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Black Women with Advanced Cancer and the Challenge of Biomedicine: A Black
Feminist Methodological Exploration of the Lived Experience of Terminal Illness

by

Jennifer Elyse James

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Sociology

in the

Graduate Division

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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by
Jennifer Elyse James

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I need to begin by acknowledging my participants. Along with their providers, family and friends, these 20 women gave up hours of their lives to tell me about their experiences. All have cancer and many were very ill when we spoke, but they still took the time to share their stories with me in the hopes that they would reach other women and have a positive impact. These women inspired me, saddened me, uplifted me, challenged my thinking, and offered insight and thoughtfulness into the incredibly complex and deeply heartbreaking process of living with a terminal illness. To say this project is dedicated to them does not go far enough. This project is their project. It is their knowledge and wisdom filtered through my analysis. It would not have been possible to create this work without them.

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Black Women with Advanced Cancer and the Challenge of Biomedicine: A Black Feminist
Methodological Exploration of the Lived Experience of Terminal Illness
Jennifer Elyse James

Abstract

This dissertation uses Black Feminist Theory as a theory-methods package to examine the lived experience of terminal illness for Black women with advanced cancer. I developed and implemented a Black Feminist Methodology, which seeks to center the voices and experiences of Black women in order to challenge positivist constructions of knowledge production and increase research on, by and for Black women. This dissertation explores the intersections of race, gender, class, spirituality and health within the lives of Black women. Analysis of multiple in-depth interviews with Black women and observations of clinical interactions with their providers reveal new insights into the way these intersections co-constitute and shape the patienthood experience, the patient-provider relationship, prognostic conversations, and treatment and end-of-life decision-making for Black women. First, I examine the impact of financial security or insecurity on the way Black women approach and understand their disease and treatment. I go beyond questions of income and insurance status to illuminate the ways in which class intersects with race and gender for women undergoing treatment for advanced cancer and the implications those intersections hold for how the women view and understand their disease. Next, I expand upon previous research on the role of religion in oncology care to explore how Black women's faith impacts not only medical-decision making but also their view of self and illness. Finally, I trouble the notion of what counts as an intersectional identity. I posit that cancer patienthood, one's identity as a cancer patient post-diagnosis, is itself an important identity in studying the experience of health and illness. I describe the way the intersections of race, gender and patient identity impact experiences of patienthood, relationships with providers and understanding of disease and prognosis.

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Chapter One: Introduction

“I’LL FIND OUT BY AND BY”—DOLLY’S STORY

I met Dolly in early August. I felt trepidation as I walked up the stairs to her home at our scheduled interview time. When I had called her to schedule the interview, she seemed to have trouble remembering why I was calling and was perhaps a little annoyed. She said something about wanting to get the interview over with, and I felt incredibly guilty. I tried to make it clear that she was not obligated to participate but she insisted I come over. Her home was somewhat rundown and the sidewalk was cracked and littered with garbage. Her caregiver answered the door and I was immediately overwhelmed by the scent of sickness. It is a smell I cannot even describe but anyone who has worked in health care knows it.

She was one of the last participants I met for my study. At the point when I interviewed Dolly, I had interviewed 18 other Black women with advanced cancer, most of whom had seemed relatively healthy. I knew they were not – I had sat in on medical visits and had their providers explain their diagnoses and prognoses to me. Still, for the most part, they were able to sit and talk with me with ease. An occasional cough or a fading memory would be evidence of the disease wreaking havoc in their bodies, but really it was only because I already knew they were sick and I was looking for symptoms. In fact, the same day I interviewed Dolly I had interviewed another woman who lifted weights while we spoke, not wanting to “waste” the hour or so we spent together.

Dolly was different.

Dolly was sitting on a couch in the living room that was made up with sheets and she had a pad underneath her. I assumed she slept there. She was wearing a hospital gown – a first for my project – and she had a scarf wrapped around her head. Her large eyes were framed by long false eyelashes. The eyelashes felt in sharp contrast to her current appearance – I assume an echo of

how she used to attend to her personal appearance before her illness. Yet, the falsies could not mask the deep sadness in her eyes.

When I first arrived I had trouble focusing; Dolly seemed so weak and frail and the house was dirty. There seemed to be feces smeared on the wall behind her. There were people (and a small dog) coming in and out of the room, including her caretaker and a couple teenaged boys I assume were her caretaker's children or grandchildren. There was an air-freshener in the corner that would spritz a chemical scent into the room every few minutes.

Dolly spoke very slowly. It took her a while to answer my questions. My mind immediately assumed she did not like my questions or did not want me there and I started to panic, but she explained to me that it was because she was so weak. "That's why I take so long to talk," she said. "I'll be pulling up enough breath to get some sentences out for you." She would often have to stop and spit up a bit as we talked. At one point she had to lie down and asked me to lift her legs up onto the couch for her.

When I asked Dolly how she kept her spirits up and what motivates her when she is feeling low, she said, "I have my family. I have my two children. I have a future." She envisioned being able to go back home to Los Angeles to be near her family. "I only have one thing to do," she said, "and that's to climb the valley. I've been on mountains before, but not these kind." Dolly had certainly had to climb mountains before. Her daughter had died young of AIDS and her husband had passed away recently of renal failure after 26 years of dialysis. Her husband was her rock for her entire adult life. Dolly spoke very profoundly of their love and of the deep faith in the Lord he helped her to hold on to. When speaking of her cancer she said, "I would say today, in my present situation that this is just another phase of life. I could be any

woman. I could have any name. I could be anybody's sister or brother or daughter or mama. I have many chapters in my life. Many chapters. This hasn't been the first one.”

She sang a song for me, in her slow, quiet voice, that her husband used to sing to her: “I'll find out by and by. If I find out right now. I don't know why some things happen, but I'll find out, by and by. And I say to you today, you may not know why, but you'll find out, by and by.” She holds on to the memory of her husband and the idea that someday she will find out, by and by, the reason for her deep suffering.

When I left, I sat in my car and sobbed. Dolly died a week later.

When I embarked on a project to understand Black women's experiences of advanced cancer, I anticipated hearing cancer stories like Dolly's. Though I could not fully prepare for the impact of meeting women like her, many in the final weeks and months of their lives, my experience as a medical social worker, my knowledge of cancer disparities and my own assumptions conjured a specific image of Black women's cancer experiences. In many ways, Dolly exemplifies what I expected from many of my participants. She is older, 65 years old, and very sick with an aggressive disease that has been undertreated for the last several years. She is deeply religious and espouses a faith strong enough to cause me to question my deep agnosticism. She wants to do whatever she can to preserve her life, yet she has put her fate in God's hands and is willing to accept whatever His plan for her may be. On the one hand, Dolly's illness was the dominating force of her life at the time that I met her. It made her unable to speak easily, care for herself, remember details, sit or lie comfortably. But on the other hand, she still firmly believed that cancer, even her aggressive, terminal cancer, was just one chapter in her life, one of many dark times she has faced and one that could happen to any woman.

In one woman and one story, then, Dolly illustrates the heterogeneity and complexity I encountered when asking Black women to speak about their experiences with cancer at the end of their lives. For many of the women I met over the course of this research project, illness is not the central or defining factor of their lives. Cancer is one of the many challenges they are facing and can even pale in comparison to these other struggles. At the same time, some of these same women, and others as well, experience cancer as life-changing, identity-upending, painful, scary, and all encompassing. Cancer, and even advanced cancer, is not the same experience for all Black women. Yet, all the women in my study found their lives shaped by it in some way.

In the dissertation chapters that follow, I share the stories I collected from Black women experiencing advanced cancer, and show how their lives (and deaths) are continuously shaped and defined by the intersections of race, class, gender, spirituality, and health. I examine the experiences of Black women with advanced cancer both as a unique life stage and through the lens of the patient-physician relationship and treatment decision-making. I sought to understand their perceptions of advanced, metastatic disease as well as their relationships with their physicians and the factors that are important to them regarding treatment decision-making. Most research at the intersections of race and gender within health research has focused on perceived genetic differences of Black women or differing epidemiological trends among Black women—that is, focused specifically on the Black female body. In contrast, I examine the experiences of Black women with cancer and how they use prognostic conversations with their physicians to make end-of-life decisions.

This dissertation is meant to be an intervention to challenge the biomedical model of research on Black women with advanced cancer. This is an intervention many years in the making. It has been shaped both by what I experienced in the clinic as a medical social worker

and by what I have read in the literature about Black women's health. I will offer a brief description of both as well as highlight the theoretical underpinnings of this dissertation before describing the research conducted for this dissertation.

FROM SOCIAL WORKER TO RESEARCHER

My interest in cancer and the end-of-life as a research subject emerged from my experiences in the clinic. In the fall of 2008 when I was 22, I started work as a medical social work intern in a hospital intensive care unit. On my first day, my supervisor, who became an incredible mentor, brought me into a room and forced me to stare at a patient hooked up to dozens of machines while a nurse explained the medical status of the patient. Writing this I can feel my body tense up as I viscerally recall the panic and emotion that overwhelmed me in that moment. Allison, my supervisor, still talks about the dazed, deer-in-headlights look I had most of that day. She knew that I had to quickly learn to adjust to the medical realities of my job if I was going to be able to look beneath and connect with patients on a human level. In order to do the job, I had to get used to death and dying. The healing power of medicine felt so distant from my daily work with patients at the end of life.

Nine months later, I began work for a cancer center. It felt like such a relief. Most of the patients I worked with carried such a sense of hope and life with them. The physicians were actively working towards a cure. I really let my guard down because I thought I did not have to anticipate death in this job as I had in the ICU. I allowed myself to connect with patients in a meaningful way. There was one patient, J., only a few years older than I and in treatment for recurrent metastatic cancer. He was coming in for chemotherapy five days a week and part of my job was to sit and talk to him every day. He was profoundly sad and completely unaware of what a sweet, funny, kind guy he was. I still cry thinking about him because I believe he died without

ever realizing what a wonderful person he was and how much he could offer to the world. He died while undergoing treatment he hated and felt was poisoning him because he felt unable to stand up to the pressure he felt from his mother and his doctor to keep treating. Another woman, Mrs. H., told me that her physician told her emphatically that she was not going to die of cancer. When I asked her physician about this conversation, he told me that she was not dying *today* and that the patient knew she would die of her disease. I sat with another patient, Mr. B., while he told me his concerns about how he would manage financially in a year when his insurance ran out. Mr. B. died three days later. I faced this situation many times. Patients would talk to me about their hopes and fears and vividly demonstrate their lack of understanding of their prognosis. Yet the physicians would repeatedly tell me that it was not time to tell the patients and that it certainly was not my place to do so. I felt utterly helpless and in many ways angry with myself for allowing these connections to be formed.

I came to UCSF because I wanted to study end-of-life and the patient-physician relationship. I was certain that physicians were doing something wrong that I could point to and ultimately I would be in a position to recommend changes in both health policy and practice. Through course work and qualitative research, I began to frame my questions sociologically. I began to think more critically about the patient-physician relationship and how both parties, and often many others, are involved in end-of-life decision-making. I learned to step back theoretically and allow other possible explanations to emerge regarding the phenomena I experienced working in the health care setting.

One critical emergence was that I began to question how end-of-life and patient-provider relationships might be different when studying Black women. The more I had learned about the ways providers and patients formed relationships, the more I saw it as a process based in the

assumptions each party made about the other. I saw a social process that was constrained by time and structure and relied heavily on perceptions and assumptions of shared goals and understandings. I began to wonder what research had been done on my community and what was known about the experience of cancer for Black women.

BLACK WOMEN AND PATIENT-PROVIDER INTERACTIONS

It has been well documented that while African-American women have lower incidence of most cancer than non-Hispanic white women, African-American women have higher rates of death (CDC 2012). This disparity has been studied extensively in breast cancer. The national incidence rate for breast cancer from 2006 -2010 was higher for non-Hispanic white women than non-Hispanic Black women (127.4 v. 121.4 per 100,000 women/year) but the mortality rates were lower for white women (22.1 vs. 30.8 deaths per 100,000 women) (Hunt et al 2014:5). This national disparity is also present in the San Francisco Bay Area, specifically in San Francisco and Oakland. The disparity between Black women and white women in mortality rates has grown steadily since 1990. While the mortality rates for both groups have dropped, the rate for white women has dropped much more sharply than the rate for Black women. Hunt and colleagues (2014:5) have estimated that “On average, for any given day [between 2005 and 2009] almost five Black women died due to this racial disparity.”

This disparity cannot be fully explained genetically. It has been ascribed to a variety of factors, most prominently, to the lack of access to health care, and to diagnostic and prevention services in particular. Yet, according to Cooper-Patrick and colleagues (1999), racial differences in health care cannot be fully explained by economic and policy factors such as access to health care and socioeconomic status. They assert that race and ethnicity can also be *cultural* barriers in patient-physician communication.

Patient-physician communication has particularly unique implications for patients with advanced cancer. Physician attitudes and adeptness at initiating end-of-life conversations have been shown to be one of the greatest predictors of when patients with advanced metastatic cancer will make the transition away from active anti-cancer therapy to comfort care (Weeks 1998). In oncology, a discrepancy often exists between how a patient anticipates her disease and treatment trajectory and what the physician knows the patient should expect based on experience. This discrepancy both produces and is a product of the patient-physician relationship. How prepared the patient and physician are for the various possible outcomes is based in their working relationship. At the same time, the quality and efficacy of the relationship is based on how well patient and physician are able to negotiate a shared understanding of expectations. Given these negotiations, it is important to understand both patients' and providers' perceptions of end-of-life conversations and any barriers they may identify to informed decision-making around the end of life. There is a need to bridge theoretical models of decision-making with empirical understandings of how decision-making works in practice. New models of care have emerged rapidly in recent years and sparked great debate on the ideal role of a patient in medical decision-making (Epstein and Peters 2009). However, there has not been a larger discussion around the applicability of different models for working with women of color. We simply do not know how best to approach decision-making with Black women.

THEORETICAL APPROACHES TO THE STUDY OF BLACK WOMEN

A pillar of my research is a belief in a Black Feminist approach to research. I strongly believe in the need for research that privileges the experiences of women of color. My work is grounded in a theoretical legacy of examining the world-views of Black women and working to integrate alternate histories and realities into the academy. I will explore and describe three key

theoretical underpinnings and how they will inform my theoretical and methodological work. Those theories are Standpoint Theory, Black Feminist Epistemology, and Intersectionality.

The first key theoretical underpinning of my work is standpoint theory, which argues that group location in hierarchical power relations produces shared challenges and positionality for individuals in those groups relative to other groups. Dorothy Smith (1974) and Nancy Hartsock (1998) were the first to discuss feminist standpoint theory and Patricia Hill Collins (1986, 1990) applied the concept to the unique standpoints of Black women. For my purposes, standpoint theory is essential in understanding the ways in which Black women view and are viewed by biomedicine. Most people cannot opt out of race and gender as these are constructed by assigning bodies socially meaningful classifications. While I expected my interviews and observations to yield a diverse set of experiences in the clinic and I anticipated a range of opinions of the biomedical complex, they were all shaped by the standpoint of participants as Black women. For the purpose of my project, it is also important to recognize the standpoints of physicians. Physicians have unique standpoints, shaped by their training in biomedicine and the organization and culture of the clinics and health systems in which they work, and it is essential that I recognize how the standpoints of patients and physicians mutually construct each other.

Second, this project adopts a Black Feminist Epistemology as a way of building and producing knowledge based in experience, theory, and methodology. In the second chapter, I will provide a detailed account of the methodology I developed for this project and the ways in which it is grounded in Black Feminist Epistemology. To provide a brief overview, Patricia Hill Collins (1990) outlines four basic tenets of a Black Feminist Epistemology. The first is that alternative epistemologies are built upon lived experience, and not upon an objectified position. Second, Collins (1990) advocates the use of dialogue rather than adversarial debate. Third, Black

Feminist Epistemology does not require the researcher to attempt to separate from her own experience or assume that it could be possible to separate knowledge from feelings. Finally, Black Feminist Epistemology requires personal accountability of the researcher to her participants and the wider community of Black women (Collins 1990).

This anti-positivist approach to knowledge and the study of knowledge is at the center of Black Feminist Theory. Black Feminist Theory utilizes the concepts of intersectionality and standpoint theory to point to the idea that there is no fundamental Truth but that we are able to produce individual and collective knowledges based on placing different individuals, groups or ideas at the center of the discussion. The intent is to place “U.S. Black women’s experiences in the center of analysis without privileging those experiences” (Collins 2000:228).

The final key theoretical underpinning of my research is intersectionality. The term intersectionality was first coined by Kimberlé Crenshaw, a legal scholar, in 1989. Crenshaw explored this concept in her critique of antidiscrimination law, as well as feminist and antiracist theory, for erasing Black women’s experiences through a single-axis framework. Her work spoke to the legal ramifications of not considering the unique discrimination that may be faced by Black women at the intersections of race and gender. When examining structural power relations, intersectionality functions as a conceptual framework or heuristic device, which “references the ability of social phenomena such as race, class, and gender to mutually construct one another” (Collins 1998:205). In specific situations, all Black women encounter expectations of themselves as ‘Black women.’ How individual Black women “construct their identities within these externally defined boundaries varies tremendously. However, [identity construction] also occurs in response to the shared challenges that all Black women encounter” (Collins 1998:204). Both standpoint theory and intersectionality are about shared histories and common locations

within power relations, not about reducing individual experiences and identity construction to group process. Intersectionality is not additive. It speaks to the co-constitutiveness of categories of oppression.

Intersectionality has particular relevance when it comes to the study of health. At its heart, intersectionality argues that race, gender, class, sexuality, and other identity markers are mutually constitutive and that they “intersect in the lived experiences of those who occupy and negotiate different social locations in systems of power in the health care system and in the larger society; and that health inequalities are produced by racism, gender inequality, and class relations” (Morgen 2006:398). By looking at the combined impact of class, race, and gender on health, I am able to paint a more nuanced picture of the complexity of health and illness and develop a richer theoretical understanding of prognostication and disease management.

DESCRIPTION OF THE RESEARCH

From both my own lived, clinical experience, as well as my reading of the literature, it is clear how little we know of how Black women facing advanced cancer understand their disease. There has not been enough research centered on their experiences living with cancer, their interactions with providers, the ways in which those providers view them, and how all of these shape their care and the discussions that surround it. All of these issues need to be explored within the frame of the complex intersections of inequality and identity with which live. Thus, for this dissertation, I sought to make a methodological intervention on the study of Black women and health. I sought to illuminate how the intersections of race, gender, class, religion and health influence Black women's experiences with cancer and cancer care, especially towards the end of life.

My project is intentionally not a comparative one. I do not “prove” that Black women have worse relationships with their physicians or a more difficult end-of-life experience than white women. While statistics around the outcomes for Black and white women are important in framing the discussion, my work aims to highlight a particular lived trajectory and explore the intersections of race, gender, class, spirituality and health within the lives of Black women. I examined the unique standpoint of Black women using healthcare interactions as a specific lens through which to view a central human experience: death and dying. This is not to imply a monolithic experience across all Black women, but rather to assert that the intersections of race, class, gender and spirituality shape the way Black women construct their experience of cancer and make life and death decisions in their last days.

In order to explore these intersections, I recruited 20 self-identified Black women with advanced cancer to participate in this study. They ranged in age from 47 to 73 with a mean age of 59. Most identified as Black or African-American with one woman identifying as Black/Hispanic and one woman identifying her race as “Original Black Woman.” The women were diagnosed with a variety of types of cancer including lung, gynecological, endometrial, colon, uterine, breast thyroid, stomach, bladder, liver, cervical and lymphoma. All cancer diagnoses were considered advanced meaning the cancer had metastasized beyond the original site or recurred.

Additionally, nine providers participated via observations and interviews. Several family members participated in observations, but were not interviewed for the study. The recruited Black women participated in up to two interviews as well as an observation of clinical encounters. Not all participated in all three aspects due to health status, provider consent and participants being lost to follow-up in the clinic.

I recruited participants from the oncology clinic of a safety-net hospital, from a palliative care clinic of an academic medical center and from a community support group for Black women with cancer. Participants were recruited using flyers and provider referrals. The majority of the participants in the study, 15 out of 20, were recruited via a safety-net hospital, which I will refer to in this dissertation as County Hospital. In addition to serving as a site of recruitment, I spent ten months attending two weekly clinics at County Hospital and observing the flow of the clinic. The safety-net hospital played a key role in my understanding of the experience of cancer for many Black women.

Safety-net hospitals are a key part of the healthcare landscape in the United States as they provide care to some of the most vulnerable and underserved populations (Coughlin et al. 2015). There is not one universally accepted definition of a safety-net hospital. In a presentation in April of 2015, Teresa Coughlin of the National Health Policy Forum of the Urban Institute used the Institute of Medicine's description, which defines safety-net hospitals as hospitals which "by legal mandate or mission... offers services to patients regardless of their ability to pay" or a "*substantial* share of patients are uninsured, underinsured, and Medicaid." She describes safety-net hospitals as often providing care for the most vulnerable, providing training for medical professionals and providing high-cost services, such as burn units and trauma centers, that other nearby hospitals do not. Not all safety-net hospitals provide all of these services, but County Hospital, the safety-net hospital where I gathered data for this dissertation, meets all of these criteria.

OVERVIEW OF THE DISSERTATION

Chapter Two: Collective Dialogue and the Ethics of Caring: A Black Feminist Methodology

In the second chapter, I will describe in detail the methodology I developed and piloted for this dissertation. As I stated above, Black Feminist Theory and Intersectionality serve as the guiding theoretical interventions for my dissertation. In this chapter, I will describe Black Feminist Epistemology and the ways I have taken it up and applied it methodologically. While my primary methods for this dissertation were interviews and observations in the tradition of constructivist grounded theory (Charmaz 2006), my methodology works to bridge Black Feminist Epistemology with these methods, going beyond them to facilitate a research process both grounded in the lived experience of Black women and produced by and for Black women.

Over the course of the chapter I provide a background on Black Feminist Theory and Black women's intersectional health research. I then describe the four core tenets of Black Feminist Epistemology and explain the methodological interventions I made to move each from an epistemological assumption about how we theorize around the lives of Black women to a methodological commitment to how we study the lives of Black women. Finally, I offer a case example from one dissertation participant to demonstrate how Black Feminist Methodology operates in practice and the way I utilized it over the course of my dissertation research.

Chapter Three: The Intersections of Race, Gender Class: Living One Day at a Time

In the third chapter, I explore the intersections of race, gender and class for Black women with cancer. I look to the impact of financial security or insecurity on the way Black women approach and understand their disease and treatment. In this chapter, I go beyond questions of income and insurance status to illuminate the ways in which class intersects with race and gender for women undergoing treatment for advanced cancer and the implications those intersections

hold for how the women view and understand their disease. I will contest the common presumption that lower class status results in a more difficult experience of cancer, or that upper class status leads to an easier one.

I will describe the experiences of two lower-income women, two middle to upper-middle class women, and two women who challenge the way we conceptualize class breakdowns. I argue that the ways in which class operates at the intersections of race, gender, and health is largely about control. I put forth the stories of two lower-income women, Linda and Jan, who both easily accept the authority of their medical providers and do not feel angry or resentful over their cancer diagnosis. I argue this is due to both women being used to a life out of control and that they thus find cancer less jarring and disruptive than other women in my study.

I then contrast their stories with those of two more well-off women, Dean and Delores. I argue that Dean and Delores both felt out of control following cancer diagnosis and both are finding ways to take back control in their lives. I argue that Dean is aware of how easily Black women are written off, and used her relative economic power to demand better care for herself when she felt her providers were not listening to her needs. I argue that Delores, on the other hand, blames herself for her cancer and turns her control inward. She attempts to regain a sense control through strict diet and exercise regimes.

I will turn, lastly, to the stories of two women who do not fit neatly into established class boundaries. I describe Flowers, a woman who is low income and receiving care at County Hospital, yet sees herself as distinct from many of the other patients there. I argue that Flowers sees cancer as a disrupter of her ability to control her self-presentation. As a Black woman, Flowers places a high value on respectability, and I argue that she attempts to maintain as much control as possible over how she is perceived by her providers in an effort to ensure she is

receiving the best care possible. I describe Marie for whom cancer has disrupted her economic control. Marie had been living a middle-class lifestyle until cancer disrupted her ability to work and drained her savings. I argue that while cancer is what caused this disruption, it is her economic situation that has left her feeling the most of out of control. I will also argue that her change in economic status impacts the ways she can enact health behaviors and attempt to control her cancer, deepening the lack of control she feels.

Chapter Four: Faith, Strength and God: Where Religion and Cancer Intersect

In the fourth chapter, I will continue my intersectional exploration by also considering the role of faith, religion and spirituality for Black women with cancer. The role of religion in oncology care is one that has been examined by biomedicine, particularly for Black women who are, as a whole, considered to be a very religious group. Yet, much of this work focuses on religion only as it impacts compliance and medical decision-making, not the lived experience of illness. Instead, I will argue that for the majority of the women in my study, and many Black women, one's faith cannot be separated from one's identity as a Black woman and it is essential to examine themes of faith, religion and spirituality from an intersectional perspective.

I will begin by exploring how physicians understand the role that faith and religion play, both for their patients and in the patient-provider relationship. I will then move to describing how the intersections of race, gender, class and religion influences the trust Black women with cancer put in their provider. While this is often framed by biomedical literature as a question of compliance, I will complicate this idea by noting the multiple systems of belief at play. I argue that some women hold two simultaneous beliefs: God works through doctors, yet humans are powerless and only God has the power to heal. I will explore the relationship between these two beliefs and the impact they have on the patient provider relationship.

I will then examine the ways in which perceived and actual religiosity shape the pervasive stereotypes of Black womanhood and the ways in which those stereotypes manifest in the clinic. I describe the stereotype of the “Mammy” and argue that her modern adaptation is that of the Black woman in the first pew at church. I will argue that while the new Mammy figure is still seen as submissive and obedient, she is also viewed as deeply religious. I assert that when patients are viewed through this lens, they may be treated in ways that utilize their perceived religiosity to encourage positive religious coping. Additionally, using this lens, providers may assume patients will be compliant based on stereotypes of submission and obedience.

In opposition to the Mammy, I will also describe the stereotype of the “Welfare Queen” and the way it is viewed in this clinic. I argue that when a patient is viewed through this lens, it was often as a way of explaining non-compliance. Women who are viewed as Welfare Queens were assumed to be “running the streets” when they missed appointments. I argue that the faith and religiosity held by these women is completely erased; they are assumed deviant and not committed to their health or families.

I will finally describe the stereotype of the Strong Black Woman. This is the stereotype that has been taken up by Black women as a means for resisting oppression. I will argue that strength not only holds specific meaning for Black women, but it also holds important connotations in the contemporary cancer experience. For Black women, strength is inextricably tied to the intersections of race, gender and religion. I will describe the intense pressure Black women face to stay strong and explore what happens in the moments when they are unable to do so.

Chapter Five: Patienthood as Identity and the Intersectional Failings of the Clinic

In my fifth chapter, I trouble the notion of what counts as an intersectional identity. I posit that cancer patienthood, one's identity as a cancer patient post-diagnosis, is itself an important identity in studying the experience of health and illness. While the importance of looking at the impact *of* identity on the cancer experience has been acknowledged, the notion of the cancer experience as being an identity itself is often ignored. Through an examination of the lived experience of three women in my study, I describe the way the intersections of race, gender and patient identity impact experiences of patienthood, relationships with providers and understanding of disease and prognosis.

In this chapter I will also describe structural intersectionality and make the case for exploring not just how intersectional identities manifest in medicine, but the ways in which medicine may reproduce structural inequalities. I argue that safety-net hospitals, like County Hospital, exist because of the multiple levels of intersectional subordination that limit access to health care. Yet, County Hospital is still unable to fully address the needs of all of their patients. I will argue this is partially due to the reality that the institution of medicine has been built around a single model of patienthood and most interventions intended to go beyond that are patchwork and incomplete. The raced, gendered and classed experience of cancer alters the identity of patienthood in a way that makes the patient-physician relationship different from that which the providers have been trained. I will argue there is a need for a more intersectional approach to patient care. Through the words and experiences of several participants I will demonstrate the way in which the identity of cancer patient shapes and is shaped by other identities such as race, gender, class, and nationality, and the ways in which patienthood itself impacts the way patients interact with their providers in the clinic.

Chapter Two: Collective Dialogue and the Ethics of Caring: A Black Feminist Methodology

INTRODUCTION

In this chapter, I will describe the methodology I developed and piloted for this dissertation. A large goal of my project, in addition to studying the lived experiences of advanced cancer for Black women, was to challenge established research methods and ways of knowing.

To begin, it is important to distinguish between epistemology, methods and methodology. I will use Sandra Harding's (1987) work and the way she defined and distinguished among these concepts. Epistemology is our theory about knowledge. It describes who can know and what can be known and how knowledge is developed. Methods are the techniques for gathering and analyzing data. Methodology is the bridge between the two. It is how the researcher chose to use the methods based on the epistemological positions she is taking. Methodology is founded on our assumptions about what knowledge is and how it is accomplished. It is where we work out the implications of epistemology. My epistemology for this project was Black Feminist Epistemology, which I will describe in detail below. My primary methods were interviews and observations, conducted and analyzed in the tradition of constructivist grounded theory (Charmaz 2006). Qualitative approaches such as interviews and observations are "thought to facilitate standpoint epistemology, whereby less powerful members of society have the potential for a more complete view of social reality than others, precisely because of their disadvantaged position" (Mullings 2000:20). However, even by incorporating qualitative methodology, I did not feel that I was fully utilizing my chosen epistemology. So I went back to the core of Black Feminist Epistemology to look for what was missing and seek an alternative way to research Black women.

In this chapter, I will begin by situating myself and my approach to Black Feminist scholarship and research. I will provide a background on Black Feminist Theory and a brief history of intersectional research conducted on Black women's health. I will then describe the four core tenets of Black Feminist Epistemology and explain the methodological interventions I made to move each from an epistemological assumption about how we theorize around the lives of Black women to a methodological commitment to how we study the lives of Black women. Finally, I will offer a case example from one participant to demonstrate how Black Feminist Methodology operates in practice. I will end the chapter by reflecting on my own experiences using this methodology.

Situating Myself

The first time I read Black Feminist Theory (BFT) as an undergraduate I felt an instant connection. As a Black woman, BFT gave me a sense of belonging. I was not alone or unique in my struggle. I was not the only one who felt distanced from academic literature or who felt that my ideas and insights were less worthy. I was not the only one who felt that what I was reading was not really for me – that I was not the intended audience. Black Feminist Theory helped me to see that while I, of course, needed to continue to grow and improve as a scholar, I could also resist the boundaries of academia. I could challenge my field and challenge the way knowledge is produced and disseminated. It was through BFT that I could see myself as a teacher, a learner and a researcher.

When I began my dissertation research on Black women with advanced cancer I knew I wanted to use Black Feminist Theory as the core of my research. As a Black woman studying Black women, it seemed like a natural epistemological fit. I felt that by grounding my work in Black Feminist Theory, I could produce research that could challenge the boundaries of

academic literature by studying health and health care in way that centers the lived experiences of Black women. I did extensive research trying to find models to incorporate BFT not just theoretically but methodologically. In exploring research grounded in Black Feminist Theory I found little in the way of new methodological interventions. While many researchers have embraced tenets of constructivist and feminist research, there has been less explicit production of methodology grounded in BFT.

I found this troubling. By seeking only to have a radical epistemology but not following through with radical methods and methodology, we may ask different questions but I think we will get very similar answers. We know from the emergence of qualitative research traditions that methods and methodology matter as they influence the types of data that are collected, the way that data are analyzed and the types of results that are found and presented. A study that uses Likert scale surveys will yield different results than an observation-based clinical trial or an interview-based Grounded Theory study. It is not only the questions that we ask, but also the ways in which we seek to find the answers that matters. Thus I knew how to articulate my questions, but I did not know how to conduct my research. Even most intersectional research methods, which I thought would be highly applicable, focused on *where* we were looking for answers and not *how* we sought them. That is, the emphasis is on doing work focused on a marginalized community at the site of intersectional oppressions – a very important goal – but I did not find any alternative methodologies for conducting such work outside of mainstream research methods. It was essential to begin by examining Black Feminist Theory in-depth to look for methodological applications.

Black Feminist Theory – Background

Black women have been historically underrepresented as both researchers and the subjects of research. In health research in particular, Black women are often only included in research that is comparative and too often it feels that we are being constantly told how we are less than, worse off, failing. Too little research holds our thoughts and experiences as central. Patricia Hill Collins (1990) made a critically important theoretical intervention towards addressing this problem with Black Feminist Theory. She offers a model of one way to explicitly bring Black women's thoughts, experiences and knowledges into academic discourse. In her groundbreaking work, *Black Feminist Thought*, she explores the oppression of Black women. Collins (1990:4) defines oppression as “any unjust situation where, systematically and over a long period of time, one group denies another group access to the resources of society. Race, class, gender, sexuality, nation, age, and ethnicity among others constitute major forms of oppression in the United States.” She asserts that Black women experience a unique form of oppression based on the convergence of many of these factors. Taken together, the “supposedly seamless web of economy, polity, and ideology function as a highly effective system of social control designed to keep African-American women in an assigned, subordinate place” (Collins 1990:5). These systems have been well set up to keep power in the hands of the dominant group and to exclude Black women from having access to power. Black women have been routinely denied access to quality education, but are then marginalized using the excuse that there are not qualified Black women to fully participate in the system.

Collins (1990) asserted the importance and existence of Black women as scholars and promoted the idea that the lived experiences of Black women can and should be studied from within the academy. Many scholars have used her theory as the underpinning for their scholarship and as a starting point for the exploration of many other groups. One area of

scholarship that has clearly engaged with Black Feminist Theory, but that has also sought to elaborate and extend it, is intersectionality.

Black Feminist Theory and intersectionality have particular relevance in the study of health. Here, intersectionality “posits that one cannot understand or reduce racial or gender disparities in health without examining the ways that institutional racism intersects with gender and class to shape” opportunities and risks associated with health and well-being (Schulz, Freudenberg and Daniels 2006:373). Further, the mutually reinforcing social relationships of race, class and gender (and many others) influence the development of unique patterns of poor health (Schulz et al. 2006). By looking at the combined impact of class, race, and gender on health, scholars and activists can “develop a more comprehensive understanding of the complex social processes that influence well being” (Schulz et al. 2006:385). By shifting our attention to the historical nature of race and the social processes of racism we are able to shift our thinking to see the constructive force of societal factors and how these shape what on the surface appear to be voluntary lifestyle choices (Mullings 2006).

The historical legacy of racism in the health care system has been theorized to contribute significantly to disparities in health outcomes in oncology care in the U.S. The National Black Women’s Health Project founder Byllye Avery described the health care system as “laced with institutional racism” and Black women as “the ones at the bottom that capitalism feeds on” (Morgen 2006:403). According to the anthropologist Mwaria (2006:289), “nowhere can the intersection of race, class, and gender be more clearly pictured than when viewing, through an ethnographic lens, medical decision-making concerning the participation of underserved populations in clinical trials.” A Black Feminist focus can broaden understanding of the decisions made between patients and physicians around the topic of end-of-life.

BFT AS A METHODOLOGY: APPLICATION TO BLACK WOMEN'S EXPERIENCES OF ADVANCED CANCER

As I described above, Patricia Hill Collins (1990) makes the case for a defined Black Feminist Thought with clear boundaries for how it is different from other forms of thinking such as feminist thought and Marxist thought. I believe the same is needed for a Black Feminist Methodology, which centers Black women's experiences and knowledges in the research process. Collins (1990:266) argues that when Black women are in charge of our own self definitions, "four dimensions of Black feminist epistemology – lived experience as a criterion of meaning, the use of dialogue, the ethic of personal accountability, and the ethic of caring – come to the fore front." In this section, I will describe each tenet in-depth and explain how I have applied it methodologically in my dissertation research.

Centering Lived Experience

The first core tenet is that alternative epistemologies are built upon lived experience, and not upon an objectified position. Instead of the tradition of turning subjects into objects of study, Collins (1990) believes that only those who experience a particular standpoint can select the topics for investigation and the methodologies to be used. This tenet of lived experience is the basis for much of my epistemological framing for my project. My work is based in the lived experience of Black women and, in service of that, I chose intentionally broad and open research questions and decided to approach them qualitatively. I wanted my research to be centered on the lived experiences, perspectives, values and knowledges of Black women living with a potentially terminal cancer diagnosis. I am striving to not privilege medical knowledge over the wisdom of my participants. I aim to let each participant shape her own story.

While I think community based participatory action research and focus groups both lend themselves well to a Black Feminist Methodology, neither seemed appropriate or feasible for my population. I wanted my participants to be involved in the shaping of my research, but it did not seem reasonable to draw women who are very ill into a multi year project. I wanted to limit their personal participation time yet maximize their individual voices. Interviews seemed like the most feasible option, so in the spirit of centering individual lived experience, I created intentionally open interview guides. My interview guide for the initial interview had only eight questions and I often did not use it at all. I allowed my research participants to set the pacing and direction of the interview. This resulted in some interviews as brief as twenty-five minutes and others that lasted two hours. While I attempted to make sure topics such as cancer diagnosis, understanding of prognosis, values and beliefs are discussed, my aim was not to have each interview be the same. I wanted to create a space that allowed my participant to feel comfortable and open speaking about whatever was on her heart or mind.

Creating a Collective Dialogue

Second, Collins (1990) advocates the use of dialogue rather than adversarial debate. The goal is not for one opinion or truth to shout down another; rather, the goal is for a conversation to exist between them and work in conjuncture to develop new knowledge. In Black Feminist Epistemology, knowledge is not seen as having an objective existence apart from lived experiences. Instead, knowledge is continually produced through lived experiences and emerges through collective dialogue.

When I began to explore the concept of “collective dialogue” in research I could only find work that positioned interviews *as* collective dialogue (DeVault and Gross 2012). While I appreciate the work many scholars have done to make interviews more closely match these

values, I disagree that interviews – as they are traditionally understood, even within the most progressive traditions – are in and of themselves collective dialogue. It is rare for the interviewer to insert herself intentionally in to the interview. In fact we are taught specifically not to do that. Our insertion comes at analysis and writing. So while we have contributions from both parties, it is not developed in a collective way. One party asks questions of the other. One party determines what will be included in the final product.

bell hooks (1989:131) wrote, “Dialogue implies talk between two subjects, not the speech of subject and object. It’s a humanizing speech, one that challenges and resists domination.” This concept of collective dialogue has historical legacies in the Black community. Scholars have traced this idea of collective dialogue as the site of knowledge production and claims assessment back to slavery. According to Belenky, Clinchy, Goldberger, and Tarule (1986) connectedness is an essential component of the knowledge validation process. Black women rarely work out knowledge claims in isolation (Belenky et al. 1986). It is a community process. Related to this is the tradition of call-and-response. Collins (1990) also speaks to the importance of call and response in the Black community. The most prevalent example of call and response can be found in worship services. Anyone who has ever visited a Black church knows that the congregation is rarely silent. The sermon is punctuated with “hallelujah” and “amen” and “Yes, Lord!” The preacher and the congregation work together to create the worship experience. It is a spontaneous, interactive process, not a passive one. All participants are active and all have a voice. A dialogue is created collectively. According to June Jordan (1985:129), “our language is a system constructed by people constantly needing to insist that we exist.” Interruption, affirmation and exclamation are an essential part of speaking patterns in the Black community.

My collective dialogue intervention involves creating a space where I echo back to participants what I am hearing from them and attempt to create a space of humble vulnerability where we can both speak about our impressions. I audio record and transcribe verbatim all interviews with participants. During and after the interview I take extensive field notes. Using both transcripts and my notes, I write up a summary of each interview, my impressions, analysis, thoughts, questions and confusions about the participant and our conversation. During the follow up interview, I read this summary – usually one to two pages – to the participant. I encourage her to interrupt me, correct me or contradict me.

My procedure of presenting a narrative summary at the follow up interview also enables me to engage in collective dialogue with the participants at the point of reflection, analysis, and knowledge production. As a researcher approaching interviews with a Black Feminist epistemological frame, I have a goal of being open and honest with my reactions, assumptions, questions and emotions during interviews. I usually respond in an open manner and do not attempt to mask my reactions and emotions. But, I am human. I cannot always articulate my response right away. I am often nervous about unintentionally offending or stumbling over my words so I do not always say what I am thinking in the moment. This process of reflection followed by sharing allows me to stay true to those ideas in a way that feels reasoned and measured. I am not merely sharing my initial response, but doing analytical research work as well as memoing on personal reactions. I am able to share with participants what they would otherwise not see until publication; how their story will be told, what themes are emerging and the analytical work involved in generating new knowledge.

In addition to my goal of establishing collective dialogue with my research participants, the collective dialogue process also has the goal of validating themes of my research. It is

important to note that I do not mean “validate” in the traditional research sense of being able to generalize my findings to the larger population. Rather, I am referring to Collins’ (2000:266) theory that Black Feminist Thought must be validated by “ordinary African-American women.” For Collins, Black Feminist scholarship needs to resonate with Black women and speak to their lives and experiences. Our knowledge cannot be produced in a vacuum from within the ivory tower, validated only after publication when it has the potential to be read and critiqued by “ordinary” African-American women. Rather, I seek to prioritize this validation as a deliberate and intrinsic *part* of data collection and as a way to incorporate collective dialogue into my research methodology.

Many feminist researchers share the transcripts of interviews or drafts of manuscripts with research participants. However, I have found in the past that most participants do not read the lengthy transcripts at all and many participants in my study have low literacy and significant time constraints that would make this process unreasonable. Additionally, while quoting from interview transcripts is obviously a part of research and knowledge dissemination, we also share impressions, we read between the lines, we ascribe themes – and I want to know how all of that resonates with my participants as well. Furthermore, sharing interview transcripts or manuscript drafts is not part of the formal data collection, nor is it a collective process. I wanted that back and forth to be done together and thus be both *about* the data and *a part* of the data itself. In this way I seek to not just ask for assent to my analysis, but to give the participants a voice in the analytic process itself. Through this process, my participants and I are able to build the narrative together. By sharing the summary I have written with participants in the second interview, the summary, the participants’ response to it and the conversation we have about it is part of the audio-recorded interview, are all recorded and transcribed along with the rest of the interview,

and therefore available for analysis with the rest of the data. Not only is the participant drawn in to the analytic process, but I also have a more clear record of my analytical thought process by capturing my own thinking and the participants' response in the recording.

Establishing an Ethic of Caring

The third tenet of Black Feminist Epistemology is the ethics of caring. This approach does not require the researcher to attempt to separate participant experience from her own experience or assume that it could be possible to separate knowledge from feelings. It is appropriate to express individual uniqueness and emotion in dialogue.

Collins (2000) describes three major components of the ethics of caring: the value placed on individual expressiveness, the appropriateness of emotions and the capacity for empathy. While many positivist researchers — or as Collins (2000) terms them “separate knowers” — try to extract individual personality from their ideas to avoid “bias,” “connected knowers” see the value that individual personality brings to the table. We all have biases, feelings, and assumptions about our research that inevitably intertwine and influence how we approach our work. The ideas that I share, the analysis I conduct, cannot and should not be separated from my person. Part of my goal in creating the collective dialogue with my participants is to bring that to the table. I allow us to dialogue about our reactions to each other. I do not attempt to hide those feelings from myself, participants in my study or the readers of my work. Collins (2000:262) uses the phrase “talking with the heart.” This is something that I do not know how *not* to do. It is difficult for me to hide my reactions and I struggle to stay present in the moment when I try. I know that I am a more effective researcher when I am honest and authentic and not distracted by the work of hiding my emotions. Sometimes this meant telling a participant I was concerned about a choice she was making or that I had heard something different in a clinical observation.

Sometimes this meant crying with patients because their heartbreak was too much for both of us. I assume that any researcher studying this topic would experience the same range of emotions that I did. I made a deliberate analytical choice to not separate those feelings from my work. I made them a part of the data, through expressing them in interviews, because I believe they are data and should be analyzed alongside the words of the participants in my study. At the same time, I did my best to ensure that my feelings, reactions, and perceptions did not overwhelm the participant's thoughts or feelings. While my feelings were very present in the initial interview, I intentionally created the space for dialogue and collaborative analysis in the second interview. This allowed my participants to freely tell their stories and allowed me time to process.

Committing to Personal Responsibility

Finally, Black Feminist Epistemology requires personal accountability of the researcher. Since knowledge is built upon lived experience, the assessment of knowledge is also an assessment of an individual's character, values, ethics and concrete practices (Collins 2000). This tenet shapes several aspects of my work. The first is the writing style and location of publications I choose. I take seriously bell hooks' (1994:71) critique that "in this capitalist culture, feminism and feminist theory are fast becoming a commodity that only the privileged can afford." That is, I want my work to be not only by a Black woman and about Black women, but to be able to be consumed and understood by Black women, across levels of education. I strive to make my research available to participants in my study in an accessible and identifiable way. I want study participants to easily recognize themselves in publications.

I have done projects in the past where I have done my best to disguise my participants. I, of course, try to protect participants' anonymity with every project I conduct because it is a pillar of research ethics. However, I also found myself wanting to ensure that my participants would

not know about whom I was referring. I found myself making judgments about my participants and drawing unfavorable conclusions that I was not able to address with the participant directly prior to publication. I did not want that to repeat that same process in this project.

I knew that I would not hold affection for all of my participants. It is just not possible. I would encounter people with whom I had little in common or whose choices I questioned. I did not want to leave that out of my writing. I did not want to be afraid of telling the negative side of stories, including the aspects of any stories participants shared that society might judge too harshly, as well as things about my participants that I might view as unseemly. I did not want to hide information to fulfill a desire to have my research be approached and seen to be approachable by my participants and other Black women. I wanted my participants to know in advance how I would describe them and to have the opportunity to refute those claims or disagree with my interpretation. And I wanted that process to be a part of my data collection. Regardless of how they responded, it allowed me to share my interpretation prior to publication when my analysis becomes public. Collins (2000) says that as a Black Feminist researcher I must be accountable for my knowledge claims. By sharing my analytic process with my participants I am striving to be accountable to them as well.

I encourage research participants to pick a code name that will be used when my research is published. I share a (de-identified) demographic description of each participant with her, which I then use as I describe participants in my writing. While I do not necessarily use the entire summary verbatim in my writing, participants are familiar with how I have described them and the types of impressions I highlight. I want to ensure that a participant can pick up a book or article published from the project and know when I am quoting or referring to her.

The history of oppression in research also guides my commitment to personal responsibility. Black women have faced a great deal of objectification in research. They have been dehumanized, had procedures done without their consent, been described in horrific terms that completely divorced them from their humanity. Research in this style is rarely approved anymore, but I know that the historical legacy has left its mark and many people of color are unwilling to engage in research because of it. Due to this history and its disparate impact on people of color, my commitment to personal responsibility is even more essential. Women of color have reason to be naturally skeptical of research and I attempt to address that potential distrust of research by holding myself accountable to my participants through the sharing of my reactions and analysis with them during the research process.

As a Black Feminist I cannot claim sole ownership of my work. It belongs to us – to Black women. My project would not have been possible without them. To take the analytic work out of their hands and concentrate it in someone who has not experienced cancer, who has great privilege in the form of education and the potential of social mobility would not be true to my epistemological beliefs.

BLACK FEMINIST METHODOLOGY IN PRACTICE—MARY’S STORY

The following is an excerpt from my collective dialogue summary with a participant who asked me to call her Mary. Mary was the sixth participant in my research study. At this point I had become more comfortable with this process but Mary had a very unique personal story and I found this collective dialogue quite challenging. What follows is the collective summary I wrote about Mary, exactly as I read it to her in our second interview. Following the summary, I will describe the process and how I utilized each of the core tenets during our interactions.

Mary describes herself as a “happy go lucky woman who ended up with cancer at 48 years old.” She’s a small woman. Much shorter than I am. She described herself as “chunky” but I wouldn't use that label at all – maybe just a little round.

She was having problems for 7 years before they found her cancer. She knew something was wrong with her and she said she went back and forth to a lot of doctors. They said gastritis, this, that. She kept having pain and lost a bunch of weight. When she was finally diagnosed, she said, very poetically, “I think one tear dropped out of my eye. It didn’t really hit me and really, it still hasn’t hit me too much”

It sounds like a lot of people in her life have had cancer. She thinks the cause of her cancer is diet related – particularly eating too much meat. She described her childhood and her mother gardening – they always ate vegetables. She had a lot of nostalgia when she described this time. It sounded like a simpler time, a happy time. A healthy time.

I was surprised she didn’t mention genetics as a potential cause of cancer since both of her parents died of cancer. This was a red flag for me but not an association she made. She did mention that she had a fear of chemotherapy because of her mom and a fear of being in a rest home because of her dad. Both seemed like very rational fears. She mentioned her sister told her she had to do chemo and was the one who really convinced her. She seemed grateful for that.

It was a hard decision for her to have chemo. She really didn’t want to get the chemotherapy and said even on the day she was supposed to start she was late because something in her mind was telling her not to take it. She thought it would do to her what it did to her mother. But, she survived it. It was hard on her – she had to come up to the hospital a lot, she had to wear a machine and couldn’t shower, bad side effects – dehydration, sick to her

stomach, affected her kidneys, finger tip problems. But, despite all that she said it wasn't an inconvenience because it helped her live longer.

She described some dementia or memory issues that frustrate her and that for the last 8 or so years since she had a surgery she has been hearing voices. She said they are mean to her. She described one day when she was feeling blue and crying about her cancer. She said the voices in her mind laughed and she thought, 'why can't I laugh with them?' It made her angry that they were laughing because she was crying and I found that heart breaking.

She mentioned she's received some psychiatric care in the past but also mentioned she isn't very fond of her current therapist. This was concerning for me. I hope she is getting proper care and I worry about the source of these voices. Is this something that can be treated? Is this the sign of a bigger problem?

Mary seemed incredibly insightful to me and I wondered if sometimes she doesn't get taken as seriously as she should or if she ever feels disrespected by the medical community. She seems to really want to help people with her story – offered a lot of advice to other women about getting checked out and going through chemo – wants to support other women.

She said she was mad at herself but I couldn't really understand why. She said she spent one day crying and asking God why me. It's when the voices laughed at her. She was angry with herself for questioning god. She shouldn't ask 'why me?' – but she feels like she shouldn't have cancer. It's just something he has to deal with. She can't be angry with god because he didn't give her the cancer. I found this heartbreaking. Why shouldn't she feel angry?

I was nervous going into the second interview with Mary. When we had spoken on the phone to schedule the interview there had been a difference of opinion over how many gift cards

she was owed in exchange for her participation. Mary had thought we had already met twice and I owed her an additional gift card but my records indicated we had only done one interview.

When we did meet for the interview Mary arrived about an hour and a half after our scheduled meeting time. I was worried she was frustrated with me based on our earlier phone conversations and the fact that I had called her several times that day to see when she would arrive for our meeting. When she arrived she was worried I was upset with her for being late. We were able to discuss this at the beginning of our interview but I was worried it would be difficult for her to be open with me.

I used all four core tenets of Black Feminist Methodology over the course of my interviews with Mary. The core tenet of centering the lived experience is one that I anticipated taking place primarily in the planning stage of my research. And, in many ways it did. I intentionally framed my research questions to be centered on the lived experience of Black women. I chose not to compare their experiences to men or to white women. I chose to center their knowledge in my analysis and use the perspectives of their providers as background and shaping information. I also chose to focus on their lives and their perspectives, rather than the biomedical scope of their disease.

Additionally, I planned interview guides that were incredibly open and unstructured to allow participants to focus on the aspects most important to them and to the telling of their stories. I found when I began my research, however, that I needed to do additional work in the interviews themselves to center the lived experiences of the participants. My first question in most interviews was something along the lines of “tell me about yourself” and many women, including Mary, would start by telling me about their cancer. They knew that I was studying Black women with cancer and that I had specifically recruited them into the study to tell me

about their experiences of cancer. That information, led them to believe that when I asked them to tell me about themselves, I was only asking to hear about their cancer. I, of course, wanted to hear about their cancer and if that is what the participant wanted to discuss, that was fine with me. What I often felt, however, is that there was an expectation that I would *only* be interested in their cancer and not their personhood. With Mary and many other women, my second question often had to be something like, “Can we back up for just a minute and have you tell me a little bit more about *you*?” I would often need to offer additional prompts like “Where did you grow up?” or “What is your family like?” or “What do you do for fun?” because the women did not understand what I meant when I asked them to tell me about themselves. Many participants told me as we were ending their first interview that it did not feel like they were doing research. It felt like they were just sharing about themselves. The concept that my research was indeed about learning about each participant was unexpected. It was not enough for me to go into my research with the intention of centering the lived experiences of Black women. I had to continually make that goal clear to the participants in my study so that they felt they had permission to tell me about their lives.

I had the intention of creating a collective dialogue with Mary, which started with the above summary I read to her. When I read her the summary I was touched by her response. She asked for a copy to keep and was pleased with my assessment of her story. There are a few places where I spoke to things that I knew could potentially challenge Mary or our dynamic. One example is around the voices she hears and her psychiatric care. When Mary told me in our first interview that she hears voices, my social work antennae instantly went up. When she seemed to not be getting stable psychiatric care I became very concerned. As a researcher I wanted to know more about these voices and as a person I wanted to make sure that she had appropriate access to

care. I struggled prior to our second interview with how to describe the voices she had been hearing. I did not want to pathologize her but, as a former social worker, I was concerned for her mental health. I was worried I could alienate her in the way I described her story, but I knew I wanted to describe it more in depth in my dissertation. I tried to balance my need for deeper exploration as a researcher with my desire to respect her humility and vulnerability for sharing a difficult part of her life with me. The joyful reaction Mary displayed when I finished reading the summary helped me to feel that I had met that goal. I chose to tell her that I was concerned and ask if she might be in need of treatment or if the voices could be a sign of a larger problem. By raising this concern, Mary was able to tell me what she sees as the origin of the voices.

Mary told me in our second interview that she does not like talking about the voices very much. She knows that people will think she is crazy. It is possible that if I had just asked her about the voices, she would have told me she did not want to talk about it, as she did with a few other subjects I broached in our second interview. But, Mary's response to the collective dialogue was to offer more explanation. She wanted to connect with me on this issue because of the way I broached it with her and because I was explicit with her that I wanted to collaborate with her in the telling of this part of her story.

In our second interview, Mary offered more insight into what she believes to be the origin of the voices she hears and her deep concerns and distrust of the medical system. My impression, that maybe she is not taken as seriously as she deserves, opened up an extensive conversation about her distrust in medicine and her theories of the true cause of the voices she hears. This is analytic work that Mary and I were able to do together. Through our collective dialogue, we were able to make a connection between distrust in medical care and worsening psychiatric symptoms, themes that would have remained separate if not for the process of sharing my

reactions and insights from our first interview. Mary believes that surgeons implanted something on her ovary during a surgery and that it caused her psychiatric issues. I have no idea if this would be seen as true medically, but it is obviously very true for Mary. She is working to resist the oppressive system of medicine and find the answers she wants. She has found people she can trust and is looking into legal options to address the injustice she believes she faced.

Similar to my concerns about discussing the voices Mary hears, I wanted to highlight what I felt was an interesting dynamic: the impact of watching her parents die of cancer with the fact that she did not see her terminal cancer as having any connection to that of her parents. I wanted to ask her about this in more detail but I did not want to come out and say that I thought the cause of her cancer could be genetic. First, I am not an oncologist or a geneticist so I am not qualified to speak to that. Second, and more importantly, I had a feeling that if I suggested that, the participant might take it as expert opinion. I wanted to be honest that it was an interesting juxtaposition to me and be honest about my reaction but I did not want to lead Mary into an uncomfortable line of thinking that might not be based in truth. Yet, I had to bring up what I thought might be an important analytic story in my project: the impact of familial experience with cancer on patienthood identity and approach to care.

Throughout this collective dialogue I demonstrated the ethic of caring that I argue is essential to Black Feminist Methodology. I highlighted my own biases and assumptions about the origins of Mary's cancer, her response to a loss of faith, and the voices she has been hearing, while attempting to still leave a space for Mary to disagree with me. I was clear that there were aspects of her story and her reaction to her cancer that I found heartbreaking. I approached Mary from a perspective of empathy, but I also did not hide the places where my own experiences and knowledge may have been in conflict with hers. Rather than attempting to distance myself from

my feelings about Mary or my assumptions about her health, I brought them into the analytic process by allowing her to comment on them.

Mary is very anxious to read more about what I write about her story. She is currently taking classes to try and learn to use computers but, with only a ninth grade education and a very limited income, is not able to access most journal articles. Even when work is published in open-access journals, the expected jargon and rhetoric may not feel accessible to someone like Mary who is not trained in sociology. As part of my commitment to the fourth tenet of Black Feminist Epistemology, I feel a deep personal responsibility to publish writing in a place where Mary and her family can read her story. She participated in my study because she wants to help other women with cancer and I want to help her fulfill that goal by making sure that women outside the academy can read my work.

Mary chose her own code name for this project. She has already heard the words above and has a sense of how she will be described in my writing. When I (hopefully) publish this work one day, Mary or her family can read it and know immediately when I am describing her. I will not be able to hide behind aggregate data or disguised participants. At the same time, because I engaged in a process of collective dialogue with Mary, I feel comfortable knowing that she is aware of my reactions to her and her story. She knows that I wonder if her cancer could be genetic and that I have concerns over her psychiatric care. My comments about the source or cause of her cancer led to a conversation about the ways other women in the study have made sense of their disease. Mary knows that I am interested in understanding how she and the other participants describe the origin of their cancer and that I will characterize and compare those answers in my dissertation. Mary knows that I will not simply be retelling or describing the voices she hears, but wondering about their origin and relating it back to the care she receives at

County Hospital. I am able to take personal responsibility for my analytical work and the way I am presenting participants in this study, and I can do so with the knowledge that they have willingly collaborated with me in that process.

PERSONAL REFLECTIONS

During the course of my dissertation research, I attempted to continually refine this methodology. I went into each interview with sweaty palms and uncertainty. It is a scary process. We do not often sit down with someone and read a summary of how we view her, our assessment, interpretation and analysis of her reaction to a major life event. Every interview I worried that I would insult the participant by representing her in a way she did not recognize or by describing her decisions in a manner that comes across as harsh or judgmental.

Traditionally, in qualitative research, we disguise our participants. We change their names, hometowns, maybe even ages and occupations so that they cannot be recognized. We use a variety of truncated quotes to tell a narrative that does not lead back to an individual. Most likely a participant would never pick up a copy of our journal article or book chapter and if she did she would not necessarily recognize a quote as her own. It allows the researcher to tell a story without regard for the feelings of the participants. I understand why that is important and how it can maintain the integrity of the researcher. One should not alter findings or manipulate details to make participants feel comfortable at the expense of the production of knowledge.

However, if we are working in service of a goal of broadening what counts as knowledge, who produces knowledge and who consumes knowledge, we are missing critical opportunities if we do not deliberately invite research participants into the process of knowledge production and dissemination. We must acknowledge research participants as partners in the production of

knowledge. It is not only researchers who are the producers; it is the participants who share from their own experiences and wisdom.

By leaving out both collective dialogue and the ethics of caring – or making them deliberately separate from the data collection process – it is easy for us as researchers to marginalize research participants. Feminist research offers new ways of thinking through important questions, but is often unable to break down the boundaries of the traditional research process. We are looking for the right things but in the same way. As Audre Lorde (1984:110) said, “the master’s tools will never dismantle the master’s house.” If the goal is to fundamentally change the way we study the experiences of marginalized groups we need to go about it in new, empirically driven ways. I have created new tools to be used in the study of Black women in a way that is grounded in a Black Feminist Epistemology.

Throughout the rest of this dissertation, the narratives used to describe each participant are based in the collective dialogue summaries I wrote and shared with the participants. Each participant is referred to by the code name she chose for herself. My writing style is often less formal than most academic writing and often speaks to my own feelings and assumptions about the participants in the study. I believe the data and analysis presented here is richer because the voices of the participants have been centered and we were able to work together to produce the new knowledges that will be described. Each participant in this study left her mark on me and on this dissertation.

Chapter Three: The Intersections of Race, Gender and Class: Living One Day at a Time

INTRODUCTION

In this chapter, I will use intersectionality to conceptually and experientially describe the cancer experiences of Black women across the economic spectrum. When thinking about intersectionality, the most common framework employed is to examine race, class and gender. In public health and biomedical literature, researchers examine how these ‘risk factors’ impact health status. Yet, there is not enough work looking at the complex intersections of these identities and their impact on the experience of health and illness.

In this chapter I ask, how does class status intersect with race and gender identity for Black women with advanced cancer? How does financial security or poverty impact the way Black women live with metastatic disease? While income and insurance status dictate many medical choices in the U.S., my questions go further than that. Through exploring the narratives of six women at various social locations, this chapter illuminates the ways in which class intersects with race and gender for women undergoing treatment for advanced cancer.

I begin by first describing the ebb and flow of waiting and care that Black women experienced in County Hospital, the site of much of my fieldwork. Despite the varied class status of the women in my study, those who were seeing oncologists at County Hospital, did so for multiple reasons: for some, this was the default hospital where they were covered for care; for others, it was the nearest hospital to their neighborhood; and for many, it was the only place where they had ever received care. This health care facility, like many social institutions that serve the poor, imposes a great deal of delay and waiting on their clients, and demands that they pass time on the premises. Waiting is a constant theme in the lives of poor women. They wait for services, they wait for appointments and, as was often the case in my study, they wait for a long time after the onset of symptoms to finally receive a diagnosis of cancer. Waiting is an expected

and often accepted part of care for patients and indeed, many lower-income women in my study are not surprised or frustrated by the wait time for their diagnoses.

I then describe the experiences of two lower-income women, two middle to upper-middle class women, and two women who challenge the way we conceptualize class breakdowns. I argue that the ways in which class operates in the intersections of race, gender and health is about control. I chose to use the term “control” to speak both to the rhetoric of the lack of control of cancer, as well as to appropriate the term from biomedicine that refers to controlling cancer as a way of treating a disease that is incurable. Cancer disrupts a sense of control and forces people to live one day at a time because so much of the future is unknown. Many women in this study look for ways to reassert control into an uncontrollable situation, but this operates very differently in the lives of Black women across the economic spectrum.

The two lower-income women, Linda and Jan, both easily accept the authority of their medical providers and do not feel angry over their cancer diagnosis or how long it took for that diagnosis to be made. Both Linda and Jan are used to life out of control and the lack of control they now have over their health due to their cancer is not as jarring as it is for other women in my study.

I contrast their stories with those of two relatively well-off women, Dean and Delores. Dean and Delores both felt the shock of the loss of control when they were diagnosed with cancer. Dean, a former corporate worker and life-long community organizer, was used to standing up to authority and demanding better for herself and others. She knew that it was easy for Black women to be written off and used her economic power to demand answers, to ensure that her cancer was diagnosed and to take back control over her treatment decisions when she felt the doctors were not listening to her. Delores, on the other hand, turns her fight for control

inward. She blames herself for her cancer and has fought to regain a sense control through strict diet and exercise regimes.

I then explore the stories of two women who do not fit neatly into established class boundaries and describe the way that cancer disrupts their sense of economic control. I describe Flowers, a woman who is low income and receives care at County Hospital but sees herself as very different than the other patients who receive care there. Flowers feels like cancer has disrupted her ability to control her self-presentation and she tries to maintain as much control as possible over how she is perceived at the hospital to ensure she receives quality care. As a Black woman, Flowers knows that presentation and respectability matter when you want to be treated well. I also describe Marie, a woman who was living a middle-class lifestyle until cancer disrupted her ability to work and depleted her savings. She was thrust suddenly into economic instability and feels like she is spiraling completely out of control. While cancer caused this disruption of control, it is her economic situation that has been the most difficult for her. Additionally, her change in economic status have impacted the ways in which she can enact the health behaviors she has valued for so long, making her health feel even more precarious and her life to feel even more out of her control.

Through these stories, I will highlight themes of blame, responsibility, acceptance of cancer and the desire for control over cancer and in medical encounters. I argue that the intersections of race, gender and class impact the ways in which these themes operate in both how women respond to a cancer diagnosis and the ways in which they approach the management of their disease. I will demonstrate that social class identities and socioeconomic status create unique sets of challenges for women based on how they intersect with their other identities. In so

doing, I contest the common presumption that lower class status results in a more difficult experience of cancer, or that upper class status leads to an easier one.

Often, intersectional or class-based research looks solely to household income as a proxy to class. Yet, particularly when studying a population of people who are older and often unable to work because of illness, factors other than income must also be considered when making class designations. While very real and tangible in our society, the way class is manifested varies from person to person, and can change in different locations or situations. That is, social and economic class, like race and gender, are social constructs. They are also relative too: For example, this study took place in a region with one of the highest median incomes in the country. While some participants reported incomes that could be considered “middle class” in some parts of the country, these women may be struggling economically in their community, which has high median income levels and cost of living. Additionally, many participants in this study are primarily dependent on Social Security or Social Security Disability Insurance and the majority were not working at the time I spoke with them. This is understandable as many were undergoing treatment or very ill. However, despite the similarity of living off a fixed income, my perceptions of their social class and their own description of their financial situations was highly variable. It was important to me to examine class as an integral part of identity. How the women talk about their own class and how they conceptualize their own class matters even more than how someone outside of their situation may classify them.

Accordingly, the individual markers of class that I looked to included:

- Education level
- Previous employment: Had she worked in the past? In what type of occupation and with what level of expected income?
- Living situation: Did she live in houses, apartments or single-room occupancy units? Did she live on her own or with family? How long had she lived in her current arrangement?

- Support network: Was she the sole breadwinner in her household? Did she have family or friends who were able to provide food or housing if needed?
- Personal narratives: How does each woman talk about her own socioeconomic position? Has this changed since her cancer diagnosis?

Based on these multiple markers, then, the social class profile of the 20 Black women who participated in this study is as follows: Only one participant in the study was currently married, though two lived with long-term partners they referred to as their husbands and several were divorced or widowed. Two participants reported completing some high school, seven reported earning a high school degree or GED, six reported taking some college class, two had earned AA degrees and three reported earning a college degree. Twelve participants reported making less than fifteen thousand dollars annually, four reported making between fifteen and seventy-five thousand dollars annually, one woman reported an income of over two-hundred thousand dollars and three women did not know or declined to answer. Three of the twenty women were currently employed with most of the others retired or on disability.

WAITING AND THE SAFETY-NET HOSPITAL

As described in the Introduction, I spent ten months attending two clinics per week at County Hospital. During each clinic, I would sit in the provider charting room and wait for potential participants to arrive. It was a space in which I always felt awkward, as if I occupied too much space. On teaching days, when hematology/oncology fellows are seeing patients and attendings are supervising, the room buzzes with energy. There are five computers and six chairs but between fellows, physician assistants, attending physicians, social workers, a pharmacist, medical students, nurses, medical assistants and patient navigators there are often fifteen or more people crammed into a tiny room.

The room is often very warm. People squeeze past each other to get to a computer or a person or to see a patient. They form into small groups of two or three to discuss a patient and

these groups ebb and flow as new people join the conversation to debate the merits of a new drug protocol or gather around a computer to examine a PET CT scan.

The attending physicians, support staff and physician assistants have worked together for years and fluctuate between treating each other as treasured friends, before abruptly switching into a more adversarial mode when they debate or advocate for a certain treatment protocol. New fellows rotate through every six months and there is always an adjustment period as they learn the ropes and the rhythm of the clinic. The providers here are world class. They graduated from top training programs and are well published and respected in their field. Most of them chose to work at a safety-net hospital because of a deep affection and respect for the unique patient populations they see. They are fierce advocates for their patients, and will fight tooth and nail to make sure their patients get necessary services.

The clinic is very old school in a lot of ways. In contrast to the advanced system and care provided, the clinic still functioned in a way that felt very low tech. It was only recently, during my fieldwork, that County Hospital transitioned to an electronic medical records system in an effort to modernize charting and patient monitoring. The clinic was hectic. There were IT staff present during the transition to teach and assist with bumps. The clinic staff slowly began the process of clearing out all the paper charts and a couple doctors resisted and resented the change. These doctors felt like the need to chart electronically changed the dynamic in clinical encounters. Other low-tech parts of the clinic process remained, however. All the providers' names are listed on a white board with their schedule of patients written underneath. A medical assistant writes "WR" next to the patient name after the patient has been "vitalized" (a medical assistant measures weight, blood pressure and temperature at the start of each visit) and is in the waiting room. They place a piece of paper with the vital signs on a shelf labeled with post-it

notes to indicate where each provider can find their patient forms. When the patient is ready to be seen the nurses crosses out "WR" and replaces it with the room number. The provider is supposed to cross out the name when the patient is done, but the fellows often do not learn the system and forget. This leads to lags as the nursing staff scrambles to find out which patient is currently being seen.

Many patients here do not speak English and medical visits are conducted in several languages, some with the help of translators and others via bilingual (or multilingual) providers. Patients at County Hospital tend to be low income. While this hospital is affiliated with a research university and academic medical center, there is a clear divide — largely based on insurance status — between the patients who are seen at County Hospital and those who receive care at the academic medical center. The city where the hospital is located has a universal health care system in place. All residents can be covered under the citywide plan and County Hospital is the in-network hospital and care provider for this plan.

The clinic tends to run behind schedule — very behind. I often found this frustrating— both vicariously for all parties involved and for myself when I was waiting to meet a patient. The providers often started their clinics late, sometimes by more than an hour, and patients would often be late or never arrive for appointments. This means waiting was just part of the ebb and flow of the clinic. In fact, waiting was sometimes built into the schedule. It was common for providers to double book time slots, with two different patients scheduled for the same fifteen-minute appointment block. It would be nearly impossible for a provider to see all of their patients if they double booked too many slots, but the providers would do it often to make sure they could see a patient if a problem arose or if a delay in seeing the patient would mean a delay in treatment. The system was able to work because providers knew there would often also be a few

no-shows. While occasionally all the patients would show up on a day when a provider was overbooked, causing the appointments to run past the end of clinic, usually there were at least a few patients who would miss appointments and the schedule would eventually even out. However, this meant that individual patients would have to wait well past their appointment times.

To an outside observer, time feels elastic at County Hospital. The schedule is slowed down by the necessities and requirements of teaching, but speeds back up by patients who do not show up for appointments or those who do not have many questions or concerns. While providers would express frustration over patients arriving late for appointments, I did not hear complaints about the reverse from participants in my study. I would sometimes ask about it directly when I knew a patient had been waiting well past her appointment time and I always asked participants how they felt about the care they received at County Hospital, but waiting was not expressed as a problem.

The experience of waiting is prevalent in health care—waiting to see the doctor, waiting for test results. When the health care systems of other countries are described in negative terms, what is often highlighted is the long wait time to see a specialist or receive a medical procedure. While waiting is an accepted, if begrudgingly, as part of health care delivery, waiting is also framed as an enemy in cancer treatment. Waiting too long for a screening or to start a treatment is seen as deadly. A patient choosing to wait to begin treatment is viewed by many, particularly healthcare practitioners, as tantamount to choosing death. Yet, for the participants I met through County Hospital, waiting was hardly mentioned.

From an outsider's perspective, I see this waiting as just another example of the lack of control these patients have over their lives. For most of the patients seen at County Hospital, they

do not have a choice in provider. Insurance status and the inability to pay out of pocket have dictated which providers would be willing to see them. Even if they were frustrated by the amount of waiting, or another aspect of their care, they would have an incredibly difficult time finding another oncology clinic where they could receive care. This lack of control over cancer and medical encounters was a constant theme for women in my study but it manifested in many different ways for women across the economic spectrum.

POOR WOMEN AND A LIFE WITHOUT CONTROL

Overall, the patients I spoke with from County Hospital were satisfied with their care. Most felt that their providers were the ones making the decisions about which treatments they would have, and they were comfortable with that. Most of the women I spoke with who received care at County Hospital were very low income. Many lived in single room occupancy units. Several had been in and out of jail over the course of their lives. The vast majority had other health issues ranging from high blood pressure, to HIV, to chronic pain, and had been receiving care at County Hospital for many years. Cancer was one component of a larger story of a foiled struggle for agency, part of a narrative that emphasized lack of control over their health and the trajectory of their own lives.

Accepting the Lack of Control—Linda's Story

Linda is a 58-year-old woman with advanced lung cancer. When I met her, she was undergoing both chemotherapy and radiation and had to go in for treatment five days a week. In her words, “it sucks.” The chemo was making her sick and the schedule was grueling. But Linda was determined to make it through her treatment.

Linda was born and raised in the city and she comes from a large family of seven sisters and four brothers. One of her sisters had breast cancer and she also has a nephew who is in

remission from leukemia. She spoke of her nephew giving her strength – she called him a soldier and knew that if he could do it, she could too. Linda has never married and does not have any children of her own, but she has a lot of nieces and nephews nearby who often take her to and from appointments and call and check on her since she lives alone.

When I asked Linda how she reacted to the news of her cancer diagnosis she said, “I didn't take it good. I didn't take it bad neither. I say, well, I got cancer. I didn't really trip on it. Every now and then it hits me, but I don't even think about it. I just think about getting better.” Linda accepted the fact of her cancer fairly easily. She heard the news and was just ready to start treatment. She also mentioned not wanting to learn very much about her cancer. She told me, “When they told me I had lung cancer I just figured I just have lung cancer. I don't want to know nothing else about it. I just want the treatment, get it over with.”

Linda did not seem bothered by the lack of control she had over her cancer. She was comfortable with her providers being in control most of the time. When I asked her how she decided which treatments she wanted she said, “The doctor decided. I didn't have none of the decision on that.” She did not see herself as a part of the decision-making process at all. She did not feel she had a voice in picking her course of treatment and she was comfortable with that. She is used to that model of medical care.

Linda started having symptoms of her cancer about three years before she was diagnosed. She had been losing weight and went to the doctor repeatedly. They did some blood work but it was not until they did x-rays that they finally diagnosed her. I asked her if she felt like they could have found it earlier and she said yes, she thought they could have if they had done the x-rays sooner. When I asked if that frustrated her, Linda responded, “No. Shit happens.” This sentiment never ceases to amaze me. My internal reaction as well as my response to the participant were

based in sadness; I know that I would be incredibly upset if I felt a diagnosis had been missed or delayed for years. I would want to know why that had happened to me. I would want to take action to rectify the situation, even knowing it would not change anything. However, upon analyzing our conversation, I was able to see how this is based in my own social location. While Linda and I are both Black women, when it intersects with elements such as my education level, work in and study of health care, and social class, my expectations for the type of medical care that one deserves to receive and who is to blame for a lack of diagnosis differ radically from Linda's. The idea of early detection of cancer as critical to cancer survival has been so engrained in my thinking that any disruption of that incites a strong reaction. Linda does not approach biomedicine and cancer from the same perspective. She does not have the illusion that she is owed something by biomedicine and does not waste energy feeling angry about the circumstance that led to her diagnosis. In Linda's life, "shit happens." She accepts that she is not in control and that there is nothing that can be done about it most of the time.

Linda told me that she is happy with the care she has received at County Hospital. She thinks the people are nice and friendly. During the clinical encounter I observed, Linda expressed some frustration with her social worker. Linda complained to the social worker about how long it was taking to have some paperwork processed. I had expected Linda to express even more frustration when we spoke about it privately, away from the social worker and her physician from whom she needed services. However, when I asked Linda about it, she said, "Oh yeah because she wasn't getting the paperwork I needed. They need more social workers. They only have like a very few for all the patients they have. So you have to wait. Just have to be patient. But I finally got the paperworks I needed so I was all right." Linda easily acknowledged that waiting was a part of the process and that the employees were working with limited time and

resources. While she had some frustration in the moment, she did not blame the social worker; she knew it was the system. Linda was used to having to wait for these types of services and, in fact, she had spent time in the past volunteering at County Hospital, and she therefore was aware of how short staffed most department are. She could accept that the timeline was out of her control.

I asked Linda if she had a sense of why she got cancer or where it came from. Linda said, To me, I smoked for 40 years but it's not just from that. It wasn't only from that factor. I think my environment, the factor – I used to live in a housing project, which had mildew. I used to work at a company, which had asbestos. And top of all those, that's what I blame it on.

Linda, like many of the women I spoke to, acknowledges that smoking may have played a role in causing her cancer. However, she also thinks that outside factors, things out of her control, were a part of it. While she accepts some responsibility, she is not really blaming herself. Her answer was similar to what I heard from many women at County Hospital who acknowledged the role that cigarettes and other lifestyle choices may have played in their cancer, but also looked to factors such as the environment and working and housing conditions that could have contributed to the disease. One woman, Oleos, spoke directly to the intersections of race and class, noting the high rates of cancer in her predominantly Black working-class neighborhood and making an explicit link to “dumping” of environmental toxins being permitted because it impacted a group at the bottom of the social hierarchy. While others did not speak to this directly, many of the women alluded to this idea of their social location creating the possibility for cancer.

Linda does not seem to have guilt over her cancer. She expressed that getting cancer is something that was not really in her control. Linda spoke about making small changes to her diet

like trying to eat less fried food and she is considering cutting out chicken because she has heard bad things about the way it is handled. She does not know if it would have any impact on her cancer, saying it “might help” but she figures it could not hurt. However, she is approaching this fairly casually. When she has the time and energy to think about what she is eating, she tries to make different choices. But, when she does not, that is ok too. She does not see these changes as directly related to her cancer, saying “the treatment itself” is the only thing that can help her beat the disease. For Linda, the ability to control her diet is not directly tied to a desire to control outcomes of her cancer.

When You Have No Control at All—Jan’s Story

Jan is a 50-year-old woman I met through County Hospital. Jan is a woman who speaks her mind and is not afraid to ask questions. She has dealt with tremendous tragedy in the last year since her diagnosis. Her son was murdered and the police do not seem to be invested in finding his killers, her daughter was arrested and has been in and out of jail for a crime Jan is not sure if she committed, and Jan was diagnosed with Stage IV lung cancer. One of the first things she said to me was that she “couldn’t say nothing” about her cancer because she knew she smoked cigarettes. That made me sad and I told her so – that I thought she had the right to feel how she felt about her cancer regardless of her health history. Jan placed some of the blame for her cancer on herself, though she later offered other possible theories for the origin of her disease such as her sub-par housing, but it was stated in a matter of fact way. She did not seem to dwell on it. She merely accepted it, to the point where she told me:

Sometimes I say I value my life. Then again, it doesn't make any difference if I die or not. Because I have stage IV cancer and I think that's the last stage, right? So it doesn't bother me. If it's my time to go—that’s one thing people don't

realize. When you're born into this world you have a birthday. And they don't realize that you also have a death day.

Jan is not suicidal or ambivalent about continuing treatment. She is still hoping for God to save her if He has a reason to, but the cancer is not the tragedy in her life. Her son being taken from her so young was a tragedy. When we spoke about her son I could see the almost physical pain of grief she experienced when remembering finding out he had died. It was a sharp contrast to the matter-of-fact way she spoke of her advanced cancer. The failings of the criminal justice system – both for her son and her daughter – are a tragedy to her. Cancer is just something that happens, and maybe she will get better, maybe she will not. While she acknowledges the role her smoking may have played in causing her cancer, she does not seem to blame herself. She just accepts that she made choices and she cannot change anything now. It does not make sense to dwell on it.

For Jan, the intersections of race, gender and class has manifested in a social location of violence. Her son was killed in a violent act. Her daughter is under the control of state sanctioned violence via the criminal justice system. For poor women of color, these are unfortunate realities. Living surrounded by this type of violence means that life is often unstable and out of one's control. It means that tragedy will strike and you have to find a way to keep living, putting one foot in front of the other. As Jan said, "I couldn't say nothing" and "I don't feel angry." She sometimes wonders, "Why does all this stuff happen to me?" but she also said that she is not worried. What she cares about is making sure she is getting her treatment and, ultimately, she said, "I just want to have a nice funeral. That's it. And I want to be buried where my son is at." Jan did not have the option to be overwhelmed by her circumstances. She had to, at least on some level, accept that which she could not control and keep finding ways to move forward with

the things that she could control. She had to plan a funeral for her son and now she is making sure arrangements can be made for her as well some day.

It seems like Jan looks for reasons and explanations for her cancer—she wonders if mildew in her apartment contributed to her cancer—but she cannot always find them. She wonders why the police have not caught the person who murdered her son. But, so far, it does not seem like she has gotten the answers she needs and deserves. At the same time that she questions criminal justice system and other authority figures around her, Jan puts a tremendous amount of trust in her doctors. In fact, part of her faith is trusting in the medical system and following the advice of her doctors. She told me that God “put the doctors here to save people” and that if “you don’t utilize their service...then when you die, you can’t say you was trusting God.” For Jan, to attempt to seize control in medical encounters or medical decision-making could be considered a sin.

For Jan, a woman who is used to facing heartbreak and tragedy, cancer is just one more thing out of her control. It is just one more disruption in her life, but not the major one. Both Jan and Linda accept that in life “shit happens.” They know that they have to just keep on living and finding ways to get through. While cancer may represent life being taken completely out of our control, Jan and Linda are used to those types of disruptions. They have been forced to accept what has happened to them and find a plan to move forward.

MIDDLE CLASS—PLANNING AND CONTROL

For the wealthier women in my study, the cancer diagnosis forced them to feel out of control in ways that were much more jarring. In this section I explore the stories of two women, Dean and Delores, who are more stable financially. I will show how the intersections of race, gender and class operate for these women and the very different challenges they face following a

cancer diagnosis.

Using Economic Privilege to Assert Control—Dean's Story

Dean is a 66-year-old woman who was diagnosed four years ago with bladder cancer. She is sweet, expressive and easy to talk to. Dean is one of the more well-off women in my study. She lives in a beautiful home that she has owned for many years.

She worked for a large corporation for her entire career and retired about five years ago, right before she got sick. As she put it, she had “one fun year.” Her cancer first presented with persistent vaginal bleeding. She went to her primary care doctor, who sent her to specialists, all of whom just gave her antibiotics. This went on for over six months before she finally said, “No, wait, wait, wait, wait, wait. I have insurance. Don't you guys believe in taking some tests?” After she, in her words, “got to hollering” and they ran some tests, they found her cancer. Dean clearly used her economic privilege to access better care. She felt that she deserved quality treatment because she pays for insurance that should cover it and she wanted to be taken seriously. She stated that she often felt that her providers did not take her concerns seriously and, in this example, she used her insurance as leverage. Dean's relative wealth and social class allowed her to be the “squeaky wheel.” Dean had the option to seek out different providers if she did not receive the services she felt she deserved. She expected, indeed, demanded better medical diagnosis and treatment, perhaps as a way to compensate for assumptions made about her because of her race and gender. In stark contrast to Linda who went three years without a diagnosis, but did not express anger over the situation, Dean was mad at her doctors and told them so.

After Dean's cancer was diagnosed, her doctors operated and found that the cancer was more widespread than they thought and referred her to an academic medical center to see a

specialist. She saw one of the most-sought-after surgeons in the country and had a very innovative surgery where they made her a new bladder out of her intestines. She was then referred to an oncologist for chemotherapy. Dean told me that she was feeling pretty good after her surgery. She had lost weight but that was to be expected. But, the doctors said that there were some “spots” on her scans but that no one could confirm for her that it was cancer. She told me, with a great deal of regret in her voice, that she let her oncologist “talk her into” chemotherapy. Dean had relinquished control to her doctor. She had allowed him to talk her into something she did not think was a good idea and she blamed both him and herself for it:

I'm going, 'Just a little spot, blink, and I can't even see it. Why are you insisting that I have chemo?' He insisted, he insisted. That chemo almost took me out of here. I did it for three or four months, and it just-I don't know, I got mad at [the doctor]. I told him he wasn't paying attention to me. I kept on telling him, 'This dosage is too high for me.' I couldn't eat, I had diarrhea all the time.

She ended up being hospitalized and they stopped the chemotherapy early. I asked her about how her provider reacted when she wanted to stop the treatment and Dean told me, “He had no choice. That decision was not up to him, it was up to me.”

This is not something I have heard from patients of a lower economic status. Many stop coming in for treatments or appointments, but they do not talk about confronting their providers in the same way. The power dynamic feels different. Dean readily expressed distrust and dissatisfaction with her providers, in a much more overt way than any of the patients I met through County Hospital. Dean was clear that, ultimately, all of the decisions about treatment were hers to make. While she felt like her oncologist talked her into chemotherapy, it is still distinct from what I heard from many patients, which is that their provider decided what the

course of treatment would be. While I know that, legally, all the participants in my study were required to consent to their treatment, it is clear that not all felt that they were making an active decision. Dean found ways to assert her authority and autonomy in her medical process and was able to recognize when she was not being treated as a priority or as a decision maker. The fact of Dean's cancer was out of her control, but the decisions about treatments and providers were not. Dean was ultimately the one calling the shots.

Dean has been a community organizer working with prominent city officials for years. She is used to standing up to power. She was able to translate that to medical encounters and ask for additional tests. Yet, she still consented to therapy that she did not want based on her provider's recommendation. While many lower-income women expressed an inherent and somewhat unwavering trust in their providers, the wealthier women in my study were much more cautious. Their trust had to be earned. As Marie, whom I describe more in the next section, said,

I question doctors. I've been thrown out of doctor's office... Because you don't know everything, just because you're the doctor. I can read books and I know my body and maybe you [the doctor] were high that day and missed that or maybe you're not as conscious or whatever. I question everybody and a degree don't mean anything to me.

For middle and upper class women in my study it was not automatic to relinquish control of their health to their providers. While many of them felt positively about their doctors and followed their recommendations, there was a much greater awareness that it was they, the patients, who were ultimately in control of all decisions being made. Cancer was jarring for many of these women because it felt so out of control, but maintaining autonomy in medical

encounters was one way to attempt to try to keep some control in an uncontrollable situation. These women were thrust into a dilemma based on their social location. Their experiences as Black women have made them naturally skeptical of authority figures while their relative class privilege and access to health resources has afforded them increased health knowledge. However, as Crawford (2004:524) writes, “On the one hand, health knowledge cannot sustain nor regenerate trust in government or corporations. Even medical authority suffers...medicalized subjects come to suspect the messengers and the knowledge they bear.... On the other hand, the dream or ‘mirage’ of health... propel the embrace of medical authority.” These women want to find ways to seek control while still embracing medical authority enough to obtain the potential goals of health and longevity. Yet, they make it clear that their trust is not a given and must be earned.

Finding Ways to Control the Uncontrollable—Delores’ Story

Delores is a 73-year-old woman with widespread gynecological cancer. She is sweet and a bit demure. When we met, she spent a great deal of time boasting about her grandson who was about to graduate high school and had a scholarship to college to play football. Family has surrounded her throughout her cancer— something that has been rare in my study - and she calls her daughters “her strength.” Her family is very important to her and she takes pride in her home; she was anxious to show me photographs of her family and artwork she had displayed. When I asked Delores about her household income, she was not sure what it was. She has a long-term partner whom she refers to as her husband even though they are not married. She told me she has never asked him about his finances. She only knew how much her own social security was. However, Delores’s home is quite large and immaculately kept. They were several cars parked in

the driveway that were newer models and she had a private Medicare supplemental insurance plan. I felt sure that Delores was much wealthier than the majority of participants in my study.

When I asked her to tell me about her diagnosis, she said, “This is so sad for me because I think my cancer is all my fault.” She was experiencing some vaginal bleeding and did not pursue it with her doctor “quickly enough.” She felt like her cancer could have been caught earlier if she had been more diligent and followed up with her provider. This idea of early detection as prevention, a way of thinking incredibly prevalent in cancer discourse, especially for women, came up rarely in my study. While many women expressed feeling at fault for their diagnosis, most were related to lifestyle choices such as smoking or diet. I assert that that, for the women in my study, there is a key distinction between the idea of early detection as prevention and the potentially causal relationship between lifestyle choices and the onset of disease. While both are potential sources of self-blame for patients with cancer, early detection as prevention speaks directly to a patient’s ability or willingness to interact with biomedicine at a time of relative health as opposed to the life-long, everyday decisions made about health. None of the women in my study were diagnosed through routine screenings and very few expressed any concern over not having been proactive enough in finding their cancer. Delores was a clear exception to this. Delores felt like she could have been in control of her health, but she failed. By not reporting her symptoms immediately, she allowed her health to spiral into an out of control situation. Delores blames herself for her cancer because she thinks she could have controlled. She believes she should have been able to secure a different outcome for herself. Delores’ identity plays an important role here. She has a different level of “health consciousness” (Crawford 2004:507) than many women in the study and, perhaps accordingly, carried her “own burden of anxiety [for] failing to act in the face of insidious disease” (Crawford 2004:510).

After her initial diagnosis, Delores did a round of chemotherapy, which she tolerated well. A few years later, her cancer recurred and it had spread. She decided to get a second opinion on her recurrence; she was one of only three women (all middle or upper middle class) in my study who has sought a second opinion. When I asked her why she did so, she told me it was because she had seen it on TV and figured, why not? She did not have a specific complaint about her doctor and did not doubt his assessment. But, she had the resources available to her and felt like it could not hurt. She decided to continue with chemotherapy with her original provider, whom she very much liked, but this was a small way of attempting to assert control over the situation.

While her first line of chemotherapy was tolerable, the second was horrible for Delores and she elected to stop treatment early. She felt incredibly sick and weak and did not think her body would be able to fight the cancer in that state. While she continues to see her oncologist, she has turned to alternative therapies. She watches infomercials and talk shows featuring doctors and buys the vitamins and supplements they recommend. She talks about them as if they are talking to her directly saying often, “Dr. So-and-so told me about this....” She believes the advice she hears and thinks that the supplements have the power to cure cancer. Delores also met a man who sells tapes of breathing exercises that he says cure cancer because oxygen can cure cancer. She beats herself up for not doing the exercises regularly and to completion. When I asked if they might be difficult for her because of the cancer in her lungs, she was quick to dismiss that idea and felt that it was a matter of determination and will power. Delores has been on a very intense nutrition plan where she eats only raw fruits and vegetables – no meat, no bread, no dairy, nothing cooked. She takes a great deal of pride in her nutritional plan. It is not easy for her to find things she can eat and she mentioned that she has stuck with the plan for

longer than it was recommended. She is in a group with others who were following the same plan and they were only instructed to follow it for a few weeks. She has continued with it for months.

This pattern of intense focus around alternative therapies is something I have seen in previous research projects, but it is the first and only time I saw it in this study. Delores is using resources available to her, mostly those outside of the formal medical system, and her current experience of cancer is defined by her quest for health and her vigilance in following miracle cures. It seems like it may be a result of her perception that she was not as proactive as she could have been. Delores is seeking to control *something*. She cannot – or did not effectively – control her cancer, but she can control her diet and exercise regimen. She has sacrificed things like friendships, activities she used to enjoy, and eating meals with her family in service of these alternative therapies. She is seeking to control as much of her health as she can in the hopes that it will, ultimately, help her control her cancer.

When I ask women in my study where their cancer came from, most are unsure and some have not thought about it. A few attribute it to genetics and some mention environmental factors – mostly things out of their control, like poorly maintained apartments and refineries in the area. Others say they know it was from smoking and say they cannot blame anyone but themselves – some keep smoking because they figure the worst has already happened. A few have made some lifestyle changes, such as eating less fried food and giving up smoking, but Delores is unique in my study for her approach to cancer.

Being able to refocus one's life, to take advantage of alternative therapies, support groups, nutrition classes, special food, is both a privilege and a curse. Most women in this study could not afford most of these interventions and Delores is finding a certain amount of control

over her disease and illness experience, noting that she feels like “chemicals are leaving my body and going away” since she has started this diet. Conversely, Delores is beating herself up over her inability to perfectly follow all of these alternative therapies and treatments. Crawford (2004:506) speaks to the “escalating spiral of control and anxiety” that has become a hallmark of modern medical culture. Delores blames herself for her cancer, which causes her anxiety. She was supposed to be in control of her health and she let herself down. Now she is trying to be back in control through diet and exercise. Yet, in a sense, the more that she is able to control, the “more apparent becomes that which eludes control” (Crawford 2004:506). Crawford (2004) asserts that patients attempt to manage the guilt, the blame, the anxiety, and the risk that are associated with disease through imagining themselves as in control, regardless of if that control is truly possible to obtain. The more control that Delores attempts to have, the less in control she is ultimately able to feel.

THE FLUIDITY AND INSECURITY OF CLASS STATUS

While many of the participants I recruited for this study were living at or below the poverty line, I encountered key differences in how women in the study experienced class identities. The physical effects of cancer diagnosis and treatment pushed some women out of their normal jobs and out of their middle class expectations. The impacts of class dynamics, poverty and insurance status influenced not only where they could receive care, but also how they interacted with medical providers and their attempts to make sense of their cancer diagnoses.

Maintaining the Image of Being in Control—Flowers’ Story

One example is Flowers. Flowers immediately struck me as different from many of the patients at County Hospital. She carries herself a bit differently. She is a beautiful woman. Her

skin is flawless and glowing and she just presents as effortlessly chic and classy. She seems so smart and in control. She has been very proactive about her cancer. She searches Google for new drugs or treatments. In fact she knew she had cancer by Googling her symptoms. Flowers likes being in control in that it is important to her to be able to take care of herself and not be dependent on others. While she expressed that she has no problem asking for help from time to time, she does not want to feel dependent on others in case no one is around. She wants to be able to live her life without worrying about when or if the nurse is coming over to assist her.

Cancer changed her life dramatically, which feels different from many of the patients I met in County Hospital. It does not sound like it is something she expected and when we spoke she asked several times, rhetorically, “Why couldn’t I get a regular cancer?” – expressing frustration that not only does she have cancer, but a rare form and an advanced stage.

Additionally, her cancer surgery led to severe kidney disease that has meant that she has had to use urine collection bags, which have disrupted her quality of life tremendously. She feels self-conscious about the bags and worries that others can see them through her clothes. She has also been on and off different medications to try and combat her kidney disease and they have each come with different and compounding side effects. Her kidney disease, in many ways, has been harder for her than the cancer itself.

Flowers is clearly frustrated by the way cancer had changed herself and her life. She looks different. She talked about feeling, as she put it, “disfigured,” and others not wanting to look at her body or her urine collection bags. Self-presentation is extremely important to Flowers. She is aware that how she looks to others matters and being able to maintain a sense of normalcy in her interactions with others is something for which she strives. She wants to be able to keep living her life and finds depression getting her down sometimes. The shifts in her health

and daily life have been very hard on her, and she feels like she has had to cope with one new health problem or medication after another.

Flowers mentioned that she tries not to bring up her cancer, and specifically that her cancer is stage IV, to most of her friends. She said that people are terrified and it makes them sad. It seems like she has the same feeling about her cancer: that it is scary and can get her down sometimes. But she tries not to let it. She seemed to be proactively seeking out ways to get herself out of the house and to do things she enjoys with friends. But at the same time, she puts pressure on herself to be “ok” and to present a view of herself to others that will not “scare people.”

During my interview with Flowers, I got the sense that she has a tendency to blame herself. She thought her cancer might be because she had gained some weight, despite having never heard this from a doctor or even having ever crossed into what is medically considered to be an unsafe weight. She called herself lazy for not having gone to Safeway recently even though the task of grocery shopping is clearly very draining on her physically. She was very frustrated with her “chemo brain” and continued to apologize for not being able to remember small details of her treatment and disease history during our conversation. I felt like she might be her own harshest critic, which made me feel sad. She seems to be managing her cancer and kidney disease amazingly well – even able to find time to literally stop and smell the flowers: she mentioned with excitement plans that she had later that week to go to a flower exhibit in a local park.

As I mentioned previously, this tendency to blame oneself for cancer was not uncommon among participants in my study. What was different about Flowers was her tendency towards self-criticism even for the things that were challenging after her diagnosis. She spoke of

wondering if she should have been trying to get care at a different hospital. She liked her doctor and felt like she was getting good care, but had some concerns over County Hospital. She was constantly second-guessing her decisions and wondering if she was doing everything she could to stay in control of her disease and treatment.

While Flowers is very low income – dependent on Social Security – she used to work as a legal secretary and sees herself as someone who is able to educate herself. She spoke at length at all the cultural events she enjoyed in the city and made comments suggesting she sees herself as different from most of the patients at County Hospital. Her primary oncologist is at County Hospital, but she has received care at other institutions and was describing talking to a nurse about if she should transfer her care to an academic medical center since it is so “well-ranked” on a national Best Hospitals list. In describing County Hospital she said,

So it's an excellent hospital. But people get turned off by the people. Some of these people are so funky. I don't know how the doctors stand it. I was sitting at the bus stop waiting on the bus and there were these two men on each side of me. They were just so funky and stinky I had to get up and walk over there and sit. I mean – and you see them in the elevator, just in the hospital. I could never come to the doctor that funky and stinky. And if you don't bathe at least wash between your legs and wash underneath your arms. Oh my goodness.

She went on to say,

See, these people at [County Hospital], unfortunately, don't ask questions. They don't do any research on the computer. And so the doctors can withhold things and not speak to them like they should. But it's because of the fact the people they are dealing with... But [County Hospital] is a lifesaver, for so many people. They

might not know how to ask questions or speak up for themselves or do any research or anything like that. Because I'm sure they don't – the majority do not. And I'm just hoping and praying that the doctors educate them enough about what they have, you know.

Flowers spoke of the other patients at County Hospital both with compassion and disdain. She was clear that she was “turned off” by many of the other patients at County Hospital. She saw herself as distinct from a lot of the population. For Flowers, social class is very tied to self-presentation. Flowers spoke at length about her feelings on her own changing appearance and how others may see and perceive her. She is careful of how she interacts with others, doing her best to make sure people can look at her in the same way they always have, or as close to it as possible. Flowers constantly checks to make sure that her urine collection bags cannot be seen through her pants and that the way she speaks about her cancer will not bother those around her. When she goes to the doctor, she is careful to dress in a well-polished manner. She had not taken the time to eat the morning of her appointment and our interview because she was concerned that she might be a few minutes late if she had a bowl of oatmeal. These practices may speak to issues of respectability politics. As a Black woman, mobilizing markers of class, like economic independence and education, became important to how Flowers navigated medical encounters. Flowers know that “how you present matters,” and for Flowers, presenting herself as polished and in control is essential to receiving quality health care.

In the passages above, we saw the ways in which Flowers made a distinction between herself and “them,” the other people who receive care at County Hospital. In addition to her previous statements about their appearance, Flowers worries that the other patients do not ask questions or do research about their health and their care. She acknowledges the responsibility

the doctors hold and that the doctors could withhold information or speak to the patients without respect. Yet, at the same time, she puts the responsibility on the shoulders of the patients. By not taking control over their health, she suggests above that they are opening themselves up to receiving poor care. It is clear that Flowers sees it as part of her role as patient to ask questions and do research. In fact, Flowers said that asking questions “empowers you.” It is not acceptable to simply approve of the plans set forth by one’s provider, as many of the patients at County Hospital do. The patient should be taking an active role and sharing control in the decisions with her provider. While she does not condone a provider withholding information from a patient, she acknowledges it as a possibility. And although she speaks with a great deal of empathy and concern for other County Hospital patients and wants them to get the care they deserve, she does not see how it is possible when they demonstrate so little care for their own self-presentation, or control over themselves and their health.

When Cancer Causes a Loss of Control in Other Areas of Life—Marie’s Story

Marie is a 71-year-old woman recently diagnosed with stomach cancer. She had spent the twenty-plus years prior to her cancer diagnosis running a day care center out of her home. She had a decent savings account, paid all her bills on time and was able to afford the organic food she preferred. She is in her early 70s and was thinking she might retire soon but she was forced into it abruptly by her cancer diagnosis. One day she had a business and the next it was gone.

When I met Marie for the first time in person, I walked into her home and she almost immediately started crying. It took almost half an hour for me to get through the consent process so I could start recording our conversation and that recording still ended up being two and a half hours long. Marie desperately needed to talk to someone, anyone, about what she had been going through and the way that her cancer diagnosis had dramatically altered her life.

When we met, Marie was only a few months out from her cancer diagnosis and currently undergoing chemotherapy, but that really was not the source of her stress and emotion. She did not know how she was going to be able to afford her life. In reflecting on her experience of diagnosis she said, “But it wasn't the cancer that got me, my mind went straight to how am I going to survive? I'm self-employed, so there's not going to be any disability. See what I mean?”

While for many of us, the news of a cancer diagnosis may lead us to question like “Will I survive?” or “How long will I survive?” for Marie, the question that came up is “*How* will I survive?” She is asking a very different question. Her concerns about survival are not rooted in death. She is not concerned about if she will live or die, but how she can possibly live. Marie’s alternative notion of survival speaks to the critical role of social class in examining the intersections of race, gender and health. Her economic concerns are superseding her health concerns in a very real way. Marie is very aware that if she cannot afford housing or food, it will not really matter how she responds to her chemotherapy. This situation left Marie feeling completely and almost helplessly out of control.

Marie is estranged from much of her family; most of them found out about her cancer second hand. She has been independent from a young age after leaving an abusive childhood home. She admits she is not good at seeking out help and is not aware of most of the resources available to low income seniors and people with disabilities because she has never tried to access them before. She has fallen behind in her bills and does not know what to do. She told me,

Legal aid took over my bills but they take \$300 – I guess they did something – and nobody was calling me, put a stop to that. And then Financial, that loan company, went in and took my money yesterday and when I looked in the bank I didn't have it. So it's just a little problem every fucking day. And then she's

[hospital worker] talking about going to the pantry. I don't want to go to the pantry. And I like organic food, I don't need pesticides dealing with this cancer.

We can clearly see the class shift playing out for Marie. She wants to focus on things like healthy eating and exercising, she has been an avid jogger for decades, but she has in many ways been forced into a working class mentality of survival mode. Her loss of income and the depletion of her savings have created the conditions for economic vulnerability, which have altered the ways in which she can approach her new reality of cancer. Her approach to health had been deeply rooted in her economic stability. Lochlann Jain (2010:173) writes of the “entitlement to normative health” that accompanies middle- and upper-class lifestyles, and that this sense of entitlement meant that she herself did not really think about survival and survivorship until her own cancer diagnosis. Similarly, Marie’s health was, in a sense, disrupted twice: first, by the cancer, but again by the economic vulnerability which disrupted her ability to control her health in the ways in which she knows and perceives to be normal and necessary. She is not only thinking about surviving cancer, but about survival in terms of securing for herself what are the standards of daily life and basic health, and the right to imagine and be prepared for a future. As she relates, “People said, ‘Well just live one day at a time.’” But from her vantage point, “Well, I never lived one day at a time because I was wanted – I always think I'm going to live tomorrow and I want to be prepared for tomorrow.”

As we saw with Jan, for many lower class women with cancer, especially women of color, surviving means facing the new crisis that arises each day. Sometimes that is cancer, but on many days it is not. Marie is not used to this way of life. Having something new come up “every fucking day,” as she put it, is overwhelming. It is preventing her from treating her cancer the way she wants to. While Delores was, in my view, burdened by the level of intense control

she was attempting to have over her diet and exercise, Marie does not feel she has the resources to be in control of those areas of her life at all. The things she used to value as an essential part of health, like organic foods, jogging and acupuncture, have been forced to the side and she feels like she cannot control her health at all. She spoke of this feeling, this loss of control, saying, “And people are like, ‘You’re going to have to adjust to it.’ Adjust to what? I’m going to have to change my whole life the way I was living?” This idea is devastating to Marie. It’s not simply that she has been diagnosed with a potentially life threatening disease; she has lost control over every aspect of her life. And other people seem to think she should learn to accept that.

Moreover, much of Marie’s anger over her situation is rooted in her history as a Black woman. Marie spoke to me about the discrimination that she has faced over the years. She spoke of clients she has lost and services she has been denied. Marie told a story of being turned away for applying for an apartment several years ago. When she had inquired about a specific listing, she had been pointed to a different set of units. She told of going back to the office after she realized what had happened and telling them,

‘You don’t remember who I am, but I was the Black lady with the white children in the stroller [her daycare chargers] who approached you about an apartment for rent. I don’t know why you pointed for me to go over there [to the other units]. Did you assume since it was for people on welfare, low income? I’m working. Why would you assume that I’m on welfare? Because I’m Black? I didn’t assume you were a serial killer or a child molester or a rapist [because you are a white man].’

Marie told this story with anger but also with pride. She knows when she is being disrespected and she knows how to stand up for herself. She has been self sufficient from a young age,

something she knows people may not expect from her. Marie has often used her class privilege to challenge the racial and gender discrimination she faced. Marie spoke of firing daycare clients who she found to be racist or disrespectful. She had the financial security to not have to accept those types of personalities at her business.

Having lost that security — the ability to buffer herself from exposure to social discrimination — is causing a major shift in Marie’s identity. She spoke of this shift, sometimes sobbing and sometimes yelling. She now has many people trying to tell her how to access different resources in the community. She deeply resents this saying,

And then people are like, ‘Oh did you know you could get that? And you get this free?’ Well how would I know that if I’ve been a productive working person? And it really pisses me off. Because I’m not supposed to know that. How am I supposed to know where you go get free food? How am I supposed to know that you can get Medi-Cal and Medicare?

For Marie, this loss of economic control represents a shift in her personal view of self. She can no longer identify as a “productive working person.” She spent many years figuring out how to survive and get by. She figured out how to raise a son on her own and how to start her own business. She figured out how to live a healthy lifestyle and feel good in her body. Now she needs to do that all over again, but has not yet been able to find a way to do so. More than that, she needs to figure out who she is now, how she sees herself. She is no longer in control, productive, economically stable. She is still a very proud Black woman, but that has been completely undermined by her health and ensuing financial vulnerability. So much of that sense of self was tied to her sense of economic stability and middle class security. In that moment, for Marie, change in economic situation is the major disruption of her life. It was caused by the

cancer and in some ways it has eclipsed the cancer in her mind. The cancer has become intertwined with class so that the two cannot fully be separated for her. What Marie knows is that she has lost control over her life and she does not know if or how she will get it back.

CONCLUSION

So much of how class operates in the intersections of race, gender and health is about control. The ability to live one day at a time is, at its essence, an ability to acknowledge the lack of control we have over the future. In many ways, cancer requires this because there is so much about the future that will be unknown.

The loss of control and a desire to assert control operate in varied ways for the women in this study. For the patients at County Hospital, waiting was an expected and accepted part of care. They had relinquished the idea of being able to control the schedule of the clinic. With Linda, we saw a woman who was comfortable not being in control. She accepted that her providers would make her treatment decisions. She did not feel anger at how long it took for her disease to be diagnosed. She understood the limited resources available and knew that sometimes she would need to wait to get what she needed. Linda was used to things being out of her control, her cancer included.

Jan's life over the last year had been completely out of control. Bad things continued to happen to her. Her son was murdered. Her daughter was arrested. She was diagnosed with cancer. She feels so little control over her life. She has problems with her housing that her landlord refuses to fix. She seeks answers from the police and they refuse to listen to her. Jan is able to accept the lack of control that comes with cancer because she is used to it. It is not the biggest problem that she is facing. She has had to live one day at a time for much of her life, and

especially over the last year that when she was faced with so many tragedies. This loss of control was not as jarring for Jan and Linda as it was for the women with more economic privilege.

Conversely, Dean, a more well-off woman, felt the loss of control that came with cancer. But, at the same time, Dean knew that her economic class could grant her more control. She knew that ultimately she was making her own decisions and was not afraid to fight the medical team when necessary. She spoke of times when she had to take back control from her providers. With Dean, we saw a woman who was used to fighting for the rights of others. She had spent years as a leader in her community, fighting for fair access to housing and advocating to improve her neighborhood. When she faced symptoms that she did not feel her doctors were addressing adequately, she used her class privilege to assert her right to more tests and to better care. She knew that having insurance should mean that everything should be done to find the cause of her symptoms. She also knew that, at the end of the day, all of the decisions about her treatment were in her own hands. While she may have deferred to the advice of her provider at times, she knew that she was the one ultimately making the decisions. Dean knew that respect would not automatically be afforded to her and that it was something for which she would have to fight.

With Delores, we saw a woman who has deep self-blame for her cancer. This blame is not rooted in a belief in poor life style choices or genetics as other study participants have expressed. Rather, Delores blames herself for not being more proactive in addressing symptoms of her cancer when they first appeared. The guilt she feels has carried over into how she approaches her cancer. Delores has taken extreme measures in the parts of her life she can control – her diet and her exercise. She constantly asserts her control over things like how much and what she needs to eat and feels guilty and lazy when she does not meet these standards.

Maintaining this control is essential for Delores to feel like she is doing everything she can now to fight her cancer.

While these examples show how the intersections of race, gender and class can operate for Black women with cancer, it is important to acknowledge that the class boundaries are not always neat and that cancer itself can cause a shift in class. With Flowers, we saw a woman whose class identity does not match her income and circumstance. Flowers prides herself on her appearance and her self-presentation. She wants to present herself as in control of her situation. This manifests in both physical appearance and how she speaks about her cancer to others, including her providers. With Flowers, we saw a woman who sees herself as very distinct from lower class patients. She sees herself as different from other patients at County Hospital who clearly do not control themselves well.

Despite being low income and receiving care at County Hospital, she draws sharp dichotomies between herself and the rest of the patient population. Her identity is complicated by her class, which cannot be fully understood by simply looking to her income. Additionally, her identity as a Black woman is very tied to self-representation. She is very aware that she will be judged by how she looks and presents. Despite her class limitations, and, in many ways, as a means to overcome her class limitations, she attempts to present herself in a positive and in-control manner. Her cancer disrupts her ability to do this. It makes her feel physically disfigured and mentally less sharp, which inhibits her ability to present as an articulate and in control person. She sees that lack of control in the other patients at the hospital and worries that they might not receive quality care because of it. She does not want her own care to be compromised for the same reason.

Marie has always been in control and cancer has shifted that. She can no longer provide for herself. She feels like she is spiraling out of control. Marie experienced a very sudden shift in class as a result of her cancer. She went from being able to provide for herself one day, to no longer being able to pay her bills the next. As a Black woman, Marie has faced assumptions about her social class throughout her life. She has felt confident fighting back when confronted with stereotypes. Now she sees herself needing to take advantage of the types of services she once adamantly insisted she did not need. Marie's cancer story is not about the disease itself. But rather how the diagnosis led to an economic downward spiral from which she cannot seem to escape. Her shift in social class is forcing her to manage her illness in a different way than she wants. She has been forced to live one day at a time instead of planning for the future and that has left her off balance and feeling unable to cope.

The stories of these women highlight the importance of looking at class more holistically and intersectionally. I think there is often an assumption made that being lower class can be equated with worse health care experience. This assumption is rooted in the idea that the more marginalized identities one holds, the worse off one is. However, that is not the lesson of intersectionality. Social class identities and socioeconomic realities create a unique set of challenges for different women based on their larger identity and social location. As we saw in this chapter, the intersections of race, gender and class created varied realities for the women in this study. It is not a simple equation of the lower the income, the worse experience of cancer. Rather, the impact of cancer and the loss of control it brought to the lives of these women was deeply connected to the intersections of their race, gender and class identities. Class is clearly important in the study of cancer for Black women, but it must be examined in ways that highlight the complicated nature of identity and social location.

Thus for Marie and the other women in my study with more economic privilege, the idea of letting go of control over the future and living one day at a time is somewhat foreign. They were planning for the future – it is what they have always done and been able to do. Women with more economic privilege are used to feeling in control. Cancer is not only an illness and a threat to your life, it changes the way you approach life in a way that is real and very traumatizing for women who are not used to it. As we saw with Marie, she was forced to change her entire way of life because of the financial power cancer took from her. With Delores, we saw a woman who turned her leisure activities and eating habits completely upside down and approached her health in a completely different manner after her cancer diagnosis. Their lives with completely disrupted due to the lack of control they felt after being diagnosed with a terminal illness. Cancer, which is inherently out of their control, then acts as a major disrupter to their imagined and assumed future.

On the other hand, women with less economic privilege are used to taking things more one day at a time. They may be used to having little control in their lives. They are used to accepting whatever medical care they are given, whatever challenges come their way and finding a way to keep going. For many of them, cancer did not radically reshape their lives because they were not forced to start thinking one day at a time – they have always lived their life that way. Often that means that on any given day, cancer is not the number one priority. Housing crises, drug use, personal safety, the criminal justice system etc. – all have the power to interrupt and push cancer to the back burner. For poor women of color, tomorrow has always been uncertain. This unique intersections of race, gender and class results in an ability to focus on today and live one day at a time. Many of the lower class women in this study had not thought to ask their providers about their prognosis. They did not know what would be the next option if their current

treatment failed. These women are focused on the problem in front of them at this moment, and that problem was often shifting from day to day. For lower class women, the experience of cancer might be harder – fewer treatment options, inability to pay for needed in home support, lack of resources– but so is their overall life. Comparatively, cancer is just one chapter, one event, one stressor.

Chapter Four: Faith, Strength and God: Where Religion and Cancer Intersect

INTRODUCTION

According to a 2012 Kaiser study (Washington Post 2013), Black women are the most religious group in the country. Nine out of ten Black women consider themselves religious. And, in times of turmoil, about 87 percent of Black women — much more than any other group — say they turn to their faith to get through. These statistics were reflected in the sample for this study. All but one participant in the study identifies as currently practicing a faith tradition. That means different things for each — some attend church every Sunday, others expressed that they do not see the value of church but pray every day. Some were raised in a faith tradition and still identify with it, but do not really speak to it very much. While others quote the Bible at length and are clear that their relationship with God is the top priority in their life. Of the women in this study, ten identify as Baptist; four as Christian but without a specific denomination (including one former Baptist now non-denominational, and one former Methodist but now non-practicing); and one each report that they are Christian orthodox, Jehovah’s Witness (non-baptized), Muslim, Pentecostal, “spiritual/Catholic,” or “a student of all religions.”

In this chapter, I will explore the intersections of race, gender, class and religion for Black women with advanced cancer. It is important to first define several terms that I will use throughout this chapter. Though they may seem interchangeable, and are in certain contexts, there are important subtle differences, which must be explored. These terms are *faith*, *religion* (or *religiosity*) and *spirituality*.

I use *faith* in this context to simply refer to a belief in a higher power. Faith is something that can be held onto strongly while undergoing cancer treatment, and it is also something that can be lost. For most of the women in this study, faith is the belief that God is watching over them.

Religiosity and spirituality both come under the umbrella of faith as I use the term. *Religiosity* “involves organized worship and practice, as well as theology;” *spirituality* “may involve transcendent experiences, and can include religion. In this paradigm, religiosity may be seen as a component of spirituality, as spirituality refers to a broader construct than religiosity” (Holt et al. 2009:250). Spirituality is thus broader than religiosity as it does not necessitate involvement in an organized religion or belief in a particular theology. Religiosity has been shown to play an important role in the lives and culture of many African Americans. African Americans are generally considered to be “more religiously involved than other groups” (Holt et al. 2009:249).

Many assumptions have been made about how religiosity impacts experience of illness and medical decision making for Black women. One of the more pervasive ideas in the study of religion and cancer is the idea of religious coping. Numerous studies have examined what role religion plays in allowing patients to cope with cancer. In a 2005 study Morgan (2005), a nurse researcher, and colleagues interviewed 12 African American heterosexual, high SES, married couples dealing with a breast cancer diagnosis of the woman. Religion seemed to play a major role in coping for these African American women and the study cites examples such as the women talking about “walking with God” and “praying for strength, endurance and acceptance” (Morgan 2005:985). The couples prayed together and tried to find strength and endurance together through God.

Phelps, an oncologist, and colleagues (2009) conducted a study of 345 patients with advanced cancer. Researchers interviewed patients and their families, and patients also completed several survey instruments on religious coping and mental health. The authors found a positive correlation between religious coping and receipt of intensive life-prolonging therapy

close to death. In this study, religious coping refers to “how a patient makes use of his or her religious beliefs to understand and adapt to stress” (Phelps et al. 2009:1140). The authors found that religious coping offered patients a greater sense of meaning and control and allowed them to experience personal growth while facing potentially life-limiting illness. Positive religious coping is defined as “constructive reliance on faith to promote health adaptation” (Phelps et al. 2009:1140). The authors also discuss negative religious coping wherein the patient tends to see the illness as some sort of divine punishment, but note that this is very uncommon. They also note that positive and negative religious coping are not necessarily mutually exclusive and that, overall, 92% of patients endorsed one or more item on the religious coping scale while only 43% endorsed any negative religious coping scale items (Phelps et al. 2009). Further, according to Silvestri and colleagues (2003), among patients with lung cancer, faith was second only to oncologists’ recommendations in factors influencing treatment decisions. Phelps and colleagues (2009) also cite broader surveys that indicate a belief by many patients that God can heal even after the physician runs out of treatment options.

In a qualitative study of African American women, women perceived spirituality and religion as “helping them to accept reality, have a spiritual surrender, overcome limitations, learn life lessons, see their purpose and destiny, build character and act in accord with their moral values, grow as a person, and trust in a higher power” (Holt et al. 2009:267). Other common themes found among African Americans include spiritual beliefs “providing comfort, coping and support, and the role of this in healing; God’s important role in physical and spiritual health; God being an instrument of the doctor; only God can decide life or death; and divine intervention and miracles can occur” (Holt et al. 2009:267). Holt and colleagues (2009) also found that many African-American women with cancer expressed a belief that “God works through doctors and

felt that they would place religious concerns above speaking with a physician if they were seriously ill.”

While my study did not focus on intensive life-prolonging therapy and most patients dismissed ideas that are aligned with negative religious coping, the general themes of positive religious coping such as patients “walking with God,” praying for strength, belief that God can heal, faith providing comfort and the doctor being an instrument of God were found across many participants in my study. It should be noted, however, that in the literature, positive religious coping is often framed in such a way that biomedical compliance is the central outcome for evaluating the potential efficacy or good that comes from religious coping. While it is certainly worthwhile to evaluate the ways in which religious coping relate to medical decision-making, this view of the value or role that religion plays for Black women with cancer is narrow and limiting. It denies the role that religion plays in shaping more essential aspects of personhood and patienthood.

I believe many of these studies do not examine the role of faith, religiosity and spirituality in a way that is intersectional and thus true to the experiences of Black women. In this chapter, I will argue that for the majority of the women in my study, and many Black women, one’s faith cannot be separated from one’s identity as a Black woman. Faith, race and gender mutually construct one another in inextricable ways and when it comes to the study of cancer, where the idea of faith plays such a pervasive role, the importance of examining the intersections of race, gender, religion and health is critical. In this chapter, I will explore a few of the above themes in depth and attempt to use intersectionality to complicate the way these notions of religious coping are framed for Black women with advanced cancer.

First, I look to the patient-provider relationship. I explore how physicians understand the role that religion plays for their patients with cancer as well as the ways faith and religion enter into the patient-provider dynamic. Next, I explore the idea of Black women with cancer viewing their provider as an instrument of God. This question is a deeply intersectional one, and I explore how the intersections of race and class for Black women with cancer influences the trust they put in their provider. While the biomedical literature often frames this question as one of compliance, I complicate this. While some participants spoke to the idea of being obedient to God through complying with the directives of a provider, I also show how a number of participants make clear that they do not see providers as God. These participants speak to the powerlessness of humans in general and physicians specifically over cancer. I explore the relationship between these two systems of belief. Sometimes these two beliefs are held simultaneously with a belief that God works through doctors. For other participants, they are held in opposition to each other with the belief that only God has the power to heal. I explore the impact these beliefs have on the patient-provider relationship and the ways in which the women describe both the origin of their cancer and their prognosis.

Second, I examine the ways in which religion shapes pervasive stereotypes of Black womanhood that participants encounter in the clinic. I describe the stereotype of the “Mammy” and argue that her modern adaptation is that of the Black woman in the first pew at church. This new Mammy figure is still seen as submissive and obedient to white authority, but is also viewed as deeply religious and the one praying for the rest of her family who may be more troubled. I argue that when patients are viewed through this lens, they may be treated in ways that utilize their perceived religiosity to encourage positive religious coping, that take their compliance for

granted, and that exemplify how their assumed good intentions subsequently lead to their being accorded the benefit of the doubt in clinical encounters.

In opposition to the Mammy, I also describe the stereotype of the “Welfare Queen.” While the Mammy is a “good” mother, the Welfare Queen is a “bad” mother, one who is lazy with poor values and no work ethic. I found that when a patient was viewed through this lens, it was often as a way of explaining her lack of compliance. It was assumed that the “Welfare Queen” was not coming to appointments because she was “running the streets.” Her religiosity was completely erased and she was assumed to be deviant and not committed to or interested in her own health.

I turn finally to the idea of the Strong Black Woman. The stereotype of the Strong Black Woman is a way that Black women have resisted oppression. She represents the best of whom the Black woman is and what she has to offer to her community. The idea of strength has important connotations in the contemporary cancer experience. Patients are told by family, friends, providers, and the media to “fight” and to “stay strong.” Strength is needed if one is going to “beat” cancer. Yet, strength is also inextricably tied to the intersections of race, gender and religion for Black women. I explore the pressure Black women face to feel strong and the ways in which the need to be strong is tied to the need to maintain faith in God. I go on to explore what happens when women cannot stay strong and lose their faith over the course of their illness. Most describe these periods as their darkest and lowest times. The times when women ask “why me?” or question God’s intentions are the times of their lives the most regret. It represents their inability to maintain themselves as Strong Black women.

Faith is largely seen as a positive in medicine. It gives hope, it gives purpose, and it helps people to get through horrific treatments. Yet, we do not fully understand the role that it plays for

Black women. This chapter will focus on the unique ways religion and faith intersects with the experience of illness for Black women.

PATIENT-PROVIDER RELATIONSHIPS AND RELIGION

My interest in examining the role that faith, spirituality and religion play in medical decision-making and care is actually based in an experience I had as a medical social worker. I remember taking part in a family meeting in the Intensive Care Unit. Family meetings were a time when a patient's family was brought in to talk with the care team. The family spoke with different members of the team on a daily basis, but this was a designated time for everyone to be in one place, usually to discuss a change in the patient's status or a decision that needed to be made. Quite commonly, this conversation was a time to discuss withdrawal of care.

This particular family meeting was to discuss the long-term future of a patient in a persistent vegetative state. The team, consisting of several physicians, social workers (including myself), and a physical therapist, wanted to give the family the choice between withdrawing care and allowing the patient to pass away, or preparing for a future where the patient would live in a nursing home receiving round-the-clock care. The second option would require surgery to place a permanent feeding tube in the patient's abdomen and a tracheotomy for long-term ventilation.

The lead physician on the team slowly and carefully explained the medical situation and the options available. He spoke with great compassion. Kleenex boxes were subtly nudged closer to the family in case they became emotional. The entire team wore sympathetic expressions and some members would offer a hand squeeze or gently stroke the arm of a family member when the doctor was making the point that this patient would never fully recover.

After the physician presented the options and other team members chimed in with their relevant information, everyone turned to the family, awaiting their decision. The patient's

mother, the matriarch of the family and the one who would clearly be making the decision, wiped away her tears and slowly looked up. She composed herself for a moment and said, “Well, I guess we will just leave it in God’s hands.” Those of us on the team began exchanging quick glances. No one knew what this meant. Both of the offered options involved taking an action. And, really, either one could be interpreted as “leaving it in God’s hands,” either by withdrawing care and allowing God to decide if the patient were to live or die, or by allowing the patient to be sustained for longer, giving God the time to work a miracle.

The family was nodding and supporting the decision of the matriarch. The care team was trying to be supportive but was clearly flustered. The lead physician, clearly not knowing what to make of the situation, thanked the family for their time and suggested we meet again in a few days. He stressed the need for a decision about the feeding tube, since the patient was currently susceptible to infection. The family thanked the team for their time and went to be with the patient. Afterwards, a resident commented to me that they wished there had been a chaplain in the room to “interpret” for us. The family’s statement of leaving things “in God’s hands” felt that foreign to her. No decisions were made. This patient would need to spend another several days in the ICU before the conversation would be broached again. The team hoped that more time would allow the family to “accept” what was going on and make a decision. A chaplain would be sent in to speak with them and attempt to do with the physicians did not feel comfortable doing: trying to understand what they meant by leaving things in God’s hands.

This family meeting happened more than seven years ago, but I have such a vivid memory of the look of panic and confusion that passed over the eyes of the care team and their reluctance to question the family member to try and understand her meaning. As I have

continued to study cancer and end-of-life issues, I have found an interesting paradox when it comes to how issues of faith and religion are treated by biomedicine. While faith is often seen as a positive coping mechanism while living with cancer – as a motivator, an inspiration, a source of strength and love – religion is often seen in direct opposition to science and scientific medicine. I have spoken with physicians about their perspectives on the role of faith, spirituality and religion in oncology care in multiple contexts, most recently as a part of my dissertation fieldwork, but also previously as a part of a study on oncologists' perceptions of end-of-life issues (James 2014). Physicians reported to me that they do not know how to interpret statements about God if they themselves do not identify as religious. One oncologist spoke of this paradox very clearly, saying,

I think some people, where religion enters into it is, I think, almost a disservice in my opinion. 'I will pray for that or my prayers will be answered.' Well, no, I don't think – actually some people who are at peace may be religious and it may be much easier for them to accept death, but they are also most likely to be the people who are fighting it the hardest.

This physician acknowledged that people who are religious may have an easier time accepting death and may find more peace at the end-of-life, something which she sees as a positive. Yet, she also stated that the belief that prayer can cure cancer or lead to positive outcomes is a disservice to the patient. She is drawing an important distinction between *faith in an after life* which may make dying easier for the patient, and *faith in miracle* or in God as a healer, which may make it more difficult to accept that a disease will not be cured. She believed that religion may encourage a patient to maintain a false or unrealistic hope. While faith can be a positive,

faith and hope past a certain point may put the patient in a position of wanting treatment or intervention that can do more harm than good.

Some providers feel that a strong belief in the healing power of God can cause conflict or discordance between patient and provider. One provider spoke of the back-and-forth he has encountered with religious patients,

But they need to hope or cling to something and so sometimes you will cling to that and that can sometimes be problematic because you say, 'I really don't think things are going well.' 'No, Jesus will save me.' I respect Jesus and I respect that you believe, but all signs are pointing toward this isn't going to work out. 'No, Jesus will save me.' It's a hard argument.

This provider sees an inherent conflict if the patient believes she will be cured or saved by Jesus and the provider believes the patient will die of the disease. This conflict, regardless if it is actual or imagined, has the potential to influence the provider's perceptions of the patient, and in turn, the provider's relationships with the patient and what and how information is shared. As another provider said, "I'd say people who are really ultra fundamentally religious usually don't want to know time frames just because they don't believe it anyway because it's whatever Jesus is going to give them." This provider is making assumptions about the type of information his patients will want to hear and what they will believe based on their religious beliefs. His view about the perceived religiosity of his patients is influencing the type of care he will provide.

Another provider spoke of the heartbreak of watching a patient with a strong faith not be cured saying,

There's times at which, sometimes religious beliefs – people expect to be cured like oh, Jesus will save me. And it seems like near the end when it becomes

apparent that that might not happen it's almost like they feel like they have been betrayed by their source of their faith which is hard to watch people go through.

This physician argues that the patient will experience a betrayal if they are not cured of their disease. Religion is not seen as a positive source of strength, but as a source of unrealistic expectations about disease progression and cure. These patients may feel betrayed, not just by biomedicine, but by God. This provider worries that patients have an expectation to be cured by God, not only a belief that God can heal. This is a potentially very important distinction. I found in this study that while there was a nearly universal belief that God *can* heal (and sometimes that *only* God can heal) the idea that God will absolutely heal was not present. Many patients expressed the idea that “God will save me if He has a reason,” but it was always with an understanding that we cannot and usually do not know God’s reasoning.

While providers express confusion and concern over how to interact with their patients about faith and religion, it is something that some patients long for. One participant, Delores, expressed a desire to have more conversations about religion with her providers. Delores told me about commercials she sees on television for a cancer treatment center in another state. In the advertisements, there is a woman who describes her experience there in incredibly positive ways. The patients in the ads speak of being cured of their disease, of course, but what really struck Delores was the way they speak of the integration of faith into the medical care:

I just wish I could go there because she was able to go to the church there and this was in the hospital every day. Whenever she wanted to. And that they talked to her about, ‘Are you – are you a Christian?’ And they would talk to her and they would pray and they would pray with her. And it was just like, oh my God. Seems like it's a good place to be.

When I asked Delores how she felt about her care and if she found her doctor to be comforting, she told me,

He is to a certain extent. I can't criticize him for anything because he's doing everything I know he's supposed to do, and he actually gives me a hug when I'm there and stuff and he looks – I can see the sadness in his face when he have to give me some news that's not so good. I can see he's caring and he's there for me. But he doesn't go through the process of saying, are you a Christian? He doesn't go that far. I can see he's there and he can just do so much as a doctor, he can just do so much.

Delores is acknowledging that she wishes her doctor would pray with her and ask her about her faith. Yet, she is also acknowledging that we cannot really expect that of doctors. She wishes it was different, but she knows her doctor has limited time and is doing everything he can for her. Yet, Delores would feel she was getting more complete care if her Christianity was incorporated into the care she was receiving. Delores recognizes that her relationship with her provider might be different if they could relate on a spiritual level and communicate about her faith. To Delores, her faith is a key part of her identity and how she experiences her cancer. It makes sense to her that it would be a key part of the way she receives care.

ARE DOCTORS GODS?

The relationship between God and doctors is one that came up often in my study. While there are often jokes made about doctors having “god complexes,” many patients expressed acknowledgement that their providers are not God. It was usually presented in a sympathetic way: a way of the patient acknowledging that she accepts that her provider, like any human,

cannot do everything and is not all knowing. Cancer is, ultimately, something that we cannot control. Oleos, in describing her provider, said,

You know I understand that she's not God and so she's not in the same – she is trying to figure out things as well as I am in a way. But I think that overall you know she tries to be attentive and respond whenever I have a question or whenever I have concerns.

Oleos acknowledges that her provider is figuring things out as they go along and does not have all the answers. Oleos appreciates the things that are within the control of her provider: being attentive and responsive to her needs.

For some patients, the comparison between God and doctors is one of admitting the powerlessness of humans. Many patients feel that we as humans are powerless over cancer. As I described in the last chapter, while some participants attempt to assert control over aspects of their care and disease, for most, cancer is generally acknowledged as being out of not just the patient's hands, but the providers' hands as well. Some women expressed the idea that doctors cannot cure or eradicate disease, that only God can do that. As Flowers said,

I just feel that man will never be able to get rid of all of the ills and sicknesses and whatnot that plagues the human race. I just don't believe he will be able to do it. I just believe that – part of my religious belief is that just God's kingdom can do that. Because none of them can walk on the water.

Flowers acknowledges the fallibility of medicine. While she respects her oncologist and follows his recommendations, she does not believe that he has the power to cure cancer. Only God has that power. Yet, Flowers is still pursuing anti-cancer therapy in the hopes that she can be healed.

The idea of God working through doctors was one that was spoken of by several patients. Linda noted that God is “helping the doctors with their hands.” As I mentioned in the previous

chapter, Jan puts a tremendous amount of faith in her doctors and sees them as part of God's plan. When I asked Jan if it is part of God's plan for her to do what the doctors tell her to do she said,

Yeah. Because He put them here to save people. And if you don't utilize their service, that's on you. If you stand there and say, you pray and you don't do anything, the chemo radiation, then when you die you can't say you was trusting in God.

For Jan, prayer is not enough. While it is important to have faith in God, Jan believes you are not truly trusting God unless you are also trusting the providers He puts in your life because "He put doctors and stuff here for us to get well."

For Jan, compliance is not simply a matter of a respect for medicine or a desire to get well; it is a part of obeying God. To trust God is to trust your providers and to trust in medicine. I asked Jan what she would do if her physician recommended something that she did not think was a good idea and she told me she would have to pray on it. She said, "He'll answer in that small, tiny voice and you know – you always have the devil over here saying do it, do it, do it. And God is over here telling you, no. You know what's best for you. And I know what's best for you." This was hard for me to understand so I asked Jan to explain to me how she can tell when it is God and when it is the devil? She told me that the devil will always want you to do wrong and God will want you to do what is right. She offered an example saying, "Say I'm outside there and the light is on red but I really want to walk. I walk out there, that's the devil telling me to walk out there. God is telling you, wait till it turns green." Yet, the application to cancer is still more complicated. There are not always clear "right" and "wrong" answers, as in Jan's example of not crossing the street on a red light. So, how does Jan decide? It comes back to her belief in doctors

working as agents of God. While Jan said she would pray about it if she disagreed with her doctor, it does not sound like that happens very often. I did not see it happen in my observation of an appointment with Jan's doctor nor did she mention any examples in our interviews. She largely believes that the recommendations from her doctor are what God wants her to do and it is in her best interest to follow them. The connection that Jan expresses between medical compliance and obeying God is not something I commonly heard from patients. While the belief that God has the ability to heal cancer was widely held by those patients who identify as religious, this notion of compliance being directly tied to God's willingness or ability to heal is an important distinction.

An interesting case study of an opposing viewpoint is that of Y. Y (the pseudonym she chose for herself) is a 50-year-old woman who has undergone treatment for both thyroid and breast cancer. She is the only married woman who participated in my study. She has been married for 25 years and has two teenaged sons. Y is also one of the wealthiest women who participated in my study, listing her income as above \$200,000 per year. The first thing I noticed about Y are her eyes. They are a shockingly light blue-green color. She mentioned that she is incredibly self-conscious about them because of how much attention they draw and when she was younger she always wanted brown contact lenses so she could blend in more easily. Her unique eyes were what made losing her hair during chemotherapy so difficult for her; being bald just drew more attention to her eyes.

Y was very forthcoming in her interviews. Yet, I struggled more internally while interviewing Y than anyone else in my study. Y is very open about her opinions and she holds those opinions very strongly. In many ways, this is an interviewer's dream: we want our participants to speak easily about subjects that are important to them. But I found myself often

taken aback by the force of some of Y's opinions and the way she framed those who disagreed with her. She also asked me a lot of questions during the interview and at times I felt like she was challenging me. It was hard for me to be present and open during the time we spent together.

Y is extremely skeptical of cancer organizations and the biomedical complex. She does not seem to put a lot of trust in medicine:

Drive by Kaiser, any Kaiser, the parking lots are full. What's wrong with this picture? The premiums go up, parking lot is full and no one is well. And it's not hereditary, I don't care if everybody in Angelina Jolie's family had breast cancer, there's no guarantee she's going to get it.

Y questions not only a medical organization that seems to be making money without curing people, but also a dominant rhetoric about cancer itself. Y does not believe that cancer is hereditary. She said she believes it is caused by things like food and the environment. Y spoke of research between the American Cancer Society and the Rockefellers back in the 1950s and 60s that she said pointed to eating well as a cure for cancer; that research, in her words, was "squashed." She also spoke of people moving to the Bay Area and getting sick and said, "I don't know if it's all the refineries, I don't know. But something is not right. And if it's known we're never going to be told. Profit is better than truth." Y does not believe the powers-that-be are honest with the rest of us and she thinks profits are motivating a great deal of what is being done, rather than helping individuals.

Y is extremely skeptical of medical providers and biomedical treatments as well. She spoke of the first doctor she had as a "nightmare, a train wreck." She spoke of going in for a consultation with the interdisciplinary care team after she was diagnosed and receiving different advice from every provider. She felt like they were "all over the map." She went somewhere else

for a second opinion and calls it the “best decision I ever made.” Y also struggled with her treatment. It was not that she had particularly bad side effects — she told me she did not — but how the process made her feel. She said the chemotherapy made her feel like she was in a Drano commercial; she felt she was being flushed out completely and could almost feel it happening in her body. She also struggled with surgery, noting that she had four surgeries and found it “unnerving.” She said, “in the medical world, you have to relinquish a lot of control,” something that is not easy for her. After the surgery to remove her thyroid, she had to take hormone replacements, a “little blue pill,” and it made her feel like a man to have to do so. But, at the same time, she is glad she had the type of cancer she did, as it is often slow growing.

What was harder for Y was feeling like cancer changed how people look at her. Y also spoke of being asked to participate in some breast cancer awareness campaigns, handing out pamphlets about mammograms. She told me, “I said I didn't want to because I don't want you to know me because of cancer. I want you to know me because of who I am prior to cancer. That did not change and didn't define me. I have a problem with it.” It bothered Y quite a bit that people she had known casually for many years suddenly wanted to form relationships with her solely because they shared the common experience of cancer. She related an exchange she had with one such woman:

So I told her, I said, ‘Listen...if someone needs to talk to me, I'll talk to them but I will not actively put myself out there for a cause. Especially cancer.’ Because everyone just looks at you differently. That should not change your outlook on me.

Y feels strongly that cancer did not change her as a person:

I might look at things a little differently but overall, no. My character has not been tainted because of cancer. I still am one of those people that do what's right when no one's looking regardless of cancer. I don't ever play the, oh woe is me card.

Y expressed several times that she struggles with how others perceive her. Y spoke somewhat defensively about her social class saying, “I have to be careful how I say this – some people when they come to my house they think, boy, you have all this and all that. No, it's called my husband and I work every day.” Y seems to worry how people perceive her and the way that her cancer has changed that perception. She said,

I mean, don't assume where someone's been. That's what's hard. I'm just a Black woman, married, mother that's working. And everyone looks at me like, ohhhh [noise and gesture that imply she thinks she is above other people], – no, I'm not. I'm not better than anybody else. I'm just, unfortunately I'm just a statistic now that's had cancer.

Y feels in many ways that she has been reduced to a statistic. She is now just a woman with cancer. While she sees herself as a Black woman, married, and a working mother, others see her as the woman with cancer. But for Y, her life is about so much more than that. She has a greater purpose. When describing her cancer, she said she looks at it as a “stepping stone.” She said, “I'm not easily broken. I have too much to do. I have too many people to share Christ about as long as I'm living on this earth.”

Y is a deeply religious woman. Her faith in Christ is incredibly important to her. She spoke to me at length, and at times, almost defensively, about what she believes. She would state that she accepted that other people do not believe what she believes, but she also expressed that

she really cannot understand why. For Y, Protestant Christianity is the one true religion. She said that God, the fact that His word is true, and all that He has done for her, is what keeps her going.

Y's long descriptions of her theology often spoke to her deeper beliefs about her cancer.

Here is one example:

Because everything in the Bible that's been written has come true. And there's a part about that is talking about what people believe to be right is actually wrong. And a lot of things that's going on now. You know if you want to change your sex, that's your business. But if it was a mistake you would have been the other sex. I'm sorry. If your body is supposed to be one thing it would have been. Everything has a purpose, everything is done in order. You can't have an egg without a chicken first. You can't. Why are there still species of different marine animals that are being still discovered now? I'm sorry. I did not come out of an ape. Some people believe they do. And if that evolution happened, why haven't we evolved into something else?

This line of discussion made me uncomfortable. As a queer woman, her discussion of trans issues made me worry that she would ask me a question that would force me to either out myself – and potentially alienate her – or lie about my identity, something I would feel goes against my research methods. I did not know how to respond in the moment. I wanted to be respectful of what she was saying but I did not want to imply in any way that I agreed with her. However, upon reflection and analysis, I realized that my discomfort and focus on the details of what she was saying, caused me to miss her overall point. Y believes that everything that happens is part of God's plan. Y does not believe that there are scientific explanations for things.

She argued against things like the Big Bang Theory and evolution because she believes in a literal interpretation of the Bible and that God is in control of all elements of life.

This worldview is directly tied to Y's beliefs about cancer. As she had already mentioned to me, she does not believe that cancer is hereditary. For Y, cancer is, in her words, "a sin problem" — not individual sin, but the result of Original Sin:

When sin entered the world so did the diseases enter the world. Our life was shortened. People in the Bible lived 500, 600, 700 years. Now people die in their 50s, their 30s. You cannot tell me there is no relationship to that. I'm sorry. All of a sudden now everybody's ill with something.

While Y had earlier described what she believed to be poor motivations of biomedicine as contributing to the lack of cure for disease, she makes it clear that the root of disease is in the sinful nature of humans. Y described being in the chemo treatment room one day and seeing a young teenaged girl going through treatment:

I didn't see any reason for her to be there. Cancer, high blood pressure, all of it, it's a sin problem. I always think about this. In the Garden of Eden Adam and Eve literally had this whole world. No problems. Until that first sin happened where she ate of the Tree of Life and she gave it to her husband. It's not because of something that we did as an individual.

Cancer is the price we all collectively pay for our sins.

In contrast to participants like Jan, Y does not believe that God is working through the doctors. While she seems to believe many in medicine to be corrupt, she mostly sees them as mortal and flawed: "Men -- Scientists can only get so far." Only God can really create or cure disease. She in many ways sees science in opposition to God. Y was not afraid to question her

providers, to change hospitals and doctors, and to refuse treatments. While both Jan and Y believe that, to quote Y, who was quoting the Book of Ecclesiastes, “There’s a time to be born, there’s a time to die,” and that everyone has free will and choices to make, it operationalizes very differently for them. For Jan, it is up to her to choose to listen to her providers whom she sees as agents of God, working to heal her. For Y, it is up to her to choose faith and eternal life.

Y’s biggest struggle with cancer has been a changing of her perceived master status. She does not want “cancer patient” to be how she is seen. She spoke of the struggle with how her social class has changed how others see her. She is used to people misrepresenting her identity and not seeing her the way she wishes to be seen. While she sees herself as a Black woman, a wife, and a mother, Y’s primary identity is as a follower of Christ. It trumps all her other identities in her mind. The way she approaches cancer is fundamentally based in that identity and worldview.

RELIGION AND DOMINANT IMAGES OF BLACK WOMANHOOD

As I have described above, faith and religion play an important role in the patient-provider relationship. Providers often struggle navigating how to broach the topic of religion with their patients. Some providers view faith as a vehicle through which patients are able to maintain hope and cope with their cancer. Yet at the same time, religion can be viewed as fostering false hope and can be a barrier to patients accepting the end of life. Similarly, while some patients view their providers as actors of God and put their complete trust in their provider just as they strive to trust God, other patients see their providers as powerless over cancer and view God as the only authority over life and death.

These varying approaches to faith and religion within the patient-physician relationship are further complicated by the other aspects of identity that shape how providers view their

patients. In this section, I present several dominant images of Black womanhood and explore how they influence and are influenced by perceived religiosity. I describe the ways in which providers unconsciously invoke these stereotypes in the clinic and the impact that these stereotypes had on patient-provider relationships and the care offered to patients.

In studying Black women from a Black Feminist perspective, it is essential to examine the pervasive and controlling stereotypes that have been historically applied to Black women. While Patricia Hill Collins (1990) identifies controlling stereotypes as one of the three main categories of oppression Black women face, it is often given less academic attention. This makes sense – it is harder to quantify stereotypes than it is to quantify disenfranchisement, exploitation of labor or the impact of racist and sexist policies. But in many ways the reproduction of negative stereotypical images of Black women and Black womanhood is one of the most dangerous forms of oppression because it is so deeply ingrained in the fabric of our culture and society that such images are not even seen as problematic. These racist stereotypes are pervasive in everyday life and they can have deep, lasting impacts on the self-images and mobility of Black women. The recent violence perpetuated against Black women and the rise of social media campaigns such as #sayhername have brought new attention to the ways in which stereotypes of Black women have real and often deadly consequences.

According to sociologist Cheryl Gilkes (1983:294), “Black women emerged from slavery firmly enshrined in the consciousness of white America as ‘Mammy’ and the ‘bad Black woman.’” The Mammy – or Aunt Jemima as she is sometimes known – is the stereotypical image of Black women as maids left over from slavery and perpetuated through the Jim Crow era. This stereotype is still very prevalent today, as can be seen in movies like *The Help*. The Mammy is the nurturing figure who takes care of others’ (mostly white) children and is

seemingly submissive to the whites in power over her, though she plays an important, and at times even authoritative, role in the family. According to Collins, the Mammy symbolizes the perceived ideal Black female relationship to elite White (male) power and privilege. Even though “she may be well loved and may wield considerable authority in her White ‘family,’ the mammy still knows her ‘place’ as obedient servant. She has accepted her subordination” (Collins 1990:72).

I think faith and religiosity plays into this dominant image in an important way. I theorize that, in many ways, the image of the “Mammy” is no longer the Aunt Jemima caricature – large asexual bosom, hair tied up in a bandana, a pot in one hand and a white baby on her hip. What I picture when I think of the submissive and obedient Black woman is the older Black woman, with a large hat sitting in the front pew of a church, fanning herself and shouting “Amen!” as the pastor preaches about the sins of the world. She prays for her grandchildren – the thugs and the baby mamas, the Welfare Queens and the absentee fathers; she raised them, all on her own, and is faulted by America for their choices in life while she herself is still seen as unthreatening and obedient. While she may have been perceived as “the matriarch” in middle age, she has crossed a line with age to being an unthreatening, obedient figure.

The stereotype of the Mammy has implications in the health care field. If a practitioner views a patient through the “Mammy” lens, he or she may be less receptive to questions from Black women. Additionally, according to Barbee and Little, Black women who have internalized this image may “consciously and unconsciously sustain gender and racial exploitation in a number of ways. One of the more dangerous consequences may be a tendency to agree voluntarily to medical procedures because they believe in obeying the doctor” (Barbee & Little 1993:184). While I have already noted the religion-based tendency to obey above, I did not

necessary see this as an internalization of the Mammy stereotype, but rather the result of a particular theology. I witnessed this theme of “compliance as obedience” across many women, yet it was the older women in my study whom I saw treated as the Mammy figure by their providers. One example is Millie.

Millie is an elegant woman. On days when she feels up to it, she wears beautiful accessories and styles her hair just so. She glides in and out of rooms (literally in her electric wheel chair but that is the air she gives). She is polite but willing to be assertive to make sure she is getting what she needs. Millie is viewed by her providers as very compliant: she shows up for her appointments, she takes her medications, and she is sweet in all of her interactions at the clinic. Yet, during an interview, I witness her immediately question a worker at her nursing home when she was given the wrong pills. She was quite assertive, admonishing the staff to pay better attention and get it right.

Millie’s family is the most important part of her life. She spoke of praying for them every day. You can see the delight she takes in her son and grandchildren. She had two children, but she lost her daughter several years ago. She also has four grandchildren and six great-grandchildren. She takes great pride in them. She said she wants to live for them. She sees her role as looking after and praying for her family.

Millie has accepted her cancer. She told me she was Stage IV and when I asked her what that meant she said,

Okay, that's the last stage of cancer. And actually you can die from it, you know at that time. And I know that. That's with me. And I try not to let it bother me. Because I'm still around and doing good. Because I've known some people who had cancer that didn't last as well as I've lasted. And I'm so pleased with that. So I

pray every day. And that's all I can do. Pray for me living to see my grandchildren and just to be here for them.

I asked Millie how she has dealt with her cancer emotionally. She told me, "I've never felt really down about it. At first I got scared... But I say, shoot, I've got to come out of this here and continue to live. That's what I've done because God has been with me."

Millie has put her cancer in the hands of God and the doctors. She believes it is all in God's plan and she has little control. While she has put her cancer in God's hands, at the same time, she is still doing her part by trying to stay positive and keep praying. That outlook seems to have served her well. She does not worry because it is futile; she will live or she will die and it is all in the hands of God. It is not that she is hopeless; she still believes that she could live for years to come. In fact, Millie feels fortunate that she has done so well with her treatment and thanks God regularly for being able to maintain the level of health that she has. She thinks she has done so well because she kept living her life. She said that she did not let the cancer bother her and she kept her faith in God. For Millie, feeling down or sorry for herself would not truly be keeping her faith in God.

That said, Millie knows how fortunate her cancer experience has been. She has not really felt sick. She has not had a rough time. She credits God for that. She mentioned watching other people go through cancer treatment and how sick they were or that they did not live very long. She mentioned that she did not want to go through chemotherapy after watching others struggle with it so severely.

Millie told me that she had heard from her provider recently that "there's not much we can do for you." Her family is still looking for other potential options for treatment, but Millie seems to have accepted that things will be ok either way. From our conversation it seems like her

main concern is her family. She seems to accept that whatever happens, happens, but she wants to protect her family from pain. She said that when she prays it is that she can be there for her family.

Millie is treated very respectfully and somewhat formally by her providers. They often call her “Miss Millie,” something that I have heard used a lot in other parts of the country as a sign of respect, but is not particularly common on the West coast. In the appointment I observed, Millie had come alone. She was transported directly from the nursing home where she lives on a gurney. The provider made sure to check in and ask about Millie’s family, asking how they were doing and saying, “It was nice to meet your granddaughter the last time. She was a sweetie.” Throughout the appointment, Millie did not ask any questions. She answered those the provider asked her and did her best to lift her legs or squeeze the provider’s hand when she was asked too.

As the provider ended the appointment she told Millie how happy she was to see her and that she would be praying for her. This is incredibly unusual in this clinic. This provider does not identify as religious, but she sees her patient that way and used the language of prayer for the benefit of the patient. I also noticed Millie be given some extra leeway by her provider. Millie has been in a wheel chair for several months. According to her provider, “I don’t know why she is in the chair. There is no medical reason for it.” The provider thinks she should be up and walking around, but during their visit she just asks gently a couple times “You never got back to walking?” She does not challenge or shame Millie. She allows her to continue with the wheelchair and does not express her displeasure or concern.

The intersections of race, gender, age, religion and family status has had a profound impact on the way this patient is cared for in the clinic. It is not that she is treated better or worse than other patients; but the care she receives is based in this Mammy stereotype. Millie is

perceived to a good and easy patient. There is little that can be done to treat her cancer at this point, but her provider sees her faith as a positive. She knows Millie is praying and maintaining hope. The provider also trusts Millie. During the visit, the provider prescribed a new pain medication for Millie to take as needed. She asked Millie about her alcohol consumption as alcohol can cause negative reactions with the drug. I have witnessed this type of negotiation before. Often the providers are quite firm, almost accusatory or threatening, to ensure that patients will not mix alcohol with the drugs. In Millie's case, the provider approached her in a light-hearted manner, asking about the nursing home's policies on drinking, but joking with her, saying with laughter, "You're not causing any disturbances." There was an assumption made that, of course, the provider did not need to worry about Millie engaging in dangerous behavior. Millie is seen as good and is offered the benefit of the doubt because of that.

Not all the participants I met were afforded that same benefit. In contrast to Mammy, the "good" Black mother, another modern stereotype of is that of the Black Welfare Queen. Labeled as a bad mother, a "failed mammy" (Collins 1990:77), she rejects working and is seen as content to live off the state. She further passes poor values and work ethics on to her children. For the Welfare Queen, religiosity is erased. While she may be spiritual or religious, her sins have marked her. She is defined by her socioeconomic status, her dependence on public housing, and her illicit drug use. She is assumed to not be able to care for herself. She needs the care of the clinic, but will fail to comply. Not too much can be invested in her because she does not invest deeply in herself.

Providers talk about the Welfare Queen with sadness and condescension. A provider described Betty to me using this language. I met Betty at the very beginning of my time at County Hospital and she never returned for an appointment after that. Her provider had heard she

had been in and out of jail during that time, but no one knew for sure. Her provider told me, with some sadness, “She could have been cured. If she would just come to appointments...” Betty had been Stage III when she was diagnosed, and it is possible, with more adherence, that her disease may have been curable. We will never know what might have been different with Betty’s cancer if she had pursued treatment more regularly. What I witnessed in my discussions with the care team about Betty was how much of her personhood was erased. It was assumed, often matter-of-factly, that she was not coming in for treatments because “she was back running the streets.” This idea of “running the streets” was euphemism for drugs, alcohol and other unhealthy and potentially illicit behavior. She was reduced to an image of a Welfare Queen without much consideration for other possible motivations for her lack of compliance.

Phoenix is another woman whose experiences with cancer and with cancer care exemplified the constant undertow of the Welfare Queen stereotype. Phoenix and I met in her room, a Single Room Occupancy (SRO) unit. She has been living in an SRO for a while and intermittently doing drugs her entire adult life. She has been in and out of jail and on and off the streets. Phoenix seems to have a lot of regret in her life. She expressed regret over the relationship with her son – that she was not enough of a presence in his life. She expressed regret about her father – he died while she was in jail and she was not able to say goodbye. She said she wants her father to be proud of her and wishes she had not been in the street life the last time he saw her. She feels like he would be proud of her now.

Phoenix’s lifestyle was very altered by cancer – in some ways she found this positive. But it seemed to me like she has had a lot of loss – her former appearance, her love of dressing up in fun shoes and hairstyles. The hair is an especially hard loss. As is the loss of connection to others – she feels “invisible on certain days.” And she said that she “get[s] lonely for company.”

But, when I asked if she missed it – if she missed her life before cancer she said “Not really. I don’t. Because this has allowed me to sit with myself.” I thought this was beautiful, that she has been able to focus inward and has seen that as a benefit of this new phase in life. Phoenix is drinking and using drugs but she says she has cut back considerably since she was diagnosed. She said the alcohol and drugs help her manage the pain and she thinks it could be why her cancer seems to be in remission. For so much of her life, drugs and alcohol were a means of “running away from being within” herself. But her diagnosis has allowed her to forgive herself and to do some soul searching. She also seems proud of herself – for the person she has become since she was diagnosed.

Phoenix’s faith in God has been the most important thing to her. She calls herself a “student of all religions” and mentioned that she believes in both Jesus Christ and the Quran. She has been able to get through cancer by keeping her faith, which she says has never stopped. All she can do right now is focus “on God through myself and my son.” Her son has been going through a “rough patch” of couch surfing and unemployment and Phoenix is determined to see him through it and make sure that he is well provided for and able to be “doing his thing.” Phoenix’s priorities have shifted and she is focused now on sitting with herself, helping her son and listening to God.

However, within the clinic, Phoenix’s religiosity is completely erased. She is seen as a “Welfare Queen.” When she missed several appointments, I checked in with her provider to see if she had heard from her. The provider told me, “She’s running the streets now but she will be back when she feels sick again.” It seemed that the only logical explanation was that Phoenix was back into drugs and not wanting to seek treatment. This could have been the case. But it may not have been. Regardless, the providers chose to attribute this explanation to her actions, and it

is difficult to imagine such stereotypical attributions not affecting their interactions with her when she does return to care. Her providers appear not to need to get to know her on a deeper level; they can rely on the stereotype to make presumptions about her behavior. The dominant image of Phoenix is that of the Welfare Queen, a caricature for whom any trace of religiosity is erased, despite being quite present in Phoenix's description of self. These are common refrains in describing a certain segment of patients I met at County Hospital. They are middle aged, without family accompanying them for visits, living in subsidized housing, and known, or assumed, to be drug users.

Melissa Harris-Perry (2011) describes the way in which our singular and ubiquitous view of the Black churchwoman – the new Mammy – obscures our ability to see other versions of Black women's religiosity. While this image of the Black churchwoman is incredibly important and telling about the Black experience and the Black church, there are a large segment of Black women who “identify as Christian and understand themselves as connected to a black religious tradition, even if they do not regularly attend church” (Harris-Perry 2011:232). Indeed, many women in my study grew up attending church regularly, and faith in God is a central part of their identity and a deeply engrained part of who they are and how they see themselves. Yet their adult lives have become too complicated by time, by a lack of resources, by drugs and alcohol, by cancer, to allow for regular church attendance. Regardless, they will do not hesitate to call on their faith as they deal with cancer and to praise God for what is good in their lives.

When providers maintain a singular view of religiosity and how it manifests for Black women, they erase a central part of who their patients are. Patients are too often dichotomized as compliant or difficult, good or deviant. The women who are viewed through this Welfare Queen

lens do not receive the benefit of the doubt offered to those who are viewed as the Mammy. They do not receive the benefit of assumed good intentions.

RESISTING OPPRESSION THROUGH THE “STRONG BLACK WOMAN”

One way that Black women have been able to assert their agency against these tropes and oppressive images is by creating alternate images of themselves. Harris-Perry (2011) writes of one new image, the *Strong Black Woman*. She describes the Strong Black Woman as “motivated, hardworking, breadwinners who suppress their emotional needs while anticipating those of others. Their irrepressible spirit is unbroken by the legacy of oppression, poverty, and rejection” (Harris-Perry 2011:184). This identity is pervasive and nurtured from within the Black community. It is used as a form of political resistance and much pride in the Black community is centered around this idea of the strength of Black women. However, there is an underside to this image in that it “allows ‘helping’ professionals to ignore African-American women when they need assistance. It is difficult to acknowledge that an African-American woman needs medical assistance when she is constantly referred to as being ‘strong’” (Barbee & Little: 1993:185).

In studying cancer, this idea of being strong is extremely pervasive. Being strong and fighting are part of the dominant rhetoric surrounding cancer and cancer treatment. But, for Black women, it goes beyond that. Harris-Perry (2011:246) describes strength as “the rent a Black woman must pay for the room she takes up on this earth” and notes that, in that sense, sadness or victimization are “not just a personal failure, but a racial failure.” A Black woman’s value, her very humanity, is tied to her ability to be strong for those around her. And, for many of the women in this study, that strength – the ability to stay strong through the hardest parts of life – is inextricably tied to a faith in God. Being strong is equivalent to demonstrating faith in God and an ability to trust in his plan. When a Black woman fails to be strong, when her faith

alone is not enough to maintain her strength, she is failing not only as a cancer patient, but as a Christian and as a Black woman.

When participants told me that they tried to stay strong, I would often ask if they feel a pressure to be strong. Jan told me, “I don't and then I do. Because sometimes when I get depressed I would be like, why is He putting me through all this? I want to know. But there's no answer. And sometimes I want to give up.” It seems that pressure is not external. While many women are staying strong for their families, the pressure to be strong for them was internal. It was a personal drive they felt to be strong and stay alive for others. And the way to stay alive is to trust in God's plan. As Dolly told me, “God has to help you when you need help. You never lose your faith, because that's all that you have.” When you lose your faith, you have nothing left at all.

However, the women in my study did experience periods when they lost their faith. One example of that is Shorty. Shorty is an engaging woman. From the first time we met I felt drawn into her story. I wanted to learn more about her and what she has experienced. She comes from a large family – she is one of 19 children – and her family is clearly extremely important to her. They have been incredibly supportive through her cancer experience. Shorty lives in the Bay Area mostly on her own and has not lived here for very long. It seems like she is very independent.

In describing her time living with cancer Shorty is both gregarious and knowledgeable. She tells stories in an animated fashion – she does other people's voices, laughs at jokes that were told years ago, cries remembering the pain she was in at times. She also describes her diagnosis, treatment and surgeries in a great deal of detail. She is an expert on her disease. It is

clear she is very familiar with the medical world both through her experiences as a patient and also as someone who worked in health care for many years.

Shorty was first diagnosed more than 12 years ago. Her diagnosis story sounds fairly harrowing. She had intense pain, which took her to the ER and they discovered a mass. She was bounced around a bit to different doctors and specialists. For over six years people told her that her tumor was inoperable. It grew and grew and grew and caused her pain and problems but no one could do anything about it. She went through chemo in the hopes of shrinking it but it did not work.

Throughout her cancer journey, her faith remained incredibly important to her. She gives God all the glory and credits Him for being alive today, saying, “I thank God. And I know all of this was possible for Him to do it – He made it possible. You have to have your faith and your belief.” Shorty grew up Baptist in the South and described going to church three times a week. Her faith became more important to her after she got sick, but she also told me about a time when she “dropped” her faith. Shorty had already gone through an exploratory surgery and several rounds of chemotherapy. She had some response, but her tumor was still very large, growing and attached to many of her vital organs. Her main provider sent her to a series of specialists to see if anyone had any ideas or treatments to offer her. She spoke of meeting with one physician in particular saying, “He didn't even look at me. He just looked at my papers and came back. They had me sit in that room for almost an hour. He came in and told me, I can't help you. He didn't say ‘I'm sorry,’ he just said I can't help you.” Shorty felt incredibly disrespected by this provider. She said, “I guess I wasn't white enough or I wasn't rich enough – I was on Medicaid at the time.” She felt like he would never really look at her. He told her that there was nothing he could do for her and she should get her affairs in order. This made Shorty livid. She

told me she said to him, “First of all, you cannot tell me to go home and get my stuff in order. Only God, the man upstairs, have that power and have that say of when I'm coming home. You don't have that say.” She left his office and never saw him again.

Despite the confident demeanor Shorty presented in her meeting with the doctor, the news of her terminal status devastated her. She told me,

I went home and – I have never told anyone – but I went in the medicine cabinet – when I went home and the doctor said there is no hope, I can't help you, I wanted to kill myself. I just wanted to go to sleep and not wake up. And my daughter knocked on the door and she said, “Mama, are you all right? Mama.” ... I said, “Yeah, Mama is all right.” But the pain was so severe. And I literally wanted to go to sleep. You know how you are just looking at all them pills. I just said, all I've got to do is just swallow them and I can go to sleep. Then my daughter and my son and my grandchildren – I started thinking about them. I closed my medicine cabinet door, went in my bedroom and laid across the bed. She said, “Mama you are in pain again too, right?” I said, “Yeah.” She said, “I'm going to call the three.” She called the three. My sisters...

Her siblings came and stayed with her and they spent the next few days in the same king sized bed, holding each other, talking, crying, praying and trying to find a way for Shorty to deal with this severe physical and emotional pain. “I had to endure the pain and the suffering,” Shorty continued. “But I didn't do it alone. And I got on my knees and I thanked God and I said, forgive me because that one time I wanted to give up.” It was only a few weeks later that she met a physician whom she described as a wonderful, warm and supportive woman. This provider found a surgeon who could stop the blood flow and finally operate and remove the tumor. After

this major successful surgery she did an experimental – and aggressive – chemotherapy and was left cancer free.

When Shorty described the time when she lost her faith and the severe physical and emotional pain she was in, I could see it in her face. Her body remembers the pain still in such vivid detail. Shorty still feels guilt about the one time when she lost her faith and was not able to be strong. She sees her inability to stay strong and not question what was happening to her as a sign of a lack of faith, a sin; for her, it is not our place to question why God allows us to go through things like cancer.

It is clear what Shorty values in doctors – kindness, openness, someone willing to explain to her the whys and hows. She is clearly engaged in her own medical care and I think resents when she is treated as body parts instead of as a human being. She's been cancer free since 2009 – something that is almost unheard of for someone with stage IV disease. Doctors sometimes do not know what to make of her. It sounds like she defied all the odds. One doctor described her as a living miracle; said her medical records are “a bible.”

Many women spoke about asking “why me” or being angry about their diagnosis. I would ask them with whom they were angry. Most were quick to deny ever feeling angry with God or questioning God's will. As Linda said, “I can't ask God ‘Why me?’ but I can ask myself, ‘Why me?’... I don't never question God. Never.” Questioning God was seen as something that should absolutely never be done. When women spoke of time when they did feel that way, it was with intense regret. Women described getting on their knees and praying for forgiveness for asking God “why did this happen to me.” Mary described being angry with herself for an entire day for asking the question saying, “It was meant for me to have so that's why I got cancer. So I've got to deal with it.” In interviews I would often express to the participants that I found this

sad. I did not understand why it was so wrong to question why a horrible thing had happened. It seemed like a logical question in my mind, but I was always quickly reminded that God did not cause the cancer and that no one has the right to question Him. These women found these questions to be an affront to God and would punish themselves for allowing the train of thought. When women spoke of feeling anger or resentment, it was describing their lowest points in their cancer experience because they were not staying strong in their faith.

Harris-Perry (2011:246) writes that when a Black woman's faith does not give "sufficient relief and consolation" she may feel "enormously guilty." For many of the women in this study, when they stumble in their faith, when they stop trusting in God's plan, when they are no longer strong, life loses meaning. For some it causes them to feel angry with themselves. For others, like Shorty, it is the time when they contemplate ending their own life. For these women, being a Strong Black Woman is being a woman of strong faith. The two are inextricably linked. Failing at strength is failing at Black womanhood; it is a failing that lies at the core of their identity as Black Christian women. When that faith slips, it represents a huge loss of identity and causes the women to question who they are and how they approach their cancer. It can be a devastating time.

CONCLUSION

In this chapter, I explored the intersections of race, gender and religion for Black women undergoing treatment for advanced cancer. I assert that the existing literature on these questions falls short because they do not adopt an intersectional perspective; they therefore misunderstand a key aspect of the role of Black women's faith in oncology care: For many Black women, and the majority of Black women in my study, one's faith identity cannot be separated or enumerated as distinct from racial and gender identity. Faith, race and gender mutually construct one another

in inextricable ways and the importance of that intersectional identity in the study of cancer is profound in several ways.

I began by examining the patient-provider relationship and how both patients and physicians describe the role that faith and religion play. I described the confusion and apprehension some providers feel around discussing these issues with their patients. I drew a distinction between how physicians view the role of *faith* and the role of *religion* in advanced cancer. Faith is often seen as playing a positive role in cancer care. Faith is linked to hope and is viewed as a motivator and a source of strength – all positive aspects for coping with cancer. Yet religion is seen as being at opposition with science and medicine. Providers view religion as potentially serving as a disservice or even a danger to their patients as it may cause them to maintain hope for too long (past the point of futility) or to undergo excessive treatment. While faith is seen as linked to hope, which is essential to cancer, religion is often seen to lead to a false hope, motivating patients to pursue aggressive treatments and risking the potential devastation of not being ‘saved’ by God.

I then moved to focus on the experiences of the Black women in my study, whose views of faith and religion differed markedly from that of providers. I used as a point of departure the common idea in the literature that Black women often see their providers as an instrument of God. Many women in my study do view God as working through their providers. I described a woman who felt an obligation to be obedient to her providers as that was, by extension, being obedient to God. However, many women also described their providers, and all humans, as being powerless over disease. Women felt that *only* God can cure cancer. This did not mean that God would necessarily heal them, but that it was only in His power to do so. Yet, while research often holds these ideas as inherently oppositional to each other – patients either trust their doctors

because of God or would not listen to or believe their doctors because of their belief in God – I found that many of the Black women I interviewed hold these ideas simultaneously. They strive to both follow the directives of their doctors as a way of taking advantage of the resources God offers to them, while acknowledging the fallibility of medicine and the inability of physicians to cure cancer.

I complicated the dominant stereotypical images of Black womanhood and the ways in which they are influenced by perceptions of religiosity in the clinic. I argued that when describing the Mammy in modern terms, what is often really being described is a ubiquitous idea of a Black churchwoman, clad in a large hat, worshiping from the first row at church. I argue that women in my study were perceived and treated as this new version of the Mammy and that their perceived religiosity was used as a part of the patient-provider dynamic. Their providers would make references to prayer and faith in their interactions as a way of building a rapport and providing comfort. Providers also assumed compliance based on this stereotype and would often offer the patients the benefit of the doubt when it came to lifestyle changes that I often witnessed contrasted more harshly with other patients.

I described the stereotype of the Welfare Queen and the ways in which she is seen as the “bad” to the Mammy’s “good.” The stereotype of the Welfare Queen is based in describing a woman who is lazy, with poor values and little work ethic. Many of the women I met were viewed through the lens of this stereotype. It often came up when the women failed to show up for appointments and the stereotype was used to explain their lack of compliance. The women I described, Betty and Phoenix, were assumed to not be coming in for treatments because they were “running the streets.” The providers were sad for them and did not overtly disparage them, yet they were treated as if the stereotype wholly accounted for their not pursuing aggressive anti-

cancer therapy. It was assumed that they were prioritizing the use of alcohol and drugs over their health and their family, and the amount of care they were offered and the investment on the part of their providers seemed to be titrated accordingly. For these women, their religiosity and the important role it played in their lives was erased. The stereotype effectively blocked their providers from seeing a deeply held part of who they are and the way they approach cancer.

I ended the chapter with a discussion of the counter-stereotype of the Strong Black Woman. Ostensibly produced by and for Black women, the Strong Black Woman is how we have resisted the oppressive forces of the other stereotypes thrust upon us. The Strong Black Woman is seen as the best version of Black womanhood. I described how the idea and importance of being strong in fighting cancer intersects with the idea of strength for Black women. For Black women, strength is inextricably tied to the intersections of race, gender, and religion. In contrast, to be weak is to fail as both a Black woman and as a woman of faith, identities that are, for many of my participants, completely inseparable. This leaves Black women who are facing cancer with an additional burden to maintain strength. I explored and described how Black women found strength through God, but also how a loss of strength or faith represented a betrayal of God. They found these moments of weakness to be some of the lowest in their lives. To be a Strong Black Woman is to be a woman of deep and abiding faith, and when women, for very human reasons, could not uphold that ideal, they felt a deep sense of regret and loss.

When it comes to studying the experiences of Black women with cancer, religion and faith are often explored. This is entirely reasonable as for many Black women, one's faith identity cannot be separated from one's identity as a Black woman. However, faith, race and gender mutually construct one another in ways that have a profound, but complex, influence on

the way Black women face cancer and the patient-provider relationship. As opposed to more reductionist understandings of faith and religiosity as positive sources of strength, I illuminate not only how religiosity can be viewed negatively by providers, but the ways in which the intersections of race and gender with faith complicate the ways providers view their patients and the relationships they form.

Chapter Five: Patienthood as Identity and the Intersectional Failings of the Clinic

INTRODUCTION

In the previous chapters I have used intersectionality as a lens for exploring the experiences of Black women with advanced cancer. I started by using intersectionality in its most traditionally used application: to explore the interaction of race, gender and class. While this is certainly important and a huge improvement in the way we study race, it still does not go far enough. In my second chapter, I broadened the frame to include religion and spirituality as another important element of intersectional identity. In this chapter I will argue that, when studying women with cancer, it is critical to examine not only how intersectional identity impacts cancer experience, but to examine cancer and the patient experience as a part of intersectional identities

Through critically examining intersectionality, I will explore the ways in which the identity category of “cancer patient” is developed and shaped and how that identity intersects with race, gender and other identity categories. In this chapter, I explore the stories of three women who on the surface are very similar: they are each low-income, unmarried, Black women who were diagnosed with advanced cancer in middle age and all received treatment in the same oncology clinic. Yet, their stories provide valuable insight into the divergent experience of patienthood as it intersects with race, gender, class, religion and immigration status. Using the stories of these three participants, I will explore how the patienthood identity manifests within the clinic, and how it shapes and is shaped by the patient-provider relationship and the ways in which medical decision-making is a product of intersectional identity and the patient-provider relationship.

EXPANDING INTERSECTIONALITY

Health status and the cancer experience shape and are shaped by identity. Identity — how we see ourselves and how we are seen by others — is what makes us who we are and it impacts the way we experience changes in health. As I described in Chapter Three, the intersections of race, gender and class had a deep impact on the way that women in my study approached their cancer. Shifts in class identity and the unique ways in which class intersected with race and gender had a rippling impact on the way the women were able to approach their cancer and treatment. The intersections of race, gender and class influenced how the women in my study made decisions with their providers and the ways in which cancer interrupted their lives, or not. For some women, cancer represented a major disrupter in their lives and they felt a new and profound lack of control. For other women, their intersectional identities and the oppressive and intersecting social forces of racism, sexism and classism had created a world in which they were always out of control, and cancer was just another out-of-control element.

In Chapter Four, I twisted the lens of the metaphorical kaleidoscope to focus more in-depth on spiritual identity as a critical piece of the intersectional story of women in this study. As we saw with class, a spiritual identity – and in many cases a very similar spiritual identity – when intersecting with other parts of women’s identity, can impact the way the women approach their disease and treatment in very different ways. For some women, a faith in God manifested in a belief in the healing power of their providers. For others, their faith allowed them to dismiss the limitations of biomedicine. Yet, I argued, that for all women, the way they were viewed within the clinic was deeply shaped by perceptions of their religiosity and thus their care was deeply influenced by their intersectional identity, whether or not it was an accurate interpretation of their person.

The experience of cancer for these women was deeply and inextricably shaped by their identities. In many ways, this concept seems obvious; who we are and how we interact with the world would impact the way we approach a major life transition or crisis. However, what also needs to be considered is not only the way in which health experiences are shaped by our identity, but how our identity is shaped by our health status and experiences. Health and identity mutually construct one another. And, in fact, I argue that patienthood should be considered as an identity category when discussing intersectionality and health. Therefore, in what follows, I offer a new and important intervention in doing intersectional health research. While most Americans have been patients for most of their lives, being a “cancer patient” is a unique and complex identity category. This identity of patient and the relationships formed with providers is both produced by our other identities and produces and shapes those identities.

Furthermore, throughout the previous chapters I have used intersectionality primarily as a means to examine the complexity of individual identity. This is how it is often used by contemporary social scientists. But, at its essence, intersectionality is a heuristic device used to examine and describe structural, institutional and political forces. As I described in the Introduction, when Kimberlé Crenshaw (1989) first articulated the concept of intersectionality, she was describing the ways in which Black women were excluded from anti-discrimination law that only considered race and gender as separate and unique strata for discrimination. Thus, she argued, domestic violence organizations, for example, failed to meet the needs of women with different race, class, immigration status and language identities (Crenshaw 1989). Crenshaw’s (1989) intention was for intersectionality to be used to examine the impact of structural, political and legal forces on marginalized groups and individuals. This chapter, while still examining the individual identity aspects of intersectionality, will use a structural intersectionality framework to

examine the patient-physician relationship and the experiences of Black women within the institution of medicine. Structural intersectionality “occurs when inequalities and their intersections are directly relevant to the experiences of people in society” (Verloo 2013:899).

Crenshaw (1991) argues that the subordination that occurs as a result of structural intersectionality is often not based in an explicit intentional bias on the part of workers in a system or organization. Rather, “it is frequently the consequence of the imposition of one burden that interacts with preexisting vulnerabilities to create yet another dimension of disempowerment” (Crenshaw 1991:249). This lack of understanding of the multiple levels of burdens faced by certain populations means that institutions are unable to serve them fully without large scale, intersectionally-minded reform.

We can clearly see structural intersectionality at play in medicine. Safety-net hospitals exist *because* of the multiple levels of intersectional subordination that limit access to health care. That is, safety-net hospitals arose as institutions to serve a population whose needs were not met by the larger health care system due to the forces of classism, racism, the immigration system, the criminal justice system and the massive indigent population created by their intersections. Yet, County Hospital is still not able to fully address the needs of their patients. This is not due to intentional bias on the part of providers. Many of them chose their professions to be of service to others and they value the relationship they form with their patients. They hold a deep and genuine desire to end suffering and cure disease. However, the institution of medicine has been built around a singular model of patienthood and a limited vision of how patients should be served. Though medicine has embraced interventions such as cultural competency trainings and accepted the need for foreign language interpreters and designated staff to address issues of insurance, the institution has not fully examined the ways in which structural

intersectionality may be reinforcing the subordination of different groups. This does not simply mean that many patients are being failed by the institution of medicine (though they are). It means that the ways in which patients are viewed, the types of identities they take on, are different.

Through the words and experiences of several participants I will attempt to highlight examples of the ways in which the identity of cancer patient shapes and is shaped by other identities such as race, gender, class, and nationality, and the ways in which patienthood itself impacts the way patients interact with their providers in the clinic. The raced, gendered and classed experience of cancer alters the identity of patienthood in a way that makes the patient-physician relationship different from that which the providers have been trained.

CANCER AS ISOLATION AND REJECTION—BETTY’S STORY

Betty was actually the first participant in my study. When I spoke with her, I did not have any questions prepared about the concept of her identity as a cancer patient. I did not even think to ask if she had family or friends who had gone through cancer. But, Betty was extremely open with me. She is funny and sassy and honest and was blunt in describing the profound impact of watching her mother go through breast cancer saying, “I didn't want to touch my mother for a long time. I thought she was nasty because of her sore. Her cut right here. And I just didn't want to touch her for a long time. I really felt bad about that because I know she needed me and I needed her.”

Betty still lives with her mother. Her mother was in and out of the room during our interview. Betty would often yell at her to give us privacy or her mother would interject a reminder about some aspect of her treatment that she was neglecting. In many ways it reminded

me of the way I related to my own mother when I was in high school and how I would probably interact with her now if we lived together.

Betty feels a lot of guilt about how she treated her mother when her mother was in treatment for her cancer. Betty's own refusal to touch her mother and not wanting to be around her while she was sick led Betty to believe that no one would want to be around her after she was diagnosed. She thought people would think she was "nasty" too. This led to a great deal of isolation and, in fact, many of her friends ended up assuming she was dead because they heard she had cancer and then did not see her for months.

When Betty was diagnosed, she was shocked. She had expected to be diagnosed with a UTI or some other easily treatable condition. And she immediately blamed her mom: "I really thought my mother had given me cancer. And I feel really bad because of the way I used to treat my mom and everything." She took out her feelings about her cancer on her mom. She would not talk to anyone other than her mom and brother, and her relationship with her mom was tumultuous for some time.

For Betty, identifying as a cancer patient meant identifying as "nasty." She immediately recognized and viewed herself as a cancer patient, which to her meant that no one else would want to be around her. Isolation was the logical step to take. When I met with Betty she was incredibly focused on wanting to treat her cancer. She told me,

I just wanted my chemo. Everything else, I don't care. I want my chemo, let's go, let's go. That's the only thing I focused on was chemo. Chemotherapy, chemotherapy. I was not thinking about no focus group, I was not thinking about any acupuncture or going to get my nails done or whatever. I want chemo. Chemo, chemo, chemo. Nothing else, chemo. Wake-up, chemo, go to sleep,

chemo. Chemo. That's all I wanted. Because I knew once that chemo started that I was on the right track. I was not thinking about anything else. I want my chemo.

But, then she stopped coming in. Betty had told me that it was important to “not be disobedient and do exactly what they [providers] tell you to do.” Yet, for a year she missed her appointments with her provider and for her therapy. I heard from her provider that she was in and out of jail a few times during that time, but they could not reach her. She would call in and make appointments occasionally, and someone would call her to confirm, but then she would never arrive. This was not atypical at County Hospital. There were many days when I would spend four hours waiting to meet with a patient who never arrived for her appointment. These patients are often labeled as “non-compliant.” The clinic is willing to see them if they come back, but the clinic staff also stops investing time and energy in their case, and that makes sense. The clinic does not have the resources or staff to call the patient to reschedule appointments. They cannot hold space for them in the chemotherapy schedule. The patient navigators and social workers have to take repeat no-shows off the list of patients they regularly call for check-ins, because resource and time scarcity demand that they focus on the patients who regularly and reliably seek care. In short, providers feel they cannot continue to invest in a patient when the patient does not herself seem invested in her own care.

Yet, Betty was desperate to treat her cancer. It had been her top priority. What shifted? I wonder how her conception of patienthood, her self view as “cancer patient” impacted her turn away from medicine. That is, Betty’s identity of “cancer patient” and her view of her own patienthood are wrapped up in guilt and isolation. For Betty, being sick equates to being rejected by others around her, just as she rejected her own mother. I wondered if, for Betty, coming back to treatment and regular care was seen as a return to patienthood and the isolation and guilt it

represents for her. Her life prior to diagnosis had involved “running the streets.” She had a lot of friends and seemed to know everyone in her neighborhood. Perhaps she did not feel she could return to that normal and be a cancer patient at the same time.

What could be shifted in the clinic to allow for providers to understand how Betty’s definition of cancer patient, along with her race, class and gender, might impact her ability or willingness to come in for appointments? Are there alternatives besides the patient being labeled as non-compliant and the assumption being made that she is no longer interested in treating her disease? The system as it exists is set up for certain type of patients, those who are compliant. Others are left behind and it is justified. The modern institution of medicine is built upon the value of informed and voluntary consent. We accept the right of a patient to refuse care. This right is critically important, yet it also relieves the institution of medicine of the responsibility of caring for those patients who, for whatever reason, do not voluntarily give themselves up for care. Is Betty simply refusing care? Or are other factors in her life and identity precluding her from seeking additional interventions?

Taking seriously intersectionality’s attention to structural and institutional forces, I argue that Betty’s providers cannot know the answers to questions about her reasons for missing appointments, nor are they in a fully informed position to judge them, without getting to know her on a deeper level. Yet they are structurally inhibited from doing so by the demands of the clinic and the structural forces at play in the institution of medicine. The providers at County Hospital see three to six patients an hour. This often means they see patients for as little as ten minutes. They are unable to form deeper relationships because they do not have the time to talk to their patients about their lives outside of what is immediately impacting treatment and disease. The providers are largely unable to follow-up with patients outside of the clinic nor should they

be expected to do so. However, this means that patients who are unable or are unwilling to come to the clinic, for whatever reason, have no other options to receive care. It is possible that Betty is simply “non-compliant.” She may have decided that she is no longer interested in pursuing anti-cancer therapy. However, the limitations of the clinic and of patient-provider interactions have created a situation in which her providers do not have the tools or the relationship necessary to establish if that is in fact the case.

“CANCER PATIENT” AS AN UNFAMILIAR IDENTITY—ANNE’S STORY

Anne’s story is quite different from Betty’s. Anne is an immigrant from West Africa. She moved to San Francisco very recently and has been staying with friends. She is a lovely woman with a strong and beautiful accent. She has gorgeous clear eyes that instantly draw you in when you see her across the room. What is most surprising about Anne is her lack of knowledge about cancer. It is something I, and I think many of her providers, probably often taken for granted: that everyone knows what cancer is. Everyone knows someone who has had cancer and gone through chemotherapy. Even if one has not lost someone close to them, they are familiar with the side effects of chemotherapy – hair loss, vomiting – and have some sort of understanding of the gravity of a cancer diagnosis. Anne was different. She had never really heard of cancer before. She had not met anyone who had gone through cancer treatment and was not familiar with terms like “chemotherapy” or “radiation.” One of the social workers in the clinic told me this was the first time she had ever met anyone who did not know what cancer is. The social worker had found out about Anne’s cancer naiveté when she met with the patient after her initial appointment and reported it back to the rest of the care team. The physicians were unaware that Anne was so unfamiliar with her diagnosis. This created an incredibly unique experience of patienthood.

I observed Anne's second visit at the County Hospital clinic. We had met briefly after her first visit and in the second she agreed to let me observe. Anne's diagnosis was very new and from my conversations with her providers, I knew her cancer was quite extensive. She had been diagnosed with stage IV cervical cancer. It was described to me by an attending physician as "Very, very bad disease" (I had underlined each "very" multiple times in my notes). Her cervical cancer was actually small cell cancer. Small cell is a common type of lung cancer, but not often seen originating from other parts of the body. It had already spread throughout her skull and abdominal cavity. The physician encouraged me to speak with Anne as soon as possible as she did not think she would live for very long.

Anne was seen by an oncology fellow – one fairly new to his rotation in the County Hospital clinic. He is one of the most polished looking providers in the clinic. He is always dressed formally – dress shirt and tie, slacks, freshly shined shoes. In fact, he carries a gold plated stethoscope. I (and many of the other providers in the clinic) had never even seen a gold stethoscope before. He did not wear a white coat during this visit – some providers in this clinic always wear white coats, others take them on and off throughout the day – but his dress and presentation was still much more formal than the patient and the friend who accompanied her.

This visit started with the very severe symptoms Anne has been experiencing. She was having severe pain in her skull and her vision had become blurred and she was now seeing double – a change in the thirteen days since her previous appointment. She was also having sharp and constant abdominal pain and had not passed stool in six days. The provider assessed her symptoms, went over some medications and made recommendations for additional interventions. They went over her schedule for finishing up radiation, which she had begun the week prior, and starting chemotherapy as soon as possible.

Anne was accompanied to this visit by John, the friend she has been staying with since she moved to the U.S. About 15 minutes into the visit, he brought up the hectic schedule and the trouble they are having managing all the components, especially with Anne's limited vision. He asked about the possibility of combining visits or appointments, noting the challenges they are facing and wanting to make sure they were seeing the right people. The fellow responded, "Right now, the people who are in place, know your case. You have an unusually aggressive cancer as we talked about." He then went on to make sure all the bases would be covered so chemotherapy could start as planned without really fully addressing the concern that was raised. I also wondered about his language in noting that the cancer was "unusually aggressive." Would this offer enough explanation to someone who had not known other people with cancer, and did not know what cancer was, much less that it had varying degrees of aggressiveness? What was the intent of this language in response to the concerns raised?

A few minutes later, Anne asked the physician, "Are you Dr. Davis¹?" "Huh?" the fellow asked. "Dr. Davis," she repeated. "Am I Dr. Davis? No I'm Dr. Ahmed². Dr. Davis is one of our supervising attending doctors. Deep breath, okay?" as he continued with his physical exam and listened to her lungs. This exchange struck me for several reasons. First, Anne did not know the name of the fellow who was seeing her that day. He had not introduced himself at the start of the visit, but I had assumed he had when they had met the first time. Second, the fellow did not ask why this question was raised but simply continued with the examination. The patient had told me prior to the start of this visit that another provider had recommended she speak with Dr. Davis because of her great reputation. I wondered if the patient was questioning something about the care she was receiving so far.

¹ Code name for an attending physician in the clinic

² Code name for oncology fellow in the clinic

After the fellow finished up with his exam, he began to transition to leave the room and check in with the attending. “So, I think we have at least a plan,” he said. “Let me talk to Dr. Davis. Do you have any questions? We discussed the timing so....”

Anne asked about her catheter, if it would have to remain attached to her after she finished with radiation, leading to the following exchange:

Dr. Ahmed: “Let’s see where things go.”

Anne: “The pain is still here. It’s still there.”

Dr. Ahmed: “Use your pain meds.”

Anne: “Will it cure it?”

Dr. Ahmed: “Will the pain meds cure it?”

The provider seemed baffled by this question. He launched into an explanation for which medicines she should be taking and noting that he needed to check on why another medication had not been prescribed as he had thought it would be. But, that was not really what the patient was asking, leading to another lengthy exchange:

Anne: “Will it, reduce that [the pain in the spot the doctor is examining] and finish it, or what is it doing, the radiation?”

Dr. Ahmed: “It’s shrinking the tumor that is making your eye have trouble moving. It’s shrinking it.”

Anne: “So, it won’t get up again?”

Dr. Ahmed: “Well, right now we’re hoping that it shrinks it and then, the chemo helps with that as well.”

Anne: “It will not get up again?”

Dr. Ahmed: “We have to watch. We have to see. There’s no way to predict.”

John: “I’m sorry to ask you a question. After the treatment of the cancer, is it maybe in 2, 5, 10 years, is it going to come up again or just after.... Call it off, that’s it and no more?”

Dr. Ahmed: “I think the important thing we have to say is that we don’t—”

John: “We don’t know how it works.”

Dr. Ahmed: “We don’t know how it works. Your cancer is distant. It’s not just in once place. We’re trying to control it. We’re not expecting this is going to cure the cancer. We’re trying to prolong your life as much as we can so that your symptoms are controlled, that we get the cancer from growing, we stop it, but the expectation is not that this is going to be something that’s cured. We’re trying to control it. Very different things. I want you to understand that we’re not expecting that you get chemo, cancer all goes away and then, 10 years from now we follow up. Right now, we’re emergently trying to control the spread. Does that make sense?”

John: “Yeah.”

Anne: “Control the spread, but it will be there?”

Dr. Ahmed: “It’s still going to be there, but we’re trying to get it to a lower level, basically.”

Anne: “The catheter’s not good?”

Dr. Ahmed: “It’s not when you have cancer that’s spread beyond one area. If it’s in one area, you can sometimes cut it out. You can get that tissue, but right now the cancer has spread to other parts of your body through the blood, and other channels so, right it’s for control, not cure.”

Anne: “Yeah.”

John: “Can it be cured finally though?”

Dr. Ahmed: “It cannot be cured, it can only be controlled. We don't even say you're cured, we say, "You have clinical response" because those cancer cells will still be there somewhere. 1, 2, 1000, 10,000, we don't know. The only way to cure is if you had it in one specific area early on and they cut it out and it had not spread, but it has spread. We are not curing, we're controlling. Does that make sense?”

Anne: “Yeah”

Dr. Ahmed: “Very important difference so that you understand what we're expecting.”

Anne: “As they start to control it, does it mean it... Will the person keep being on drugs through the lifetime?”

Dr. Ahmed: “Let's see how things go. Let's see ... I can't predict 6 months from now because we don't know how your symptoms are even going to respond to the chemo. Good questions. Difficult to know before you're body ... Every cancer is different. Every person responds differently. Okay? All right, I think we have what we need here. Give me 2 minutes. I'm just going to talk to Dr. Davis real quick.”

In this conversation, we can see that Anne and John wanted to have a prognostic conversation with Dr. Ahmed and that Dr. Ahmed may not have been fully prepared to have that conversation in that moment. We can see Anne asking questions, sometimes repeatedly, seeking to understand the goals of care and her treatment trajectory. During my observation, it was clear from the body language of all three people that no one was fully satisfied with the direction of

the conversation. In order to understand this dissatisfaction, it is important to understand prognostication, which I define as the social processes through which providers help patients reshape their understanding of the probable disease and treatment trajectory.

But rather than being just a single social process or way of explaining future disease trajectory, I argue that prognostication takes at least three forms (James 2014). First, quantitative prognostication uses numbers (such as odds ratios, probability or statistics) based on the relevant medical literature and the physician's own experience and expertise to convey information about future disease. Second, in categorical prognostication, the physicians position patients within categories (either their own or commonly used ones) to explain the risk of a particular outcome in relative terms. The physician uses language that is intentionally somewhat vague. This is the strategy used by Dr. Ahmed: he repeatedly drew a distinction between "curing" the disease and "controlling" the disease. He attempted to be very clear that the disease cannot be cured, but also never used words like "death" or "terminal." By using a terminology of "control," he highlighted that the interventions can have an impact on the disease, but the specifics of that impact are left vague. He did not promise a timeline or offer any odds.

From my previous research (James 2014), I learned that this strategy is used to allow a patient who *wants* to hear a poor prognosis to be able to hear it without *forcing* a patient who does not want to know to take in the information. However, I think Anne's unique circumstances – her immigration status, how unfamiliar she is with cancer – change this dynamic. Anne does not initially understand what the provider means by control. She continues to ask if her cancer will still be there, if it will grow back. The category of control versus cure does not inherently mean something to her; it needs to be explained in more detail. She does not appear to be in denial or to not want to know, because she continues to ask. She just did not understand the

answer when it was first offered. The provider's potential assumption that if Anne wants to know her prognosis, she will be able to figure it out does not work here. Anne's unique relationship with biomedicine and her patienthood identity have not been shaped by the same cultural and familial influences that may allow other patients to pick up on the cues being offered. Categorical prognostication can only have the intended impact when there is a shared understanding of language between the patient and the provider.

Dr. Ahmed also leverages a third type of prognostication (James 2014): Qualified prognostication — which can be employed both independently and in conjunction with the other two forms — is used by clinicians to amend trajectory-shaping information they have presented previously to patients. It is intended to deliberately undermine other prognostic strategies or as a strategy to avoid a prognostic conversation. Dr. Ahmed clearly qualified his prognostication. He used phrases like “I can't predict” and “Every cancer is different. Every person responds differently.” He attempted to tell the patient that he cannot be sure what will happen with her cancer. He can only focus on “control.”

Both of the forms of prognostication that Dr. Ahmed used — categorical and qualified — leave Anne and her friend John with no sure footing about what to expect. It does not appear that Anne understands the categories of “control” and “cure” in the same ways that Dr. Ahmed used them. And the post-hoc qualifications he offered gave them further grounds for uncertainty. Unsurprisingly then, after Dr. Ahmed left the room, Anne and her friend turned to me. This is a situation that I dread. I am often asked questions as a medical expert, when I am clearly not. I also do not want to insert myself into the observation more than I already have by the simple fact of me being in the room; I have experienced multiple cases of the provider or patient addressing me instead of each other and I feel horrible when that happens. I do not want to alter the dynamic

or the relationship between the two, nor do I want to disrupt the care being provided. But, at the same time, I could feel the frustration and confusion Anne and John were exhibiting. As soon as the provider left the room, John turned to me and asked, “You understand the question we asked regarding the cancer?”

I thought I did. It was very clear to me that they were trying to find out if there was going to be a time away from medicine, if Anne’s quality of life would be improved and if they could hope for a time of health and normalcy. They were not satisfied with the answers they received. I wanted to make it clear that I heard them and that their questions were important and valuable. But, I did not want to speak for the provider – it would be unethical as a researcher (and a human) to pretend that I had the medical answers.

Jen: “I think what the doctor is saying is, it depends on the type of cancer and how far it's spread. Sometimes cancer can, but they usually don't use that word for a long time. If you're cancer free for 5 years they might say that you're cured, but yeah....”

John: “I understand they must say 5, 10, 15, 20, or maybe ... The question is ... if someone has to be on drug throughout their life? That's what we're just trying to find out. If it is to be on the drug after when they ... just like he said, it cannot be cured when it's spread. OK. That means that person has to be on drug or medication in case if eventually eventuality something like that come up. I'm just trying to know if something like that can....”

Jen: “I think those are really, really important questions and you should definitely keep asking them. He's going to come back in, I think he's going to bring Dr. Davis in as well. She's a super expert so, she's a good person

to ask questions to as well. She's the supervisor. I know it's a lot of information that he's given you.”

I worried that I had not said the right thing. I worried that maybe I had thrown Dr. Ahmed under the bus in some way with that comment. I just wanted Anne and John to know that it was ok to keep asking these questions if they were not satisfied with the answers. We chatted about the research schedule for a few minutes – how we would coordinate the next interview, making sure I had the correct contact information.

Dr. Ahmed came back and briefly reiterated the plan to schedule chemotherapy to begin the next week. Anne immediately asked if Dr. Davis was coming in. Dr. Ahmed told her,

She's finishing up with some other patients. Is there something you want to discuss with her because she's in another patient's room? We've been in communication so, she and I are one simultaneous team.

Anne mentioned that another doctor said she should talk to Dr. Davis:

Dr. Ahmed: “Yeah, I can ask her. I can find her. What that doctor meant was that you need to come to and see the clinic because the fellows are supervised by the attendings. Dr. Davis is one of our attendings.”

Anne: “OK.”

Dr. Ahmed: “Would you like me to... Would you like to wait or have her come and talk to you in a little bit? Why don't we do this, why don't I have her once she's done and has a second, talk to you and you can wait in the waiting room because I have some other patients.”

Anne agreed to wait to see the attending physician who, it turned out, was available to come in right away. It was interesting to observe how quickly the dynamic shifted when Dr. Davis came into the room. Dr. Davis is fairly diminutive in stature, but she has a large personality and a strong presence. You can feel a room shift when she walks into it. She has been in practice at County Hospital for decades. She did her residency there and often tells stories about the way it has changed over the years. She can always tell you the secret short cut through the basement tunnels to get anywhere on campus in the shortest amount of time. She speaks very lovingly for many of her patients. She speaks with a great deal of authority on every topic. Cancer and patient care, of course, but also travel, or language or current events. It is not uncommon for her to have conflicts with other members of the team in the clinic. She seems to always speak her mind, even if it is not one of her patients being discussed.

She came into the room and immediately began offering suggestions. She thought Anne should get an eye patch to help with her vision issues and mentioned that she could have it bedazzled so she would look like a “fancy pirate.” She sat down next to Anne on the exam table and put her arm around her as if they were old friends, even though I am not sure they had met before; if they had it was only briefly in passing. As they were speaking, she would gently touch the area of Anne’s body she was referencing: stroking her temple as they discussed the skull radiation, moving her hand across her abdomen as they spoke of how cancer spread. It was very familiar and affectionate, a drastic shift from the previous clinical encounter.

The first part of the conversation revolved primarily among the two physicians and John. Anne was clearly the subject of the conversation and all eyes were on her, but she was not really speaking and in fact mostly kept her head down. She seemed to have withdrawn into herself a bit. She spoke up after a few minutes to note that her pain was bad, and Dr. Davis reiterated the

plan to start chemotherapy as soon as radiation was finished. Dr. Davis was explaining all the places cancer had been seen and would interrupt herself to ask the fellow which scans had been done and what was shown so she could give a full explanation.

She was generally optimistic and spoke slowly and carefully, wanting to be understood:

Yeah, it's in the bone, it's not in the brain. That's the good news. You're brain is just fine. A lot of times this cancer likes to go into the brain. There's no cancer in your brain. It's in the bone, in the bottom of the skull, right where that nerve that comes out to here to move this eye. Right where that nerve goes past there is. It's no surprise that it pressed on it and it made it not work right. We're hoping that we got it quickly enough that it will get better.

She went on to explain that the cancer in the abdomen was the same cancer; it was spreading throughout her body via her blood.

John interrupted to ask, “What does the radiation do? How does it work?” Dr. Davis explained the purpose of both the radiation and chemotherapy and why both are necessary. She explained – in overly simplified terms – how each attack the cancer differently and what the goals of care are. Several times, she used the term “shrink.” John jumped on this as a point to re-ask some of their initial questions.

John: “When you said shrink – after when they shrink, after when the radiation or the chemo, after when they shrink... a couple of years, can it come back?”

Dr. Davis: “Yes. Yes.”

John: “It doesn't cure completely”

Dr. Davis: “One of the things we would consider if we get a really nice result down here and a nice result here with the bone, and we get the chemo to shrink the lymph nodes that are back in the back of her belly are big, too. We would consider if that shrunk down, putting some radiation there and then, we kind of sit back and go, ‘Okay, now what?’”

Again, Dr. Davis finds another way to restate the goals of care. While the fellow had initially used the word “control” – a common language used in prognostication – Dr. Davis heard the patient and her friend understanding the word “shrink,” and reframed her prognostication using that language. Dr. Davis is still using categorical prognostication, but she is using a different word and tone. But, she is still leaving the future a bit unclear. She is not outlining exactly what will happen but allowing for a future where more decisions will need to be made. The fellow jumped back in to restate what he had said early. He wanted to make it clear that this was the same information he had provided before, just stated differently.

Dr. Davis then continued her explanation, saying they wanted to “get as much of the bulky as we can find, wiped out.” When this new term was brought in, John pressed her for more explanation, wanting to understand “wiped out.” She responded, “It will come back, but it is usually very responsive to chemo and to radiation.” This was information that Anne and John had been waiting to hear. The cancer would in fact come back. Dr. Davis stated definitively that it would.

Yet it is still unclear if Anne and John fully understood Dr. Davis’s answer, as they pressed, once again, to find out when it comes back, whether Anne will have to undergo this process again. Dr. Davis’s answer is quite long as she explains that she cannot predict if it will be the same chemo again or something new. Her response includes two levels of potential

misunderstanding: For one, Dr. Davis does not seem aware that Anne does not understand that there are different types of chemotherapies. Secondly, what Anne and John really want to know is if there will be more treatment, lifelong medication, not the specifics of which exact therapies will be used.

John wants more information. He continues to press with his questions and advocate for his friend. He asks next, “When we say it might come back, how they think, maybe 2, 3, 4, 5 years –?” Here, he wants to know how long of a remission Anne might have; moreover, he still phrases the possibility of the cancer returning as “it might come back” rather than the more definitive language of “it will come back” that Dr. Davis had used above. Dr. Davis says that remission time is extremely variable and provides one benchmark for an estimation: “When this is in the lungs and it’s spread around like this, we’re happy with 2 years.” That is, when this cancer originates in the lungs, Dr. Davis is expressing that it would be a *phenomenal* response if they were able to stop progression for two years. However, it is not at all clear whether Anne and John understand that, because Anne’s cancer had begun as a cervical cancer, this number of two years may or may not apply to her case at all. Complicating the matter, Dr. Davis then further qualifies her prognostication to say that she does not know enough about this specific cancer: “We don’t have enough information right now.” She elaborates that there is a lack of research on Anne’s rare incarnation of this cancer, that they know the treatment to offer in the lungs, and so they are following that path. She ends by promising that the team will continue to update Anne as they go along. Then she abruptly switches back to describing ways to glamorize the suggested eye patch, noting the colors of the soccer team from Anne’s home country. It is clear that Dr. Davis wants to shift back to finding a rapport with the patient. She wants the patient to feel comfortable and engaged with her around something, and is finding ways to bond with her.

Dr. Davis has been primarily engaging with John, answering his persistent questions in a way that is more direct and more detailed than Dr. Ahmed, but still within the context of categorical and qualified prognostication. Doing so still leaves open the possibility of new treatment options, as she noted that there are “new, new ways of treating cancer” that can possibly be explored after they try the plan that has been outlined. She has attempted to make clear that cure is not the goal, and words like “control” and “shrink” were used to describe the goals of care. Dr. Davis has offered the possibility of a time without cancer, perhaps as much as two years, but only after being asked repeatedly. She and Dr. Ahmed made it clear to Anne and John that they could not say for sure what would happen and were not able to predict accurately. However, this was in opposition to what they described to me both before and after this clinical encounter: I was told in no uncertain terms that Anne did not have long to live. It was clear to me that they wanted Anne to maintain hope and to move forward with the plan of care. But when Anne and John raised questions about the utility or the interventions or the possibility of being on medications for life, those questions were answered less directly.

It is possible that by offering more direct, quantitative answers around the likelihood of the chemotherapy being effective at controlling the disease or of Anne being on medication for the rest of her life, Anne’s goals of care and willingness to continue with the plan might have shifted. In order to know for sure, Anne’s providers would have needed to have a discussion with her about her goals around treatment and quality of life. But while the providers explained the goal of reducing symptoms, they did not fully address Anne’s concerns in a way that allowed her to make an informed decision. She was not offered choice in this encounter. She was only offered the chance to assent to the plan on the table via scheduling her next appointments. Anspach (1993) clearly delineates the difference between the decision-making models of

informed consent and assent. In informed consent, patients are treated as the principal participants in life-and-death decision. In the second model, patients are viewed as giving assent to decisions that members of the medical team have already made. This is what I witnessed with Anne. Anne was not a part of the conversation where options were weighed and a plan was decided. Anne's preferences and goals were not a part of the conversation in creating a treatment plan. Instead, she was offered the opportunity to agree to a plan already in place.

What operated so differently in Anne's case was her own lack of knowledge of cancer and how that impacted her experience of patienthood. Her identity as a cancer patient cannot be delinked from her identity as a Black woman, as a person with limited means, as an immigrant. For the majority of patients in this study, the experience of watching family and friends experience cancer, chemotherapy and end-of-life has profoundly impacted the way that they experience their own cancer and their own identity as cancer patients. Anne did not have these experiences to draw from. Anne's providers and the institution of medicine did not have the language to reach her. The institution operates based on a set of assumptions about the type of patienthood experienced by patients. However, these assumptions were not true based on Anne's social location, given her immigration history, her lack of familiarity with the health care system, and her lack of experience with cancer. The language that Anne's providers used is language that they have used with many other patients and with very different impact. Anne's experience of patienthood was too distinct from other patients.

It is also essential to examine the structural oppressions Anne faced in this interaction. Anne and her friend John asked repeatedly for more and deeper information. They had many specific questions that did not get answered. Yet, Anne has limited power in this situation. As a low-income immigrant woman, Anne does not have another place to access care. She is

receiving care at County Hospital and it would take a tremendous shift in resources or medical savvy for her to find care elsewhere if she was not satisfied with the plan being offered to her or the answer to her questions. Anne does not know about alternative therapies. She does not have family or friends encouraging her to seek a second opinion or to try a miracle drug they have read about. That is not necessarily a bad thing. As we saw with Delores in Chapter Three, having these additional resources can also put patients in a position of self-blame when they are unable to change their health status. Yet, the fact remains that the intersections of Anne's race, gender, class, immigrant status and concept of patienthood have left her with few options other than following the advice of her providers and assenting to the plan already on the table.

PATIENTHOOD AS A THREAT TO INDEPENDENCE—OLEOS'S STORY

Oleos, like Anne, is an immigrant. She is from Panama and identifies as Black-Hispanic. When I first met Oleos I was quite struck by her. She is a beautiful woman. I love the way she speaks and her smile really lights up a room. When we first met, soon after her diagnosis, I never would have guessed she was sick. The overarching word or theme I would use to describe Oleos is independent. Oleos's sense of self is deeply tied to being independent. She has lived on her own since she was a teenager and never had to depend on others. I got the sense from her that she does not want to burden others and it seems important to her to be able to handle her own affairs. She mentioned several times not wanting to lose "control." She feels grateful and lucky to be able to access services through the city, but she does not want to feel like others need to care for her on a daily basis.

Oleos mentioned that she has limited the number of people she has told about the cancer. She said she is private and reserved – I can definitely see that. She emphasized not wanting to burden others or changing the way they view her. She said when you tell people you see

“people’s sincere, true will” - and sometimes it is not what you hope or expect. When we spoke, she had not even told her parents about her diagnosis for fear of burdening them, though she mentioned her cancer had helped her repair her relationship with her brother from whom she had been estranged for years. The change from always being healthy and independent is very hard for her. She says she feels shame for looking sick, and mentioned to me in our first interview that she had noticed a shift in her appearance. By the next time we met I could see it too: she had lost weight over those few weeks and seemed more frail and ill. I was worried about bringing that up to her since I know it is something she worries about – how others will react to her “looking sick.” For Oleos, being a cancer patient means looking sick, being out of control and dependent on others.

Oleos is the only participant I observed having a quantitative prognostic discussion with her provider. She is also the only participant who asked for one. In her second visit with her provider, a Physician Assistant, Oleos mentioned that her surgeon had told her that she might live for two to five years with her cancer and asked if that was true. The PA confirmed this as a reasonable estimate, but was quick to qualify her prognostication, saying, “We can’t know for sure. No one knows for sure.” There are many factors that made Oleos’s interaction with her provider different. She came in with numbers she had already heard from another provider and asked for them to be confirmed or denied. She also presents as very medically savvy. She speaks in a self-assured manner. She also sees a Physician Assistant instead of a physician. From the limited sample size in my study it is impossible to say if that makes a difference in patient-provider interactions. However, I did notice a few differences. Patients address physician assistants by their first names, even if they refer to them as “my doctor” when talking about them with me. All of the patients address physicians as “Dr. So-and-So.” The participants in the study

tended to describe the Physician Assistants in terms like “warm” and “sweet.” Descriptions of physician assistants were much more personal and the descriptions of physicians – including fellows – were much more professional.

It is not surprising to me that Oleos is one of the only participants in my study who reported asking her provider about prognosis. Or more accurately, perhaps, I was very surprised that more patients had not asked (several reported that they planned to but kept forgetting), but the fact that it was *Oleos* who asked was unsurprising. Oleos wants to live as long as possible. While she heard and understands the two to five year prognosis she was given, she still holds out hope that she could live ten to fifteen years. However, her goal of therapy is not based solely in extending her life. It is based in maintaining her independence.

Oleos mentioned several times that she does not want to “be hanging around too long suffering.” She stressed that she wants to live and wants to keep treating her cancer, but not at the expense of her independence. She told me,

You know, I'm going to try to do the best that I can to give myself the best chance. But it's also comes a point where you have to be realistic also. And I'm more for quality rather than quantity.... I don't necessarily want to be bedridden. I don't want to be able not to walk or to have a tremendous amount of difficulty breathing or lose a great deal of my independence. You know, having to have other people change me or that kind of thing I think is it's kind of hard for me seeing myself at that. And particularly in my case when I don't have a lot of close family. So, you know if I have to end up at [a nursing home] for six months but, you know, a mess. Might as well just [laughs] turn off the lights.

Oleos is clear that she values *quality* of life over *quantity* of life. This approach to her cancer treatment and decision-making is deeply rooted in her identities. Oleos is a Black immigrant woman. English is not her first language. She never married and does not have any family near by. All of this has meant that she has been independent for most of her life and that independence is core to her identity. Oleos has witnessed other people sick with cancer, and sees cancer as a threat to that independence. Her experience of cancer is shaped in her concept of patienthood and her attempt to resist the dependence that she sees as core to being a “cancer patient.”

Additionally, Oleos’s view of cancer is based on being a Black woman living in one of the few predominantly Black neighborhoods left in her city. Oleos spoke at length about the way that cancer disproportionately impacts her community. She has been able to take advantage of social services and support offered because of the progressive nature of the city in which she resides. She sees cancer as a social problem – one that has been caused by environmental factors and policies, which ignored the needs of the poor and people of color and sometimes directly targeted them. She believes that society has a responsibility to help care for people when they are sick. Oleos is very aware of the social factors at play that could have potentially caused her cancer and that impact her ability to seek services now that she is sick.

Her identity of cancer patient and her experience of patienthood profoundly shape how she approaches her disease. For Oleos, cancer patienthood means looking sick and being dependent on others. She assumes that her identity of cancer patient will change the way people see and interact with her, so she has resisted sharing her identity with many of the people she associated with prior to her diagnosis. While she has used her identity of cancer patient to build new relationships with others who have similar identities, including joining a support group for

Black women with cancer, she has resisted building closer relationships with her neighborhood community because she does not want to be a burden on others as she becomes sicker. Being a burden and being dependent are what she fears about her cancer. She is willing to forgo treatment options that might leave her unable to maintain her independence and care for herself. This is also tied to her immigrant identity. As someone who lives in the US, primarily independent of her family, she is used to not depending on others.

Oleos has already felt resistance to this line of thinking from her providers. She speaks very positively about the PA she sees at the oncology clinic, noting her positive energy, her attentiveness and that they are working together to “figure things out.” However, Oleos also noted that she felt a resistance from the PA to Oleos’s desire to discuss palliative care options. Oleos felt that her provider thought it was too soon to be discussing topics that might hint at end-of-life. For Oleos, being a “cancer patient” means a certain clarity that she does not have a desire to extend her life by any means necessary. Medicine often sees life prolongation as the goal in and of itself (Kaufman 2015). This speaks again to a need to examine patienthood as a part of intersectionality. Unless providers work to gain an intersectional understanding of their patients and discuss such critical and existentially important issues as the goals of care near the end of life, they will continue to assume a narrow understanding of what it means to be a cancer patient. This will continue to fail those most vulnerable to intersectional structural oppression.

CONCLUSION

Betty, Anne, and Oleos each exemplify how women differently and intersectionally conceptualize themselves as cancer patients. It is deeply tied to their other identities and has a profound impact on the way they form relationships with their providers and the decisions they make about treatment. For Betty, cancer is about rejection, disgust and isolation. Betty rejected

her own mother when she went through cancer and then subsequently worried that others would reject her. She isolated herself to preempt being isolated by others. And, despite a strong desire to treat her cancer, she stopped coming in for treatment entirely. With Anne we saw how a lack of any experience with cancer left her without a strong sense of what it means to be a cancer patient. Her identity as an immigrant could not be separated from her cancer story. Yet Oleos, who is also an immigrant, had a very different experience. For Oleos, her race, gender, spirituality and immigrant identities operated in a very different way, despite the similarity that might be seen on paper. Anne's identity shaped her ability to hear prognostication from her provider and changed the dynamic she experienced with him. Oleos's identity shaped her expectations for her treatment and how she prioritizes quality versus quantity of life.

The three women described in this chapter, Betty, Anne and Oleos, appear similar on paper. All three are low-income Black women, diagnosed with advanced cancer in middle age. All received care at the same oncology clinic. None were married. Two are immigrants. All are cancer patients, yet the identity of patienthood is different for each. It has been shaped by their other identities as well as the structural inequalities they encounter daily. Their patienthood also shapes and is shaped by the way they interact with biomedicine. While County Hospital exists because of structural failings and has a goal of countering the impact of social class on health status, many of the other important forces are, perhaps unintentionally, ignored. Interventions are built haphazardly. Interpreters are offered, resources to access food or shelter are provided. But, without taking an intersectional approach and offering more specific interventions, the clinic will continue to miss opportunities to fully and more equitably service their patients.

Chapter Six: Conclusion

In this dissertation I have examined the lived experience of Black women with advanced cancer. The chapters build on one another conceptually. If we think of intersectionality as an heuristic kaleidoscope, each chapter offered an additional twist of the lens, to center a new identity and look at the lives and experiences of these women in new and complex ways. Each chapter examined new intersections and added additional complications to the way we think of cancer and the lived experience of dying. I focused on the narratives of individual women, highlighting what was analytically salient across many participants in my study. This was an intentional choice to keep my dissertation centered on the voices of Black women with cancer.

SUMMARY OF KEY FINDINGS

In Chapter Two, I described Black Feminist Methodology, which I developed and piloted for this project, in order to ground my research in the lives and knowledges of Black women with cancer. I articulated the ways in which I took up the four core tenets of Black Feminist Epistemology (Collins 1990) and elaborated them as methodological principles to form the core of Black Feminist Methodology. The first core tenet is that alternative epistemologies are built upon lived experience. I applied this methodologically by centering my work on the lives of Black women through asking broad research questions and creating intentionally-broad interview guides meant to allow my participants to drive the direction of the interviews. Second, Collins (1990) advocates for the use of collective dialogue rather than adversarial debate. I challenged the notion that interviews themselves are a form of collective dialogue, and instead operationalized this tenet through creating a space during the second interview where I echo back to participants what I have heard from them in addition to sharing my insights, perspectives and initial analysis. I then allowed participants to respond to me and together we created a collective dialogue about her story. The third tenet of Black Feminist Epistemology is the ethics of caring,

which Collins (1990) separates into three components: the value placed on individual expressiveness, the appropriateness of emotions and the capacity for empathy. I used this tenet to challenge the idea of objectivity in research and asserted my commitment to being open and honest with my participants about my own emotions and reactions during our interviews. I did not attempt to separate my research from my personhood. The final tenet is personal responsibility. I committed to making my work accessible to Black women in the style and location of publication. Additionally, I ensure that my participants can recognize themselves in my writing by having each woman pick her own code name and through hearing a summary of how she will be described through the collective dialogue process. As a part of personal responsibility, I argued that I must be accountable for my research claims both to my participants and the larger community of Black women for whom my research is intended. I argued for the importance of involving research participants in more phases of the research process and acknowledging them as partners in the process of the production of knowledge.

In Chapter Three, I explored how the intersections of race, gender and class operate in the lives of Black women with cancer. I argued that a large part of the diagnosis and treatment of cancer is about a loss of control and a forced shift to living life “one day at a time.” I found that the intersections of race, gender and class produced varied approaches to this reality for women in my study. For many lower class women, the intersections of race, gender and class manifested in social locations where a lack of control was the norm. Linda and Jan, whose stories I tell in this chapter, were used to living a life in circumstances not of their own choosing. They therefore seemed to accept the lack of control they had over their cancer and many aspects of their diagnosis and care as largely normative, and simply a continuation of their social conditions of life characterized by constraint, limits, and marginality.

I contrasted their experiences with those of women with more economic privilege, who expressed to me a profound loss of control with their cancer diagnosis and took steps to assert and regain control in the areas of their life where they could. One woman, Dean, often sought to take power back from her providers. She recognized the times when she was not receiving the best possible care and was not afraid to say so. She argued for additional testing and saw all of her treatment decisions as being firmly in her own hands. Another woman, Delores, blamed herself for her cancer and viewed herself as responsible for the lack of control she now has over her health. Her attempts to reassert influence over her own health included extreme diets and exercise regimens. I argued that maintain this control is essential for Delores, so that she feels like she is doing everything she can now to fight her cancer.

I finally told the stories of two women who do not fit neatly into class boundaries and also highlight the shifts in class that can be caused by cancer. I described Flowers, a woman whose class identity does not match her income and circumstance. I argued that Flowers was very aware of how the intersections of race and class can impact the way one is treated in the clinic. Flowers attempts to carefully control the way she presents herself in the clinic to avoid the potential for being treated poorly by providers, as she sees happening to many other patients at the safety-net hospital. I argue that Flowers views herself as different from other patients at the hospital whom she perceives are not in control of their appearance, their bodies, their behaviors, or their lives. I also argue that her emphasis on self-presentation and respectability is tied to her identity as a Black woman; she is very aware that presentation matters in all interactions. I also described Marie, who had been economically comfortable prior to her cancer diagnosis but thereafter was unable to work and thus thrust into financial insecurity and a fight for economic survival. As a result, Marie feels that her life is spiraling out of control. She is no longer able to

provide for herself as she was accustomed to; in many ways, her cancer experience is defined by her economic status more than her health status. I argued that, as a Black woman, Marie had been fighting assumptions about her social class throughout her life but was successful in countering and shielding herself from many of them through her economic resources. Now that she is facing the realities of being in a lower social class, her identity has been turned upside-down. Marie's shift in social class has forced her to manage her life and illness in a "one day at a time" approach, a present- and immediate survival-oriented mentality that leaves her unable to think about and plan for the future, and thus feeling out of control.

In this chapter, I argued for the need to look at class more holistically and intersectionally. Too often, an assumption is made that being lower class can be equated with worse health care experiences, as we assume that the more marginalized identities one holds, the worse off one is. Yet, I argue this way of thinking is not in line with intersectionality theory nor do they reflect my own empirical findings. Instead, social class identities and socioeconomic realities create a unique set of challenges for different women based on their larger identity and social location.

In Chapter Four, I turned to the themes of faith, spirituality and religion. I explored the unique intersections of race, gender and religion that exists for many Black women and asserted that much of the literature on the role of religion for Black women with cancer misses a key understanding: For many Black women, and the majority of Black women in my study, one's faith identity cannot be separated or enumerated as distinct from racial and gender identity. The way that faith operates for many Black women is inextricably tied to their race and gender identity.

I described the ways both patients and providers understand the role of faith and religion in their interactions and highlighted two seemingly oppositional ideas – that patients either trust their doctors because of God, or would not listen to or believe their doctors because of their belief in God. I found, however, that many of the Black women I interviewed do not subscribe to one or the other view, but instead hold both these ideas simultaneously. Many participants strive to follow the directives of their doctors as a way of taking advantage of the resources God offers to them, while also acknowledging the fallibility of medicine and the inability of physicians to cure cancer.

I then examined dominant stereotypical images of Black womanhood and described the ways in which they are influenced by perceptions of religiosity in the clinic. I argued that a contemporary version of the Mammy is a ubiquitous image of a Black churchwoman, clad in a large hat, worshiping from the first row at church. I understood the ways in which women in my study were perceived and treated in clinical encounters as structured by this new version of the Mammy, from providers' use of prayer and faith as a way of building a rapport and providing comfort to some of my participants, to their assumed compliance and obedience to biomedical advice and treatment.

I contrasted this stereotype with that of the Welfare Queen and described the ways in which several women in my study were viewed through the lens of this alternate stereotype. I argued that many women who were no-shows for treatments were assumed to be so because they were “running the streets.” Providers, often quite matter-of-factly, believed these women were prioritizing illicit behavior over anti-cancer therapy and the needs or desires of their families; providers then invested less energy into their cases based on those assumptions. Yet for some of these women, faith played a significant role in their life, but their religiosity — which for other

women slanted providers' perceptions of them favorably to subtle influence care — was erased, trumped by the Welfare Queen stereotype.

I turned finally to a discussion of the counter-stereotype of the Strong Black Woman. I described how the idea and importance of being strong in fighting cancer intersects with the idea of a particularly racialized and gendered notion of strength for Black women. I argued that for Black women, strength is inextricably tied to the intersections of race, gender, and religion. In contrast, to be weak is to fail as both a Black woman and as a woman of faith, identities that are, for many of my participants, completely inseparable. I asserted that Black women with cancer face an enormous and complicated burden to maintain strength, both outwardly and internally. I described the ways in which women found strength through God, but also how a loss of strength or faith represented, for them, a fundamental betrayal of God. I argued that these moments of weakness and of doubt in God and His plan represent a failure of both faith and Black womanhood.

In Chapter Five, I argued that, when studying women with cancer, it is critical to examine not only how intersectional identity along the usual dimensions of race, gender, and class impacts cancer experience, but to examine cancer and the patient experience as a critical part of those intersections. I explored how the identity of “cancer patient” is developed and shaped in the experiences of my participants, and the ways in which that identity intersects with other identity categories such as race, gender and class.

I used the stories of three women who all had very different experiences of patienthood to exemplify how Black women differently and intersectionally conceptualize themselves as cancer patients. I found that each woman's concept of patienthood is deeply tied to their other identities and that the ways in which they enacted their ideas about what it means to be ‘a cancer patient’

impacted how they formed relationships with their providers and how they approach their disease and treatment trajectories. For Betty, her cancer identity reflected her own perceptions of her mother who herself suffered from cancer when Betty was a teen, as an experience characterized by rejection, disgust and isolation. Betty stopped coming in for all cancer treatments and appointments. With Anne, I described how a lack of experience with cancer left her without a strong sense of patienthood identity; she did not know what it meant to have cancer or to be a cancer patient. This shaped Anne's ability to hear prognostication from her provider and impacted the information they were able to share and hear. While this could be attributed largely to Betty's immigrant status, I also shared the story of Oleos, another immigrant, whose race, gender, spiritual and immigrant identities operated in a very different way. Oleos' identity shaped her expectations for treatment and how she prioritized quality versus quantity of life.

While all the women I described in Chapter Five were similar in many aspects of their identities, each conceptualized their own patienthood very differently. Their identities as cancer patients were shaped by both their other identities and the structural inequalities they encountered daily. I also argued that each woman's patienthood shapes and is shaped by the way they interact with biomedicine. Hospitals, including safety-net hospitals which are intended to serve the under-served, are unable to fully meet the needs of their patients if they are not taking an intersectional approach and offering more targeted and specific interventions.

IMPLICATIONS FOR SOCIOLOGICAL THEORY AND METHODOLOGY

My dissertation makes several important theoretical and methodological interventions into the fields of qualitative methodology, cancer research, and intersectional research and theory. My primary intervention is in the study of Black women through the development and implementation of Black Feminist Methodology.

Black Feminist Methodology

When I approached potential participants to explain my study and solicit participation, it was not uncommon for me to be told something along the lines of, “It’s not about Black or white. Race has nothing to do with it. Cancer is cancer.” This response always took me a bit by surprise. I obviously believe very strongly that race *does* matter or I would not have embarked on this project. I also assumed that kind of reaction meant the woman was not interested in participating in my study. I was usually wrong. Many women were willing to speak with me even if they did not fully understand what I was getting at with my research questions. However, I think this pervasive sentiment speaks to the challenge and importance of engaging with this type of research.

Most people do not think of their lives in raced and gendered terms. While we identify with and are aware of our race and gender, we do not think about how each aspect of our life is shaped by it on a daily basis. For one thing, it would be exhausting! The process of examining one’s own oppression on a daily basis would quickly take a toll. But, more than that, it is generally the only reality we know. I could not ask the women in my study, “What is it like to be a Black woman with cancer?” They have never experienced cancer any other way. We know that identity and social location matter, but finding ways to approach the questions of *how* and *why* can be complicated.

A few women in my study spoke easily and directly to the influence of race and gender on their cancer experiences. There was Shorty who described a physician who would not even look at her during her interactions and she wondered if it was because she was not white enough or rich enough. Or Oleos who described how her neighborhood had served as a toxic waste dump and she was not surprised by the high rates of women’s cancers in the neighborhood or the fact that the city had allowed the problem to occur in one of the only predominantly low-income

Black neighborhoods left in the city. Most women, however, described the influence of race, gender and class in much more subtle ways.

The challenge of this dissertation was finding ways to illuminate these unique intersections while keeping my research and interview questions open and my work centered on the Black women who participated in my study. Black Feminist Methodology allowed me to discover and describe the influence of these intersecting identities while still allowing my research participants a voice in the research process.

Cancer Research

As I stated in the introduction, the majority of scholarship on Black women with cancer is focused on either biomedicine or epidemiological trends, both of which highlight the poor outcomes faced by Black women. This research is critically important in framing the problem and making the case for additional research in this area. Yet, most of the research still operates from a place of deficiency; it looks to *why* Black women do not access screening or services or *why* Black women use so many interventions at the end of life. Even most qualitative sociological work focuses on the perspectives of women at the time of prevention and screening or at the point of cancer survivorship. Yet, for many women, cancer cannot be prevented or survived. For a large group of Black women, they will live and die with cancer. There has not been a substantial body of work focused on the lived experience of Black women with *advanced* cancer.

My central questions of how Black women understand and make sense of terminal disease add substantially to the literature. Through deploying my methodology and asking questions based in the lived experiences of Black women with advanced cancer, I have filled an important gap in the cancer literature. My research has helped illuminate the perspectives and

knowledges of Black women with advanced cancer and highlighted an important area for further research.

Intersectional (Health) Research

Lastly, through this dissertation, I was able to complicate how we describe and conduct intersectional health research through considering patienthood as a central identity category that shapes and is shaped by biomedicine. As I described in the preceding chapters, most “intersectional research” focuses on the intersections of race, gender and class. It is often centered only on the ways in which an increased number of marginalized identities create a greater experience of oppression. While this work has been critically important in social science research, I have found that not enough research strives to truly embody intersectionality by going beyond simply studying individuals with multiple marginalized identities.

About a year ago, I had the opportunity to hear Kimberlé Crenshaw speak about intersectionality and to speak with her about her perspectives on the ways in which intersectionality is taken up in both policy and scholarship. Professor Crenshaw encapsulated one of my biggest frustrations with intersectionality: it is simultaneously everywhere and nowhere. There has been a tremendous advancement in the concept of intersectionality and of its importance over recent decades. The term appears in books, on websites and in political conversations. In many academic and popular circles, an author can be attacked for not referencing intersectionality. And, in fact, a critique of intersectionality is that it is used as, in Crenshaw’s words, “a bully tactic” to force people to examine their privilege. Yet, while intersectionality, in both name and application, is used widely, often it is used in a way that is not true to its intention.

This manifests in both benign and dangerous ways. There are those scholars who take intersectionality to mean simply that they research individuals who check more than one category of marginalization, but without attending to intersectional identities. That is, they look to the influence of race, gender and class but without a critical examination of what it means to be, for example, a poor Black woman. Too many scholars treat intersectionality as additive instead of co-constitutive.

I wanted this project to speak back to the flaws I see in how intersectionality is used. I hoped to use intersectionality in a way that was both true to its original intentions, but also advanced how it was used both theoretically and methodologically. I wanted to create a space for examining new intersections, not often considered in health care, as well as studying intersectionality in a way that was true to its ideals. I did not want to simply say I was doing intersectional work because I was studying Black women. I wanted my work to critically examine complex intersections and provide more nuance for the ways in which they manifest both in and outside the clinic for Black women with advanced cancer. I believe my dissertation met these goals.

While I began by examining the intersections of race, gender and class, I did so in a way that did not assume that marginalized identities are additive. I asserted that these intersections create a diverse set of responses to cancer and that having fewer oppressions does not necessarily mean that a woman's cancer experience is "easier." I also examined the role of faith and religion in a way that highlighted how they cannot be separated from the identity of Black womanhood. I made the case for why religion *must* be studied intersectionally when examining the experience of Black women with cancer because it is so intrinsically tied to Black womanhood. Finally, I added a new and important intersection to study when doing intersectional health research:

patienthood. I asserted that the identity of “cancer patient” shapes and is shaped by both other intersecting identities and a woman’s experiences in biomedicine. We cannot simply examine the impact of intersecting identities on cancer and the cancer experience. We must acknowledge the power held by the identity of “cancer patient” and how it will mean very different things for different people based on the ways in which it intersects with their other identities.

LIMITATIONS

Although most qualitative research makes no claims to representativeness or generalizability, there are still some important potential empirical gaps in this study that should be noted for the benefit of future research.

The majority of my interviews and all of my observations took place with participants I met through a safety-net hospital. This hospital was chosen as a site for recruitment and fieldwork precisely because it had a larger proportion of Black patients than many neighboring hospitals. Yet, I noticed many differences between the participants I met at the safety-net hospital and those I recruited elsewhere. A larger and more economically diverse sample would allow for a greater understanding on the role that the type of care institution plays on the lived experiences of cancer for Black women as well as produce more varied ideas about the way that class intersects with other dimensions of inequality.

An additional limitation is that the women in my study were recruited at many different points along the illness trajectory. Some were newly diagnosed, some were in treatment, others were in remission and waiting to hear about the status of their cancer, and still others were close to the end-of-life. While I attempted to draw comparisons and highlight differences across the women in my study, this was difficult as there realities of cancer varied so widely. Although all the women in this study had cancer that was classified as “advanced,” with so many different

specific types of cancer and with participants at such different phases of treatment, the way they approach and understand their illness may differ remarkably based on the fact that their interaction with their disease is incredibly different. While all women were able to speak to the uncertain reality that comes with such a serious diagnosis, the way the diagnosis plays out in their daily lives was quite distinct.

RECOMMENDATIONS FOR FUTURE RESEARCH

When I initially thought about conducting qualitative health research on cancer at the end-of-life, I envisioned a study where I would meet and follow participants over the course of their illness, treatment trajectories, and as their relationships with their providers unfolded. Also, as most people who have observed medical encounters (or participated in one themselves) know, most clinic visits are fairly uninteresting. There is a focus on symptoms, a process of updating medication lists, a time for making future appointments. Very little of the time is spent engaging in conversation about the illness itself or even relating one-on-one. While this data is still useful and much can be learned from how patients and providers interact in the more day-to-day visits over the course of cancer treatment, most of the visits did not address the topics I had hoped to observe such as goals of care, prognosis, understanding of disease or treatment decision-making.

Ideally, a study could be designed that would follow Black women from diagnosis through the course of their treatment trajectories. It would be fascinating to attempt to follow women through the diagnosis process as well, since so many of the participants in my study struggled for months or years to achieve a proper diagnosis, but it seems logistically difficult to recruit participants to a study on cancer when cancer has not yet been diagnosed. However, by bringing the point of entrée closer to that point, richer data could be collected.

If one were able to follow a woman throughout the course of her disease trajectory, many more details would be able to be captured. A fuller understanding of how the disease and prognosis are presented could be obtained and all of the conversations surrounding treatment decision-making — between patients and their providers, family members, and even the internal conversations they might have with themselves — could be asked about or observed. By asking women to reflect on more encounters after they were observed by the researcher, rather than simply recalling these conversations from memory, the researcher could gain a greater understanding of both what is occurring in the patient-provider dynamic and how the participant is interpreting and reacting to the information, options and decisions being offered.

I am also interested in learning more about how women's views of their disease, their faith, and their providers change as they move closer to the end-of-life. Do they approach these topics in the same way? Are there shifts over time as the realities of their disease change? Studying this topic longitudinally while still retaining the commitments of Black Feminist Methodology could produce compelling and important work on the illness experience for Black women.

I am hopeful that this project will serve as a launching point for more work utilizing Black Feminist Methodology across a wider array of topics. I am personally interested in utilizing Black Feminist Methodology to study the illness experiences of incarcerated women as this is a group who has been traditionally marginalized by research and one with so little control over their own stories. Research with this group utilizing the methodology I have put forth in this dissertation can produce work, which would highlight lived experiences and the voices of marginalized women in a way that is deeply lacking in the literature. I hope other scholars will take up this methodology as a way of advancing research on, by and for Black women.

CONCLUSION

This study demonstrated a new way to study Black women. I hope more scholars take up Black Feminist Methodologies as a way of conducting research centered on the lived experiences of Black women. I hope Black women, both in and outside of academia, see the potential for research that is by, for, and about our experiences.

Most of all, I hope that this work reaches Black women and speaks to their view of the world. Maybe someone will see the experiences of a sister, or mother, or aunt reflected in one of the stories; perhaps a woman will gain some insight that will help her as she approaches her own cancer treatment. The women whom I interviewed wanted their words, stories, and lives to live on beyond them. They wanted to be able to help other women facing cancer and to offer strength to those in need.

As Dolly said, “I could be any woman. I could have any name. I could be anybody's sister or brother or daughter or mama.” While Dolly’s story, and the story of each woman in this dissertation, is unique, all hoped that their stories would touch other women. I hope that providers and patients alike can learn from this research and examine the way we offer oncological care to Black women.

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