she was at home. I believe this to be a mix of chronic acrimony in their relationship, as well as the burden of other caregiving in the midst of poverty. It is perhaps not surprising then that they did not begin taking care of her once she was hospitalized.

As in additional piece of context, in my experience of older adults being hospitalized on St. Croix, it was not common for family caregivers to maintain active caregiving roles while their older relative was in the hospital. I was surprised on a number of occasions by the virtual disappearance of caregivers—often for several days— once the person they were caring for was brought to the emergency room (before they were even admitted into hospital care). After my initial confusion in the face of the disjuncture between their normally devoted caregiving and

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[305] Once, during one of our visits at her house, Ms. Hanks told me that Vincent would complain about being too tired to cook. When he says this, she told me, she would say to him: "I said shut your mouth. I used to be tired too but I didn't complain. (?) now for, little three four years, what you complain for? What about my forty years I put in to this business?" The attitude displayed here both gives a sense of the strong fierce streak in Ms. Hanks's personality, as well as the extent to which she felt that the care she was being provided now (and indeed, much more than she was being provided) was owed her by the "forty years" she had put into caring for her family. (The "little three four years" I believe refers to the time after Ms. Hanks had surgery on her hip, in 2012. Since her hip surgery, Ms. Hanks had required much more intensive care.) Later, when she was in the hospital, Ms. Hanks echoed a similar attitude. She told me that her caseworker was always telling her how tired Vincent was (as in, to give him a break, to go easy on him): "Cuz she is always, 'He's tired', (mhm) How does she know he's tired. (mm) She don't know him! (right,) But he's tired. He's tired. He's ti-so I had oh, well, he's so tired, what about me. (yeah) Who put in over forty-five years of work. (hm) Nobody ev' see my tiredness. Mine. Just he alone gets tired." Here, Ms. Hanks is putting her "tiredness" head to head with Vincent's, making it evident that from her perspective there is no comparison between the two and that he has a long way to go before catching up to her.

their seeming abandonment once the person they were caring for was brought to the hospital, I came to understand the hospitalized time as a welcome, much needed break for these otherwise overburdened caregivers. From this perspective, Vincent's absence from his ex-wife's hospital room[306] was the norm, rather than something extraordinary. By not coming to see her very often in the hospital, he was enacting what I observed as the typical pattern for long-term caregivers on St. Croix, one that speaks to the harsh difficulties of long-term caregiving.

When Vincent was not with Ms. Hanks in her hospital room, or not cooking food for her at home, then, he was taking care of their daughter, Cynthia, who could not take care of herself. Now that Ms. Hanks was not in the same house as Cynthia, spreading his care to both women would have been extremely difficult. Exhausted from years of caregiving, and with a child who relied on him for all of her everyday needs, Vincent did not spend much time with Ms. Hanks in the hospital, nor did he, as far as I'm aware, ever cook for her while she was there. But there were reasons for his disregard: he was caring for someone they both loved, and his energy and endurance had been worn thin from decades of caring for two loved ones at once.

At the Hospital

The Emergency Room

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[306] Vincent and some of her children did come to visit Ms. Hanks several times during the 3 ½ weeks when she was in the hospital. As far as I could tell though, and as Ms. Hanks reported to me, they only came when the hospital would call the house to inform them that her health had taken a turn for the worse—that is, that she might soon be dying. These were semi-emergency calls beckoning the family to her bedside to see Ms. Hanks for what was perhaps the last time. After one of these calls, even Ms. Hanks's daughter who lived in Florida came down to see her, jumping on a plane as soon as she heard the news that her mother might not have long for this world. She stayed only a couple of days, however, and I am not sure how much time she spent at the hospital (I never saw her there, despite visiting Ms. Hanks while she was in town).

It was the last week of May. When I called Ms. Hanks to let her know I was on my way over for a visit, Vincent picked up. He told me, in a way that was like he was relating an everyday occurrence, that she was in the hospital. When I asked why, he said something about her "not breathing good." I headed straight to the hospital's Emergency Department. There, I found a surprisingly upbeat Ms. Hanks. Unlike other times I had seen her in the hospital, she appeared to be basically the best version of how I would find her at home. She was talkative, in good spirits, and relatively energetic. She even had her book-on-tape player on the stretcher with her, blaring in the small, curtained off room where they had temporarily parked her gurney. When I asked her what was wrong (why she had come to the ED), she said that she "couldn't take the weakness anymore" and plus she had been coughing, but that they had taken some blood tests so hopefully she would be able to go home anytime now. I wasn't really sure what to make of that—if she was hiding something more serious from me perhaps, or didn't feel like talking about it, or if this was more or less all there was to say on the matter. Whatever the case, I wrote in my fieldnotes that night that she "didn't seem sick at all," and I remember thinking that they surely wouldn't be admitting her to the hospital.

I stayed a while to keep her company, and we had a good time. We had known each other several months at this point, so could make each other laugh and were comfortable in each other's company. She was excited to tell me, for instance, that a doctor's appointment earlier that week had shown that she had gained seven pounds, which meant she only had fifteen more pounds to gain before she could have knee surgery.

At one point, our playful, upbeat conversation led to her telling me stories about how Vincent always “wanted to be sick.” She laughed while making fun of how he checked his blood sugar every day, hoping to get high readings because a doctor had told him he was borderline diabetic. When I joked back that the two of them should switch places (since she was so tired of being sick, and he apparently wanted to be sick), Ms. Hanks told me how sick he had been in the past, including, for instance, a spinal cord infection that kept him hospitalized for months,. This was immediately followed up with her recounting her experience of this time:

Ms. Hanks: so I was back and forth
to the emergency room all the time
DF: wow
Ms. Hanks: I have to stay with him
all the time.
I will never do that again.
DF: yeah
Ms. Hanks: I won't do it again
DF: yeah
Ms Hanks: leave my children
to come and take care of him
I had to cook!
because he won't eat the hospital food
DF: oyoyoy
Ms. Hanks: so I have to cook
breakfast lunch and dinner!
DF: mhm,
Ms. Hanks: I'm-oh my g-

I will never do that again!

DF: yeah I know

Ms Hanks: no I won't

This revelation of the kind of care Ms. Hanks had to take of Vincent when he was in the hospital shows it as an extension of the laborious care she was providing him and the children at home during this time.[307] Instead of getting a break for cooking for Vincent when he was in the hospital, instead she remembers having to work even harder, cooking and transporting three meals a day while taking care of their kids.[308] The coming about of this memory at this moment in the ED is eerily prescient for what was to come in the weeks to follow: Ms. Hanks expecting Vincent to reciprocate her care by cooking and bringing her food when she was in the hospital. It is an indication of her enduring attention on food preparation as familial care, attention that was likely drawn to this memory because she was, at that moment, finding herself in the very physical environment—St. Croix's one ED—that she had come to when bringing Vincent food. She was surrounded at this moment by the same sounds, sight and smells as she would have been years ago, when Vincent was the patient. The appearance of this memory at this time also might indicate some latent fears that her care would not be reciprocated when she was to find herself in the same situation.

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[307] It is difficult to place when this "all the time" is situated in Ms. Hanks biography, because she had told me that his spinal cord infection was five years ago, but also indicates here that she had to "leave her children" to come take care of him, while five years ago all of her children were already grown up. Five years ago, the only child she would have potentially had to leave to go to the hospital would have been Cynthia, her developmentally disabled daughter One of the consequences of this chronological ambiguity is that it's unclear whether or not Ms. Hanks and Vincent were still married at this time.

[308] Ms. Hanks's repeated assertion that she would "never do it again" is one of many moments at which Ms. Hanks spoke in a mode that disclosed her belief that she was going to be returning to her healthy self.

Immediately after telling me this story, Ms. Hanks evoked another memory of laboring to prepare and bring Vincent food:

Ms. Hanks: myeah.
I was thinking the other day
once he was doing some jail time,
DF: mhm,
Ms. Hanks: but only on the weekends
DF: what?
Ms. Hanks: myeah.
DF: I don't understand.
Ms. Hanks: yeah, t-he was doing some weekend time.
and, and I worked,
cook, and bake,
he went in on fridays
came out on sundays
DF: mhm
Ms. Hanks: ya know,
so I had to bake
so he could eat
on the um-friday,
and if he didn't have visits on saturday
DF: mhm,
Ms. Hanks: I would cook
and carry lunch
and all that foolishness

After a very brief interlude in which I express more confusion about “weekend (jail) time,” Ms. Hanks continued:

Ms. Hanks: did this twenty six weekends.
and there your girls [the wives/female relatives of the prisoners]
cooked for twenty six weekends.
DF: mhm
Ms. Hanks: and I had six children too
DF: yeah,
Ms. Hanks: n'see me walking all six children,
DF: yeah
Ms Hanks: and the basket with the food

At this point, we were cut off by a nurse coming in to start an I.V. line in Ms. Hanks’s arm, and discussions with various nurses took over the rest of my visit. This story again emphasizes the difficulties that Ms. Hanks endured in providing food for Vincent, going back and forth to prison with a meal she had prepared several times each weekend for a year, with six kids in tow. These two stories being told in a row show that upon entering the hospital, the recollection of the difficulties she endured and the lengths she went to in order to provide Vincent with home-cooked food when he was institutionalized was on her mind. Her enduring attention to these memories was providing a significant orientation in her experience before she was even admitted to the hospital.

“This Didn’t Even Have to be”

Despite my (now clearly misguided) assessment in the ED that Ms. Hanks was actually doing relatively well, she was admitted to the hospital. And, in the weeks to follow, her health progressively got significantly worse. In the midst of this decline, she had some better days—at times saying she had been “a mess” but was “coming along,” other days saying she was feeling a lot better. But she never had another day when she was feeling as well as she had in the ED that first day.

Throughout, she talked about food, and about reciprocity. The first day I visited her after she was admitted, two days after we spent time together in the ED, I began by asking her how she was doing and what her blood tests had shown. She responded by immediately connecting the problems found in her blood tests with what her family had been feeding her at home:

DF: did the blood test,
what did it show
did it show that you needed-
Ms. Hanks: that, the hemoglobin was a mess
DF: okay,
Ms. Hanks: so I needed blood. [a blood transfusion]
DF: I see, I understand
Ms. Hanks: you know,
this didn't even have to be.
if they would just
go to the corner (?) grocery,

an' buy the right foods

DF: mm

Ms. Hanks: b-I keep asking them to do that,
I keep telling them,
need to buy the right food,
need to buy greens and stuff,

DF: yeah

Ms. Hanks: eat, healthy

DF: yeah

Ms. Hanks: they (?) don't care
if he cook chicken and rice,
that's all he could cook,

DF: mhm,

Ms. Hanks: every day!
chicken and rice!
nothing to go with it,
maybe sometimes some red beans
if there's red bean-
red beans and chicken and,
just one thing over and over

DF: mhm

Ms. **Hanks**: nothing healthy
no greens, no greens,
oh lord,
lord help me,
oh excuse me alright?

As Ms. Hanks was saying “oh lord, lord help me,” at the end of this segment, she was being struck with a wave of weakness (and perhaps also of pain), sinking back into her pillow, and then rolling listlessly away from me as she asked me to excuse her (for no longer facing me). It felt to me like a backlash from becoming worked up—her weakness reasserting its control over her. Before becoming too weak to continue speaking, Ms. Hanks drew a direct causal explanation from the ingredients Vincent and Candy had been buying at the grocery store (with her food stamps) and the meals that Vincent had been preparing for her at home, to her current condition of desperate illness. As I described in the last chapter, Ms. Hanks’s complaints against the ingredients bought at the store and the meals cooked for her were not new. However, it is powerful that Ms. Hanks attributes the downward turn in her health directly to the failure of her family to prepare certain foods for her. Here, her experience of disregard encompasses not just the fact that her family is not bringing her food now, but that in the past they did not do what was needed to protect her wellbeing.

I would suggest that in Ms. Hanks’s connection here we have a window into certain aspects of her experience of disregard. There is the culturally shaped materiality of food—that consuming certain foods contributes to health and strength while consuming others doesn’t—that links her memories of missing greens to her current state of illness and weakness. This state is an embodied, sensory one through which she was currently inhabiting the world. The way she has to cut off our conversation shows particularly how unwell she was feeling, an unwellness she attributes to poor nutrition and that is grounded in physical sensations. This experience is further constituted by her resentful mood toward Vincent and Candy, who from Ms. Hanks’s perspective, are in large part to blame for her current condition. In asserting that she “keep[s] telling them" to buy healthy food like greens, Ms. Hanks discloses her sense that both her wellbeing and her explicit desires are ignored and disregarded by her family.

Not Eating

As her stay in the hospital continued, Ms. Hanks continued to orient toward nourishing cooked prepared by her family as a way out of her experiences of illness, and disregard. She still wanted greens, fruit, and fresh fish (her usual 'healthy' foods), and she still wanted them to come from her family. As time passed, this desire for her family to share nourishing foods with her was set in powerful relief with her refusal to eat any of the food the hospital was providing her. Refusal, perhaps, is too strong; what is certain is that she was not eating it. The disregard she was feeling became constituted through the effects of extended periods without food took their toll on Ms. Hanks's health, her changing embodied feeling of being in the world, and the moods that accompanied these shifts.

For weeks, every time I visited, there was either an untouched tray of whatever the most recent meal was, or the nonperishable foods from that meal left on Ms. Hanks's nightstand (see Figure B). Or, sometimes, food would arrive while I was there and she wouldn't eat it. The reasons for this were, I think, overdetermined. Sometimes, the food the hospital fed her was sometimes exactly the kind of food Ms. Hanks wanted to avoid. For example, a few minutes after the exchange above, in which Ms. Hanks was telling me about the incessant chain of chicken and rice she was served at home, lunch arrived. As always, it came with a large, doming plastic cover over it, with a handle. When I took the cover off to see what they had served her (hoping I could entice her into eating a few bites), it was chicken and rice. Needless to say she didn't eat any of it. In addition to this, as sick as Ms. Hanks was, and as many medications as she was on, she didn't have a very good appetite most of the time. But it wasn't that Ms. Hanks didn't want to eat at all, and it wasn't that more often than not the hospital served food other than chicken and rice. She knew that she needed to eat healthy foods to help her get better, and she wanted her family to bring her those foods.

Figure I: Ms. Hanks's nightstand, about 2 weeks into her hospital stay. On the left, two containers of fruit juice topped by a container of canned fruit. Behind them sit three un-opened Ensures provided by the dietician (this was more than a day's worth, they were building up). In the middle, there is another juice (and perhaps some sugar or milk on top), and in the background there is some ruby red grapefruit juice (her favorite, brought by me) and a couple of other boxes of an ensure-like beverage. Note also her book on tape player on the right, topped with a book on tape in its case.

Ms. Hanks's hunger, it seemed, in all of its embodied and mooded dimensions, was a very particular hunger: one that could only be satisfied by her family preparing healthy food for her. She wanted them her to take care of her the way she had taken care of them over the years. By refusing to eat the hospital food, she was both providing her family with an opportunity to reciprocate her care and, as time went by, was disclosing their lack of caring for her through her gradual physical decline. Indeed, as the days went by, this lack of care, this continual absence of prepared food brought from home began to erode what was left of Ms. Hanks's fragile health. Her extremely low body weight, compounded by low to no intake of food, was making her sickness worse, making her more difficult to treat, and making her treatment more complicated.[309] This was not lost on Ms. Hanks, who, as I have said, felt that eating healthy foods was her way out of her present condition.

A week after Ms. Hanks was admitted, I again came to her hospital room to visit. As the first line of my fieldnotes from that visit state: "she is so weak when I get there, it's scary." Trying to make sense of seeing her like this, I immediately started asking her questions, probing for clues that would explain her current condition:

DF: so how-
how have the last few days been?
Ms. Hanks: nnwell,

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[309] When a lack of nutrients began to have a severe impact on Ms. Hanks's condition and treatment options, a hospital dietician was assigned to her who (among other things I was not privy to) provided Ms. Hanks with bottles of Ensure in an attempt to get calories, vitamins, and minerals in her body. While there was some evidence that Ms. Hanks occasionally took sips of these, it was not a very successful intervention

you know how it is
DF: mm,
Ms. Hanks: it's kind of uh,
come and go
touch and go
you know
DF: myeah
Ms Hanks: what can I do
DF: yeah
Ms. Hanks: I...
DF: have they told you
anything about, why
you're feeling so weak?
Ms. Hanks: mmno,
DF: mm
Ms. Hanks: I-I do believe
I need to eat some food
DF: yeah
Ms. Hanks: yeah, mm
because family brought nothing,
you know,
I know they cooked they ate, mm,
nothing for me,
but I'll survive that

While I am not able to put into words the extreme weakness in Ms. Hanks's voice as she spoke to me, it is partially conveyed in her fragmented speech (e.g. "family brought nothing"). Here, she attributes her weakness to her need to eat some food, but then explains (elliptically) that she hasn’t eaten any food because her family hasn’t brought her anything. The three large meals she is brought by the hospital each day do not even figure into her logic of hunger, weakness and decline. The claim that her family isn’t bringing her any food is always, as it is here, paired with the claim that they are of course cooking and eating themselves. Here, this claim has a strange, atemporal quality to it. Set in the simple past tense, “they cooked they ate” indicates a one-time event that has passed, not a continual cooking and eating without her—an odd assertion that seems out of place in the context of a week in the hospital without once having been brought food from her family (see Capps and Ochs 1995 and Ochs and Capps 2001 on the role of grammar in narrative). Spoken in this way, it seems to index an event in Ms. Hanks’s imagination: perhaps as a mealtime went by, she imagined them cooking and eating, and then not bringing her anything. Indeed, when Ms. Hanks was this weak, she seemed not fully to be in the world of the here and now, her mind somewhat confused, her mood dreamy— drifting, perhaps, to imagined goings on at home, goings on that she was excluded from.

During this same visit, Ms. Hanks spent a good deal of time telling me, once again, about her father. Her voice was weak and her thoughts seemed cloudy. But as usual, she praised him unconditionally, describing his commitment to cooking for his children every day while working a full time job. During our conversation, I decided to ask if Vincent had come to see her since the last time I was there (a question I usually avoided). Ms. Hanks replied by telling me “oh no no no, nobody comes to see me.” The casting of this in the realis mood of the indicative present tense connotes an enduringly factual state of affairs: it indicates that it is not just that nobody has come to see her since my last visit a couple of days earlier, but that we live in a world in which people do not come to see her. The evoking of this kind of world is disclosive of her mood, which as Throop (2014: 70) quoting Daniel (2000: 333) has put it, is "'a state of feeling—usually vague, diffuse, and enduring, a disposition toward the world at any particular time yet *with a timeless quality to it*'" (emphasis mine). Experiencing disregard, in the context of the possibility of care, is here inhabiting Ms. Hanks's being. She felt herself growing weaker and weaker, attributing it to her family cooking and eating without including her. She thought nostalgically of her father, the ultimate caretaker, and what it was like to have him cook for her every day. And she felt that no one visited her. She felt, through her bodily sensations, mood, and memories, disregarded and alone in a way that perdured.

Returning to Sharing a Pear

I opened the previous chapter describing an interaction during which Ms. Hanks and I sharing a pear in her hospital room. I discussed how, as I sat next to her, alternating cutting a piece for her and then for me, her mood shifted dramatically. As we ate the pear together, she became happy. Now that I have discussed more of the context surrounding that moment, I hope that it is clear why an activity like this may have had such an impact on Ms. Hanks. She was in the midst of experiencing disregard. For some time, her she had been undergoing the bodily sensations brought on by hunger and declining health, thoughts about her family not reciprocating the care she had labored to provide for them, and moods that variously showed her family as to blame for her suffering, and the world as a place in which no one ever came to visit her. During this time in which she was so hungry for her family to share food with her, sharing a pear with me, a loyal friend, seemed to be close enough.

Seeing how this brief reprieve from this specific form of disregard changed Ms. Hanks puts in stark relief how much her family not sharing food with her was impacting her being. To return to Schutz (1967), in the moments when Ms. Hanks and I were sharing a pear, we were "growing older together." Mutually attuned to our simultaneous experiencing of the smell, taste, and other sensory qualities of the pear while talking about the deliciousness of the pear, we were truly sharing something: her and I had become a we. Ms. Hanks question "Are we sharing?" (Chapter 13) discloses the significance to her of this form of togetherness: she has her attention on whether or not we are truly undergoing something together, and is very pleased to find out that we are.

Anthropologists and other scholars of commensality have asserted the powerful role of sharing food in creating social bonds and feelings of togetherness. Indeed, I am certain that this likely universal power of food was at play here. However, sharing the pear with me did not just make Ms. Hanks feel bonded and included in a group with me. Eating together changed her mood in a way that made her feel cared for in a much broader way. In my description of the event in the last chapter, I noted that Ms. Hanks's higher energy and better mood were evident during the time that her caseworker and nurse came into the room. I'll now provide a more elaborate discussion of one aspect of what took place during that interlude, in order to concretize my claim that growing older together with me for a time changed Ms. Hanks's mood in such a way as to make her feel that she was in a world in which she was being cared for.

"Everybody's Feeding Me"

Ms. Hanks and I were eating pieces of pear and chatting about how good it was, when her caseworker from the Ryan White HIV/AIDS Program came into the room. She was an Afro-Caribbean woman in her thirties who had been working with Ms. Hanks for some time, and visited her, at home and in the hospital, on a fairly regular basis. We stopped our snacking while the two of them discussed a few things, including the delivery of oxygen to Ms. Hanks's house for when she would be released, how her appetite had been recently, which books on tape she had out of the library, and if Vincent had been to see her recently. Ms. Hanks didn't like her caseworker very much, generally finding her to be incompetent and not helpful. But during this conversation Ms. Hanks was quite pleasant with her and seemed even to be enjoying her company.

At one point during the visit, which lasted about fifteen minutes, her caseworker and thehospital nurse who was most often tending to Ms. Hanks[310] were checking in with each other on a few ongoing issues related to Ms. Hanks's health (such as whether or not she needed ARV refills soon). They were standing near the foot of her bed, while I was sitting in a chair up by her head. In the midst of their conversation, Ms. Hanks dreamily turned to me and said, looking toward her caseworker "my mother," and then, looking straight at me "my best friend." I responded to both of these utterances with a smile, and a slight chuckle. Then she thanked me: "oh my thank you so much." A moment later, her caseworker addressed her, pulling her into the conversation. About two minutes later, though, her caseworker declared that she thought that as all she "had for her," indicating an approach to the closure of the visit. The three of us were still

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[310] This nurse was a kind, friendly, white woman from the states. Ms. Hanks was extremely fond of her.

all around her. “That’s the mother, you know,” Ms. Hanks said, indicating her caseworker: “the mother, the sister, the nurse”. The three of us chuckled and smiled.

In these moments, it seems that Ms. Hanks was feeling fully cared for: she transformed her three main caretakers into archetypes of love and care. In this new world, disclosed by her shifted mood, she was the daughter, the sister (or the best friend) and the patient, somebody who had people around her who loved her and could expertly care for her. As she put it, “I am-bum so happy I’ve got good nurses, good friends (mhm), and a good case worker. (mhm) It’s just, things seem to be coming together.” This sense of feeling truly cared for was also disclosed in Ms. Hanks’s response to her caseworker’s question of how she was doing: “Everybody’s feeding me.”

Here, I suggest, we have a few minutes of sharing a pear with me catalyzing not only a profound shift in mood (and thus in outlook on the world), but also the traces of a shift in embodied sensations. Moving from a state of hunger and disregard into a place where she had been sharing the taste, smell, and feel, and nourishment of a favorite fruit with a friend, Ms. Hanks’s may have, for a time at least, felt that her body had been fed. The effects of sugar in her bloodstream, after little food for many days, likely heightened this embodied, mooded effect. We were in a world completely opposite to the one in which “nobody comes to see me.” She no longer felt alone; she felt she inhabited a shared world in which she was taken care of, paid attention to, and fed.

Social Death

A couple of weeks after we shared the pear, Ms. Hanks passed away. Vincent told me that "everybody" was there when she passed, which I took to mean him, their on-island children (except for Cynthia), and likely some of her grandchildren. She didn't die alone. In the weeks before her biological death, though, Ms. Hanks was experiencing a social death. To end this chapter, I discuss the phenomenon of the social death, and how Ms. Hanks, through her feelings of disregard, was maintaining her claims to a place in the social world.

Just as sharing food can create interpersonal bonds and group identity, so can bonds be severed through the halting of commensality. "Food," Fajans (1988: 164) writes, "the medium for creating social bonds, is just as aptly the medium of their severance." As children are brought into families and into the broader social world through processes socialization that often rely on and integrate eating together (Ochs, Pontecorvo, and Fasulo 1996; Riley 2011; Schieffelin 1990), so individuals be pushed out of the shared world by no longer sharing food with them. The ending of commensality can be a form of enacting social death.

Social scientists studying the end of life in communities worldwide and through time have established the importance of the notion of "social death" (versus "biological death") to understanding how groups manage the deaths of their members (e.g. Bloch and Parry 1982; Counts and Counts 2004; Justice 1997; Lawton 2000; Marshall and Sutherland 2008; Seale 1998, 2004). The idea of social death is primarily in distinction to "biological death," or "the termination of bodily function" (Bloch and Parry 1982: 15) however that is locally reckoned. It has been argued that "in *all cultures* there is a distinction between biological and social death" (Long 2005: 24, emphasis mine).

There is a wide range of ways in which groups enact the social death of their members.[311] It has been thought that social deaths may be enacted in part to take a measure of control over the timing of what is otherwise an uncontrollable event.[312] In one that attempts to represent more emic perspectives thatn some, the death of a member is presented as great disturbance to social life, and thus mitigating that disturbance by enacting a measure of control over it is desirable, motivating social actors.[313] Broadly speaking, social death achieves the disintegration of a particular individual from society at large.

We find parallel functions, then, between the creation of a social death and the halting of commensality: both exclude the individual from a shared social world, setting them alone and apart from the group to which they had previously belonged. From here, we can see how halting commensality can be a way of creating a social death, especially for individuals—like Ms. Hanks—who seem to be close to their biological death. By not bringing her any prepared food, her

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[311] See Biehl (2005) for a particularly in depth, person-centered example of how social death is created for certain categories of people in contemporary Brazil. Biehl's incisive analysis extends the concept of 'social death' to account for those not necessarily near their biological death, but who have nonetheless been relegated to "zones of social abandonment" by their families in complicity with the state. In other prominent examples, Glaser and Strauss noted in their 1965 study how immanent death is managed in a hospital setting that patients who are completely comatose are regularly treated as objects rather than as people for some time before they are declared dead. Pool (2004), drawing on the research of Lienhardt (1961) and Deng (1972) has noted that among the Dinka, religious leaders known as the "masters of the spear" were traditionally expected to request to buried alive soon before sensed they were about to die, but before their biological death.

[312] In the symbolic approach, this control is needed because death is conceived as being a threat to society itself. As Hertz (1960) has written (here embedded in writings from Bloch and Parry 1982): "the problem which has to be met at death stems from the fact that the deceased was not only a biological individual, but a 'social being grafted upon a physical individual,' whose 'destruction is tantamount to sacrilege' against the social order ([Hertz] 1960:77)" (Bloch and Parry 1982: 4).

[313] Counts and Counts (2004) describe well one way this manifests, among the Lusi-Kaliai whom they studied in Papua New Guinea: "Everyone in Lusi-Kaliai society who enjoys fully human status is entangled in the complex web of exchange, sharing and obligation that holds society together (...) It is, therefore, desirable for an influential person—especially a bigman—to sort out these complex relationships, settle debts and economic affairs to a steady state before death. If this is not accomplished, if social and economic ties are not balanced and severed, then a person retains interest in the affairs of the living and the completion of his death and transformation into the spirit world remain incomplete" (Counts and Counts 2004: 893).

family could be seen as cutting ties with her in advance of her final passing, distancing her from the world of the living.[314] While Ms. Hanks acknowledged that her family was distancing her, she, however, continued to desire inclusion, clinging to her place in the social world.

In making continued claims to having her family share food with her Ms. Hanks was repeatedly announcing her continued legitimacy within this shared world, despite her experience of disregard. Indeed, her experience of disregard was a manifestation of her claims to inclusion. Had she no longer felt she belonged in our shared world, and in her family, it would not have been disregard that she experienced. Furthermore, in its connection to Ms. Hanks's memories of caring for her family, the constitution of her experience of disregard is grounded in her enduring personhood that reaches back throughout her life course. Ms. Hanks's experiences of disregard themselves claimed that personhood, that she was still who she always had been, even as she was dying.

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[314] In her ethnography of a British hospice, Julia Lawton (2000) has described the way that many patients felt that they had "lived too long," that is, past the time that family and friends had drawn away, disintegrating them from their network of relationships (see especially Lawton 2000: 148-149, 153-155). Such patients felt very much alone, often feeling that they indeed no longer belonged in the social world, and wishing for biological death.

Chapter 15

Conclusion: Disregard and Aloneness in an Aging World

This dissertation has traced disregard across social scales as it relates to aging, end of life and caregiving on the island of St. Croix in the U.S. Virgin Islands. I began with a history of St. Croix that presented it as a place subject to governmental modes of disregard throughout the colonial and (post)colonial eras (Section II). I then analyzed aspects of the Medicare system as disclosing the (post)colonial bureaucratic disregard that is at play within contemporary modes of American governmentality involving St. Croix. I argued that this form of disregard has direct and substantial consequences for possibilities for care and end of life for older adults on island, particularly through creating a healthcare landscape in which it is very difficult for companies to make Durable Medical Equipment available and easier to make hospice care available (Section III). An important part of this argument was the demonstration of how this healthcare landscape shaped the end of life experiences and trajectory of one woman, Ruth, who found herself in need of concentration oxygen and had little choice but to turn to hospice care (Section IV).

While Ruth's case brought attention to the ways that interpersonal forms of disregard also shape end of life possibilities, experiences, and trajectories, this is a topic I turned to more rigorously in subsequent sections. In my consideration of interpersonal disregard, I argued for the role of disregard in shaping patterns and experiences of familial caregiving (Section V). At this stage in the argument, I focused the phenomenon of a sole family member taking care of an older relative (usually in the context of large families), which is quite a common caregiving pattern on St. Croix. I engaged the narratives of local professional caregivers and the narratives of family caregivers themselves to analyze the role disregard plays in understandings of and experiences of caregiving through particular familial configurations. Once again, this discussion also touched on what would be the focus of the next section, namely experiences of disregard at the end of life (Section VI). In this final stage of the argument, I focused again on the case of one woman, Ms. Hanks, whose final weeks of life were substantially inhabited by her feeling of being disregard by her family. I trace how this was an embodied, mooded experience that was constituted through meanings of care built up over the course of her life, thus offering one portrait of how disregard can disclose itself as experience.

Interwoven throughout and within this multiscalar argument about disregard was a discussion of aloneness. Aloneness was the phenomenon that originally drew my attention in the field, and which I came to see as constituted by forms of disregard. And as I have argued for disregard as a phenomenon that functions at multiple social scales, so I have argued that aloneness is an important phenomenon shaping aging and end of life on St. Croix across social scales. Indeed, the geopolitical aloneness of St. Croix as a disregarded island far away from the American continent, the aloneness that arises in situations of familial caregiving, and the experience of being alone—whatever relationship that has to others' perspectives on the state of affairs—all play important roles in what it is like to grow old and die on St. Croix today.

Throughout my theoretical argument and the ethnographic case studies I've used to elaborate it and support it, I have approached disregard (and the aloneness that is constituted by it) as a phenomenon best understood as occurring *through time*. In order to properly consider the work of disregard, I have argued, we must consider it not through an examination of a single moment, interaction, or decision, but instead with attention to its continual development over time. Different variables become salient when considering the development of governmental or bureaucratic disregard over the course of history, and when considering the development of interpersonal disregard and experienced disregard over the course of a life—however, there are similarities. At the level of the state, we must consider primarily how legislative infrastructures, ideology, and material artefacts come together to shape patterns of attention for the sequence of individuals occupying governmental roles. This is something I demonstrated (in Sections II and III) within the historical discussion but more explicitly within the discussion of Medicare bureaucracy and the possibilities for regarding and disregarding St. Croix residents available to contemporary employees at Medicare-contracted entities. At the interpersonal and experiential level, we must consider primarily how patterns of attention develop within certain sociocultural milieus in relationship to local norms and ideals and always in the context of singular life trajectories and experiences. I have explored these ideas (in Sections V and VI) through examinations of how normative Caribbean kinship patterns and other local understandings configure patterns of disregard within families over the life course, and through how the experience of disregard at the end of life can be constituted through shared and idiosyncratic meanings of particular forms of attention (e.g. care enacted through sharing food) over the life course.

This emphasis on a diachronic approach to disregard is firmly rooted in the phenomena of human attention. While at any given moment our attention is arrayed in a particular pattern, this is not a pattern that simply spontaneously arose and can just as easily drop away. What we pay attention to and in what ways; what our attention is drawn to; what we are able to pay attention to; these are all products of development over time. As Throop and Duranti (2015) have argued, a great deal of this patterning is due to our lifelong socialization into particular cultural and social communities. And, this patterning is what defines the makeup of our experience of the world; the way the world as disclosed to us through our lifetime cannot be other than what we have paid attention to. At the core of my argument then is a claim that multiscalar social processes cannot exceed or circumvent human being in the world.

As much is this dissertation is about disregard and aloneness, it is, in a more general way, about the social processes affecting contemporary aging populations. I have discussed how modes of governance directly affect possibilities for affordable and available care, how families configure themselves to provide caregiving and the effects this has on the everyday experiences of older adults, and how the final weeks of life can be experienced. As global aging develops, more and more communities will be aging, and more and more substantial portions of populations everywhere will be involved with these issues. This dissertation has been a bid to consider patterns of attention as a central player across all of these domains, and thus as a key component of how global aging will unfold. It is thus also a potential locus of intervention.

As human communities all over the world age, what might it mean to ‘grow older together’ in a global sense? Clearly, this represents an expansion from Schutz’s meaning (1967), in which growing old together is based in a face-to-face relationship. However, expanding along the lines that I have delineated in this dissertation, how might we collapse forms of aloneness across social scales? How might we create more togetherness at these different levels? The answer is surely not a simple one. It is certainly not merely an issue of “awareness,” no matter the power of awareness discourse in contemporary social activism nor the concept’s putative affiliation with “attention.”

I am wary of grandiose statements about the power of us all to change perduring habits of attention, to break free from the material, social, and cultural shackles that has held our attention in particular patterns of disregard. And yet, I also feel that reframing questions of aging and aloneness in terms of patterns of attention is an important step. For decades, “loneliness” has been a major topic of study among older populations (e.g. Gaev 1976; Moore and Schultz 1989; Mullins, Johnson, and Andersson 1989; Peplau et al. 1982; Townsend 1973; Tunstall 1971; Woodword 1988). It has recently been declared a public health crisis in the United Kingdom, a problem not just for those experiencing it but for society at large (The New York Times 2017b and 2018c). Meanwhile, anthropologists are arguing against the “demonizing” of distance between families and older adults (Baldassar 2016), with suggesting that not only is co-presence is now possible across distance, thanks to communication technologies, but that long-distance relationships might even be more beneficial for many families (e.g. Ahlin 2017; Baldassar 2017; Baldassar et al. 2016; Madianou 2016). Certainly, the meanings, effects, and experiences of aloneness vary interculturally and interpersonally, and loneliness can be a problem among some while others find ways of doing family across great distance. My point is that aloneness remains a central topic for understanding experiences of aging throughout the world. I have shown how particular forms of aloneness shape aging and end of life experience and trajectories in St. Croix, and have argued that they are quite consequential to what aging and end of life is all about there. However, this is not a phenomenon limited to St. Croix, and it is not a phenomenon limited to the particular forms I have elucidated here. My suggestion is that by re-framing approaches to aging, and to aloneness among the aging, through a framework of patterns of attention, and particularly disregard, we can have a better understanding of how various forms of aloneness are constituted. And this, in turn, is central to understanding the experiences and trajectories of older adults in communities around the world who are, in diverse ways, growing old alone.

Epilogue: Hurricane Maria

The St. Croix that I have recounted in this dissertation both still exists, and does not. In September 2017, one year after I finished fieldwork, the island suffered catastrophic damage caused by a major hurricane. Many of the institutions I described in this dissertation are gone, as are many of the homes that I spent so many days in. However, the patterns of disregard that undergirded social life in St. Croix have remained. To end this dissertation, I provide an account of the hurricane and its aftermath, both as one final demonstration of the role disregard plays in shaping aging and end of life possibilities for older adults on St. Croix and as a way of acknowledging and responding to, in one small way, the massive change, loss, and pain the community has undergone since my departure.

On September 6, 2017, Hurricane Irma bore down on St. Thomas and St. John as a Category 5 storm.[315] Both islands were ravaged, with little let standing, and five people were reported to have died in the storm. St. Croix experienced tropical storm conditions, causing minor damage. Due to Irma's size and the proximity of St. Thomas, St. John, and St. Croix, it hadn't been clear until hours before the storm which islands were going to receive the most damage, and St. Croix had prepared for much worse. When it became clear that the situation on

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[315] This is the highest rating on the Saffir-Simpson Hurricane wind scale, indicating sustained winds of over 157 miles per hour. Any storm rated Category 3 or above on the scale is considered a "major hurricane" due to the "potential for significant loss of life and damage" (National Hurricane Center 2018).

St. Thomas and St John was substantially more severe than that on St. Croix, emergency response resources from St. Croix were deployed to the other island (The Virgin Islands Consortium 2017d). However, less than two weeks later, on September 19, 2017, another Category 5 storm came to the territory, this time to St. Croix: Hurricane Maria. With it's emergency resources and first responders across the water in St. Thomas, St. Croix was caught in an extremely vulnerable moment. The storm's effects were devastating. Not only could St. Thomas not help St. Croix in the immediate aftermath of the storm, but Puerto Rico, St. Croix's much larger American neighbor, had been hit by both storms and was itself in the midst of a major island-wide emergency.

There were no known fatalities in St. Croix in the Maria itself. However, it became apparent even while Maria bore down on the island that St. Croix's older residents were in trouble. On September 13, as St. John and St. Thomas reeled from Hurricane Irma, some local media on St. Croix were still functional as Hurricane Maria approached. One local newspaper recounted the social media SOS calls of adult children whose elderly parents were caught in Hurricane Irma a week earlier: "My mom is stuck with flooding up to her knees and more water pouring in. If anyone can please help": "I need help for my mom after storm passes (...) House is in bad shape — windows and doors gone; she is in a closet. Glass and water everywhere"; "My mom needs help (...) Last I heard from her she was hiding in a closet and water was rising up through the floor from the cistern. Glass door and windows busted" (The Virgin Islands Consortium 2017a). These posts included the names of parents and their addresses, and sometimes their ages. In most of them, it wasn't clear whether these children were somewhere else on-island or if they were writing in from far away.[316] Six days later, as Maria passed over St. Croix, all communications went dark.

In the few days after the storm passed, it became clear that St. Croix had experienced one of the worst disasters in its history. Many homes and other buildings had lost their roofs, exposing them to the torrential rains and wind; power had been completely cut off; roads were impassable due to fallen trees and power lines.[317] Recovery would take years, if not decades. In short: Hugo had happened again.

No social media SOS calls from children of older adults on St. Croix were publicized in the local media, but given the severity of the storm they were no doubt sent out. Thankfully, no known deaths occurred in the U.S.V.I. during Maria. However, the island had overnight transformed from a place with a precarious, spotty health and services infrastructure to one with no infrastructure at all. A major piece of this destruction was that The Juan F. Luis Hospital had been one of the buildings whose roof had been ripped off by the wind, making the facility completely unusable. Hospital patients were evacuated off-island, and any patient who needed hospital care in the coming months was also evacuated. However, while these patients would normally all be taken to Puerto Rico, the level of crisis there meant that many were taken to stateside institutions, a great deal farther from home.

In the days after Hurricane Maria passed through St. Croix and Puerto Rico, mainstream American media was filled with hurricane news. However, as was obvious to anyone with

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[316] It is interesting, given the gendered dynamics of care I discussed in Section V, that all of these reported SOS calls were for mothers.

[317] See Navarro (2018) for a photo-essay documenting the damage.

connections in the territory, and as Navarro (2018) has pointed out, this presence was marked by an acute disregard for what those in the U.S.V.I. were undergoing. During the period between Hurricane Irma and Hurricane Maria's arrivals in the U.S. Virgin Islands, Hurricane Irma had continued on to the U.S. mainland, killing 92 people. Then, after Hurricane Maria passed through St. Croix and Puerto Rico, it too was headed for the mainland. A week after Maria passed through St. Croix, the storm skirted the North Carolina coast. The shoreline experienced tropical storm conditions and material damages were relatively minor, although sadly four people were killed. Navarro (2018) has pointed out the extent to which American news coverage of the storms was not only focused on effects for the mainland, but did so within a discourse that indicated that these storms had not yet touched American land or American lives. While I agree with Navarro that this form of media coverage was one indicator of "the ways in which the U.S.V.I. has been selectively included in—and positioned outside of—the United States since its purchase" (2018: 174), I also see it as disclosive of disregard. More specifically, as I have argued in this dissertation, I see patterns of attention, particularly that of disregard, as being the constitutive processes that bring these forms of exclusion and inclusion into being.

In the weeks that followed the storms, a few pieces were published in the mainstream media 'revealing' the disregard toward U.S. Virgin Islanders. These articles had titles like "With Little Relief in Sight, U.S. Virgin Islands go Ignored," (ThinkProgress 2017), and "US Virgin Islands: The American citizens battered by Hurricane Maria—and forgotten" (The Guardian 2017). These pieces read like exposés—the crisis you didn't know existed, the Caribbean islands that are (can you believe it?) *also the United States.*[318] In taking up this genre, pieces like these actually index the entrenchment of the disregard, both in the media (which is what makes these pieces pop with supposedly novel interest—their very claim to the popular reader's attention) and in the nation more broadly.

Another theme across these pieces is the extent to which they represent Virgin Islanders as a group who expects to be disregarded by United States.[319] For instance, one U.S.V.I. resident is quoted, as the conclusion to one article, as saying "'We got hit twice,' (...) 'By two hurricane. ...I'm not surprised [by the lack of concern]. We're used to not getting attention'" (ThinkProgress 2017).[320] An event that seemed for many on St. Croix to crystallize the kind of disregard they were feeling was President Trump's missed visit to the islands. After claiming that he would be coming to come to the territory to see the damage for himself and meet with the territory's governor, the President stayed on a U.S. military boat off the coast of Puerto Rico and had the governor meet him there (Virgin Islands Consortium 2017b; see Navarro 2018). The president did not set foot in the territory, a fact that at least for some seemed to smack of disregard. "'I never actually expected him to come here.'" said one resident, quoted in a national news service: "''We're non-voters, what does he care?'" (ThinkProgress 2017).

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[318] These articles at times index their own entrenchment in this collective stance of disregard in other ways, as well. For instance, the piece published in The Guardian (2017) notes that the St. Thomas's hospital "has evacuated 300 people to the US." Coming from an understanding of St. Thomas *as* a part of the US, this claim is nonsensical.

[319] A New York Times article published in between Hurricane Irma's and Hurricane Maria's arrival in the U.S.V.I. skirts the boundaries of the exposé genre and leans much closer toward the genre of national news. The article, covering the situation in St. Thomas after Hurricane Irma, makes the claim that "[m]any here complained that their suffering was being ignored by the United States and local government" (New York Times 2017a). It goes on to quote a St. Thomas resident as saying "Locals are mad their not hearing talk about St. Thomas" (New York Times 2017a). Alongside offering this U.S.V.I. perspective, the article also reflects the stance likely inhabited by most of its readers: "To most Americans nervously watching the path of Hurricane Irma, the United States Virgin Islands were little more than marks on a map as the storm churned its way to the mainland" (New York Times 2017a).

[320] Brackets filling in the implied speech were included in the original article.

The experience of medical evacuees from the U.S.V.I. presented something of a microcosm of the more general experience of disregard within the territory post-Irma and Maria. About three weeks after Hurricane Maria, the plight of the medical evacuees was brought into public discourse in the territory through a local online newspaper article (The Virgin Islands Consortium 2017c).[321] This article both announced that 3 of the 140 medical evacuees who had been relocated to Georgia had passed away (two of whom were from St. Croix), and that the surviving evacuees were feeling very neglected. However, instead of being pitched at the national level, this feeling of being disregarded was in relationship to the local government. The article claimed that medical evacuees "were frustrated with the Virgin Islands government's lack of communication with them," and said that it was causing a great deal of stress as well as depression among some of the evacuees. One was quoted thus: "'I feel like we are the forgotten people and no one has ever inquired how do we feel'" (The Virgin Islands Consortium 2017c).

This was a feeling that was to remain central in the discourse around the territory's medical evacuees. As months went by and the promised mobile hospital units had their set-up continuously put off, hundreds of U.S.V.I. residents in need of medical care were evacuated.[322] By February 2018, 531 residents in need of medical care had been evacuated (The Virgin Islands Consortium 2018a); by April, the count was up to 782 (The Virgin Islands Consortium 2018b). The idea that the territorial government was neglecting—as I see it, disregarding—these

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[321] This is not to say that this was "news" to everyone; many people in the territory knew someone who had been evacuated.

[322] The "modular hospital units" that FEMA in partnership with the local Department of health were originally promised to be functional by December 2017 (approximately 3 months after Irma and Maria). However, by February 2018, they had still not been erected, with the new expected date pushed to summer. In the meantime, there was no hospital-level care anywhere in the U.S.V.I. (see The Virgin Islands Consortium 2017c, 2017e).

evacuees dominated the media coverage of their continued existence. Local articles kept track of whether or not territorial politicians had or had not visited the medical evacuees (only one had, and it wasn't the governor), and, in an echo of the reaction to President Trump's perceived refusal to set foot in the U.S.V.I., articles cited the frustration created by the fact that these politicians had not actually met with medical evacuees, instead only meeting with local officials (The Virgin Islands Consortium 2017c). Once again, it seemed that there was a feeling that togetherness was sorely lacking. Instead, aloneness was cast as the structuring frame: sick people sent away from their home island, abandoned, with supposed visits that never actually brought them together.

As in the article breaking the news of the first deaths of medical evacuees (The Virgin Islands Consortium 2017c), the growing number of dead amongst the medical evacuees seemed to further indict the local government's treatment of the situation. While it seemed that many medical evacuees were getting good medical care, a hearing at the local legislature featuring family members of evacuees who had died brought to light the nature of the neglect that at least some were facing (The Virgin Islands Consortium 2017e). One woman, for instance, told of how her 90-year old father had been in the hospital in St. Thomas for knee surgery when Hurricane Irma came and he had to be evacuated (ibid). Concerned about his well being, she and other family members went to Puerto Rico, to find him in a tent outside of a hospital, in dirty clothes and with sores covering his body (ibid). Her father later died there (ibid). In speaking to my contacts in the legislature, I learned that some families in St. Croix could not locate their relatives who had been airlifted as medical evacuees; the local government had not told them where they were taking them, and the families were now contacting senators directly in order to try to find their missing relatives. In a particularly inscindiary article, a local newspaper quoted a source involved in the care and logistics for medical evacuees in Georgia as saying "[i]t's as if they're waiting on them to die. The federal government no longer wants them and the local government doesn't seem to care" (The Virgin Islands Consortium 2018b).[323]

The idea that governments at the local and federal level were just "waiting" for medical evacuees to die instead of figuring out a long-term plan for them dovetails with the broader discourse about the insufficient speed, quantity, and quality of aid that was being deployed in the U.S.V.I.. and in neighboring Puerto Rico post-Irma and Maria. That is, as time went on, it became clear that people were dying because of the storm—but months after the storm itself. In Puerto Rico, a study was undertaken to estimate the number of residents who had died due to the after-effects of the storm (New York Times 2018a). These were conditions that had perdured largely in rural areas peripheral to the main urban centers, including enduring lack of electricity, running water, and access to medical supplies and facilities. The study, undertaken by a group of independent researchers some of whom were based at Harvard's school of public health, concluded that approximately 4,600 people had died in the wake of Hurricane Maria, "many of them from delayed medical care" (New York Times 2018a). At the time, the official death count was 64. Months later, in late August 2018—nearly a year after Maria—a study commissioned by the government of Puerto Rico concluded that approximately 2,975 people died as a result of

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[323] This quote was presented with a screen shot supplied by an anonymous source working with the evacuees in Atlanta. The image showed a tally of the number of medical evacuees still within institutional care, which had a line by line account of how many had died, as of that day.

Hurricane Maria (New York Times 2018b).[324] The government of Puerto Rico adjusted the official death count to reflect this figure.

The divergence between the official death count of those who died in Maria itself and those who died in the aftermath of the storm indexes processes of disregard integral to the post-Irma, post-Maria disaster recovery. After a storm of this size, when almost everyone needs help, the attention of those in a position to help (e.g. FEMA, etc.) is drawn to certain zones and certain people over others. Puerto Rican residents living in San Juan, the territory's capital, had a much swifter and more inclusive recovery experience than those living in the large swaths of rural Puerto Rico (Bonilla 2018). It wasn't until the month the official death toll was changed—August 2018—that power was restored to every home in Puerto Rico. The Dean of the George Washington University's School of Public Health—the institution that had carried out the study whose conclusions changed the official death count—stated that what these results showed is that "'efforts for assistance and recovery need to focus as much as possible on lower-income areas, on people who are older, on people who are more vulnerable, because of having fewer of their own resources'" (New York Times 2018b). Indeed, it was clear that recovery efforts had disregarded those already inhabiting societal peripheries—especially the old and the poor— and that many had died because of it. Studies of deaths in previous hurricanes have shown that older adults are far more likely to die because of a hurricane. For instance, 64% of the people who died in New Orleans because of Hurricane Katrina were over sixty-five years old, even though they only made up 12% of the city's population at the time (Christensen and Casteñeda 2014: 826).

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[324] This study was conducted by researchers at George Washington University's Milken Institute School of Public Health.

Where attention and resources are directed following a disaster of this kind thus have a disproportionate effect on the life chances of older adults.

No study like the ones conducted in Puerto Rico was conducted in the U.S.V.I.. For those of us paying attention to what was going on in St. Croix, it felt like residents there were even more peripheral to relief efforts than those in Puerto Rico whose deaths could have been avoided by a quicker, more effective response and which were, for months, were not recognized by the state as even having taken place. In the U.S.V.I., local media conducted and published (in part) an interview with the territory's Attorney General arguing for why deaths of medical evacuees were not being counted within the official death count from Maria or Irma, despite families' feelings that they should be (The Virgin Islands Consortium 2018c). There was no official investigation into what was happening with those still in St. Croix who might have needed medical attention, or how many died on St. Croix in the wake of the storm due to not having electricity to power their oxygen concentrator, or to keep the fridge cooling their insulin. The Puerto Rico study that officially changed the death count cited causes of death like these (New York Times 2918b),but there is no account of how those on St. Croix were faring. Meanwhile, in weeks after the storm a close friend on St. Croix, a native Crucian in his mid-fifties, told me that it was really sad to see how the community was treating its elderly. He said that young people are stealing older people's insulin and their other medications, and leaving them to die.

In discussions of disregard after a disaster like Hurricane Maria, the connection between disregard and aloneness is clearer perhaps than in other instances. Perhaps it is because of the urgency of the need for help and for care, and the consequences when attention brings help and care other places, and to other people, first. I have briefly traced different forms of disregard here

—the mainstream media silence, the presidential snub, the "forgotten" medical evacuees—which themselves constitute different forms of aloneness. I'll conclude this discussion by briefly telling the story of one of my focal participants, Ms. Donovan, who was evacuated stateside after Hurricane Maria.[325]

Ms. Donovan was an Afro-Caribbean Crucian woman who had been born on St. Croix and spent almost all of her life there. She had raised a son and two grandchildren there, and had spent most of her career working for the local government in a variety of posts. During the time of my fieldwork (2015-2016) she was in her early seventies, and was in poor health. She was enduring a number of chronic illnesses, including chronic heart failure, diabetes (which she did not do daily management of), and high blood pressure. For these and other reasons, she had lived the last few years of her life in a great deal of discomfort, and was in and out of the hospital frequently. By the end of my fieldwork, she was having a hard time walking, I learned through phone calls with her in the months that followed my departure that she had become completely immobile.

After Maria passed through St. Croix, I was frantically trying to get a hold of my friends there. Since the island had no power and most cell phone towers were destroyed, it was impossible to reach most people. A few days later, I got a text from Sharky, Ms. Donovan's caregiver. Sharky was a longtime friend, a few years younger than Ms. Donovan, who had become her full-time caregiver during my fieldwork[326]. I responded telling him I was worried

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[325] While Ms. Donovan is not included elsewhere in this dissertation, she is someone I spent a lot of time with during my fieldwork and was one of the main participants in my study. I have written about her elsewhere (Flaherty 2018).

[326] Ms. Donovan couldn't text. Her fingers were too swollen (a symptom of chronic heart failure) and her vision was too poor.

about them and asking him how he and Ms. Donovan were doing. “We lost the roof so we wet,” he wrote back, “just duck and pray for like 5h [hours] but we made it.” The text included a big happy-faced, practically silly icon at the end--typical of Sharky’s demeanor. Ms. Donovan was living by herself in the house she had grown up in, and I worried about her living in a flooded house without a roof. I wasn’t sure what she would do, but Sharky was an able-bodied man who had a big network on-island, and Ms. Donovan had lived through Hugo, so knew what the next few months were likely to hold.

A week later I got another text from Sharky: Ms. Donovan had been evacuated to Louisiana. He gave me the number of where she was being cared for. I tried to find out details—why was she taken? Was it a medical emergency? This was before details about the medical evacuations were in the local news. He told me she had been having trouble breathing (a symptom of chronic heart failure) so he had called the hospital. It was determined that she needed hospital care, at which point she was flown out stateside. I looked up the town that she had been evacuated to, and was shocked. It was a tiny town in the middle of the state with one hospital. I went to the hospital website to try to get a feeling for what it might be like there, and to assure myself that she was in good hands. I thought to myself how, even though she had a large family spread all over the country, she didn’t know anyone in Louisiana.

Over the next several weeks, I thought often about calling Ms. Donovan—and then my attention would get drawn to other things. I missed her voice and wanted to hear the happiness in her voice when she heard mine. But things felt busy in my life, and I kept forgetting. One day, over a month after getting her number from Sharky, I called. The hospital told me she had been discharged. That doesn’t make any sense, I told them, getting panicky. I told them she doesn’t know anyone in Louisiana, she couldn't have been discharged, she can't walk, where would she have gone? After being transferred and put on hold a few times, and then calling another number who directed me back to the original number, fear had taken over my body. Nobody had any record of where she was. She must be dead. She must be dead somewhere and nobody knows. I called back, explaining what had happened and asking if there were any other possibilities for where she might be. This time, I got transferred to the nursing home wing of the hospital. The woman who picked up knew who she was: "Yes, she's here," the woman told me, as if it was the most natural thing in the world, "she's sleeping." I told her not to wake her, that I would call back later. Just knowing that she was there, that she was safe, felt like enough for the time being.

On November 16, though, Sharky texted me again: Ms. Donovan had passed away. I had never called her back, and the guilt hit me immediately, along with the sadness. Sharky and I texted back and forth a bit, me asking how her grandkids were doing (okay, they knew it was coming), and if there were plans for a funeral (not yet, he would let me know). I asked if she had still been in Louisiana when she died. Sharky wrote back "yes, that proble [probably] break her down." I told him that even though I guess we all knew it was coming at some point, she had lived through so much that it sort of felt like she was going to live forever. After Sharky wrote back, I couldn't bring myself to respond: "Being a lone hurt."

What I saw in Sharky's brief message was that Ms. Donovan had survived everything else—two Category 5 hurricanes, a number of chronic illnesses that had been expected to kill her years before—but that she hadn't survived being alone. Ms. Donovan, like most of the medical evacuees, had been receiving competent care from medical professionals, but she had still felt alone. My guess is that she felt disregarded, as well. Disregarded by the local government that she had spent her career working for, disregarded by those who hadn't come to visit. Disregarded by those whose attention was being drawn to other things.

This dissertation has been pitched at multiple social scales. However, I have argued that disregard at all of these scales, in addition to showing us something about how social processes at that level are proceeding, have direct impacts on the experiences and trajectories for older adults living and dying on St. Croix in the contemporary moment. In ending with this account of Ms. Donovan's death, I hope it is clear how the disregard in the national media for the crisis in St. Croix, how the local government's disregard for the medical evacuees, and how interpersonal disregard, of my own and of others, were all constitutive of the aloneness that characterized her death.

APPENDIX A

List of Research Sites

When appropriate according to norms for research ethics, names have been changed but the type of institution has remained. This includes sites on St. Croix only (ie. this list does not includes sites at which research was conducted during the one month of pilot research conducted on St. Thomas)

Homes of participants, *including focal participants and their family and other intimates, and non-focal participants including professional caregivers*

Shepherd Hospice

Helios (Medicare-certified QIO) administrative offices and off-site meetings

Juan F. Luis Hospital

Frederiksted Healthcare Center

Herbert Grigg Home for the Aged

University of the Virgin Islands Library

U.S.V.I.. Department of Human Services

U.S.V.I.. Department of Health

U.S.V.I.. Department of Health off-site events, *including Foster Grandparents Events, Diabetes Awareness Day, Caregiver Awareness Day*

U.S.V.I.. "Data users group"

AARP administrative office and off-site activities, *including zumba class, old-fashioned tea party, awareness events*

U.S.V.I. Agricultural Fair

Flamboyant Gardens (housing facility)

Whim Gardens (housing facility)

Sunset Palms (housing facility)

Lutheran Social Services

V.I. Partners for Health Communities

U.S.V.I. Legislature

U.S. Housing and Urban Development public proposal meetings

Joseph Funeral Home

Private practice doctors' offices

Superior Court of the Virgin Islands

Local non-profit Breast Cancer Awareness conference/fundraiser

Two Christian churches

A variety of local businesses, especially grocery stores and restaurants, but also including nail salons, the movie theater, etc.

APPENDIX B

Research Design

Pilot Phase

The main aims of the pilot study were to collect preliminary data on hospice care in the U.S.V.I., determine the feasibility of conducting a long-term ethnographic study on hospice care in the territory, and identify the optimal site for such a study to take place, whether that be on St. Croix or St. Thomas exclusively or on both islands. After initial contact through Shepherd Hospice, I travelled to the territory with the aim of working both with hospice workers and with hospice patients and their families. It was through participant observation with Shepherd Hospice's nurses and other caregivers on visits to patients' homes that I recruited hospice patients and family members to participate in the study. The scope of research with hospice workers, hospice patients, and their families was replicated in Phase 2 of the yearlong phase of the project and a comprehensive description can be found below. As in this phase of the yearlong project, pilot research included participant observation, semi-structured, informal, and person-centered interviewing, audio and video recording, and photography. I spent one month on St. Croix and one month on St. Thomas, engaging in the same research approach on both islands. In the month I spent on each island, I made many more contacts and grew a much stronger network on St. Croix than on St. Thomas, through which I determined that the possibility of successfully conducting a long-term ethnographic study on St. Croix was much more likely than doing so on St. Thomas.

Year-long Phase

This phase of the research was conducted on St. Croix exclusively. The original study design for the twelve consecutive months of field research consisted of four phases. These phases were altered slightly due to the shifting of possibilities on the ground during the research itself, and many of the phases overlapped.

During Phase 1 (1 month), I conducted archival research in the University of Virgin Islands (UVI) library and in the Christiansted public library and conducted interviews with healthcare administrators, policy makers and other stakeholders in domains related to older adult care and services on island. During this phase, I constructed a recent history of St. Croix (2010-2015) not available in scholarly sources and established a baseline of the main issues, patterns, discourse and events that had been shaping older adult care in the years leading up to the period of research. Interviews of this kind and archival research continued, less intensively, throughout the twelve months of study, turning toward particular issues that were arising as the study continued. The institutions I engaged most significantly within this realm of the study (excluding those I focused on in other parts of the study) included the U.S.V.I.. Department of Health, the U.S.V.I. Legislature, Lutheran Social Services and the AARP state office.[327] During this phase, and during my continued work in this domain throughout the year (see below).

In Phase 2 (4 months), I focused on ethnographic research with Shepherd Hospice, one of St. Croix's two hospice care services and the institution through which I carried out pilot research. Shepherd is a small home-hospice service serving all of the U.S.V.I., with one administrative office on St. Croix, and one on St. Thomas. It opened in 2001, and was the first hospice service in the U.S.V.I. (since that time, another Puerto-rican based hospice has opened on

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[327] It is called the "state office" and not the "territorial office" even though the U.S.V.I. is not a state but a territory.

St. Croix). It is owned by a couple from the states who now live on St. Croix. Gloria, one of the two owners, is in charge of the everyday clinical and administrative operations of the hospice. While the staff fluctuated slightly, during the yearlong study Shepherd's St. Croix branch employed five nurses, one social worker, one chaplain, one medical director, and around ten certified nursing assistants (CNAs). On the administrative side, they employed two office workers and one warehouse worker, who was in charge of all medical equipment (hospital beds, oxygen equipment, etc.) and often took on other side tasks as needed. The patient census hovered at about 25-30.

During this phase of the study, I conducted two related scopes of research. The first was in-depth case studies based on focal participants I recruited from among the hospice's patient census. These case studies were constructed by following the trajectory of their care and health as closely as possible while simultaneously trying to learn and document as much as I could about them and their life history. Because it was known among the Shepherd Hospice healthcare staff which patients I was following, I was brought in as a care team member for these focal participants, and was included in all communications regarding their care and developments at the home. I shadowed hospice caregivers (nurses, medical director and social worker) to as many home visits as possible, and often audio recorded these interactions (always with permission). I conducted informal or semi-structured interviews with either the hospice caregiver or the patient or family caregiver before/after each interaction for which I was present, tracking expectations, attitudes, goals and impressions on both sides of the caregiving interaction. When for some reason I could not be present at an interaction, I interviewed both hospice caregiver and family member/patient about the interaction. I also conducted person-centered interviews with the hospice caregivers of my focal patients (nurses, medical director, social worker, and Certified Nursing Assistants), and conducted participant observation in their lives both within and outside of work where I learned about their own families, homelives, dispositions and perspectives. I participated in all weekly nurse-only and full-team meetings, in which my observations were focused on discussions of my focal participants. I conducted participant observation in patient homes where I helped with caregiving when appropriate. This included a wide range of activities, including cooking, running errands, and conversation. In addition to the interviews conducted specifically around hospice caregiver interactions, I conducted and person-centered interviews with patients (as possible, given their state of health) and with caregivers. I also in some cases conducted person-centered interviews with other significant people in the patient's life.[328]

Seven of my nine focal participants whose were recruited into the study through my engagement with Shepherd Hospice, however only six of them were patients with Shepherd Hospice (one was introduced to hospice services but did not sign on).[329] Additionally, 15 of the 17 professional caregivers I worked with were involved in hospice care to some extent. Of the six focal participants who were hospice patients, two participated in the pilot study and four participated in the yearlong study.

The second scope of my research with Shepherd was to learn more generally about the role of hospice care on St. Croix. In this capacity, I conducted semi-structured interviews with

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[328] The design of Phase 2 is the same design, with some minor changes, that I used for the length of the pilot study, which focused exclusively on hospice care at Shepherd Hospice.

[329] There was one additional participant who I recruited through Shepherd Hospice who I do not count as a focal participant due to my slightly less intensive work with him and his wife.

the owner-administrator and with the hospice nurses, medical director, social worker, and conducted participant observation at a number of meetings and trainings within the hospice office itself and at other events in which Shepherd was participating (e.g. talks that the owner gave at conferences and interest groups around the island).[330] Single research activities were often split between focus on focal participants and more general research.

Phase 3 of the study took place at St. Croix's one nursing home, Herbert Grigg Home for the Aged. Herbert Grigg is a facility run through the local Department of Human Services. Approximately 42 people reside there at a given time, and there is a sizeable waitlist.[331] I conducted participant observation and conducted interviews with administrative and clinical staff, including the head of nursing and the director of the facility. This phase was intended to last 3 months, however after two weeks I was informed that I was no longer welcome at the facility awaiting authorization from higher up within government. Such authorization never came, and my research activities were cut short. While I had begun developing rapport with certain residents whom I hoped to recruit as focal participants, the sudden halting of my research activities came before I was able to recruit anyone into the study. My findings are thus limited to general observations and proceedings of the interviews I conducted with clinical and administrative staff. I spent approximately 25 hours at Herbert Gregg, in the public spaces and

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[330] This broader scope of research also brought me to Shepherd's involvement with Helios, the Medicare-contracted Quality Improvement Organization I discuss in Chapter 7. Because Shepherd was so well-known within the healthcare community on island, following the professional commitments of its owner, Gloria, was an excellent way of finding people and organizations working on aging and end of life on island I would have otherwise not known about.

[331] I was told by multiple parties on separate occasions that the list was six months long, although I don't know how that would be measured.

in patients rooms. I do not discuss my findings in this dissertation, beyond a general description of life at the facility in Chapter 6.

Phase 4 (6 months) of the study took place among older adults in need of care in the community who were not receiving hospice care. While the study design called for finding such individuals through the Herbert Grigg waiting list (to ensure their need for daily care) this proved to be unnecessary. Six months into my study, word had gotten out that I was willing and able to spend time with older adults and to help with their caregiving. There were more leads than I could follow. My main activities during this period were continuing to work with the two surviving focal participants recruited during my work with Shepherd hospice, to intensify work with one other focal participant who I had met through community connections, and to begin work with a fourth focal participant who I had met in a similar way. These latter two participants lived in their own homes and required daily care. Additionally, I intensified my work with other older adults in the community who were not focal participants but who nonetheless greatly enriched my research and extended and strengthened my findings. During this time, my research also extended to these older adults' family and/or professional caregivers and other people important to their everyday lives, as I had during Phase 2 with hospice patients' family and hospice caregivers.

Although originally not in the design for Phase 4, during the final six months of my research I also intensified the interviewing work I had begun in Phase 1, tracking down new administrative, political, and clinical participants who could help expand my ever-growing understanding of the network of care and services for older adults on St. Croix. The extent of my engagement across multiple institutions during this phase is detailed in Chapter 6 and Appendix

D. I also continued, during this time, to work with the families of hospice patients in my study who had passed away.

Across these sites, I took copious fieldnotes (a total of 3000 typed pages and 28 hours of recorded notes [when writing wasn't possible]) Overall, I collected approximately 411 hours of audio recordings and 96 hours of video recordings. Out of this corpus, I collected:

- 195 hours of audio recordings and 35 hours of video recordings of focal participants and their family/friend caretakers in the form of person-centered, semi-structured, and informal interviews, as well as naturalistic interaction between them.
- 83 hours of audio recordings and 7 hours of video recordings with professional caregivers for older adults, in the form of person-centered, semi-structured, and informal interviews, and naturalistic caregiving interactions.
- 71 hours of audio recordings and 10 hours of video recordings with healthcare services and policy administrators. These recordings included all forms of interview mentioned above, as well as meetings and training sessions.
- 26 hours of audio recording and 9.5 hours of video recording at other community events related to aging, end of life, healthcare policy, and caregiving on St. Croix.
- 43.5 hours of audio recording and 23.5 hours of video recording with older adults other than my focal participants and those involved in their lives. This includes person-centered, semi-strucutred and informal interviews, as well as naturalistic interaction.

In addition, I obtained tens of hours of recordings of radio and television broadcasts related to aging and end of life, healthcare policy, and caregiving on St. Croix. I have created an archive that consists of hundreds of newspaper articles from local newspapers and hundreds of publicly available government documents (testimonies to the legislature, bills, etc.) that speak to the recent history of healthcare and senior services on St. Croix.

I constructed detailed kinship charts for three focal participants and drew six to-scale maps of the homes of participants (two of which are featured in Chapter 12) and of certain other key spaces, such as an apartment in one of the larger senior residential facilities on St. Croix. I took photographs of participants and spaces throughout all phases of the research.

APPENDIX C

Focal Participants

Focal participants whose cases are focused on in this dissertation:

1. Mr. Parker- Mr. Parker is an Afro-Caribbean man in his early eighties who was born in the Eastern Caribbean island of St. Kitts. He moved to St. Croix in in the 1970s, when he was in his forties. He was receiving care from the Department of Human Services' Homemaker program, and receiving food from Meals on Wheels (see Chapter 6). Mr. Parker was completely bed-bound, with severe arthritis in all of his main joints. Besides that, he was in relatively good health. During the period of research, Mr. Parker was living alone. When research began, he lived in a small shack-like house in the middle of town that he had occupied for several decades. Several months into fieldwork, he relocated to a new looking one-bedroom apartment on the outskirts of town (see Section V for the reasons behind this move). Mr. Parker had six kids, only one of whom, Robby, who was in his early thirties, lived on island. Robby was his dad's caregiver. As of writing, Mr. Parker is alive.

Participation in Care/Services Programs: During the period of fieldwork, Mr. Parker was receiving Meals on Wheels and Homemaker Services from the Department of Human Services. He was a Supplemental Nutrition Assistance ("food stamps") beneficiary. He received Social Security benefits and he was a Medicare beneficiary. He signed up for the Medical Assistance Program while I was conducting fieldwork, with my assistance.

2. Mr. Edwards- Mr. Edwards was an Afro-Caribbean, ninety-six-year-old man who was born in the Eastern Caribbean island of Antigua. He migrated to St. Croix in the 1950s, when he was in his 40s. Mr. Edwards was a patient with Shepherd Hospice. He was bed-bound, and had advanced prostate cancer and likely gout. During the period of research, he lived with his grandson, Eli, who was in his mid-twenties, and was his caregiver. They lived together in a relatively average middle class Crucian home, a single-story house with five small bedrooms and a large yard surrounding it. Mr. Edwards had built the house himself, but during the period of research, it was in disrepair. Mr. Edwards passed away during period of research.

Participation in Care/Services Programs: Mr. Edwards was a Medicare beneficiary and received Social Security benefits.

3. Ruth-Ruth was a white, seventy-one-year-old woman from New York. She migrated to St. Croix in the 1980s, when she was in her early forties. Ruth was a Shepherd Hospice Patient. She had Chronic Obstructive Pulmonary Disease (COPD, otherwise known as emphysema), and had severe back trouble. Ruth was house-bound when she entered the study and eventually became bed-bound. During the period of research, she lived with her daughter, Jess, who was in her forties. The two lived in an expansive one-bedroom apartment that had views of the sea, but were struggling to pay rent. Ruth was divorced, and had a second daughter with whom she was estranged. Ruth passed away during the period of research.

Participation in Care/Services Programs: Ruth was a Medicare beneficiary and received Social Security benefits. During the period of research she briefly received Meals on Wheels.

4. Ms. Hanks-Ms. Hanks was an ethnically Afro-Caribbean woman who was sixty-four years old. She was born in Trinidad and migrated to St. Croix in the early seventies, when she was around twenty years old. Ms. Hanks had AIDS, and so her medical condition was quite complicated and she experienced a variety of symptoms. It is not clear to me if all of them were AIDS-related or if some of them, such as her persistent knee pain, had independent aetiologies. She was mostly bed-bound, although I was told it was possible for her to walk with a walker for short distances. Ms. Hanks was divorced and had seven children. Her ex-husband was her primary caregiver. During the period of the study, she lived with her adult developmentally disabled daughter, who was about forty, and her son who was in his mid-twenties. They lived in a small, three-bedroom, single-story track home that had been built decades earlier for migrant laborers coming to work for the aluminum plant. Her ex-husband lived with one of their daughters down the street from her house, and their other daughter, her daughter, and her son also lived very close by.

Participation in Care/Services Programs: Ms. Hanks was signed up for the Medical Assistance Program, and was also receiving services from the Ryan White HIV/AIDS Program housed at Frederiksted Health Care. She received Supplemental Nutrition Assistance Program benefits (“food stamps”).

Case studies not focused on in the dissertation

5. Ms. Donovan- Ms. Donovan was an Afro-Caribbean woman in her early 70s who was born on St. Croix. She was a patient with Shepherd Hospice during the majority of the study. She had high blood pressure, chronic heart failure, and unmanaged diabetes. When she first became a hospice patient, no one was taking care of her, but a short time later a longtime male friend began spending most days at her house caring for her. While she was fairly mobile at the beginning of the study, by the end of fieldwork she was having more trouble walking and was primarily housebound. Ms. Donovan was a widow and lived alone during the period of research. She lived in the house she had spent some of her childhood in, a fairly average middle-class Crucian home, with a single story and three bedrooms. During the period of research the house was very dirty and unkempt. Her house was not in town, but was in a relatively populous and commercial part of the island. She had one son, with whom she was estranged, and three grandchildren aged 9-14, who lived in the U.S.V.I.. and who she saw frequently. Ms. Donovan passed away in 2018.

Participation in Care/Services Programs: Ms. Donovan was a Medicare beneficiary and she received Social Security benefits. She received Meals on Wheels and was enrolled in the Energy Crisis Assistance Program.

6. Mr. Frances-Mr. Frances was an ethnically Afro-Caribbean man in his early eighties. He was born in St. Vincent and moved to St. Croix in the 1960s or 1970s. During the period of the study, Mr. Frances was diagnosed with Paget's disease of bone, which explained the deformities he had developed in some of his leg bones and the trouble and pain he had when attempting to walk. Mr. Frances lived alone during the period of research, and he had no family on St. Croix. He lived in a one-room shack without running water in the middle of town. He was being taken care of Josiah, a man who had become his friend after his past caretaker, who had lived in the same housing compound as Mr. Frances, had been hit by a car and died. Josiah was in his early fifties and was homeless. Mr. Frances passed away in 2016, shortly after research was completed.

Participation in Care/Services Programs: Mr. Frances was a Medicare beneficiary and received Social Security benefits. Mr. Frances received Meals on Wheels and signed up for the Medical Assistance Program during the period of research.

7. Angelica-Angelica was an ethnically white, hispanic woman in her early sixties. She was born and grew up in Puerto Rico, and moved to St. Croix when she was in her thirties, in the 1980s. Angelica was a patient with Shepherd Hospice. When she signed on, she was in the advanced stages of cancer. During the research period, she was living in a sizeable, well kept-up house by herself. She had been working in a white collar job until not long before she became very sick. When she got too sick to take care of herself, many of her friends from church began coming over, in shifts, to take care of her. When she was nearing death, her sister from Puerto Rico came and stayed at her house with her. Angelica was not married and did not have any children. She passed away during the research period.

Participation in Care/Services Programs: Angelia did not, as far as I know, participate in any welfare or human services programs. She was too young to be eligible for Medicare or for full Social Security benefits.

8. Mr. Landry-Mr. Landry was an ethnically white man in his sixties from the mainland United States. He and his wife, Ms. Landry had moved to St. Croix several decades earlier. Mr. Landry was a patient with Shepherd Hospice. When he signed on, he had advanced throat cancer. He lived together with his wife in a very small house. They couple did not have any children, and they did not have any other family on island. Mr. Landry passed away during the pilot phase of research.

Participation in Care/Services Programs: Mr. Landry was a Medicare beneficiary and received Social Security benefits.

9. Mr. Clarence-Mr. Clarence was an ethnically Afro-Caribbean man in his early eighties. He was originally from Nevis, and he and his wife had moved to St. Croix via the U.K. in the 1970s. Mr. Clarence was a patient with Shepherd Hospice. While the etiology of Mr. Clarence's condition was somewhat murky, when he came onto hospice care he was bed-bound, and it had been discovered that he had two masses in his head. He lived together with his wife, who was his full-time caregiver, in an average middle class home that was well kept up. The couple had raised three children who now all lived stateside. Mr. Clarence passed away in 2014, in between the pilot phase and the yearlong phase of research.

Participation in Care/Services Programs: Mr. Clarence was a Medicare beneficiary and received Social Security benefits.

APPENDIX D

Detailed Research Activities at Select Sites

These descriptions are intended to be additive to the activities mentioned in Chapter 6.

Department of Human Services: In addition to engaging in participant observation of many of the aid programs offered by DHS through my focal participant's involvement with them, I stayed up to current with issues relating to DHS's operations by attending (and obtaining video recordings of) all hearings of the Health, Hospitals and Human Services committee of the Territorial Legislature, and obtained the video recordings of other committee meetings and sessions of the whole regarding issues pertaining to DHS (such as budget hearings) that occurred between September 2015-2016. Additionally, I obtained copies of all testimonies given by DHS at the V.I. legislature from 2010-2016. In my research and archive of local press articles from 2010-2015, DHS was one of my foci and I thus has a substantial collection of articles relating to DHS during that time period.

I conducted additional research into DHS by conducting an extended person-centered interview series with a recent longtime Commissioner of the agency, which provided a great deal of insight into the agency's everyday workings. It was also a very helpful behind-the-scenes look at the challenges DHS faces, the way the agency attempts to surmount those challenges, and recent attempts at improving senior care and services on island that did not come to fruition. I conducted two weeks of participant observation at Herbert Grigg Home for the Aged, which included three weeks of semi-structured interviews with the director of the facility. Throughout the year, I also engaged with Herbert Grigg more peripherally in a variety of ways. For instance, I sat in on meetings between the owner of Shepherd Hospice and the administrator of Herbert Grigg as they attempted to plan potential partnerships; I sat in on meetings between a hospice social worker and the wife of a hospice patient who was attempting to have her husband stay at Herbert Grigg temporarily; and I conducted participant-observation with a social worker from Adult Protective Services, a senator, and the son of one of my focal participants (Mr. Parker, featured in Chapter 12), as they spent several months attempting to get him a permanent bed at Herbert Grigg. Lastly, while none of my focal participants lived at Whim Gardens, I conducted a semi-structured interview with the manager of the property.

Department of Health: I participated in several meetings of the Department of Health's Chronic Disease Working Group, which took place on the administrative floors of the Charles Harwood Medical Complex. I also participated in the bimonthly meetings of the "Data User's Group," a group led by DOH's Data Analyst with the purpose of bringing together relevant local stakeholders who could a) share health data collected within their agency/organization and b) given input on the content of the territory's next BRFSS (Behavior Risk Factor Surveillance System Survey), a survey created by the CDC that had not been conducted in the territory in several years. I also conducted a person-centered interview series with this Data Analyst through which I learned a great deal about the practices of health data collection in the territory, how particular methods of collection become particular statistics representing levels of health and disease in the territory, and the dynamics between federal and local data collection.

I got to know the Gov. Juan F. Luis Hospital (JFL) best by accompanying focal participants on many trips to the Emergency Department and visiting them once admitted. Over the course of the year, I spent several nights in the Emergency Department with focal participants in various states of pain and medical crisis as they waiting to be admitted, and many of my days included a visit to the hospital to visit a focal participant. However, I also conducted a person-centered interview series with one of the hospital's physicians, a cardiologist who was born and raised on St. Croix.

Additionally, Shepherd Hospice dealt with JFL on a regular basis as patients from the hospital were discharged into their care, and I was present for many of these discharge conversations and for other conversations relating to the hospital's treatment of patients and their administrative workings. Representatives from JFL played a very large part in the Community Care Coalition that I introduce in Chapter 8, with the majority of participants at every meeting being employed by the hospital and the meetings largely geared toward ongoing happenings at the hospital. All in all, JFL

Lutheran Social Services: My work with Mr. Judd (resident at Flamboyant Gardens) included a three-session person-centered interview series as well as between 5-10 hours spent engaging in participant observation at Flamboyant Gardens itself, mostly in the residence's community room and my participant's apartment. I also conducted a person-centered interview series with a past longtime Director of LSS, who had worked there for a total of over 20 years, until the mid-2000s; a semi-structured interview with the manager of Flamboyant Gardens; and a semi-structured interview with the current Director of LSS. Representatives of LSS are frequent testifiers at the territorial legislature, particularly in hearings before the Committee of Health, Hospitals and Human Services. My attendance at all these hearings between 2015-2016 and my collection and review of testimonies from hearings of the legislature 2010-2015 provided additional insight into LSS's role in the community as well as their organizational perspective on policy issues pertaining to senior services and care.

AARP:The State Director of AARP was a presence at local legislature hearings, at the Department of Health meetings I attended (including the Data Users Group), and at the Community Care Coalition meetings. Basically, we ran on the same circuit (we would often laugh when we ran into each other at things—until we just came to expect it). This meant that we often engaged in informal conversations about the topics being raised at the event, and that I was able to observe how she represented AARP's interests and how those interests were responded to throughout a variety of contexts related to older adult care on St. Croix.

Early on, I was offered an internship at the AARP office (which I did not take), but ended up, (as the only one toting a camera nicer than an iphone) being the unofficial photographer of AARP events for the year. These events, which I normally filmed as well as photographed, included a variety of activities that AARP either hosted or had a strong presence at. Some examples are a free flu-vaccination event at their headquarters, the annual day-long Caregivers Workshop, or a free Zumba class held at the National Guard. On a particularly strange—although refreshing—day of fieldwork, AARP flew me over to St. Thomas, and then put me on a boat to St. John, to use my videography skills to film what they understood was going to be an old-time St. John Tea Party. (When we arrived, my AARP companions were dismayed to learn that this was only a meeting *planning* the Tea Party, which itself wouldn't be happening for approximately a year. I filmed the event anyway.)

Shepherd Hospice: My research design for studying hospice care paired intensive case studies with more general research into the activities, care, and organization of the business itself, as well as the role in hospice in the care of older adults on island more broadly speaking. Each case study focused on one focal participant, the patient, their family caregivers, and the members of the hospice team (nurse, social worker, Certified Nursing Assistant, chaplain) that were assigned to them. I would shadow these caretakers on all visits to the home, interview them frequently about the case (usually before and after each visit), and conduct person-centered and semi-structured interviews with them with the intent of putting what I was seeing and learning about the specific case into context. I also made sure to be present for all meetings about these focal participants. In this way, I would follow the trajectory of their case from the institutional perspective.

I also did extensive work solely with my focal participants and, when possible, their caregivers. I would visit their homes several times each week just to spend time together—sometimes running errands, chatting, or just watching TV—and to conduct interviews when they agreed to them and when their health allowed it. This gave me a good sense of the everyday lives of these hospice patients. In July 2014, I conducted two intensive case studies. In October 2-15-February 2016, I conducted four, continuing to work with two of those patients (those who were still alive) until I left the field in September 2016.

Home Healthcare-Shepherd and Clear Waters: I became familiar with the workings of Shepherd Home Health due to my intensive fieldwork with Shepherd Hospice, however during the research period the Home Health business was a very small part of Shepherd's operations. Regarding Clear Waters, I sat in on meeting between the owner of Shepherd Hospice and the Director of Clear Waters in which they discussed upcoming closure, the reasons for it and how they were managing letting patients go. I attempted to interview the Director of Clear Waters some time later, but was unable to. Additionally, the closure of Clear Waters was discussed repeatedly in the Community Care Coalition I participated in, and I further discussed it in informal interviews with many members of the Coalition.

Doctor's offices: On a few occasions during the year, I accompanied older participants to private doctor's offices for minor complaints or routine check-ups. I thus have a sense of the quality of care and the facilities at these two offices. I also received care at one these doctors offices throughout fieldwork. Additionally (as mentioned in the JFL description above), I conducted a person-centered interview series with one physician. He had been born and raised on St. Croix and had attended medical school stateside. During the periods of research, he worked at JFL hospital and had his own private practice. For a time, he was also the medical director of Shepherd Hospice .

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