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Publication Date
2022

Peer reviewed|Thesis/dissertation

Beyond Coping: Responses to Chronic Illness Among Religious Black American Women

by
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DISSERTATION
Submitted in partial satisfaction of the requirements for degree of
DOCTOR OF PHILOSOPHY

in

Sociology

in the

GRADUATE DIVISION
of the
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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ACKNOWLEDGMENTS AND DEDICATION

To the Divine —

And to my Ancestors —

This work is through you.

For my grandmother, Estella Manning Massey,

And for my grandmother, Dr. Dolly Desselle Adams —

I dedicate this work to you, who inspired it.

To my mother, Gaye Adams Massey,

And my father Dr. Harold Eugene Massey —

I stand on your shoulders in all things, I learn to become myself through your example.

For my brother Amilcar Kamau Massey,

And my sister Nyah Estelle Massey —

I want to give more to the world because you are in it.

To my devoted sister-friends,

Courtney Smith,

Carolyn McNamara,

and Anaid Blee Alarcón —

You have been my support, my comfort, and my joyful encouragement.

To my teachers and advisors, who sat on my dissertation committee, engaged the work with genuine interest, and offered guidance on this journey,

Dr. Howard Pinderhughes,
Dr. Rachel Harding,
and Dr. Jacqueline Mattis —

And to the SBS faculty and staff, and to the UCSF administrators who facilitated the processes that supported my education —

Thank you for your generous support, for seeing in me what I could not always see, for understanding the value of my work. Thank you for believing that I can do what I am called to do.

This research was partially funded by:

- NIH, National Institute of General Medical Sciences (NIGMS), Initiative for Maximizing Student Diversity (IMSD) Fellowship (1-R25-GM56847)

This dissertation is dedicated to the women in my family who have made me who I am,

and to all the ancestors who survived,

and to all the ancestors who did not.

Beyond Coping:
Responses to Chronic Illness Among Religious Black American Women

Amina D. Massey

ABSTRACT

Although disproportionately high rates of chronic disease and limited access to medical care are consistently reported among Black American women, there have been few empirical studies of the ways in which Black women themselves navigate illness experiences. Individual choices in responding to illness have the potential to support specific physical, social psycho-emotional, and spiritual priorities. Women who are members of cultural and religious communities often engage shared meanings as they interpret their circumstances and construct strategies for response. This dissertation identifies common themes in religious Black women's experiences of chronic illness, explicates the meanings and strategies important in their responses to illness, and describes the effects of these strategies in their lives. Qualitative interviews were conducted with religious Black American women diagnosed with at least one chronic illness in San Francisco and the surrounding Bay Area. Recruitment took place in African Methodist Episcopal (AME) and Baptist churches, and in local organizations addressing the health needs of women of color. Data was collected through extensive participant observation and Photovoice, a participatory-action ethnographic research method designed to facilitate participants' active role in directing research around issues that affect them. Semi-structured participant interviews utilized photo-elicitation methodologies, in which participants' photographs served as illustrative prompts to guide and contextualize descriptions of social and physical experience. In narrative and visual analysis, several themes emerged regarding women’s changing relationships to divinity, other people, and themselves. Religious and organizational communities establish structure for members to seek and provide one another with meaningful support, yet also frequently promote interpretations that encourage women to prioritize the needs of others over their own. Changing social expectations and physical abilities constituted an ongoing challenge to each woman’s personal identity. Participants characterized faith as an orientation towards possibility, particularly in contexts of normalized uncertainty. Participant narratives describe coping as a nuanced, strategic process of response, guided by an individual’s priorities in responding to illness. Insight into collective systems of meaning can facilitate the development of social supports that address the immediate concerns of chronically ill individuals, particularly those who are members of systemically underserved populations.

TABLE OF CONTENTS

LIST OF FIGURES

CHAPTER I

CONTEXTUALIZING RESPONSES TO ILLNESS AMONG RELIGIOUS BLACK AMERICAN WOMEN

"Are you sure, sweetheart, that you want to be well?"

— Toni Cade Bambara, *The Salt Eaters* (1980)

Introduction

In the opening line of Toni Cade Bambara's landmark novel, *The Salt Eaters* (1980), a community healer named Minnie Ransom asks activist Velma Henry if she is truly prepared for the work of healing. The exchange takes place in a hospital, with a council of community healers, a physician, and medical students present. The novel tells the interwoven stories of community members and clinical encounters that shape the circumstances of Velma's healing. Velma, a Black woman, is a political organizer who is exhausted and disillusioned from the constant struggle of fighting and advocating for the safety of her community. Her healing journey is long and complicated, and Velma seeks different kinds of support in different parts of her life to see it through. Bambara's novel reveals the varied and nuanced meanings of health that shape an individual's options and choices for healing. Bambara provides a way to understand healing as a process, an ongoing reconfiguration of meanings, choices, and actions. The character Minnie Ransom's opening question frames healing as a journey that Velma Henry will have to choose.

The conceptualization of health as a process is very different from dominant definitions of health in medical science and public consciousness, which have envisioned health as a relatively static ideal of physical and mental balance and function. According to the static ideal framing, health is defined as the absence of disease or disability. This definition has guided the development of medical science and healthcare systems for decades. As a result, medicine has focused on the genetic factors that lead to disease, while public health has prioritized interventions that address behavioral health factors. As a result, differences in health outcomes between populations are often attributed to genetic difference and individual behavior when they are, in fact, largely attributable to social factors (West, Blacksher, Burke 2017).

In 1948, the Constitution of the World Health Organization (WHO) expanded the definition of health to describe it as "a state of complete physical, mental and social well-being," even beyond the absence of illness. This definition acknowledges that a complex combination of physical, mental, and social influences impact an individual's health. In 1986, at the First International Conference on Health Promotion in Ottawa, the World Health Organization went a step further to declare: "Health is the extent to which an individual or group is able to realize aspirations and satisfy needs, and to change or cope with the environment. Health is a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities." The 1986 definition opens up the meanings of health in several important ways. First, it includes a consideration of group circumstances as a determinant of population health. It also transforms the perspective of health from one that views a healthy state as an achievable end point into an understanding of health as dependent on resources and capacities.

It is this conceptual framing of health that allows us to understand it as an ongoing process of negotiation, rather than a static equilibrium. Our health is influenced in large part by the resources available to us in responding to the circumstances of our lives. Research into social determinants of health has described the ways in which social policies and social power relationships impact the health outcomes of marginalized populations who experience systemic inequalities. Studies that identify the social factors that impact health represent an important transformation in the way medical science approaches disease. In addition to genetic and behavioral factors, these studies have made it clear that equitable access to social resources and safe environments are necessary conditions of health equity.

> Health equity is the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing social efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities. (Healthy People 2020)

The World Health Organization has established health as a fundamental human right: "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (WHO Constitution 1948). If we understand health as a human right, and it has been proven that social inequalities undermine health, then we can understand equitable social conditions as a human right. For this reason, much of the research in social determinants of health has focused on guiding changes in the public policy to create equal opportunities in housing, employment, education, food access, transportation, healthcare access, political representation, and every aspect of civic life and resource distribution.

In addition to access to resources, chronic stress has proven to be another significant means by which social experience impacts health outcomes. A prolonged stress response has direct negative consequences for physical and mental health, and can exacerbate existing health conditions. The less ability an individual has to determine the circumstances of their own lives, the higher their levels of chronic stress are likely to be. Socioeconomic factors and social status are common sources of chronic stress, increasing the risk of major health conditions among people facing social and economic obstacles (Taylor 2010, Belkic et. al. 2004, Chandola et. al. 2006).

Potential chronic stressors are ubiquitous for Black women in U.S. society. Black womanist scholars have described the ways in which Black women as a population encounter specific commonalities in experience, shaped by their unique social locations (Collins 1990). Black women consistently confront barriers to accessing every major social resource, including healthcare systems, and their knowledge of their own experience is frequently undermined and discredited in dominant discourse (White 1990, Dotson 2011). Black American women navigate health and illness from social locations shaped by a matrix of intersectional and mutually-reinforcing axes of oppression (Crenshaw 1989, Collins 2000). Racial and gender-based social hierarchies are fundamental to the organization of U.S. society. Specific meanings and interpretational frameworks are created at the intersection of racism and sexism, interpretations that are often developed according to a logic of oppositional power in order to regulate the lives of Black women – physically, socially, and psychologically. However, as much as the meanings of health, illness, and healing among Black women in the U.S. are informed by experiences of systemic and interpersonal exclusion and exploitation, they are also shaped by the culturally-specific meaning systems that Black women participate in with family and community.

Black women's choices in navigating for their own survival and the survival of their families depend upon how they negotiate layered systems of meaning and interpretation. Dominant meanings specific to Black women are reinforced through interactions in mainstream society, cultural meanings are communicated in community and familial contexts, and Western biomedical meanings take precedence in clinical contexts and throughout the course of medical care. Individual Black women engage these layered meaning systems to develop their own interpretations of health and healing as they respond to the changes chronic illness produces in their lives. Individually and collectively, Black women have organized and sustained traditions of resistance to social control and external definitions of their identities. Their resistance creates space for their own self-determination, autonomy, and expanded identity (Hull, Bell-Scott, and Smith 1982; Combahee River Collective 1974; White 1990). How do individual Black women make decisions about how to navigate these layered meaning systems? What are their objectives and priorities? What resources do they access to interpret and respond to their health circumstances?

I began investigating these questions by exploring meaning-making processes through qualitative interviews with chronically ill Black women in the U.S. and in Brazil. The related themes of religion, spirituality, and faith emerged as dominant in a majority of those first interviews. I have continued an exploration of Black women's descriptions of their experiences with chronic illness through this project, which specifically includes religion and spirituality as a central factor in an analysis of the strategies of response to chronic illness among religious Black American women. Black women who consistently engage religious community and institutions have access to collective beliefs and practices that provide explicit systems of social, cultural, and spiritual meanings. These meanings, and their interplay with the individual psychology and personal spirituality of the individual, have the potential to influence their interpretations of illness experience. This study offers an exploration of the meanings of health and chronic illness among religious Black American women, in order to understand the priorities and strategies that shape their responses to illness.

What are the changes that chronic illness produces in the lives of religious Black women? How do individual women interpret these changes? What meanings become important to them in the experience of illness? What are the effects of their choices and strategies in response to illness? What are the factors in their social environments that support or impede their response strategies?

Research Statement and Theoretical Foundations

This project explores the ways in which religious Black American women interpret and respond to chronic illness, with the aim of identifying strategies of interpretation and response and describing their effects. The design of the project was shaped by several key theoretical frameworks.

Research within the sociology of chronic illness describes several common changes that characterize the illness experience, including changes in physical ability, social relationships, and personal identity, and the types of work done by individuals and communities to manage such change (Hocschild 1979, Charmaz 1983, Corbin and Strauss 1988, Bury 1991). This paper takes a womanist approach to the examination of the changes that chronic illness produces in the lives of religious Black American women, and their strategies for response. Womanism is a development in Black feminist epistemology that seeks to provide accurate representations of Black women's choices and priorities through an engagement of the knowledge produced by Black women about their own circumstances (Collins 2000). Black feminist epistemology and womanism engage feminist theory and critical race theory in order to address the multiple social forces that shape the social forces of Black women's lives. The concept of intersectionality, put forth by Kimberle Crenshaw (1989), accounts for the compounded effects of interdependent systems of oppression. Processes of marginalization including racism, sexism, classism, homophobia, transphobia, and ableism are mutually reinforcing in the lives of individual people. Intersectionality accounts for the ways in which social forces shape Black American women's social reality simultaneously, and hold diverse meanings dependent on individual circumstance and social context.

The multiple systems of hierarchal social oppression that Black women navigate are known as the matrix of oppression (Collins 2000). Black women who share overlaps in social location within this matrix may encounter common challenges, and they may also access shared knowledge and meanings when responding to these challenges. Within the range of Black women's individual experiences, the knowledge that is produced from their shared social location constitutes a collective "standpoint" (Collins 2000:28). This project considers narrative and visual data produced by Black women participants, in order to explicate and contextualize common themes in their experiences and perspectives of chronic illness.

The design of this study is influenced by the fundamental supposition of symbolic interactionism, which asserts that the interpretation of meaning guides human action (Blumer 1969). Central to the project is an investigation of the meanings that become significant to individual women throughout their experiences of chronic illness, in order to understand their decision-making in response. Individuals routinely engage collective meanings in order to make sense of their personal circumstances, including meanings generated through cultural and religious systems of interpretation. These meanings influence an individuals' priorities and potentially guide their choices. It is therefore important to understand the meaning-making processes of chronically ill individuals and to describe changes in their priorities over time, in order to understand their actions in responding to illness.

The womanist and sociological theoretical foundations of the project guide the identification and analysis of participants' responses to illness, the strategies constituted by their responses, and the effects of their responses. In addition to an interactionist approach, the project is informed by Foucauldian discourse analysis. Michel Foucault's theories regarding power, knowledge, and language provide a useful framework for a description of the forces that structure Black women's lives, as well as the strategies they engage to negotiate said forces. Foucault defines power as a multiplicity of force relations that characterizes all social interactions. The strategies that individuals develop to navigate social situations have the potential to resist or reinforce the effects of the individual strategies of other people (Foucault 1990). Dominant discourse is constitute by a socially privileged system of ideas, which combines knowledge and power to define the social landscape. Individual engagement of discursive structures organizes knowledge by uniting chains of associations to produce meanings. The shared meanings created through participation in dominant discourse define "truth" in our shared social reality.

According to Foucault, a multiplicity of discursive elements structure social positions, characterized by roles and expectations. The way in which an individual participates in discourse depends upon her position in society (Foucault and Gordon 1980). Discourses maintain social hierarchy and exclusive privileges; certain claims receive more discursive support, and authority is required to access specific modes of discourse. Individual strategies for navigating subject positions both reproduce and resist the discursive elements that define social location and identity. Foucauldian discourse analysis provides a means of identifying the diffuse power relationships that influence individual Black women's responses to chronic illness and determine the effects of their responsive strategies.

This study engages womanist texts, qualitative narratives, and participatory visual data for information regarding Black women's descriptions of their own subject positions. One primary aim of the project is to understand the way individual strategies may engage shared interpretational frameworks. Black women diagnosed with chronic illness engage both privileged and marginalized discourses in their families, communities, workplaces, churches, and healthcare centers. This project seeks to expand and contextualize descriptions of Black women's navigation of distinct and potentially competing discourses as they respond to the physical and psychosocial changes associated with illness.

This investigation must account for Black women's social locations and corresponding subject positions. How are the roles chronically ill Black women are expected to assume shaped by discourses of race, gender, and health? What strategies do individual women engage in negotiating these roles? What are the choices that Black women make to meet or resist social expectations, and what are the effects of these choices? Where do participants encounter resistance or support in achieving their objectives and addressing their priorities? The focus of this project is the multitude of ways in which Black women participate in various discourses to re-construct their identities and social relationships during chronic illness. Insight into this process of negotiation will facilitate an examination of the ways in which women evaluate options, establish priorities, and make decisions in response to illness and the changes it creates in their lives.

Study Design

The theories that guide this study and the participatory, qualitative methods it employs are designed to center the knowledge and experiences of Black women in the discussion of the conditions of their lives. It was important to me to begin this project by familiarizing myself with the landscape of religious institutions and supportive health services available to Black women with chronic medical conditions in the San Francisco Bay Area. I began by conducting participant observation in Black Protestant Churches and health-focused organizations serving Black women.

I chose to focus on Black Protestant Christianity in general, and the AME Church in particular, for several reasons. First, it is the religious context most familiar to me. I was raised in the African Methodist Episcopal (AME) Church, a Black American denomination of Protestant Christianity. My maternal grandfather was the Head Bishop of the church, a formal authority in its leadership structure. I grew up attending Sunday service and the social gatherings afterwards, Sunday School, Bible Study, Young People's Department (YPD) field trips, and the many other events in the church social calendar. The Black Church in the United States is an established cultural institution, historically the site of religious and social community organization. My socialization into the culture of the Black Church has afforded me a familiarity with the collective religious and spiritual beliefs it supports, the structure of the institution, and the protocols of the service. This familiarity allowed me to engage multiple levels of meaning in conducting participant observation. Although there are notable differences across denominations, Black American Christianity consistently engages culturally-specific language and symbolism. These discursive elements both construct and emerge from social and religious double consciousness among Black Americans, creating layers of signification in the meanings of Black Christianity. These meaning systems provide context for the meaning-making processes of individual religious Black women navigating chronic illness. Although there are participants in this study who practice other religions, I chose to primarily recruit within a religious meaning system that is familiar to me, in order to be able to better recognize the systems of interpretation that it supports.

Christianity is the dominant religion of the United States, and its meanings are privileged in U.S. society. Although the country formally insists upon the separation of church and state, Christian meanings have fundamentally shaped American ideologies and national identity. Protestantism is the most prevalent form of Christianity in the country, and enslaved Africans were forcibly converted to Protestant Christianity across North America. Slavery and continued racial violence against Black Americans has been justified on Christian religious grounds within mainstream American politics throughout history.

Within this context, Black American Christianity has developed as a combination of adapted, extended, and created cosmologies that has served the spiritual and social organization of Black communities. Black Christianity has existed alongside and in relationship with a myriad of religious belief systems and institutions, often with multiple traditions maintained in the same family. Adapted African cosmologies have been passed down through family lines in sacred and secular contexts – as religion, hoodoo, conjure, plant medicine, culinary recipes, folk wisdom, and secular tradition. In addition to Christianity, Islam, Buddhism, and Nation of Islam have played prominent roles in Black American civic life and collective meaning-making. According to the PEW

U.S. Religious Landscape Survey, however, a majority of religious Black Americans describe themselves as being affiliated with historically Black Protestant churches (PEW Research Center's Forum on Religion & Public Life 2007). Christian meanings are a dominant norm in American society, and among Black Americans. Mainstream narratives of Black American history have focused on the role of Black Protestant churches as sites of community organization, political mobilization, and cultural production.

My decision to examine the meanings of Black Christianity in the lives of religious women is motivated in part by my love of the Black Church. I have an intimate understanding of the ways in which Black Christian meaning systems have developed to provide networks of safety and healing for the Black people who inherit them. I also carry a critical awareness of the ways the meaning systems, ideologies, and structures of the church can maintain social hierarchy and have the potential to limit individual possibilities. I myself have frequently encountered dogmatic interpretations of scripture that have been used to justify systemic exclusion and marginalization in Christian communities. It is my goal to explicate the aspects of collective Black Protestant Christian systems of interpretation that serve Black women's physical, mental, and emotional health – as well as the aspects that create barriers to their health and healing. How does the organization of Black churches limit or support Black women's access to social resources, particularly during difficult experiences?

Recruitment

In order to begin exploring these questions, I began participant observation in Black Protestant churches throughout the San Francisco Bay Area. I started by regularly attending services at one church at a time, for about six to eight weeks at each church. The first time in attendance at a new church, I introduced myself according to church protocol during the part of service designated for announcing guests. At the end of six weeks of regular attendance, I contacted the pastor and requested their permission to describe this project during the announcements, asking churchgoers interested in participating to speak to me after the service.

At the same time, I contacted the leadership of several community-based organizations in the Bay Area that serve the health needs of Black women in different ways. I requested and received permission to attend public group meetings for ongoing participant observation. I also announced the project at meetings and on public bulletin boards in order to recruit participants. I recruited participants at church services, organizational meetings, and through snowball sampling (participant referrals). Once potential participants expressed interest, I determined their eligibility and scheduled a meeting to further inform them of the study protocol, and to obtain informed consent and demographic information. Ultimately, 24 women participated in the study (n=24), with 11 of the interviews offering the most data-rich narratives for phenomenological analysis. Names have been changed in this text in order to protect participant confidentiality.

Research Methodologies

The methodologies utilized in this study are a combination of Photovoice, photo-elicitation, and qualitative interviewing. Photovoice involves providing participants with cameras and asking them to take photographs that represent their perspectives on an established issue. Developed by Caroline C. Wang of the University of Michigan and Mary Ann Burris of the School of Oriental and African Studies at the University of London, Photovoice is an activist, participatory research method designed to allow for study participants to take an active role in directing research around issues that affect them (Wang and Burris 997). Over the past decades, this method has been adapted to conduct health research to assess community priorities and inform research agendas.

Photo-elicitation is an interviewing method involving photographs or other visual data as prompts (Harper 2002). The use of visual data in the interview is intended to further evoke memory and emotion, serving as a common reference point for the interviewer and the participant. Together, Photovoice and photo-elicitation offer a means to create a participant-guided interview beyond structured, researcher-generated questions.

In this project, participants were given a disposable camera for two weeks. Once enrolled in the study, an initial meeting was scheduled to review the study objectives and obtain informed consent. At this meeting, each participant was trained in how to use the camera and given a brief overview of guidelines for ethical photography. They also received several "Consent to Photograph" forms to obtain written consent from any human subject in their photographs. Each participant received a $30 incentive and travel reimbursements in exchange for their participation. In our first meeting, participants provided demographic information, and were asked if they were willing to be contacted in any follow-up studies. We then discussed the aims of the project, asking participants to focus on two questions: First, what is it like to live with chronic illness? Second, how do religion and spirituality influence your experience of chronic illness? Each participant was asked to take photos in the course of their daily life, over a period of two weeks, with these questions in mind. At the end of the two weeks, they were given a padded mailer with postage paid to send in the disposable camera and the photographs they had taken. I developed two sets of the photographs, one copy for the participant, and one for me, the researcher.

When we met again for the qualitative interview, I provided participants with a copy of each of the photos they had taken. At the start of each interview, I asked the participant about her experience taking photos. Before discussing the photos themselves, each participant was asked to look through the developed photos and to remove any photographs they would rather not discuss. Participants signed a photo release form for each photograph they consented to be included in the study. We then proceeded with a qualitative photo-elicitation interview, using the participant's photographs as a reference point for our discussion of the guiding questions of the study.

This combination methodology was well-suited to the aims of this study. Photovoice created a participatory element, in which participants were able to guide the conversation. The format of the interview was intended to mitigate the imbalance of power in qualitative interviewing, in which the questions and underlying assumptions of the researcher frame the narrative data. Photovoice allows participants to determine their priorities in the narrative of their experience. They choose what subjects are raised, they interpret the guiding questions for themselves, and they have the space to respond according to the meanings that are important to them. The visual data utilized in photo-elicitation serves as a prompt for the memory of the participant. Rather than a snapshot of how the interviewee is feeling at the time of the interview, photo-elicitation facilitates a long-term perspective of changes in emotion and meaning over time. The result is rich narrative data, supplemented by visual data, about the experience of illness as a dynamic and fluid process of interpretation and response. This combination methodology also supplies visual data for another level of analysis, intentionally composed by the participant to convey her own perspective.

The audio-taped qualitative interviews lasted from 40 minutes up to 4 hours. Each interview was conducted in a location chosen by the participant — locations included the participants' homes, a community center, and a public library, among others. Interviews were conducted according to an open interview guide, referencing participant photos and exploring key themes as they emerged.

Data Analysis

I conducted a thematic analysis of the narrative and visual data gathered in qualitative interviews, as well as the contextual data gathered through participant observation. The analysis was guided by multiple approaches, including narrative analysis, phenomenological analysis, grounded theory, and visual sociology. This study is concerned with the lived experiences of religious Black American women diagnosed with chronic illness, as a means of understanding the strategies of response developed by individual women. A combination of narrative analysis and an interpretative phenomenological approach to the data facilitates an exploration of the meanings that become important to a participant in her experience of social, psychological, and physical changes associated with chronic illness.

The method of analysis was guided by grounded theory, with the intent of constructing a theory from the data (Glaser and Strauss 1967, Charmaz 1995). I developed codes from the data according to categories of meaning, beginning with line-by-line open coding. Through the development of codes, I identified themes in the data and grouped the codes by theme. These themes, which emerged from repeated ideas and concepts across interviews, are the foundation of the analysis presented in this project. Grounded theory provided the method for a phenomenological investigation of individual women's experiences, through narrative and visual data. Narrative analysis of the qualitative interviews provides information about the discursive elements a participant engages to interpret her circumstances. The stories told by participants, the meanings those stories rely upon, and the commonalities among participant narratives offer insights into the personal and collective belief systems that characterize various aspects of her process of interpretation and response to illness.

In addition to the narrative data from interviews, the participant photographs offer valuable visual data that provides further insight into a participant's physical and psychological perspective. The analysis of visual data was guided by principles of visual sociology, recognizing the visual image as not only descriptive, but constructive of the consciousness of an individual. The images composed by each participant were considered both individually and as a sequence. Codes were developed according to both the visual elements present in each photograph, the participant's verbal description of the photograph, and the narratives identified within the verbal interview. In each thematic category that emerged in the study, there are codes informed by narrative data, visual data, and contextual data from field notes and memos.

The findings of this study are presented thematically, according to organizing concepts referenced in the qualitative data to the point of theoretical saturation. The codes developed in data analysis were summarized according to major categories of meaning, including: factors that influence the experience of chronic illness, changes produced in the experience of chronic illness, and interpretations and response to chronic illness among religious Black American women.

Study Limitations

Although it was directed in-part by participants, this study was conceptualized and executed by the researchers. As a result, it is inherently limited in certain ways by researcher perspective, experience, and understanding. Following data collection and analysis, I have identified several key limitations of this project and the generalizability of its conclusions.

One potential limitation of this project is its focus primarily on Black American Christianity, although some participants practice other religions. I chose to focus on recruiting participants who practice Black Christianity due to my own familiarity with the cultural and religious context and practices, which facilitated my ability to understand layered meanings within them. Although the inclusion criteria for the study included any organized religion, recruitment focused heavily on Black Churches and

Black Protestant Christian spaces. As a result, a large majority of participants exclusively practice Christianity. Black Americans practice a diversity of organized religions, and Black American spiritual practices often engage hybrid meanings and traditions from a range of religions. Traditional spiritual knowledge has often been passed down through generations outside of Christian practice. The emphasis on Christianity in this project may have led participants to omit information about non-Christian aspects of their spiritual practice, due to the normalization of Christianity within the study.

Another potential limitation of the project is its treatment of gender. The inclusion criteria simply specifies that participants must self-identify as a woman. To my knowledge, all of the participants in the project are cisgender women. There is ample documentation of Christian beliefs being used to justify violent prejudice of thought and action against queer, non-binary, transgender, and gender non-conforming people. Transgender women, particularly Black transgender women, have faced disproportionate violence even within their own communities. It is likely that my decision to recruit primarily in churches increased the probability of the absence of transgender women from this study, since they are less likely to be well-represented in spaces that have historically excluded them. Although recruitment was also conducted in organizational spaces and community groups that serve many trans women and gender non-conforming people, I believe that the information gathered in this project could be expanded by an intentional inclusion of transgender people and their accounts of illness experiences.

Despite my efforts to accommodate all forms of physical and mental ability, there are a few populations for whom this project was ultimately less accessible or inaccessible. The inclusion criteria states that participants must speak English. This decision was based on my own linguistic competency and the financial limitations of the study (no translators), so the project only included people who speak and understand English. People living without vision and people with low literacy were less likely to be recruited through promotional materials, which were entirely written, although all materials were read aloud in the informed consent and interview meeting to accommodate all levels of literacy. There were also barriers to participation in the project for people without hearing. Accessibility is especially important in a study about chronic illness experience, and this project would have benefited from the intentional recruitment and inclusion of participants with a wider range of ability.

It is worth noting that socioeconomic status is always a factor in accessibility for multiple reasons, and this project is no different. The inclusion criteria specifies that participants must have been diagnosed with chronic illness. Diagnosis requires access to western biomedical healthcare and being received as credible by medical professionals, both rights that are systematically denied to large swaths of the population based on socioeconomic status. As a result, many people living with chronic illness in the U.S. are undiagnosed and/or do not have access to treatment. All of the participants in this study were diagnosed and had received medical care at some point, which means that this data set is not representative of people who have been excluded from the healthcare system and who likely face additional challenges in their illness experience.

Although my own closeness to the subject may be a limitation of the study, it is also an asset in the research. My familiarity undoubtedly brings me to the research with pre-existing assessments, biases, and personal experiences that inform my perspective.

In some cases, my past experience in the Church and in my own illness experiences may lead me to seek certain data or make biased interpretations. At the same time, this familiarity facilitates a deeper examination of the meanings engaged by project participants. Particularly in participant-led interviews, my experiential knowledge of Black religious contexts, medical systems of chronic care, and participation in health advocacy organizations ultimately served me as a researcher in gathering and interpreting relevant data. Of course, the findings of this study are not representative of the experiences of all Black American women, but they offer useful framing devices for understanding commonalities in experience that emerge among certain groups of Black women. I have presented the findings of this study according to the demographics of the population that is truly represented in the data.

Significance

The findings presented in this research have the potential to expand our understanding of the ways in which individuals cope and respond to chronic illness, and how their strategies for response may change over time. This study is intended to expand the conversation on coping to account for spiritual and cultural meanings and their influence on individual strategies in responding to illness. Black women's experiential narratives offer insight into the meanings that become important to them over the course of their illness experience. Narrative analysis facilitates an explication of the range of actions these meanings may support. In particular, the use of participant-led interviews and visual data allowed for an investigation and explication of the non-linear phases of coping and response.

These insights have the potential to support social and medical support for people diagnosed with chronic illness, within and beyond medical care. In particular, an understanding of an individual's priorities in the responses to illness can be used to understand their coping strategies and contextualize their decisions as they engage medical therapies. A perspective of individual responses to illness that accounts for their social, psychological, and spiritual strategies will ultimately inform more effective support for patient health.

This is particularly significant for Black American women, who confront multiple forms of physical, psychological, and epistemological violence in mainstream American society. Black women are often not afforded credibility in healthcare systems; their communication about their own illness experiences is consistently ignored or undermined in clinical encounters. Narrative data from Black women themselves about the shifts in their perspectives and priorities over the course of illness can provide more information about the internal psychological and external social factors that impact their access to resources and influence their decision-making.

CHAPTER II

SOCIOLOGICAL APPROACHES TO BLACK WOMANIST MEANING-MAKING

“they ask me to remember

but they want me to remember

their memories

and i keep on remembering

mine.”

– Lucille Clifton, *why some people be mad at me sometimes* (1988)

This project engages several theoretical frameworks to guide narrative and visual data analysis. The scholarship reviewed in this chapter covers key theoretical concepts that are relevant to the interpretation of empirical data produced in qualitative interviews. These include concepts from the sociology of chronic illness, the history of the development of Black American religion and cosmology, the history of womanist epistemological traditions, and psychological examinations of coping.

Sociological Approaches to Chronic Illness and Identity

The sociology of chronic illness explores the ways in which chronically ill individuals negotiate changing physical abilities and corresponding changes in their social reality. In addition to their own psychological responses to illness, chronically ill individuals are confronted with the expectations that other people hold for their behavior and emotions. These expectations are shaped by dominant ideologies and influence the options and choices of individuals in their responses to illness.

Scholars within the sociology of chronic illness examine the impact of chronic illness on personal identity and social experience. With the onset of symptoms that limit their ability to embody familiar social roles, individuals face fundamental challenges to their sense of self. The concepts of biographical disruption and loss of self serve to elucidate this crisis of identity and describe common strategies of response (Bury 1982, Pranka 2018). Identity reconstruction is influenced by the social and clinical meanings of disease, which may legitimize or stigmatize the consequences of illness. Individuals engage several types of work in the illness experience. In addition to identity work and daily self-care, chronic illness necessitates strategies for regulating emotion, navigating medical care, and coping with moral judgment. The literature reviewed in this study explores the work involved in reconfiguring one's identity and navigating social expectations in the experience of chronic illness.

Sociological descriptions of the experience of chronic illness have focused on the internal and external challenges it presents. While early accounts of illness experience emphasized physical difficulties, more recent qualitative studies have addressed the decisions and actions of individuals in response to chronic illness (Bury 1991). Interactionist approaches to illness experience illuminate the meanings that become important to people as they navigate the changes brought on by illness and medical care, potentially contextualizing their choices in responding to those changes.

The physical and social realities associated with chronic illness influence the processes by which individuals define and assert their own identities. Sociologists have often written about the experience of illness using either crisis models or negotiation models (Gerhardt 1989). Crisis models emphasize identity changes and changes in social position, while negotiation models describe chronic illness as a process of responding to changes within the self. In crisis models, physical changes prompt changes in social experience. In negotiation models, individuals navigate decisions about the presentation of physical illness. In both cases, the self is influenced by the experiences and feelings associated with illness, while identity is shaped by the various social processes involved in the management of illness (Kelly and Field 1996). Both embodied experience and social experience directly shape the process of constructing personal identity. In the course of chronic illness, individuals must revise personal narratives in order to make sense of the present and re-imagine the future.

The concept of biographical disruption specifically addresses the ways in which the uncertainty that characterizes chronic illness experience impacts personal identity. Illness potentially disrupts an individual's taken for granted assumptions and explanatory frameworks, which necessitates the reconstruction of personal narratives and conceptions of self (Bury 1982). Scholarship that describes biographical disruption establishes a framework for understanding the response to chronic illness as an ongoing process, in which an individual must simultaneously navigate changing relationships, social position, and public identity.

A major part of the work associated with chronic illness involves continuously constructing and reconstructing life circumstances and corresponding biographical narratives. Corbin and Strauss (1988) describe this process as biographical work. Biography and illness trajectory have continuous reciprocal impact, since transformations in either one impact the other. An individual may need to change their lifestyle in order to accommodate changes in physical capability; by the same token, lifestyle changes have the potential to impact the experience of illness over time. Chronically ill people and those who support them must also manage everyday tasks—everyday life work—as well as the work necessary to manage the uncertainty of illness (Corbin and Strauss 1988). The concept of biographical work highlights individual agency in the processes of biographical reconstruction and adjustment to changing illness trajectories.

Although the concept of biographical disruption has proven useful in understanding the relationship between chronic illness and identity, there are limits to its applicability. Whether interpreted as obstacle or opportunity, models of biographical disruption often fail to account for the experience of childhood chronic illness, in which illness occurs as an individual is still developing a personal identity (Williams 2000). The idea of illness as a particularly disruptive and defining life event also assumes an absence of normalized interference in a person's daily life. Illness and its consequences may not always represent the most significant life challenge necessitating response. It should be acknowledged that other disruptive and potentially traumatic events can negatively influence individual health, even within the experience of illness (Williams 2000). Identifying changes in adult identity across life circumstances facilitates an understanding of the meanings that guide responses to chronic illness.

In her scholarship, sociologist Kathy Charmaz (1983) identifies several significant social and psychological changes that occur as the result of chronic illness. These changes include restrictions on movement and activity, social isolation, failure to meet self-expectations and the expectations of others, and dependence on other people. Without strategies for managing these changes—including altered social position and loss of independence—chronically ill individuals face social and emotional consequences that Charmaz refers to as 'loss of self(1983) '. Chronically ill individuals frequently experience an erosion of their former self-images without simultaneous development of equally valued new ones. The experiences and meanings upon which they had built former positive self-images are no longer available to them (Charmaz 1983). Without being able to participate in meaningful activities and relationships in familiar ways, people may feel they have less control over their lives and futures.

Charmaz contends that the self-definition of chronically ill individuals is altered as their interactions and relationships with other people change (1983). Transitions in social identity increase the strain on social relationships and networks of support. Charmaz writes that the descriptions of isolation, self-doubt, guilt, and changing perceptions of self provided by chronically ill people in qualitative interviews were characterized by a sense of loss. The amplified need for support and affirmation complicates the reconstruction of an independent identity. Several authors have critiqued accounts that present illness as a personal tragedy, emphasizing instead the agency of individuals as they manage changes in their personal identities and social relationships (Charmaz 1983, Frank 1995). These accounts highlight individual choices within the embodied, daily process of responding to chronic illness.

In their interpretations of illness, individuals frequently engage meanings that connect their personal illness experience to their relationship to the world and their position in society. The concept of "narrative reconstruction" illuminates identity formation in the context of changing social position precipitated by illness (Williams 1984). Chronic illness represents a rupture in the individual's relationship to the world. Understanding illness in terms of past social experience affirms the value and trajectory of life and the self. In interviews with chronically ill individuals, Gareth Williams (1984) identifies conceptualizations of illness that define it according to the relationship between personal identity and the social processes that define identity. By connecting the individual illness experience to meanings beyond the self, narrative reconstruction has the potential to facilitate the development of new and valued social identities (Williams 1984). The processes of biographical revision and identity reconstruction are characterized by changing orientations in time. As individuals revise their concerns and expectations for the future throughout the course of chronic illness, there are corresponding changes in the aspects of identity that become important. Individuals continuously reconstruct the narratives of their past, redefine their current identities, and revise their concerns and expectations for the future (Charmaz 1983).

The ongoing work of reconstructing personal and public identity within the experience of chronic illness may also be compounded by alienating experiences in clinical contexts. Patients seeking medical treatment for chronic illness are regularly forced to engage systems of care designed to treat acute illness. These health care systems value independence and a return to former routines, objectives that may be impossible with a chronic condition. American ideologies prioritizing independence and self-reliance often lead chronically ill people to blame themselves for their limited ability to fulfill former roles and responsibilities, and their care may not address these experiences in any way (Charmaz 1993).

Biomedical diagnosis of chronic disease is an influential factor in the development of personal explanatory narratives and the reconstruction of identity. The medical labels applied to the body during diagnosis create new meanings in the experience of illness. Williams describes the ways in which patients revise their personal narratives to include clinical conclusions (1984). As patients form and revise their own narratives, biomedical explanations become intertwined with accounts of lived experience. Socially privileged scientific language and technological precision can undermine experiential knowledge of illness. The integration of medical knowledge into personal narrative reconstruction connects social and medical experience. Depending on how it aligns with personal narratives and interpretations, medical diagnosis can legitimate and/or undermine aspects of the experience of chronic illness.

In the time between the onset of symptoms and professional diagnosis, individuals may experience what Corbin and Strauss refer to as “diagnostic limbo” (1985). During this time, an individual’s concerns regarding physical changes and discomfort are frequently dismissed by others. Legitimation of symptoms is often achieved through medical diagnosis. Nettleton et. al. (2004) highlight the significance of biomedical explanations for personal illness narratives, and the difficulty of constructing such narratives in the absence of any diagnosis. Improvements in technology and the increased emphasis on precision in medical contexts serve to define “genuine disease” as opposed to the experience of illness. These classifications create a hierarchy of diseases, based on the extent to which symptoms can be localized and explained by medical professionals (Nettleton et. al. 2004). This hierarchy reflects the ideological prioritization of scientific explanation over lived experience within and beyond clinical contexts. Without a biomedical label, an illness is less socially visible and potentially less conducive of the formation of illness identity. In cases of unexplained illness, personal narratives are not supported by expert knowledge. As a result, an individual not only contends with the constant uncertainty created by not knowing what will alleviate or exacerbate their symptoms, they also face social challenges to the legitimacy of their experience.

> So when the patient's story does not elicit a 'doctor's story', as Hunter puts it, they are adrift and they have to live with and make sense of their chaos. But how do people talk about their illness when there is no medical narrative to engage with? What discursive resources are they able to draw upon? (Nettleton et. al. 2004:53)

People with conditions that have not been legitimated by diagnosis struggle to navigate changing abilities and relationships without necessarily receiving the support of medical systems and social networks (Nettleton et. al. 2004). Individual decisions in responding to diagnosis, or in navigating the absence of diagnosis, are integral to their illness experience and trajectory.

In addition to the social meanings created by medical diagnosis, the chronic illness experience is characterized by moral ideologies that determine which behaviors and emotions are appropriate in response to disease. Biological facts become social facts as an individual confronts the ways in which other people interpret the changes associated with their illness. Chronic illness presents changes in the physical, social, and emotional realities that determine possibilities for responding to illness. Depending on the visibility of illness and its impact on a person's ability to meet social expectations, there are different possibilities for individual choices in the presentation of illness. Moral imperatives guide individual responses to physical limitation as people with debilitating illnesses reconstruct a sense of self and develop strategies for social interaction.

In the experience of chronic illness, physical limitations may become socially visible changes in the self. Rosenfeld and Faircloth (2004) emphasize the impact of ideology on the moral self in the description of a "movement mandate," which attributes moral meanings to movement through time and space. An individual's failure to perform in familiar roles casts doubt not only on a patient's physical competence, but also on her/his moral character. Patients are expected to demonstrate the assumption of personal responsibility through a commitment to physical and social recovery. Chronically ill individuals often feel the need to perform movement in order to maintain a sense of self that projects moral competence, despite the physical pain it may cause. The management of this pain is part of the work of preserving a sense of self and maintaining relationships with other people (Rosenfeld and Faircloth 2004). In this way, movement becomes an integral part of the embodied response to illness and reconstruction of identity in the face of moral judgment.

Rose Galvin (2002) explicates the widespread perception of chronic illness as a moral failure. In a society that defines and emphasizes health risks and prevention strategies, avoiding risks to one's personal health has become a moral responsibility associated with good citizenship. Chronic illness is frequently viewed as the result of an individual's failure to avoid known risks. The concept of wellness, according to which individual behavior is deemed responsible for negative health outcomes, is utilized as a tool of government in social regulation. The dominant view of chronic illness as a personal failing obscures broader social realities that determine individual health behaviors, and forces chronically ill people to confront moral stigma in the illness experience (Galvin 2002). Moral assumptions may therefore account for a great deal of the strain placed on personal relationships during illness.

Chronically ill individuals make strategic decisions about self-representation and illness disclosure in order to manage the strains of moral stigma and behavioral expectations. Charmaz (1993) identifies different ways of experiencing and responding to illness. While some people respond by constructing their lives and selves to account for illness, others work to keep it separate from their personal and social identities. Charmaz's analysis of personal illness narratives reveals that at various points in time, people make decisions to either conceal or disclose their illness and its consequences in order to maintain relationships and social standing (1993). Decisions to conceal illness or avoid disclosure constitute an effort to distance the diagnosis from personal identity and any associated stigma. Patients make decisions to manage the impressions of other people, particularly medical professionals and those family members whose reactions might limit chronically ill people's sense of independence and control over their own lives. Disclosure has the potential to change the way an individual is perceived physically, socially, and morally. It can affect the way one is treated by others, potentially increasing social isolation and self-blame (Charmaz 1993). In this way, ideologies that attribute moral culpability to disease limit the possibilities for individual response, potentially exacerbating the challenges of chronic illness.

In addition to the work of coping with moral assumptions, chronic illness experience necessitates the strategic management and presentation of personal emotion. Emotional regulation represents another type of work involved in managing chronic illness. Arlie Hochschild (1979) introduces the concepts of feeling rules and emotion work in order to elaborate the process by which ideological assumptions incentivize and direct the regulation of emotional response. She identifies certain rules for feeling and behavior that shape interpretations and responses to life circumstances. These rules are determined by the ideologies of power that perpetuate social hierarchies including race, gender, and socioeconomic status. These ideologies create social and cultural prescriptions for normalcy that guide behavior and emotion. Hochschild refers to these prescriptions as feeling rules, which dictate socially acceptable interpretations of and responses to any information or event (1979). Individuals navigate feeling rules on a daily basis and may internalize them to varying degrees, often to the point where they believe they “ought to" feel certain ways in certain situations. In instances where an individual feels differently than they believe (or are told) that they “should,” she or he may either change their presentation of emotion to meet expectations, or they may actively work to change the emotion itself. Hochschild calls the former response “surface acting,” and the latter “deep acting” (1979). It is this latter response of deep acting that Hochschild elaborates upon most fully. She recognizes the attempt to change a feeling itself as “emotion work,” which goes beyond attempts to regulate emotions to the actual evocation and suppression of feeling (1979:561). Of course, this is not simply the work of an individual actor. Hochschild writes that “emotion work can be done by the self upon the self, the self upon other, and by others upon the self" (1979:562). Other people offer "rule reminders'' of how we are "supposed to" feel, and may reprimand or make pointed comments to individuals who do not regulate their emotions in ways that are deemed appropriate for the situation (1979:564). The internalization of feeling rules and their role in shaping social interactions often create situations of social exchange in which feeling itself is the commodity being exchanged. Individuals may believe that they "owe" it to other individuals or communities to feel a certain way, and their fulfillment of an emotion may be seen as a gift. In this sense, emotion work has a function in social exchange (Hochschild 1979, 1983).

Feeling rules inherently limit the expression of a natural range of emotion as individuals respond to chronic illness. Dominant ideologies create mandates for appropriate interpretation and emotional response to the psychological challenges presented by the transformation of self-image and public identity within the illness experience. Feeling rules function as a mechanism of behavioral regulation according to social location, thereby contributing to the reproduction of social inequalities. Social mandates for the interpretation of illness limit the social resources available to individuals as they respond to the emotional realities of chronic illness, particularly when their interpretations do not align with dominant narratives.

Black American women confronting chronic illness and its consequences navigate these changes by engaging strategies that have been communicated across generations. The ways in which individual women construct personal narratives and the extent to which they are able to seek and receive support are simultaneously influenced by biomedical definitions and the societal forces that create hierarchies of race, gender, and socioeconomic status.

Black American cosmologies and religious meanings

This study examines the influence of Black American cultural cosmologies and religious practices to understand the meanings they may create in the lives of Black women, particularly within their experiences of chronic illness. The distinct origins and orientations of Black American religious practice shape the production of shared systems of knowledge and meaning, and it is these systems of meaning that are employed by individuals in their interpretations of experience and responses to circumstance.

The literature discussed here reflects a shift within the scholarship on religion away from the ongoing debate over whether or not Black American practices maintained any cultural continuity with African traditions. Instead of focusing upon the extent to which African traditions have been preserved or replaced, the scholarship relevant to the aims of this study describes the ways in which African and European cosmologies were transformed within the collective experience of Black Americans. Black American religious traditions have developed in circumstances of collective trauma, and the dual systems of meanings these traditions create and engage have shaped Black American cultural production. Protestant churches of multiple denominations that minister primarily to Black American communities, widely known as the Black Church, have been the institutions that maintain and perpetuate the beliefs and practices that create shared religious meanings.

The debate within the scholarship on Black American religion regarding whether or not any elements of traditional African cosmologies survived in the ritual practices of Blacks in North America is epitomized by the arguments of sociological scholars Melville J. Herskovits and E. Franklin Frazier. Frazier asserts that the process of enslavement completely stripped Africans of their culture and traditions, assimilating them into European American systems of belief. Herskovits, on the other hand, argues that the slave system did not entirely destroy African cosmologies among the enslaved, and that African patterns were retained in Black American practices (Raboteau 2003, Herskovits 1941).

The theory of complete deculturation put forth by E. Franklin Frazier posits that the violent repression of slavery and the eventual passing of enslaved people who had been born in Africa led to a total absence of cultural meaning among enslaved people (Raboteau 2003). The theory posits that the physical experience of slavery isolated Africans from one another, and this isolation was exacerbated by the fact that several different ethnicities and languages were represented in the enslaved population of each plantation. Frazier wrote: "Negroes were plunged into an alien situation in which whatever remained of their religious myths and cults had no meaning whatever" (in Raboteau 2003:248). He asserts that in this context, Black Americans were quickly acculturated into Western systems of belief, which subsequently gave meaning to their experience and became a bond of social cohesion. According to Frazier, Western Christianity entirely replaced African cultural meanings in the lives of enslaved Black Americans (Raboteau 2003).

Herskovits (1941), on the other hand, argues that Christianity did not simply replace African beliefs. Instead, he maintains that the flexibility of their belief systems allowed enslaved Africans to imbue coerced Western practices with more culturally relevant meanings. In particular, he notes the prevalence of ecstatic experience and shouting in Black religious practice as vestiges of African culture (Herskovits 1941). Herskovits intended to discredit certain dominant interpretations of history, which maintain that Black Americans had no past other than one of "savagery" in Africa, while colonizers were cast as "civilizing saviors." He worked to debunk theories of African inferiority by indicating the ways in which African systems of belief were less dichotomous in content and more flexible in form than Western cosmologies (Herskovits 1941).

The Herskovits-Frazier debate has served as a point of reference for contemporary scholars of Black American religion, particularly in the discussion of acculturation and dual meanings. Albert J. Raboteau (2003) provides a summary and critical analysis of the debate. On the one hand, he criticizes Herskovits for the claim that Black Americans have a natural proclivity for religiosity, and for exaggerating his thesis by over-generalizing certain instances of African retention. Raboteau challenges Herskovits' thesis of retention most extensively in his comparison of Black religious life in North America to the more traditional African-derived religions in Latin America and the Caribbean. The organized structure of traditional African religions did not persist to the same extent within North American Black Christian religious practice, leading Raboteau to conclude, "In the United States, the gods of Africa died" (2003:273). He suggests several explanations for the greater preservation of African traditions outside of the U.S. First, he asserts that North American Protestantism was more hostile than Latin American Catholicism in its silencing of African religious philosophies. Second, enslaved Africans in the U.S. were more isolated from one another due to smaller numbers on each plantation. Raboteau references the fact that the majority of people enslaved in North America were not African-born, and therefore would not have been as familiar with traditional practices (2003). Additionally, enslaved people on North American plantations were often ethnically diverse, and would not necessarily have shared cultural and religious traditions. Rather than focus on the preservation of specific rituals and beliefs, however, Raboteau emphasizes the ways in which African orientations took on new meanings in the Americas. Although the title of his essay, Death of the Gods (2003), seems to rearticulate Frazier's thesis of cultural loss, he acknowledges the ongoing influence of African tradition within the religious practices of Black Americans:

> Even as the gods of Africa gave way to the God of Christianity, the African heritage of singing, dancing, spirit possession, and magic continued to influence Afro-American spirituals, ring shouts, and folk beliefs. That this was so is evidence of the slaves' ability not only to adapt to new contexts but to do so creatively. (Raboteau 2003:278)

In recognizing this capacity for creative adaptation, Raboteau acknowledges the hybrid nature of Black American religious practice. Although African traditions may not have been preserved in their original forms, African cosmologies have continuously informed the way Black American religion and secular culture have developed in response to collective experience in the United States. The so-called "gods of Africa" did not, in fact, ever die.

Specifically addressing the North American context, religious scholar Charles Long elaborates upon this supposition by describing the "distinctive nature of black religion" (1986:188). Long asserts that Christianity does not encompass all of the meanings of Black Protestant religious practice (1986). Long defines religion as "orientation in the ultimate sense, that is, how one comes to terms with the ultimate significance of one's place in the world" (1986:7). He writes that the structure of a group's religious consciousness is constantly renegotiated, but remains present "as a datum to be deciphered in the context of their present experience" (Long 1986:193).

Long describes some structural unity among the ritual practices of several ethnic groups in West Africa. The similarity of diverse African cosmologies allowed for their survival among Black Americans, even as the process of enslavement worked to systematically eliminate African cultural and linguistic patterns. Long recognizes the more immediately apparent "Africanisms" in the Atlantic Islands and Latin America (particularly Brazil) as a useful point of reference in identifying the unique nature of Black religion throughout the Americas (1986). He unifies observations of the African retentions within these practices by employing the term "soft culture" to describe "a characteristic mode of orienting and perceiving reality" (Long 1986:189). This shared orientation has informed the development of both sacred and secular practice within Black American communities.

For the most part, scholarship on Black religion has moved beyond the limitations of the debate over African retentions to recognize the ways in which African traditions were adapted and transformed in American contexts. Long contends that the creative responses of Black Americans to hostile circumstances in the Americas are central to the study of Black religion (1986). He introduces three principles that should directly inform the study of Black religions. These principles emphasize the unique development of Black American religion, while maintaining an awareness of the fundamental influence of African cosmology. These perspectives constitute symbolic images as well as methodological principles. They are:

> 1. Africa as a historical reality and religious image
> 2. The involuntary presence of the black community in America
> 3. The experience and symbol of God in the religious experience of blacks. (Long 1986:188)

Long's first principle, Africa as a historical reality and religious image, refers to the meanings of African origin in the experience and religious imagination of Black Americans:

> The image of Africa as it appears in black religion is unique, for the black community in American is a landless people...Their image of the land points to the religious meaning of land even in the absence of these forms of authentication. It thus emerges as an image that is always invested with historical and religious possibilities. (Long 1986:190)

In the experience of racial oppression, the circumstances of Black Americans were largely determined by the dominant interpretations of their phenotypic characteristics and their African ancestry. Long connects these physical criteria for racial oppression to the significance of physical being and place of origin within Black religion. For a displaced people, Africa became important to collective identity as a historical homeland and imagined motherland, "a place where the natural and ordinary gestures of the blacks were and could be authenticated" (Long 1986:190). In the religious consciousness of Black Americans, Africa was represented as a place where Black physical appearances and collective knowledge could be fundamentally affirmed and enacted.

In explicating his second principle, the involuntary presence of the Black community in America, Long asserts that Blacks in America could not accept as normal a condition that denied their humanity. Instead, they confronted the conditions of racial oppression while creating oppositional alternatives for their physical, cultural, and psychic survival. Due to the various limitations on cultural expression imposed by the conditions of oppression, alternative systems were developed most extensively in Black religious consciousness. "Not only did this transformation produce new cultural forms but its significance must be understood from the point of view of the creativity of the transforming process itself" (Long 1986:191).

The tension between Western Christianity and Black American systems of association laid the groundwork for the creative religious process that has established a fundamental relationship in Black religion between the difficulty of life and "the ecstasy of religious worship" (Long 1986:191). Theophus H. Smith (1994) expands upon the idea of creative transformation, observing the ways in which Black religion alternates between both African and American meanings. Smith recognizes the alternation itself as a creative process, producing a new level of meaning that supports spiritual transcendence (Smith 1994).

Long's final principle reveals the effects of layered meaning within experiences of divinity in Black American religion. He explains that although Africans and their descendants were forcibly converted to Christianity, they invested its practice and scripture with meanings related to their own experience. Long specifically examines the meanings of the Bible and the Holy Trinity in Black religion (1986). He illustrates the way in which certain Biblical texts became meaningful in Black Christian experience:

> The Biblical imagery was used because it was at hand; it was adapted to and invested with the experience of the slave. Strangely enough, it was the slave who gave a religious meaning to the notions of freedom and land. The deliverance of the Children of Israel from the Egyptians became an archetype which enabled the slave to live with promise. (Long 1986:193)

Smith provides an extended analysis of culturally relevant Biblical meanings in Black Christianity (1994). Although the majority of enslaved Africans and their descendents were prohibited from learning to read, the stories of the Bible were continuously present in Black American religious metaphor and cultural expression. "Here the sacred text of Western culture, the Bible, comes to view as…a book of ritual prescriptions for re-envisioning and, therein, transforming history and culture" (Smith 1994:3). Smith also hypothesizes a direct connection between the roles of traditional African deities and folk representations of Biblical figures in collective religious imagination. He highlights the similarities between several distinct understandings of Moses in Black American folklore and the roles of diviner, herbalist and messenger/trickster deities in Yoruba tradition (Smith 1994:38). Even within an unfamiliar religious structure, African content and Black American cultural emphasis were sustained and developed in ways that affirmed collective knowledge and posed an inherent challenge to the moral assumptions of a racist society (Smith 1994).

Long describes a similar transformation of meaning in the Black Christian experience of the Holy Trinity. In Black American religious language and practice, the Trinity operates less as religious dogma and more as a way to designate "modalities of experience" of divinity (Long 1986:194). These modalities are represented in God as omniscient Creator, Christ as companion and fellow sufferer, and the Holy Spirit as embodied communion with divinity (a continuation of African cosmology). These modalities of experience informed interpretations of spiritual and religious experience in ways consistent with the history and collective experience of Black Americans. Alternative meanings attributed to Christian worship provided Black Americans with a standard for social organization, self-critique, and cultural valuation that was not determined by their oppressors. In Black American religious practice, the persistence of African cosmological orientations and the emphasis on cultural history create a system of meaning that supports positive cultural identity formation and potential social transformation (Long 1986). The principles outlined by Charles Long provide a foundation for the development and organization of theories regarding Black American religion. His analysis accounts for the simultaneous influence of both dominant and marginalized systems of meaning upon Black American religious practice, revealing a consistency in orientation even within changing ritual form.

Several scholars of Black religion present theories that further illustrate processes of creating and transforming meaning. Rachel Harding (2000) builds on Long's thesis with her contention that the various religious expressions of African descendants in the Americas display commonalities in their fundamental organizing principles:

> This shared orientation, this cosmology, explains the basic functioning of the universe and gives meaning and order to social relations, societal institutions, and the state (or process) of being human. It provides certain keys for understanding historical circumstances…It also establishes the parameters of human response to situations in which individuals and groups find themselves. (Harding 2000:19)

Harding notes that African belief systems tend to exhibit flexibility, an "ability to incorporate new symbols, rites, and myths and reorganize older ones in an effort to respond to the immediate needs and situations of their adherents" (2000:19). Importantly, she asserts that some aspects of African tradition have remained constant in Black American practice, despite the creative adaptation of religious ritual to new material realities. It was this combination of constancy and adaptation that facilitated the development of dual systems of meaning in both sacred and secular contexts (Harding 2000).

In her analysis of Haitian Vodoun, Joan Dayan (1995) assesses the potential consequences that result from the adaptation of African belief systems to new ritual structures. Dayan asserts that to some extent, Afro-Haitians internalized the Western paradigms to which they were forced to adhere. Even if participation in Christian ritual began as a superficial camouflage for African cosmologies, she contends, "the codes and trappings of Europe contributed to how the spirits of Africa would be received, comprehended, and sustained in the New World" (Dayan 1995:66). Further exploring the effect of coerced religion on the faith of enslaved Africans, Dayan notes the "dual processes of association" that developed within syncretic religious practice among Afro-Haitians (1995:67). She largely focuses on the relationship between religious and political imagination during the Haitian Revolution, and her analysis reveals the political significance of double meanings in ritual context. Vodoun ritual invokes the language and terminology used by Europeans to establish their dominance, thereby opening it to alternative interpretations informed by the historical experience of Afro-Haitians. In ritual context, the meanings that support ideologies of white dominance are made ambiguous, and the premises of European dominance are destabilized in the experience of worshippers (Dayan 1995:71). One important way in which this is accomplished is within dance ritual, which Dayan recognizes as a manifestation of history. She refers to religious performance as "collective physical remembrance," informed by the history of Black Americans (Dayan 1995:56).

The scholarship of anthropologist Yvonne Daniel offers a way to understand the connection between performance rituals in religious contexts across the African Diaspora. In a comparative study of three African Diasporic religious traditions, Daniel recognizes dance ritual as a means of spiritual communication and physical healing (2005). Similarly to Dayan, she explains religious dance as a physical way of knowing, which she calls “embodied knowledge,” gleaned from the collective memory of multiple African ethnic groups (Daniel 2005:352). This knowledge communicates several different kinds of information. In the context of ritual performance, the humanity of participants is affirmed in reciprocal relationship to divinity. In particular, spirit possession facilitates a mutual recognition between humans and the divinities they incorporate, a recognition that is specifically salient when Black humanity is consistently denied in dominant discourse. Daniel writes: “The concrete act of dancing affords the immediacy of both the learned and intuitive realms of knowledge, and empowers humans as well as transforms and identifies them with and as spiritual entities” (2005: 357).

The structure of worship reinforces social and spiritual relationships in the ritual community, and ritual performances offer constructions of Blackness, and specifically Black femininity, that are alternative to those provided in a society characterized by hierarchies of race and gender. The spectacle of religious performance creates sites of collective identification founded in historical experience (Daniel 2005). Collective identification with a dancing body affirms the silenced knowledge of Black Americans and locates familiar gestures in a ritual context layered in symbolic meaning. The alternative systems of interpretation that are cultivated in ritual space often present an implicit challenge to the foundational assumptions of the dominant paradigm.

Although these analyses center on Diasporic religion outside of the U.S., shared orientations within Black American religion have also facilitated the perpetuation of collective practices with origins and meanings beyond Western Christianity in North America (Chireau 2003). The "ring shout" and related rituals are frequently referenced as examples of direct African influence in North American practice (Hurston 1981, Randolph 1893, Chireau 2003, Harding 2000). The tradition of the ring shout involved collective movement in a counterclockwise circle, accompanied by rhythmic clapping or stomping and repetitive song (Harding 2000). The ring shout was a ritual in service of ecstatic worship, in which the human embodiment of divine Spirit was central. Smith asserts that the ecstatic experience was not the goal of collective religious practice, but rather an anticipated by-product of the creation of "the phenomenal conditions conducive to their subjective apprehension of the divine" (Smith 1994:124). The improvisational interplay between levels of meaning transforms a hostile environment into a sacred space in which Black humanity and community are affirmed in relation to divinity; the embodied manifestation of divinity (catching the Spirit) is part of this process.

Religious meetings among enslaved Africans and Black Americans were generally prohibited, particularly after planned uprisings of enslaved people in the American South, such as those led by Denmark Vesey in South Carolina and Nat Turner in Virginia (Sernett 1999). To escape the surveillance of slave owners and missionaries, traditional practices were performed at secret, late night meetings in slave quarters, swamps, and small makeshift places of worship called "hush harbors" (Sernett 1999; Harding 2000). Another example of the concealment of cultural symbols is evidenced in the fact that public religious expressions often contained coded meanings that were unintelligible to observers unfamiliar with their alternative orientation and structure (Smith 1994).

Layers of coded significance are also present in Black cultural production beyond the sacred, including musical expression (Bennett 1964, Cone 1972, Smith 1994, Harding 2000). Describing the religious songs known as spirituals, Rachel Harding makes the observation that "the songs, almost always accompanied by ritual movement and dance, melded Biblical language to African religious values and New World experiences of struggle" (2005). DuBois (1903) described spirituals as "sorrow songs," referencing the most immediately recognizable mood of the music. Smith, however, insists that Black cultural forms reprise negative experience in order to transform its meanings and make transcendence possible. Smith compares this technique in religious spirituals to the secular music of the blues, in which the melancholy tone is a meaningful disguise for double interpretations (1994). In an essay entitled *The Negro Mood* (1964), Lerone Bennett explains that the dichotomies introduced by philosopher Plato and subsequently developed in Western philosophy and theology are not applicable to African-derived cultural systems. He disputes any distinction between sacred and secular cultural forms, noting that religious meanings permeate cultural expressions beyond explicitly sacred practice (Bennett 1964). Smith's analysis echoes Bennett's claim by identifying double meanings as central to Black cultural production in multiple social spheres.

Smith observes that the duality of Black American experience informs what he refers to as the "Black aesthetic" (Smith 1994:117). He describes the Black aesthetic as a distinctive form of cultural production characterized by the alternation between double systems of meaning. In sacred and secular contexts, the duality of Black expression evokes collective suffering to facilitate spiritual possibilities. The persistence of this extreme duality and the cultural meanings it creates are essential to the maintenance of alternative orientations within Black American communities.

The practices informed by this duality not only respond to the psychic effects of collective experience, they also have the potential to address the circumstances that have shaped that experience. Smith emphasizes the importance of conjure as one way in which religious imagination confronted material circumstance. He includes all realms of Black cultural production in his broad definition of conjure as “black people’s ritual, figural and therapeutic transformations of culture…More concisely and comprehensively stated: conjure is a magical means of transforming reality” (Smith 1994:4).

This definition includes religious forms such as those mentioned above, but it also encompasses “secular” root work, herbalism, and the ritual practice of magic among Black Americans. Smith describes magic as ritual performance that intends to subject hidden powers to human manipulation (1994). In many of its formulations, conjure creates connections between supernatural powers and natural processes. One example of this ritual linkage is the folk practice of making and wearing gris gris bags, a form of root work that survived the disintegration of the organized African religion known as Voodoo in the U.S. (Raboteau 2003:266). The bags frequently contained a strategic mixture of natural materials, elements representative of the force to be transformed, and materials to invoke supernatural intervention. These bags epitomize the way in which conjure has engaged divinity through material circumstance in order to create new possibilities in everyday life.

Historically, conjure has addressed the need for physical and psychic healing among Black Americans. Yvonne P. Chireau elaborates the ways in which Black ritual practice met needs that dominant institutions did not. In a chapter entitled *Medical Doctors Can't Do You No Good* (2003), Chireau demonstrates the heightened importance of culturally relevant ritual healing in a time when most Black Americans lacked access to dominant forms of medical care, and when white doctors frequently treated their few Black patients with contempt (2003:93). Black Americans have engaged traditional African, Native American and some aspects of European systems of knowledge in order to create new ahd hybrid forms of spiritual knowing, and to negotiate the violence and uncertainty that characterized their existence. The widespread use of conjure as a healing force is identified by Smith as a pharmacopeic tradition, a form of "folk pharmacy" (1994:5). He notes that the dominant rhetoric has overemphasized the use of conjure for mal-intent, failing to acknowledge the range of meanings the traditional practice has in the lives of believers (Smith 1994:6).

As with other forms of cultural expression among Black Americans, conjure was characterized by multiple systems of meaning; it often utilized material elements of the situation to be transformed. Smith refers to conjure as "homeopathic," a treatment that mimics the disease in order to cure it (Smith 1994:168). He connects this technique to the ways in which other aspects of Black American ritual practice engage the tension between the limitations imposed by oppression and the possibilities created in communion with divinity.

Smith's scholarship describes the ways in which Black Americans have developed and employed multiple systems of meaning as an improvisational performance borne of a traumatic past (1994). Symbolic representations of collective history are prominent in ritual context, and remain significant in the collective consciousness and interpretational frameworks of Black Americans.

The interplay of multiple meanings produces hybrid forms of expression that undermine the dominance of any single cultural system. The performance of layered meaning in Black cultural expression is known as "signification" (Smith 1994). The very images and symbols that represent negative experience are invoked, opening them to the meanings produced within alternative cultural paradigms. Smith provides an example of signification in Sojourner Truth's famous speech, "Ain't I a Woman?" (1851), in which Truth asserts her womanhood to reveal the fundamental flaws in dominant logic that serve to undermine her femininity (Smith 1994). Charles Long describes signification in religious practice, Henry Louis Gates emphasizes its appearance in Black American literature (also noting the centrality of the trickster/transformer hero in Black American folklore), and several theorists have asserted its fundamental influence in Black American musical traditions (Long 1986, Gates 1989, Smith 1994, Caponi 1999).

The widespread transformation of meaning through signification has the potential to influence the development of alternative belief systems, and to foster social action. Smith observes that signifying "performances" were crafted to produce "recognitive breakthroughs" in service of a political agenda (Smith 1994:170). Similarly, Joan Dayan's analysis of religious imagination and its role in political mobilization during the Haitian Revolution illuminates the significance of alternative meanings in the collective definition of freedom (1995). In the United States, Nat Turner stated clearly that his interpretation of the Bible according to Black American historical experience reinforced the purpose he felt in leading a violent insurrection of enslaved people in South Carolina—after which the state passed a law prohibiting Black Americans from gathering for religious purposes (Sernett 1999). Still, Smith is troubled by his conclusion that Sojourner Truth's masterful significations "seemed powerless at the level of massive psychosocial transformation" (1994:173). He lauds the healing potential of her performance, but laments that similar practices have not affected change at a broader societal level (Smith 1994).

Smith concludes that performances informed by layered systems of interpretation are not reducible to calculated political action with the sole objective of transforming the consciousness of the audience. He accounts for the development of double meanings in ways that are consistent with historical experience; signification arose from the hybridity that has characterized the cultural lives of Black Americans. Signification destabilizes dominant meanings, which has been important in its affirmation of Black humanity and in the development of Black American collective identity. As a common practice, signification operates in varied ways that cannot be entirely accounted for by their effects on the dominant paradigm (or lack thereof) (Smith 1994).

Scholars of Black American cultural production have documented the ways in which religious and secular practices have served to transform the meanings of collective experience. The deployment of layered meanings undermines the foundational assumptions of the dominant paradigm. Although collective practice has frequently reinforced agendas of social transformation, its primary significance is within the experience of Black Americans themselves (Smith 1994). Religious ritual in particular has rearticulated the meanings of history in order to undermine and potentially transform its devastating psychic consequences. Cathy Caruth describes trauma as a pathology of history:

> It is not a pathology, that is, of falsehood or displacement of meaning, but of history itself…it is not so much a symptom of the unconscious, as it is a symptom of history. The traumatized, we might say, carry an impossible history within them, or they become themselves the symptom of a history they cannot entirely possess. (Caruth 1995:5)

According to Caruth, trauma is a disease of impossible experience, a history that can only be comprehended "in its repeated possession of the one who experiences it" (1995:4). This theory is striking in its compatibility with theories of Black religious development that emphasize ritual engagement of collective history. In particular, religious practice that evokes the past serves to open it to re-interpretation (Harding 2000).

It is the process of attributing new meaning to traumatic experience that makes collective healing possible (Smith 1994, Harding 2000, DeLoach and Peterson 2010). A community "possessed" by its traumatic history, Black Americans created a sacred space in which to be recognized and possessed by benevolent divinity. Caruth's theory reveals the potential of collective practice to directly address the physical and psychological scars of slavery and its aftermath. Alternative truths concerning the past are enacted and affirmed, present material circumstances are opened to alternative possibility, and collective experiential knowledge is communicated and affirmed in performance ritual (Long 1986, Dayan 1995, Harding 2000, Daniel 2005).

In her description of Afro-Brazilian Candomblé, Harding notes the importance of religious grounds as physical spaces for the cultivation of alternative cultural orientations (Harding 2000). In the U.S., physical spaces for religious ritual transitioned from an "invisible institution" to become increasingly visible and unified after the abolition of slavery (Randolph 1893; Sernett 1985). Black Americans were able to establish social institutions that served a similar purpose, increasing the organization and resources available within Black civil society.

Black American Christianity and the Development of the Black Church

Black religious practice became institutionalized with the development of Black churches during racial segregation. In 1978, the Congress of National Black Churches (CNBC) was established as an umbrella organization for eight major historically Black denominations. CNBC fosters collaborative programs in order to assess and address the specific needs of Black communities. Black American Christian institutions continued to perform central functions in Black civic society after segregation. Churches have facilitated social and political organization, as well as the development of independent theology and practice.

The formation and development of Black religious institutions has been a contested process, characterized by deliberations regarding the relationship of Black Christianity to white Christianity, as well as the role and authority of women in the church (Higginbotham 1993, Jones 2006). In addition to the internal negotiations that characterized its growth, the Black Church also struggled to explicitly define its theological stance in relation to European Christianity. The question of the Church's relationship to power has always been central to studies of Black religion, particularly in regards to the Black American struggle for freedom. In fact, theologian James Cone asserts that Black theology is a "theology of black liberation" (1993:269). He argues that Black theology developed as the theological arm of the Black Power movement, and is therefore completely independent of Eurocentric theology.

Cone describes the way in which the ideology of the Black Power movement challenged the Black Church to "move beyond the models of love defined in the context of White religion and theology" (1993:266). The National Committee of Negro Churchman (later known as the National Conferences of Black Churchmen) debated whether to reject Black Power as a contradiction of Christian love, which would corroborate the white church's condemnation of Black Power as neither American nor Christian. The other option was to "accept Black Power as a socio-political expression of the truth of the gospel" (Cone and Wilmore 1993:266). A rejection of Black Power ideologies would negate the historical centrality of the Church in Black American political struggles, and it would deny the Church's responsibility to engage in the Black struggle for liberation. At the same time, it was difficult for many members of clergy accept Black Power as a Christian expression after being trained in white seminaries and internalizing Eurocentric definitions of Christianity. Perhaps more significantly, Rev. Martin Luther King, Jr. had openly rejected the ideology of Black Power in his position as a leader among the clergy (Cone and Wilmore 1993).

Within this social context, Black Theology emerged as an expression of the Black American theological imagination that was "derived from and thus accountable to our people's fight for justice" (Cone and Wilmore 1993:268). Initially, there was resistance among clergy who believed that theology itself was foreign to Black culture, and others who insisted that Black Theology should be primarily informed by African philosophy and religion. Still, Black Theology developed in ways that prioritized a commitment to earthly freedom. Cone writes:

> Thus we sang our Black Power songs, knowing that the white church establishment would not smile upon our endeavors to define Christianity independently of their own definitions of the gospel. For the power of definition is a prerogative that oppressors never want to give up. (Cone and Wilmore 1993:268)

Despite a theological legacy of political consciousness, Cone warns that the Black Church has wavered in its commitment to social and political justice in modern times. He critiques "negative practices" that value economic and institutional survival over the concerns of oppressed people, in America and elsewhere. There is little in our theological expressions and church practice that rejects American capitalism or recognizes its oppressive character in Third World countries. The time has come for us to move beyond institutional survival in a capitalistic and racist society and begin to take more seriously our dreams about a new heaven and a new earth. (Cone and Wilmore 1993:271)

In his assessment of the history and development of Black Theology, Charles Long identifies Cone's original thesis in Black Theology and Black Power (1969) as a turning point in the study of Black religion (Long 1971). The idea that Christianity is fundamentally a religion of oppressed peoples had been put forth before, notably by Reverend Howard Thurman (1949). Cone went beyond these familiar claims to challenge all Christianity with his declaration that Black Power was "not an antithesis to Christianity…It is, rather, Christ's central message to twentieth-century America" (in Long 1971).

Referencing the theory of double consciousness put forth by DuBois (1903), Long asserts that simultaneous double meanings shape Black cultural and religious life in ways consistent with collective experience (Long 1976). The hybrid meanings created within Black cultural production destabilize hegemonic norms, creating the possibility for a unified political stance of resistance (Cruse 1967).

> Even when the slave, ex-slave, or colonized person becomes aware of the autonomy and independence of his consciousness, he finds that, because of the economic, political and linguistic hegemony of the master, there is not space for the legitimate expression for such a human form. The desire for an authentic place for the expression of this reality is the source of the revolutionary tendencies in these

> religions. But on the level of human consciousness religions of the oppressed create in another manner. The hegemony of the oppressors is understood as a myth—myth in two major senses, as true and as fictive. It is true as a structure with which one must deal in a day-by-day manner if one is to persevere, but it is fictive as far as an ontological significance is concerned. (Long 1976:411-2)

Even as African cosmological orientations and hybrid Black American religious developments continue to influence the meanings and interpretations that become important for Black American Christian communities, Black theology and the Black Church provide structure and ideological context for both meaningful individual and collective action. The fluidity of the sacred and the secular allows for the expression of various dimensions of Black life within religious practice, creating relevant meanings for daily practice. Religious meanings and spiritual community therefore influence individual choices in managing uncertainty on a daily basis, including the uncertainty and change brought about by chronic illness.

Womanist Epistemologies and Identity Formation

In exploring the meaning-making of religious Black American women, it is relevant to discuss the forces that play a role in determining their social location, and to explore the knowledge they generate individually and collectively in order to navigate their circumstances. This includes an examination of the realities Black women face in

American society at large, within their communities, and within their families and personal relationships.

The discussion will be primarily framed by the theories of Patricia Hill Collins and Michel Foucault regarding power and epistemology. Foucault examines relationships between power and knowledge, explicating the way in which individual choices shape comprehensive systems. His theory regarding the creation of subject positions establishes a useful framework for the analysis of social expectations and individual decision-making processes.

Sociologist Patricia Hill Collins focuses specifically on the collective knowledge and experiences of Black women in her discussion of power. Her scholarship describes the consequences of mutually reinforcing systems of oppression, as well as the choices individual women make in responding to the social realities created by those systems. Collins' theories effectively describe the transformative potential of knowledge produced from marginalized social positions.

This study engages sociological, psychological, theological, and feminist literature to describe Black women's formal and informal roles within their churches and communities. This includes a discussion of the daily work to organize and support community members and institutions, the development of women's organizations in the Church, and the elaboration of Black womanist theology. The literature reviewed here connects Black women's spiritual beliefs and practices to their personal, social, and political actions in the context of community. It is concerned with the conditions that shape Black women's choices for agency and self-actualization, as well as the systems of knowledge and meaning that have been produced from collective and individual experience within a shared social location. The discussion will explore the processes by which Black American women interpret and respond to complicated social realities.

Although the nature and effects of oppression vary for individuals within the group, Black women in the U.S. face similar obstacles and unjust limitations on their citizenship. Processes of marginalization including racism, sexism and classism are mutually reinforcing in the life of each woman, mediated by social context and individual circumstance. Kimberle Crenshaw's (1989) concept of intersectionality, elaborated upon within feminist literature and critical race theory scholarship, describes how various forms of oppression are mutually influential in ways that compound the effects of each. Rather than reducing Black women's experiences to the sum of racial experience and gender experience, the concept of intersectionality accounts for the ways in which race and gender shape Black women's social reality simultaneously and hold diverse meanings dependent on context (Collins 2000:206).

In her book *Black Feminist Thought* (2000), Patricia Hill Collins describes interdependent systems of social hierarchy as a matrix of oppression. This matrix structures similar social circumstances among Black women as a group, although Collins recognizes the heterogeneity of the experiences of individual Black women and the diversity of choices they make in negotiating their circumstances. She notes the difficulty of theorizing about intersectionality, precisely because of the wide range of ways in which multiple oppressions are experienced and interpreted within the group.

Within this diversity of experiential knowledge, however, the shared social location of Black American women facilitates the production of collective knowledge and the communication of strategies for resistance and survival (Collins 2000). Collins recognizes traditions of resistance and self-definition as being characteristic of Black women's responses to oppression throughout American history.

Black American women occupy a unique location within the social hierarchies of race and gender. In *Fighting Words* (1998), Collins observes that race and gender operate very differently as organizing principles in society. While racial groups generally occupy separate social spaces, gender functions within racial groups. Women experience the consequences of sexism in their personal relationships and in organizational settings of every kind, including places of employment, religious centers, and social movements. The knowledge produced from these experiences of gender inequality informs a collective awareness of the form and functions of patriarchy. This awareness informs the strategies engaged by individual women as they navigate structural constraints and negotiate social relationships (Collins 1998).

In addition to an awareness of gender inequality in their own communities, Black women have historically maintained intimate familiarity with dominant systems of Eurocentric knowledge. Collins attributes a large part of this awareness to the fact that the work available to Black women has so often been domestic work—labor in the homes of wealthier, white families. Despite her observation that racial groups occupy separate social spaces, Collins asserts that generations of Black women have been exposed to the private activities of white homes. As a result, Black women have become familiar with white cultural systems of knowledge in addition to their own. Collins refers to this as "boundary crossing," and contends that it facilitates a broader and more comprehensive social perspective (2000:10). \

Although Black women are frequently aware of the dominating practices that construct racial and gender hierarchy, they have maintained alternative systems of interpretation rooted in cultural and personal experience. Familiarity with multiple systems of knowledge facilitates Black women's ability to recognize contradictions within the logic of oppression and confront epistemological violence. Collins suggests that due to its hybrid nature, the knowledge produced by Black women has a unique potential to foster critical analyses of power and transform the society in which it is both produced and silenced.

Although there exist significant tensions, Collins' work aligns in many ways with Michel Foucault's theories regarding power. Foucault defines power as a multiplicity of force relations that characterizes all social interaction. Power is attributable neither to structure nor institutions. Rather, it is "the name that one attributes to a complex strategical situation in a particular society" (Foucault 1990). According to Foucault, individuals engage various strategies as they navigate their social situations. Individual strategies for negotiating power have the potential to reinforce the effects produced by other individual strategies, forming comprehensive systems with widespread effects (Foucault 1990). Although the effects of these systems are unstable, each force relation reinforces certain hegemonic norms. It is this characteristic of power that can facilitate major dominating systems, maintained by the mutually supportive effects of various force relations (Foucault 1990).

Foucault asserts that power and knowledge are joined within discourse, which he defines as "practices that systematically form the objects of which they speak" (1972:49).

Discourse refers to the socially privileged theories of respected thinkers and philosophers, as well as the less formulated thoughts, impressions, and general interpretations of everyday people. It consists of the ideas, concepts, myths, shared attitudes, cultural systems and ideologies—systems of ideas—that define the social landscape. Discourse is constituted by language and symbolic exchange. Language itself is governed by rules, conventions, assumptions and expectations of which participants may or may not be conscious. Patterns emerge in the content and form of language, and individual participation in discourse supports the effects of individual choices made by other people (Foucault 1972).

Knowledge itself is organized through the discursive structures and associations that characterize language. Discourse unites chains of associations that produce meaningful understanding, shaping individual perceptions and behaviors. Objects of knowledge and accepted “truths” are defined and produced by multiple, competing discourses. In this way, the social reality is constructed through discursive elements, which structure all social spaces, situations, and interactions (Foucault 1972).

Foucault’s definition of discourse depends upon his understanding of power as diffuse, rather than being exercised exclusively by those groups and individuals at the top of the social hierarchy. He warns that there is not a single, dominating discourse, but rather a diversity of discursive elements in which individuals may participate. Foucault writes:

> We must not imagine a world of discourse divided between accepted discourse and excluded discourse, or between the

> dominant discourse and the dominated one, but as a multiplicity of discursive elements that can come into play in various strategies. (1990:100)

Accordingly, individuals are involved in the articulation of power through their participation in the discursive formations that produce knowledge (Foucault and Gordon 1980). Foucault asserts that it is impossible to communicate meaningfully outside of discourse; therefore, individuals are both subjects of and subjected to discourse.

In shaping the social reality, discourse structures social positions—characterized by roles and expectations—that may be occupied by various individuals. The way in which an individual participates in discourse depends upon his or her position in society (Foucault and Gordon 1980). Discourses maintain hierarchy and exclusive privileges; certain claims receive more discursive support, and authority is required to access specific modes of discourse. Individual strategies for navigating subject positions both reproduce and resist the discursive elements that define social location and identity. As Foucault states in his description, resistance is generated wherever power is exercised. He defines to discourse in the following way:

> …both an instrument and an effect of power, but also a hindrance, a stumbling block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines and exposes it, renders it fragile and makes it possible to thwart…(Foucault 1990:101)

According to Foucault, discourse actualizes the effects of power and is also responsible for the social construction and political organization of resistance. He describes resistance as being generated by the exercise of power (Foucault 1990). Although it recognizes transformations in discursive elements over time, Foucault's conceptualization of power has been critiqued for limiting the possibilities of resistance.

One way in which theorists have sought to more fully account for resistance is by expanding the definition of subjectivity to include internal reflective processes and human agency. Stuart Hall (1996) describes the relationship between discourse and subjectivity as mutually influential. The externally produced roles and representations of discourse make subjectivity possible. Individuals engage a "personal, reflective intrapsychic structure" as they struggle with the inaccuracies of discursive representation (Hall 1996). In this conceptualization, the subject chooses to identify with the "positions to which they are summoned" in part, in full, or not at all (Hall 1996:14). Identity is therefore constructed at the complicated intersection of these external and internal processes. The choices that individuals make as they negotiate the roles and expectations of their subject positions reinforce discursive elements of both power and resistance. The expanded definition of subjectivity and personal identity accounts for the possibility of marginalized groups and individuals confronting dominant structures of representation with alternative knowledge.

Patricia Hill Collins focuses specifically on the transformative potential of knowledge produced in social locations that are misrepresented or unrepresented in existing discourses. The experiential knowledge of Black women consistently contradicts dominant representations, despite the fact that the truths of their social experience may receive very little dominant discursive support (Collins 2000). The conscious and strategic ways in which Black women choose to represent their social realities produce and affirm alternative systems of meaning relevant to their lives. Collins' theories therefore account more fully for the intentional deployment and resistance of discursive elements by individuals, and for the creation of alternatives for self-representation.

Although the subject positions of Black women have been largely structured by dominant discourses that maintain racial and gender hierarchy, Black women themselves have defined and embodied their identities according to their own knowledge and experience. The collective traditions in which Black women participate often communicate explicit strategies for negotiating power structures, informed by Black American cultural priorities and the experiences of generations of women (Collins 2000, Harding 2000). Black women's systems of knowledge production support their participation in discourses that construct them as subjects of their own history. These systems have the potential to create transformational meanings within collective experience. By rendering visible the common features of individual lives, alternative knowledge production creates new possibilities for subjectivity in the social and political imagination of Black women. Collins refers generally to this body of shared cultural knowledge as Black feminist thought (2000).

Collins' scholarship is committed to the alternative tradition of Black feminist knowledge. She quotes Maria Stuart's advice to Black women: "Turn your attention to knowledge and improvement; for knowledge is power" (Collins 2000:2). Knowledge production is a central concern of Collins' project in *Black Feminist Thought*. She observes that Black women's intellectual history has not been well documented, and that scholars have only begun to reference the tradition of Black feminist thought in recent years (Collins 2000:3).

Existing beyond written texts, Black women's intellectual history is different in form and purpose than the histories of dominant traditions. Perhaps most significantly, Black women's knowledge has maintained a central awareness of the cruelties and contradictions of power. As a result, it produces discursive elements that support a logic of resistance in multiple social arenas. Collins asserts the transformative potential of Black feminist epistemology is attributable to this fundamental orientation (2000).

Collins identifies four characteristics of the positivist approach to knowledge that has guided the Eurocentric dominant culture in the West (2000). These characteristics include: the prioritization of objectivity, the absence of personal emotion, the absence of personal ethics or values, and progression through cumulation and adversarial debate. In contradistinction to these qualities, Collins describes the characteristics of epistemologies (such as Black feminist epistemology) that confront the status quo (2000). First, alternative epistemologies are founded in lived experience. Rather than prioritize a lack of bias, alternative systems assume that a personal connection to a given issue facilitates the informed selection of topics and methodologies for research (Collins 2000:258). Second, Collins' alternative epistemology progresses through dialog rather than debate. Knowledge emerges through discussion and shared information, not through competition. Third, alternative epistemologies are centered on an ethic of caring. Emotion is understood as a factor that contributes to intellectual exploration, rather than detracting from it. Fourth, Black feminist thought and other alternative epistemologies must maintain moral and ethical accountability. This includes the acknowledgement of personal biases and insights (Collins 2000).

Because Black feminist knowledge is produced primarily from personal experiences, it is characterized by an awareness of the diversity that exists among Black women as a group facing shared realities. There is an ongoing dialog between individual and group knowledge, in which personal experiences contribute to the general consciousness. Collins observes that although it is impossible to generalize the experiences of all Black women into a single perspective, “a Black *women's* collective standpoint does exist, one characterized by the tensions that accrue to different responses to common challenges” (2000:28). Both personal and collective systems of knowledge shape the decisions of individual women as they navigate hierarchy and social expectations.

Roles and Representations of Black Femininity

The representations and corresponding expectations that receive discursive support in dominant rhetoric are also reproduced in Black women’s homes and communities. Black communities have created their own public sphere and supporting institutions, widely necessitated by their historical exclusion from public debate. Despite the history of awareness of and resistance to racial oppression that is central to many Black organizations, women have had to navigate the effects of racialized sexism and confront the gender hierarchy that characterizes Black communities and institutions of every kind (Grant 1989, Collins 2000, Gilkes 2001, Frederick 2003, Collier-Thomas

2010). Collins identifies family, church, and Black civic organizations as “complex sites where dominant ideologies are simultaneously resisted and reproduced” (2000:86).

Black women’s femininity is defined largely in opposition to norms of Black masculinity. Gender is constructed as an oppositional, hierarchal binary in which masculinity depends upon the domination of women. In behaviors that can be understood as “microlevel power practices,” the performance of masculine gender in formal, casual, and intimate environments contributes to the reproduction of gender hierarchy (Pyke 1996). Discursive formations construct idealized masculinities and attribute them with power and authority. In order to be identified as men, individuals must negotiate the specific expectations of a dominant identity. Although masculinity is constructed and interpreted as inherently superior to femininity, there also exist hierarchies among masculine identities. “Masculinities are configurations of social practices produced not only in relation to femininities but also in relation to one another” (Pyke 1996:531). Certain demonstrations of masculinity are more privileged, and the behaviors and beliefs required to perform these masculinities are most accessible to individuals in positions of social power (Messerschmidt 1993:94).

Despite a widespread acknowledgement of gender inequality, many Black feminist scholars have traditionally been hesitant to offer public critiques of gender dynamics in Black family life. Black families have consistently been pathologized in dominant rhetoric and public policy, and feminist scholars have feared that honest critiques of patriarchy in Black family life could be de-contextualized and interpreted as supportive of racist ideology (Collins 2000). A major consequence of the discursive silence surrounding the lived experiences of Black women is the profound absence of supports—social, pscyho-emotional, and medical—available to women as they confront marginalization in their intimate communities (Colman 2008, Collier-Thomas 2010).

Although formal scholarship has not consistently focused on gender inequality in Black families, Black women themselves have shared collective knowledge and communicated strategies for negotiating power dynamics to their daughters and granddaughters (Collins 2000, Harding and Harding 2006, Harrison 2009). The systems of knowledge produced and communicated across generations of Black women play a significant role in informing the way individuals interpret and respond to power inequalities.

Recent Black feminist scholarship has explicitly addressed the ways in which specific norms of masculinity among Black men shape expectations for the social roles of Black women (Collins 2000, Barker 2005, Wingfield 2008, Beauboeuf-Lafontant 2009, hooks 2004). The positions assigned to women in their families and within Black civil society contribute to the reproduction of gender hierarchy through their implicit support of masculine roles. There are consistent social and structural incentives to prioritize the needs of others, even at the expense of self-care. Black women's physical, social, and psycho-emotional needs are rarely considered or addressed in the social obligations assigned to them.

These roles and associated expectations are defined and enforced through a wide variety of representations that receive dominant discursive support. Black feminist thought has identified several images of Black women that are widely deployed in all forms of cultural media. Prominent among these are five images of the Black woman: the overbearing matriarch, the invulnerable superwoman, the obsequious mammy, the lazy welfare queen, and the hypersexual jezebel. These dominant representations, discussed here, support ideological mandates for the behavior of Black women through implicit moral judgments (Collins 2000).

One of the major projects of Black feminist thought has been to challenge these representations, which Collins refers to as “controlling images” (2000:69). Controlling images have roots in the first descriptions of racial difference among Europeans during colonial expansion. In the travel writings of some of the first European explorers in Africa, accounts of women’s nudity and sexuality were used to support ideas of African savagery (Morgan 1997). Pathologized descriptions of Black women’s bodies and behaviors facilitated the development of theories about the women themselves that were used to rationalize the exercise of colonial power. The representations of Black women that developed in the imperialist exploration of Africa laid the groundwork for more recent controlling images (Collins 2000, Morgan 1997).

Shirley A. Hill (2009) describes the eventual transformation of the controlling image of the “matriarch” image into the more acceptable trope of the strong Black woman:

> The Black matriarch concept became the most politically contentious issue in the study of African American families during the civil rights era, and it was gradually replaced with a cultural strength perspective on Black families. As the heads of many of these families, Black women were also redefined as strong and capable. (Hill 2009:738)

“Strength” in this context has been defined as self-reliance, resourcefulness, and independence (King 1988, Collins 2000, Hill 2009). The image of the “Strong Black Woman” pressures women to meet the needs of their families and communities without acknowledging distress or seeking support. The expectation that Black women demonstrate this conceptualization of strength often requires that they regulate their emotional responses to avoid showing signs of vulnerability or depression (Beauboeuf-Lafontant 2003, Woods-Giscombe 2010, Harris-Perry 2011). This expectation normalizes experiences of high stress for Black women with the assumption that they have an abnormally high tolerance for hardship, and women who acknowledge difficulty and seek support are represented negatively as weak.

In focus group sessions with Black American women, Cheryl Woods-Giscombé (2010) found this role and corresponding expectations to be influential in shaping experiences of stress and coping. Woods-Giscombé developed what she refers to as the Superwoman Schema (SWS), a conceptual framework for understanding changes in the role dependent on context and its potential benefits and limitations (2010). She asserts that the mandate for constant strength as interpreted and defined by Black women could be supportive of their efforts to protect themselves and their families, but could also precipitate further stress, harmful strains on relationships, and negative stress-related health behaviors. Indeed, despite the fact that Black American women are more likely than women of other races to feel depressed and experience chronic stress, the mandate that they exhibit strength often fosters silence and social isolation among individual Black women (Gibbs and Fuery 1994, Wyatt 2008, Hill 2009). Although often evoked as a positive representation, the image of the Superwoman has serious consequences for the social and emotional well-being of Black women.

Definitions of Black femininity have consistently required that women work to meet the needs of their family members and social networks without support or recognition (Hull, Scott and Smith 1982, Collins 2000, Frederick 2003, Hill 2009). Black institutions and community organizations have historically been dominated by male leadership, and controlling images of Black women have been used to justify their exclusion from positions of authority. Despite the lack of formal recognition, Black women have been responsible for much of the work involved in organizing and mobilizing Black social and political movements (Gilkes 2001, Collier-Thomas 2010).

Black churches have historically been a key site at which much of this organizing work occurred. Despite their systemic exclusion from formally powerful positions within the institutional hierarchy of Black churches, Black women have often occupied social positions in their religious communities from which they could do foundational work to organize religious networks for political movements.

> Black women take seriously their own issues and problems, and they also pay special attention to the problems of black men in their conferences, national organizations, writings, and every day lives… Ironically, the concern that black women evince for the emergencies facing black men—criminalization, joblessness, poverty, hyperghettoization, and social isolation—is not reciprocated by a similar concern for black women by the male leadership of black churches. The perception that black women have survived and

> succeeded obscured the realities of poverty, welfare, social isolation, joblessness, and single parenting that create unparalleled stress in black women's lives. (Gilkes in Harris-Perry 2011:237)

The Black church is one of many civic institutions characterized by gender hierarchy. Despite the fact that women constitute the bulk of the membership of Black churches, there is a history of struggle over women's roles within the church (Dodson and Gilkes 1986, Grant 1989, Collins 2000, Frederick 2003). Women in the church have been assigned roles with significant responsibility yet limited authority, working as ushers, choir members, Sunday school instructors, Bible study facilitators, and active participants in church groups and missionary societies (Frederick 2003, Collier-Thomas 2010). Even as they have done the work necessary to support the activities of their religious communities, they have consistently been excluded from formal church leadership. In 1893, author and activist Gertrude Bustill Mossell declared, "The usual plan is for the women to do the work and the men largely [get] the credit" (in Collier-Thomas 2010:124).

In addition to the limits on their formal authority, religious Black women have faced moral judgment and specific expectations for their behavior within their religious communities. The concept of "respectability" in Black Christian contexts has served to enforce social and sexual norms for women (Frederick 2003). These behavioral mandates are enforced by friends, family, and the circumstances structured by dominant society. According to Melissa Harris-Perry:

> To uncover the complex process by which black women of faith engage in a search for recognition, we must acknowledge that black American Christianity contains both oppressive and liberating aspects for black women, whose faith expressions are constrained by the structures of white supremacy and patriarchy. Black Christianity has resisted racial domination, but it has perpetuated sexism and gender inequality. (Harris-Perry 2011: 231)

In confronting the oppressive aspects of Black Christianity, women have worked to organize their communities, engage in active spiritual practice, and develop formal theologies that accurately reflect Black women's experiences and creative strategies for survival. Black women's religious activities have historically addressed multiple forms of oppression, developing traditions of politicized spiritual work and womanist theology.

Social activism has remained central to Black women's understanding of their Christianity (Collier-Thomas 2010). Although they were still systematically excluded from positions of authority, the late 1800s saw significant expansions in women's roles in Black churches across denominations. Women's social and political commitments were increasingly formalized in the development of women's missionary societies and the founding of gender-specific religious organizations (Collier-Thomas 2010).

Women's missionary societies have historically focused on issues of both race and gender, organizing programs to support the well-being of Black communities within the U.S. and abroad. Working within these organizations, women developed organizational skills, systems for cooperation, and learned to identify and value their skills and abilities. Collier-Thomas asserts: "The women's missionary societies and conventions unwittingly laid the groundwork for a national Black feminist awareness" **(2010:120).** Although women's missionary societies exist within the church and are subject to the authority of male leadership, they managed to organize women around shared beliefs in ways that became meaningful beyond religious contexts. In 1947, editor of the Christian Methodist Episcopal *Christian Index* Rev. E.P. Murchison wrote:

> In some denominations...the women's missionary society became so strong that there were tendencies to compete with the main church organization, to reject authority of the Church, and act separately on certain matters. This tendency has not been completely absent from all women's missionary societies. It was in reality a revolt against the dominance and discrimination practiced by men in the church. (in Collier-Thomas 2010:122).

Murchison went on to describe women's religious organizations as a "woman's church within the church," the existence of which male leadership frequently interpreted as threatening to their power (Collier-Thomas 2010).

Women's groups developed differently within each denomination: for example, the leadership of women's organizations within the African Methodist Episcopal (AME), AME Zion, and Christian Methodist Episcopal (CME) denominations was generally composed of wives of the clergy. As a result, these organizations were structured in ways that supported their compliance with church authority, and often did not seek to operate autonomously as often as groups within other denominations that had more diverse participation and leadership. Other organizations, however, specifically addressed repressive norms for women's roles in religious contexts. These organizations drew a direct connection between their spiritual practice and their political work, within and beyond their own communities. Women frequently organized within their religious communities in ways that confronted oppressive social expectations.

In the pursuit of "respectability" in a society that deemed black women hyper-sexual jezebels or asexual matriarchs, the Black Women's Club Movement of the early 1900s interjected key dialogue about marriage and sexuality which at the time served to redeem black womanhood from derogatory white social commentary. These issues, though seemingly private, weigh heavily in any discussion of black women's experience in a race- and gender-conscious United States. This more personal dynamic of women's lives is crucial in a holistic evaluation of faith. How does one's faith influence one's activism from without as well as one's activism from within? (Frederick 2003:13)

Marla F. Frederick (2003) recognizes the ways in which Black women engage and expand the meaning of their faith on a daily basis, primarily through their relationships to other people. She contends that "women's level of activity in the larger public is contingent upon their ability to channel righteous discontent with the prevailing social order into a viable, responsive alternative public sphere…Their spirituality leads them to view their lives as ongoing commitments to the lives of those in their community" (Frederick 2003:26).

Frederick defines spirituality as a personal and experiential process, distinguishing it from religiosity, the participation in religious structures and repetitive ritual practices (2003:14). She encourages scholarship on the work that is produced in the context of faith, rather than perspectives that reduce faith to a coping strategy without productive potential. She focuses on the rich history of Black women's daily engagement with spirituality in church settings and in their personal lives.

The presence of women reflects at some points their acceptance of male-centered theologies of female subordination, as well as their larger commitments to the community in which the church resides and their social relationships within the church. Most important, however, their commitment reflects a level of faith that encourages a desire to be a part of what they consider God's work wherever and however it is taking place. Often this work takes place within the church; even more frequently, however, it takes place in everyday situations outside of the church. Women's expressions of faith reflect what I refer to as their spirituality—their understanding of God and God's work in their day-to-day lives. Spirituality in discernible ways embodies both the personal and public areas of life (Frederick 2003:4).

Black women's self-motivated leadership in their churches and communities—through social programs, missionary work, religious education and organization, and the occupation of significant but unrecognized supportive roles in the church itself—has afforded them informal authority in their own communities (Collins 2000, Frederick 2003, Collier-Thomas 2010). Religious Black women who are involved in their religious communities operate from positions of influence, whether or not this power is acknowledged or affirmed by their religious institutions. The fact that they do much of the work to support and organize their communities places Black women in the unique position of being able to offer guidance and support that is rooted in cultural wisdom and collective experience.

Womanist theological scholars have worked to represent the experiential wisdom of Black women in their interpretations of Christian religious meanings. The ways women are silenced in the Black Church are echoed within the history of Black theological scholarship. Liberation theology formalized culturally-relevant interpretations of Biblical text and explicated the belief that God would recognize Black humanity even in the context of its denial by American social and political ideologies. Despite its agenda of social justice, liberation theology neglected any meaningful gender analysis, and perpetuated many patriarchal religious interpretations (Grant 1993). Black feminist theologians have addressed this marginalization with the creation and elaboration of Black womanist theology.

Womanist theology is directly informed by the spiritual work and political action of Black women. One of the first scholars to use the term “womanist theology,” Delores S. Williams (1993) references Alice Walker’s concept of womanism as a specific form of Black feminist thought and action. Williams identifies four key characteristics of a womanist theology, including: multidialogical intent, liturgical intent, didactic intent, and womanist theological language (1993). Multidialogical intent requires dialogue and action concerned with quality of life for oppressed peoples within diverse communities. The liturgical intent of womanist theology directs the ideologies, worship, and action of the Black church to consciously impact the liturgy with principles of justice. Didactic intent refers to the teaching function of theology, centered on Black folk wisdom in general, and Black women's moral wisdom. Finally, Williams asserts that the language of womanist theology should serve as a force of change within social and theological thought, introducing knowledge centered on Black women's history, culture, and religious experiences.

For many women invested in Black religious communities, "faith in God navigates how individuals respond to almost all life's circumstances" (Frederick 2003:3). The systems of interpretation that inform Black women's acts of faith often rely upon experiential and shared knowledge outside of the theological paradigms of the church leadership. Black women have fostered alternative interpretations of Christian cosmology and text, and have continued traditions of spiritual expression over generations.

Mother and daughter scholars Rosmarie Freeney Harding and Rachel Elizabeth Harding discuss the ways they were taught to enact their spirituality, and identify the roots of these traditions in African and Black American experience (Harding and Harding 2006). Adults in the family demonstrated hospitality to all guests, communicating the value of respecting others and withholding judgment. Meaningful ghost stories served to acknowledge of the presence of spirits and establish boundaries for relating to them. Dreams and sight alerted children to the many ways of accessing collective knowledge and communicating with the spirit realm. Practices around death and dying prepared young generations to be spiritual companions for people facing death. A focus on healing and transformation taught family members to recognize opportunities to channel healing potential and engage healing practices. Secrecy and discretion established protocol for the treatment of traumatic memory, and in other instances, communicated the intimate connections of human beings to the life-force. Finally, the Hardings identify "Mariah's legacy" as an orientation of openness to the various ways of experiencing and participating in God's witness (Harding and Harding 2006). All of these perspectives of Black womanist enactments of faith connect the collective experience of hardship to the production of culturally-specific knowledge and the work towards liberation that it inspires.

The combination of formal and informal Black womanist knowledge shapes the personal cosmologies of individual Black women. Psychologist Jacqueline S. Mattis (2002) describes the significant role of religious and spiritual orientations in individual processes of interpretation and meaning. Religious Black women engage the world through their faith, creating new ways of understanding and being in the world (Mattis 2002). Through narrative examples collected in qualitative interviews with religious Black women, Mattis concludes that religion and spirituality are not crutches for women in times of hardship, but rather are utilized as a means of understanding, engaging, and transforming the meaning of their circumstances:

> First, contrary to traditional social scientific perspectives that posit that individuals use religion and spirituality exclusively as sources of emotional comfort or to shield themselves from the realities of their circumstances, the participants in this study suggested that religion/spirituality help them to confront and accept reality.

> Religion and spirituality are described by these women as analytic devices that promote rational and critical thought. The clarifying and analytic functions of religiosity/spirituality should inspire researchers and practitioners to explore more fully the ways in which Black women use religious and spiritual ideologies to formulate or challenge particular ideas about their experiences and the worlds in which they live. (Mattis 2002: 317)

Referencing Collins' work on Black feminist ways of knowing, Mattis connects the process of meaning-making to cultural epistemology. Religious Black women's processes of interpreting and responding to the circumstances of their lives are shaped by a history of womanist knowledge and religious meanings. The form and content of Black women's communication with one another, in material and symbolic contexts, provides a system of meaning rooted in the collective experience and historical memory of Black women in America.

In times of hardship and in the experience of chronic illness, individual Black women access shared cultural and religious systems of meaning in order to interpret and respond to changing circumstances. The way in which individual women construct their own identity and manage social relationships is directly influenced by Black women's history and strategies for survival. Although the political and religious institutions in which they participate have not always recognized or addressed the specific social realities of Black women, they have provided structure and context for the communication of affirming ideologies. For religious Black women with chronic diagnoses, daily spiritual practice and religious participation shape the illness experience in fundamental ways.

Descriptions of Coping Among Black American Women

Within sociological and psychological scholarship, the concept of coping establishes a framework for understanding conscious behavioral responses to stress. Descriptions of coping within the literature focus on the decision-making processes that inform the way individuals attempt to minimize the negative impact of current and future stressors in their lives. Coping is understood to play a significant role in the relationship between stress and health. The more effective a person's coping mechanisms, the less negative impact a stressor will have on their lives. There now exists a wide range of research dedicated to measuring and determining the impact of certain coping behaviors and the factors that shape them.

In psychological studies, coping behaviors are widely categorized according to the aspect of experience they address. Behaviors that directly address the stressor are considered problem-focused coping, while managing the emotional impact of the stress is emotion-focused coping. The ways an individual reconfigures meanings of the situation to cope are categorized as meaning-focused coping, and seeking support from other people is considered social coping. While these categories guide certain levels of analysis, they overlap and interact in the lives of individuals and in the literature that describes them. Qualitative descriptions of coping have revealed the interpretations that guide individual actions in response to stress, and the meaning systems that inform those interpretations. People simultaneously engage a range of coping mechanisms to respond to both internal and external pressures. The meanings that are important to an individual will influence the focus and intention of the responses they enact, although a combination of factors will determine the effectiveness of those responses.

Several research tools have been developed to measure and describe individual coping mechanisms (Kato 2015). These measures support the identification of coping styles, which are patterns of individual behavior that remain consistent over time. An individual's coping style often changes over the course of their life, as the result of personal experience and changing systems of belief. Realizing this, researchers have come to value assessments of flexibility and adaptation in any discussion of coping behavior over time (Heffer 2017).

When faced with prolonged or ongoing stress and uncertainty, an individual must make a series of decisions regarding how to respond. Taken together, these decisions may constitute a strategy — particularly when they are guided by a specific set of meanings, interpretations, and objectives. Individual coping strategies are developed within multiple social contexts, according to multiple systems of meaning and varied personal interpretations. By understanding the context of an individual's decision-making, we can explore dynamic coping strategies and their relationship to changing personal priorities and circumstances.

This project contributes to existing descriptions of coping through an investigation into the specific ways in which religious Black American women engage shared and personal meanings, construct interpretations, and make decisions in their experiences with chronic illness. Through an analysis of participant narratives, static definitions of coping are elaborated to recognize it as a nuanced and potentially strategic process of interpretation and response.

As a result of the prevalence of documented stressors in Black women's lives created by systemic racial and gender inequality, there also exists a range of correlated investigations of Black women's coping responses. These studies have expanded ideas of coping to include concepts specific to the experiences of Black women and femmes. Although not specific to the experience of chronic illness, these concepts are useful reference points for the analysis presented here, as they offer insight into the social incentives that influence the options and choices available to Black women.

Within the disciplines of sociology and social psychology, the concept of the "Strong Black Woman (SBW)" or "Superwoman Schema (SWS)" has been developed by Black womanist scholars as a way to describe how ideological mandates impact the lives and coping decisions of Black women (Woods-Giscombe 2010, Liao et. al. 2014). The Strong Black Woman trope is sustained at the intersection of racial and gendered expectations for Black women' social behavior and emotional self-regulation. Qualitative studies of Black women's coping strategies have consistently identified the Strong Black Woman role to be characterized by the priorities of personal strength and caregiving (Beauboeuf-Lafontant 2009, Romero 2000, Woods-Giscombe 2010). Black women often report internalized definitions of strength as a positive value that require them to suppress certain emotions perceived as negative, such as feelings of anger, sadness, and overwhelm. These "negative" emotions are considered to be markers of fragility, deemed inappropriate for Black women and reserved exclusively for attribution to white femininity. The Superwoman Schema also encourages Black women to prioritize the needs of other people over their own. The ethic of caregiving ascribed to Black women calls for self-sacrifice in the service of social roles including (but not limited to) motherhood, marriage, religious participation, and social citizenship. In studies of coping among Black American women, managing social expectations and obligations to other people are consistent themes in the way individual women describe their priorities in navigating stress and hardship.

The trope of the Strong Black Woman is based in constructions of Black womanhood that have historically been developed to justify the physical and emotional exploitation of Black women. It has become a prescription for an idealized behavior through correlated emotion rules, constantly reinforced within and beyond Black families and communities. Black women are consistently told they are inherently able to manage more stress than other people ("you can handle it"), told to avoid becoming or being perceived as the "angry Black woman," and told to push through pain and depression with little or no acknowledgment, let alone support. While many of the community members who offer rule reminders have the positive intention of encouraging the person managing stress, both qualitative and quantitative studies have demonstrated that its internalization consistently leads Black women to seek and receive less support from other people than they may need during their experiences of adversity, and often leads to negative mental health outcomes.

> "Strong Black Woman" is a mantra for so much a part of U.S. culture that it is seldom realized how great a toll it has taken on the

> emotional well-being of the African American woman. As much as it may give her the illusion of control, it keeps her from identifying what she needs and reaching out for help. (Romero 2000:225)

The trope of the Strong Black Woman functions as an emotion rule alongside several other dominant prescriptions for the choices and behavior of Black women, all constructed at the intersection of racial and gender oppression. In general, understanding how these controlling images support hierarchy provides important context for an exploration of Black women's meaning-making in coping. However, as noted by Dr. Jacqueline Mattis (2002), many qualitative descriptions of Black women's coping strategies focus almost exclusively on the oppressive forces in their lives, with little discussion of their agency in decision-making and strategy. Although the SBW trope was a consistent theme in the participant narratives of this study, participants had different ways to engage and transform the meanings of "strength" within their interpretations of illness and its consequences in their lives.

Another consistent theme in the scholarship on Black women's coping experiences is the influence of religion and spirituality on the way they make meaning of their circumstances. Explorations of religiosity are prevalent in research that describes coping among Black Americans in general, in both individual and collective meaning-making. Womanist scholars, activists, and educators have worked to recognize and uplift the foundational and ongoing contributions of women in Black churches. Patriarchal hierarchy in Black Christianity (and in Christianity worldwide) has been well-documented. Not only have women been officially excluded from formal leadership roles in most denominations, but the content of Christian religious education has widely been explicitly patriarchal. In Black churches, which have been central sites for political organization and community mobilization, Black women have done a significant amount of the labor to maintain the church and engage the community while being consistently excluded from formal authority.

Although Christian communities are often characterized by patriarchal structure and ideologies, shared religious spaces and spiritual community can also offer sites of healing and self-recognition within Black civic life. Black Christianity developed in contexts of traumatic racial oppression, where such spaces have been especially necessary. Shared religious beliefs and practices among Black Americans have developed in ways that directly address this collective need for healing spaces, affirm the humanity of Black people, and communicate generational wisdom (Long 1971, Harding 2005).

For generations, Black women have navigated the patriarchy of the Church in order to access social and spiritual resources. In addition to maintaining traditions of self-determination within religious institutions through women's groups and prayer circles, Black women have re-interpreted Biblical texts and theological teachings to account for their own experiences. Qualitative research on Black women's coping strategies reveals the multitude of ways women engage religious and spiritual meanings to interpret and respond to difficult situations in their lives (Mattis 2002).

Many of the challenges described by participants are consistent with descriptions of chronic illness experience established within the sociology of chronic illness. How do religious and spiritual meanings influence changes in identity, including the experience of biographical disruption and the process of narrative reconstruction? How does membership in religious community impact changing social roles and expectations?

Religiosity and spirituality are not themselves reducible to coping strategies or responses to adversity. Rather, religion and personal spirituality are sources of shared meaning available to individuals in both stable and uncertain times. These meaning systems may inform the priorities and choices of religious women as they cope with the long-term stressor of chronic illness. The various ways in which participants in this project reference these shared meanings reflect a range of meaningful interpretative frameworks that are engaged in dynamic ways by individuals over time.

CHAPTER III

EMERGENT THEMES IN THE ILLNESS NARRATIVES OF RELIGIOUS BLACK AMERICAN WOMEN

“Narrative is radical, creating us at the very moment it is being created. ”

— Toni Morrison, *The Nobel Lecture In Literature* (1993)

There are a variety of factors that may influence the effectiveness of religious Black women’s coping strategies as they respond to the changes produced by chronic illness. The transitions described in this study are physical, social, and psycho-emotional, and women experience them simultaneously. Utilizing data from the narrative and phenomenological analysis of qualitative interviews with individual Black women, this project a) identifies common experiences within the participants’ diverse illness experiences; b) describes coping behaviors, styles, and strategies engaged by participants in response to these experiences; and c) explores the meanings that inform participants’ decision-making as they cope.

Several recurrent themes emerged in qualitative interviews with participants as major factors in the development of effective coping strategies in the experience of chronic illness. These descriptive themes anchor an analysis of the influence of religiosity and spirituality on the ways participants interpret and respond to physical, social, and pscyho-emotional changes in their lives. The themes include: 1) Access to social and material resources; 2) Religious community and spiritual practice; 3)

Biomedical diagnosis and treatment; 4) Social roles and relationships; and 5) Identity and self-image.

The range of ways these themes emerge within participant narratives reveals a complexity of response based on a combination of personal and shared meaning systems. The effectiveness of an individual's coping behavior or strategy is not reducible to a positive or negative outcome. Rather, each decision in response to the challenges created by chronic illness has multiple effects in the lives of participants. Religious and spiritual meanings play a large role in determining the priorities established by participants and the courses of action they choose in pursuing their coping goals. While some of the social and ideological impacts of religion described by participants may inhibit their ability to engage effective coping strategies, much of the narrative data reflects the myriad of ways in which religious Black women strategically resist, engage, and transform shared meanings to support their priorities in responding to chronic illness.

Access to Social and Material Resources

Given the extensive literature on the impact of social factors on health, it is not surprising that a majority of the women in this study referenced material resources for themselves and their families as one of their primary considerations in thinking about their health. Participants described how their ability or inability to access housing, food, sleep, and transportation for themselves and their families directly impacts every aspect of their lives. In the words of one participant, Jada: "When you're not dealing with stuff -

or when you're dealing with stuff but you're dealing on life's terms, you get sick, you wear down, your body wears down."

For those women who did not have consistent access to necessary resources, providing for themselves and their families dominated the majority of their time and energy in their daily lives. Participants described being unable to focus on other priorities in their lives, given the stress involved in seeking security while meeting their daily obligations and commitments.

Figure 3.1
Photograph taken by Jada

"I put that bag in there, because homelessness is all about carrying bags. But meeting your responsibilities at the same time."

In the United States, a lack of material resources leaves an individual far more vulnerable to various forms of structural, social, and physical violence. The experience of navigating public resources – public housing, public transportation, public healthcare – requires more risky interactions than private resources. This is particularly true for Black women navigating intersectional power dynamics in American society. A clear majority of women in this study described surviving traumatic events, including physical and sexual assaults, institutionalization, the incarceration of partners and children, the loss of family members, and intimate emotional betrayals. Every participant described a sense of the effects of chronic stressors and traumatic events on their physical and mental health. In fact, four participants marked time by these stressful events. For example, when I asked about the timing of their diagnosis, Imani referenced the loss of her mother to determine the year of diagnosis: "I found out I had the virus, um, in 1994…Actually, yeah, this was before my mom died." An overriding theme in participant descriptions of life difficulties was the feeling that they had managed the material and emotional fallout from these events alone, with limited emotional support from other people. Participant narratives reveal that external stressors are compounded by a lack of emotional support.

A lack of access to basic social and material resources limits an individual's control over the circumstances of her own life – one of the key determinants of chronic stress. Often, participants described learning that they needed certain resources in order to obtain other resources. Jada said she needed a birth certificate (which she didn't have) in order to gain housing in a shelter, and another recounted needing housing and an address in order to access certain social services.In understanding the potential health impact of lack of access to basic resources, we must consider 1) the impact of not having the resource itself, 2) the emotional stress of being without, and 3) the stress of navigating access.

The physical and emotional energy required to navigate these layers of access makes it difficult for some participants to prioritize aspects of their own physical and mental health. Uncertain life circumstances can make it difficult to maintain healthy responses to stress, establish healthy habits and routines, and to address personal priorities in health. For one participant, Nina, the sudden loss of her daughter became the center of her choices, as she navigated her own grief and the grief of her family:

> *My eldest daughter was killed in a car accident in 2003. So I had a lot of anger built up around that, and didn't want to deal with it. It was very difficult to accept, and ask God why, because she had so much promise in life…Gradually I felt that I needed to get closer to God, maybe that was something that was the problem, but it was me. I think that me not being cynical about life – not having a purpose in life – I continued to have the structure for my children, but for me, I got away from doing things that I knew I shouldn't be. Like remembering the Sabbath day, to keep it holy; not partying all week long into Sunday, cursing a lot, going out drinking, when I would go out, drinking a lot, being drunk to the point that you can't stand up…And then I just felt that I needed to do better. I expected more for my children, even though they didn't see that.*

Even before any chronic illness diagnosis, a majority of the women interviewed described a journey of learning to prioritize their personal health in the midst of chronic stress. Every participant described having experienced depression or extended grief, usually in response to emotionally difficult life events. Rose describes the way grief triggered periods of depression for her:

> *Oh yeah, after the death of my husband—I lost two husbands. My last husband, he died in November, the 30th, of 2008. You know so I went through some bouts of depression, because of the grief period, and you know, with the first husband—not diagnosed, now, this was not diagnosed depression. But you know, the grief —the grief period.*

Sometimes major changes in emotional state were simply referred to as “bad days.” When the women interviewed in this study described depression, they usually referred to it as a period of time, something they pass through. There is a sense that depression and extended periods of sadness are a natural part of life. In the quote above, Rose references “diagnosed depression,” a medical condition, in contrast to a “grief period” in response to loss. The idea that there are naturally seasons of deep sadness after painful events was present across participant narratives, distinct from a description of diagnosable depression. Only two participants described seeking mental health support for mental health (not including substance dependency). Patricia described feeling that there is a resistance to therapy with Black communities:

> *So twice, you know I was like truly depressed. And you know, you know that something's not right, you know that you're sad, but you never say, I'm depressed. And you know, you kind of think, It'll pass, it'll pass. A lot of times we don't think that we need some help to make it pass. And you know, we as a people are not real fond of therapists. And hearing, somebody says that we need to talk to somebody, we get insulted. Or if we need some medicine to kind of level things off, I'm not crazy. No you're not crazy, but we have emotions. And you know, sometimes when you're in a situation, those emotions just go up and down and in and out and you need some help to kind of keep things level so you can think. So you can think.*

Religious Practice and Religious Community

Prior to medical diagnosis, participants made meanings of their experiences through personal meaning systems, into which are woven shared cultural and religious meanings. The women interviewed spoke about religion and spirituality in several meaningful ways.

It is notable that most participants described having chosen their religious practice as adults – even if they currently practice the religion within which they were raised. All participants were raised within various denominations of Black American Christianity. Those who had converted to new religious practices described a process of questioning or feeling uncomfortable with their childhood beliefs and seeking an alternative practice. Imani described being attracted to a peaceful practice of Buddhism:

> *I was born into the Baptist religion, coming from birth. Because in my family, my grandfather was a pastor and a reverend. My uncle—I had two uncles that one is pastor now, one was an usher. I mean, it's like I was born into it. But it really wasn't my type of — I really didn't like it. Because I used to get scared of the people when they get the Holy Ghost, and they get to jumping and hollering and…oh my God. And speaking in all these foreign tongues, and oh, God… It was scary seeing, that there is a true, true thing called the Holy Ghost really that takes over the body and everything like that, as far as that religion goes. And it was scary to me, but I would get the lesson, or my blessings, from the sermon that the pastor read, that the pastor spoke. It wasn't so much the singing, or anything like that, but it was like the Bible studies…because in Buddhism they don't have Bible study, so. We have, just [chanting]. It's real soothing. I feel calm. I feel like well within my soul, you know what I'm saying?*

Another participant, Dinah, described questioning her Christian belief system when her mother died: "What really happens when you die? Do you really have to burn in eternity, why would a good God do that?" Ultimately, she converted from Baptist Christianity to

Universalism. Four of the participants who still practiced Christianity as adults described having stopped attending church at some point in their lives for similar reasons – questioning their beliefs in the face of a major life event. Each of these women returned to a practice of Christianity later in life. In many cases, their return was motivated by a desire for the structure and community that religion provides, particularly for their children. Rose stopped attending church when she lost her daughter. "I was asking God why," she says. She eventually returned to the same religious community to find support for her other children in the emotional aftermath of the loss of their sister. Three other participants described converting from one denomination of Christianity to another in order to join their husbands' churches – two of them are married to pastors. In all of these cases, the women interviewed had chosen their current religious practice by determining what they valued about it as adults.

A recurring theme in discussions of religiosity centered on the idea of religious community. The concept of "community" included descriptions of people who share beliefs and practices, offer potential networks of support, and communicate expectations for behavior and emotion. Some participants explained that they valued simply being expected to show up for service. When they miss religious gatherings due to life difficulties or depression, someone from service would notice and call to check on them. Women in stable living situations often attended church multiple times a week, and several of them describe having special roles in the service. They described finding solace in participating in shared practices, and in regularly being around a group of people who share their religious beliefs. Several participants echoed Imani's sentiment that the most powerful parts of religious service were the music ministry and shared testimony:

> *At Glide, when I do Sunday services, I try to make it before, before [the pastor] does—before he even gets to the, to the welcoming of the congregation, yadda yadda yadda. I try to make it like when the choir sings the first song. I go there actually for the choir. You know, I get my…I get pumped just from the message and the songs that the choir sings. And they have beautiful, beautiful, beautiful voices. I love that choir.*

Testimony and witness emerged as important themes in discussions of religious community. Testimony and witness refer to the acts of sharing personal accounts of religious and spiritual experience. Testimony tends to focus on one's personal journey of faith, while witnessing can involve stories that describe how God and Spirit have moved in the life of the individual or people they know (usually intended for people outside of the religion). In Black Christian services, there is often a time designated in the service for these accounts to be shared with the congregation. Testimony provides an opportunity for churchgoers to learn about each others lives, and to interpret the events of their lives according to their shared belief system. In her interview, Rose spoke to the communion of religious service, and the potential acknowledgement and affirmation available through testimony:

> *Oh, the, I think the practice, or whatever you wish to call it, of going to church, some people might call it a ritual, but whatever*

> *you call it, it's very important. Because, it's like anything else that you practice, if you don't practice it, you gonna get off course some. Going to church every Sunday, you are meeting with other saints, other religious people. It takes your mind away from some of those internal struggles. It also, again, reminds you of what you need to be doing, and some people say, Oh I can stay home and listen to the radio, listen to the television—when I'm sick I do that, too, you know, if you're extremely tired, whatever— it's not like the energy of the people around you at church. Very important that you continue to go to church, you never know when you're gonna need it—not only that sometimes you just need, sometimes to verbalize whatever the internal problem is. And sometimes it's very small, but just talking to somebody, hear it reverberate, sound, it, you know it's outside of you, and it comes back, and you can resolve your own problem, because someone else is just listening. So there you find listening, people who will listen to you, you get to learn people that you can trust, you build a relationship with, who you can build a trust with them. It's just very very important. That routine, that practice, that ritual, whatever you would like to call it, is very important.*

In addition to the chance to feel heard and affirmed among trusted community, learning about each others' lives also creates an opportunity for churchgoers to support one another socially, within and beyond church. Many participants described their church community as extensions of their social networks. Women who participated in their church's Women's Missionary Society and other special church organizations tended to socialize more with other members of their congregation, even outside of meetings.

Figure 3.2
Photograph taken by Patricia

"So we meet, support each other, and we do things together, so that's been very helpful. You know, they'll call [me]—things like that. You know, just support."

Not every participant felt comfortable sharing details about their personal lives with their religious communities. Most participants described the understanding that their religious communities had specific expectations for their behavior, and even for their emotions. Across interviews, women used the language of "right" and "wrong" to describe different choices or types of behavior. These moral guidelines are communicated in sermons, Bible study, and through interpersonal interactions with other churchgoers.

Participants who had left the church and returned were more likely to describe the expectations of their religious community as positive. This is likely due to the fact that these expectations provided the positive influence they were seeking in returning, adding discipline to their lives and/or the lives of their family members.

> *When I hear the sermons, gotta let some of that stuff go. Those weights, we call 'em. Oh yeah, oh yes, [the sermons] remind you of where you should be, and where you might be, and where you ought not to be.* (Rose, participant interview)

> *Having my religion in place again helps me be more disciplined, because there are things that you need to do — you have to have discipline and will of mind, like fasting and praying, going to church with a set schedule.* (Nina, participant interview)

Some participants, however, described the expectations of the congregation as limiting. The two women who are married to pastors described feeling especially aware of expectations for how they behave and how they feel. They both expressed feeling that they were expected to lead by example, to demonstrate their faith through their actions on a daily basis. Feelings of constant scrutiny, potential judgment, and possible imitation led these two participants to present details of their lives that they felt would align with the expectations of their religious community. These two women both belong to church organizations for ministers' spouses and still describe feeling that they have to be careful not to share too much information with others, especially about their spouse. According to Josephine:

> *I would not feel comfortable taking my problems to the people in the church. I pray about it….I didn't want to be a pastor's wife, because I want to be me – sometimes I want to change my hair, or wear something different. You have to be really strong to be a pastor's wife.*

Women married to pastors describe a specific kind of isolation within their religious communities. They expressed that the consequences of deviating from the expectations of their congregations would be more severe than they would be for any other church member. They are expected to naturally align with all shared interpretations, and they may feel the need to hide their personal views when they differ from expectations. They also describe the social pressure of representing their spouses, the ministers of their churches, in ways that honor their commitment to their faith in the perception of others. In her interview, Josephine explained that women in the church are held to a more stringent standard of behavior than men. She expressed feeling that her husband doesn't feel as stifled in his role as she does in hers, and that he has told her that no one will tell her what to do as a minister's wife. Her fear, however, is not only that people will tell her what to do, but rather that they will judge her as unworthy of her leadership role if she does not meet their expectations.

Even for women who were not married to clergy, the fear of judgment and potential exclusion could lead them to limit what they share. None of the participants diagnosed with HIV, a heavily stigmatized illness, had chosen to disclose their diagnosis with anyone in their religious community. Their fears around stigma and blame were amplified by the additional layers of expectation imposed by others in their religion. Despite these limitations, most participant narratives described the ways in which they sought refuge within their religious communities. Whether or not other people knew the details of their personal lives, most women described being able to receive certain kinds of meaningful support.

Faith and Personal Spirituality

In addition to describing experiences of shared practice and religious community, participants referenced their religiosity and spirituality in terms of their personal practice. An understanding of the ways in which participants integrate their spirituality into their daily routines provides insight into the coping strategies that their beliefs may support.

Prayer and meditation were the most frequently referenced forms of personal spiritual practice among the women interviewed. Based on participant narratives, these intimate routines offer the possibilities of increased intimacy with God and Spirit, an exploration of personal needs and desires, and a disciplined practice of spiritual self-care. Several participants described prayer or meditation as offering solace in solitude.

Particularly in moments of social isolation, prayer and meditation create a direct relationship to divinity in ways that other dimensions of religiosity may not. As Jada put it:

> *When there is no one else that can hear or wants to know your most deepest, intimate thoughts and needs, you can always go to the Lord and he hears you, and he helps you. Knock, seek, and ask, and it will be provided to you. Those are things that I live by. Knock and it shall be opened.*

The practice of prayer, in particular, offers the chance for an individual to examine her own thoughts, needs, and desires. Women described regular prayer as an exercise in self-knowledge and humility – an intentional way to further understand themselves, as well as to identify and reckon with their material concerns. Meditation and mindfulness practices – including yoga and chanting – also offer a moment of peace and self-reflection. Dinah began practicing yoga at the suggestion of one of her doctors. Today she is a yoga instructor who offers special classes for people living with chronic pain. She describes yoga as having transformed her relationship to her body and to her health. In each of these forms, personal spiritual practice creates space in a woman's life for her to consider her own needs. Most participants created disciplined routines to support their practice, giving themselves time to reflect and re-align with the belief systems that guide their lives.

Figure 3.3
Photograph taken by Rose

> "*I try to do it when I start my day, before I get out the bed, I get into my clothes, the first thing I wanna do is get my two books and the Bible, go through every day—it's isolated by days, and each one have a different devotion, so I will read those, and then it refers to a Scripture reference, I will go to the Bible, read that Scripture lesson. What it does is it has a real, real calming effect—as my husband used to say, the minister, he used to say it gets your day started, you begin it in a different tone, a mindset up here, you are more relaxed, you are just sort of in sync with yourself, and with the Spirit...But it has a very positive spiritual—a connecting, reconnecting effect on you. So it puts you in sync with God again. Reconnecting.*"

Participants described prayer as a way to feel balanced, to remind themselves of how they see themselves, and how they are seen by divinity – separate from the way the rest of society may perceive them. For these women, their spiritual practice affirms their priorities beyond their material concerns. In these descriptions, prayer and meditation create an opportunity for a woman to affirm her own value and purpose beyond external expectations.

Perhaps one of the most significant effects of personal spiritual practice named by participants was the fact that it provided a constant in their lives, despite changing circumstances. Even in situations of ongoing uncertainty, into which new stressors are constantly being introduced, their personal practices of spirituality create a reliable routine of safety and self-affirmation.

> *My strong belief in God, my faith and all of that, it's a way, again, to relax you, not to concentrate on diabolical things. You know, if you stay inside, you can just think of all kind of evil things— You need to let those go, get outside of it, um, get into the word again, which helps you, with your daily living. Just reading the words, and it reminds you of some of the things you should be doing, and some of the things that you need to let go.* (Rose, participant interview)

These practices are ways that women support themselves in maintaining emotional balance. Imani describes how even without a physical altar, her practice of Buddhist meditation helps her to manage her perspective and approach to situations in her life.

Figure 3.4
Photograph taken by Imani

"It's real soothing. I don't have it my place now, but I have one area that I just visualize. And sometimes I find myself chanting more than I actually may wanna go hear a sermon. Because it's soothing, and it helps. And I know that, since I been diagnosed—AIDS, disabled and AIDS, you know, my stress level, my patience and my tolerance with people…or, the things that's going on in my life, my tolerance, it's…I can manage it. You know, I still don't really like people, but I have more care for them. You know, chanting, it's like a world peace type of thing. And it's like a customized religion for me, where I can customize it and chant for the things I want changed in my own self, person, or my life. And it works."

Faith is often conceptualized as a blind belief that things will resolve themselves, without human action. The characterizations of faith that emerged during interviews were radically different from this definition. In this study, women described faith as an active choice, an orientation towards possibility. Women referenced their faith when they were able to pursue positive outcomes in the face of overwhelmingly negative circumstances. Rather than allow their perspectives to be dominated by perceived obstacles, participants described faith as the ability to choose a perspective that will support their actions to overcome and transform those obstacles. No one in this study referenced faith or religious belief as a reason for inaction or avoidance of medical care. As Rose asserted, “Some churches don’t believe in medicine, but we do, because God put things here for us to use.”

Faith, prayer, and religious practice offer individual women a way to chart a course through uncertainty guided by their own values and meaning systems. Women make active, intentional choices to engage religious systems of meaning and spiritual practices that affirm and address their needs. For these participants, faith is not a passive coping mechanism to avoid choice or action, but rather a consistent way to choose how they approach their lives.

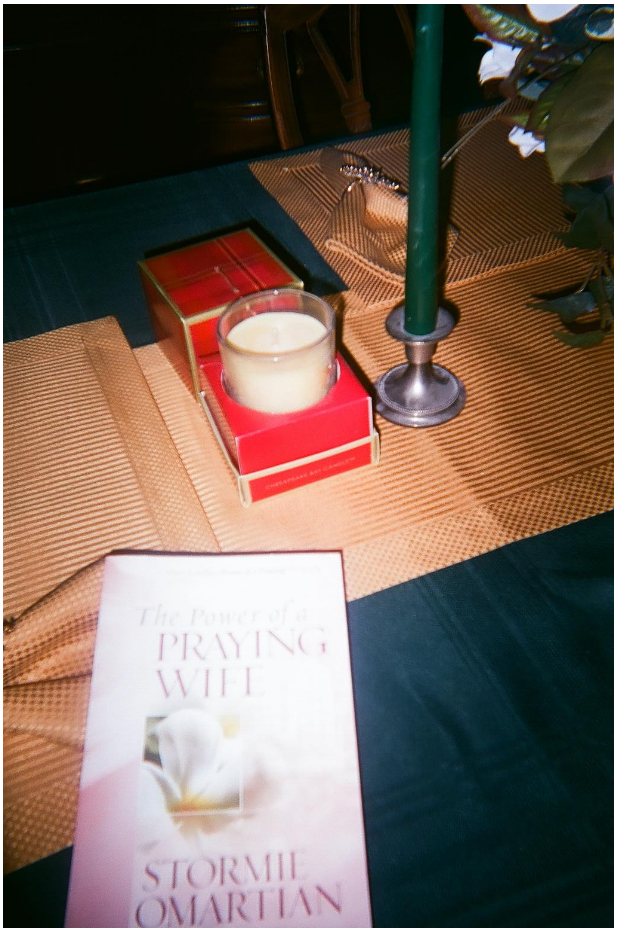

Figure 3.5
Photograph taken by Josephine

> *"I am a witness, because I have seen the results of things I have prayed for. I am truly one, I am one that believes in prayer. I have truly seen miracles happen through prayer, and I don't think it's because I'm so great sometimes. I think it's just my faith and believing that prayer is just that real."*

Biomedical Diagnosis and Treatment

Diagnosis with chronic illness introduces a new set of meanings, priorities, and potential stressors into an individual's life. Since all of the women included in this project had all received diagnosis, they had all received biomedical care at some point in their illness experience. The reasons they sought care and the ways in which they accessed it varied depending on circumstance.

Some participants were motivated to seek care, even without physical symptoms of illness. In these cases, women were concerned about the health risks associated with certain choices, social vulnerabilities, or coping behaviors. Imani described seeking regular STD tests and pregnancy tests when she was engaged in sex work, and was diagnosed with HIV while receiving medical care for pregnancy. Jada referenced first getting medical care when she entered rehab for drug addiction. I For some participants, the risks associated with certain forms of social precarity motivated them to prioritize their own health and to seek care without experiencing symptoms.

For other participants, unhealthy conditions had become normalized and even expected. In these instances, women were less likely to seek support – medical or otherwise – even when they experienced physical symptoms. Josephine, a teacher, described getting sick on the job and assuming that there was mold in the classroom. She waited months to seek care, and only saw a doctor because she was planning to travel. For these women, the assessment that they were in a situation without resources led them to attribute physical symptoms to unhealthy choices, external stressors, or environmental toxins, rather than to assume that they might be experiencing a diagnosable illness. Most of these participants did not seek care even when presented with physical symptoms.

Women who previously had negative experiences in the healthcare system were also less likely to seek care. Although everyone in this project received a medical diagnosis, some participants were very clear about wanting to avoid medical systems because of uncomfortable or outright traumatic histories. Imani shared that she had been sexually assaulted by police at San Francisco General Hospital, and had never returned until her HIV test and diagnosis years later.

About half of participants sought care when presented with symptoms – even if they waited until those symptoms became extreme or inhibited their daily routines. Most women cited a lack of time to focus on their health concerns, despite worsening symptoms. Patricia describes seeing blood in her urine and still waiting weeks to seek medical attention:

> *I would go to the bathroom, and you know, when I would wipe there would be a little tinge of blood on the tissue. And I thought, oh God, you know, I got this post-menopausal thing going on, I'll have to see my GYN. And I put it off because you know we had audits — it was always something that kept me from making this appointment. Now mind you, I work in a hospital, and all I had to do was go to the other floor to see my doctor, I could just slap myself sometimes. But anyway, this blood thing had started getting a little deeper and deeper. You know at first it was just maybe once a day and then it got to be twice a day, and then it got to be whenever I would go pee. So I went to go see my doctor.*

When they did seek care, each participant had different levels of access to health care. Some were seen at public clinics, while others had primary care providers who could recommend specialists. Often, diagnosis was delayed by the fact that providers considered existing co-morbidities more urgent than new symptoms. Some participants needed to see a specialist for diagnosis, which required an extended engagement of medical care. After seeking care due to blood in her urine, Patricia described feeling like her concerns were not addressed by her provider in her initial appointment. When her symptoms worsened, she re-engaged her provider and was referred to three more providers before being diagnosed with stage three cervical cancer.

> *I was telling her what was going on, and she says, oh you have a bladder infection. And she gave me antibiotics, and I told her, I said well I never had a bladder infection before, but I heard that bladder infections and urinary tract infections are painful. I said and umm, you know I have no pain. And she says 'Oh well, maybe yours is just brand new.' And I was trying to reason with her to tell her that this has been going on for about three weeks now, but she was insistent that it was a bladder infection. And I thought, okay well, she has the medical knowledge. Gave me antibiotics, I took the antibiotics, and then the week of —well the week before thanksgiving, I went to the bathroom and it was like on a Thursday, and I went to the bathroom and peed blood. Just straight blood. So I went into panic mode, called my GYN. And you know I told her, I says, it's probably some kind of post-menopausal thing. And she says well let's just have you checked. So I went to see her Monday. She said she didn't see anything but she wanted me to see a uro-gynecologist. And he did a cervical biopsy. He said, Patricia—this was on Tuesday—he*

> *said Patricia, he says everything looks fine, he says but I want you to see a urologist. Before I could come from the seventh floor back down to my office on the first floor, urology had called. And you know they wanted me to come in that day and I told them I said what are you gonna do so they were telling me the procedure they would have to do and I told them I have just had a cervical biopsy—and that's where they go in, no anesthetic, no aspirin, no nothing—and they snip off a piece of your cervix. And I said I just can't handle that today, so they gave me an appointment for tomorrow, which was Wednesday. And I went and they stuck this probe, this camera, through the urethra into the bladder, and when he got finished he says, um, you have cancer.*

It is notable that Patricia works in a hospital system, and that it was relatively easy for her to seek and receive care. Still, it was her insistence on being seen ("panic mode") that resulted in her successful diagnosis, despite her initial concerns having been downplayed by providers.

When participants had received medical care that addressed their physical illness, they also described other considerations that impact the effectiveness of care and their likelihood to continue receiving care. Establishing a relationship of trust with at least one provider emerged as a major factor in whether or not a participant continued to engage medical care after diagnosis. Even if a participant did not develop trust with a specific provider, those who continued care described trust of a specific medical location, and/or participation in support groups that encourage medical treatment.

There are several factors that were presented as foundational to this trust, including the provider's belief in the patient's description of her own physical experience, the provider's ability to address the patient's concerns, and the provider's clear communication to the patient.

The above narrative, in which concerns were dismissed by a provider, is particularly significant to her now because it may have delayed an urgent diagnosis. Most participants expressed wanting to receive care in places where they felt that their accounts were believed and their concerns were addressed. In particular, it was important that their treatment plan was sensitive to their life circumstances. Multiple interviewees recounted recommendations from their doctor that they were unable to implement in their lives, often due to competing priorities. Jada noted that protected sex was not always possible in sex work, and Nina observed that the cost of her medications made it more difficult for her to afford the healthy food that would support her health. Nina was also frustrated that she was expected to manage her stress levels as a single parent supporting her family through loss: "The doctors told me to reduce my stress to help my hypertension, but nothing in my life had changed, so how could I change my stress?"

For the women in this study, cultural and religious beliefs were also significant in their assessment of care. Women expressed being happier with their providers when they expressed a respect for the beliefs of their patients. At the minimum, this meant that providers were sensitive to a participant's beliefs in the way that they communicated information about their illness. In the most extreme cases, participants described how providers expressed admiration for their faith or even shared Christian beliefs. Patricia described how meaningful it was to her that her provider shared her beliefs:

> *I was telling people, I said you know, there's something that God wants me to do. Because He spared my life. And even my doctor, he's a believer, he told me, he says, "There is nothing but your faith that has kept you alive. He said, I did what I was supposed to do, but it's your faith.' And that's what all my doctors—my doctors, my oncology nurses, all of them said you know, 'Your faith is so strong.'*

Even when providers were sensitive to a participant's beliefs, their ability to communicate medical information with clarity and compassion were important factors in how a participant received this information. Providers who offered understandable explanations were described more favorably. Across interviews, participants asserted that it was especially important for them to understand the medical markers for improvement in their condition. This could mean understanding their viral load in the case of HIV diagnosis, or understanding a healthy range for blood pressure readings in the case of diagnosis with hypertension.

Descriptions of sensitive (or insensitive) care extended beyond communication and clarity. Three of the women in this study actually stopped receiving care for periods of time due to concerns about their confidentiality. Particularly for women diagnosed with HIV or other stigmatized illness, their concerns about the impact on their lives if their families or communities found out outweighed their concerns about their physical health. If they felt that their care would compromise their confidentiality, they were less likely to continue with medical treatment. In some instances, threats to privacy were due to the lack of attention from providers, but in others, it was simply due to the requirements of continuing treatment. Regular visits to the hospital, for example, could mean that a participant would have to risk being seen by anyone when seeking care. In these cases, participants often took measures to protect their own privacy – sometimes including an avoidance of or resistance to medical treatment.

Patricia describes her hesitation to seek care: “I wasn’t happy about it, Amina, but I wanted to live. And I was willing to do whatever it took in order to be alive. You know, that’s what it came to.” In all of these cases, it was important to participants that their medical care took their personal priorities into consideration, within and beyond a course of medical treatment. Social concerns, access to resources, and personal beliefs were major factors in whether or not participants continued care, expressed satisfaction with it, and were able to implement recommendations from providers.

When a participant received a diagnosis, it introduced a new set of medical meanings into her experience of illness. For some people, this is a moment of relief, brought on by the realization that there is a name (and possibly a treatment) for the physical symptoms they are experiencing. This was more often the case for women who sought treatment due to symptoms they could not explain, rather than for those who sought routine testing. In these cases, diagnosis meant that there were potentially other people having similar experiences with illness. It could mean that a person had options in choosing a path forward, and that there might be a way to alleviate troubling symptoms. Medical diagnosis can provide an explanatory framework beyond the meaning systems already engaged by the individual.

In the case of a stigmatized diagnosis, medical meanings may evoke social meanings to which the participant might be resistant. Even if the diagnosis itself is not stigmatized, several participants expressed surprise at medical descriptions, especially those who see themselves as maintaining healthy habits before diagnosis. When the diagnosis was a surprise, or when participants associated it with negative meanings, they were less likely to accept it immediately. Even accepting the diagnosis, however, did not necessarily lead a woman to seek treatment or continued care. A participant's relationship to medical care was influenced by many factors, but ultimately directly related to the extent to which they had integrated medical meanings into their personal meaning systems. In interviews, women who had continued care from the point of diagnosis regularly applied medical meanings in their casual descriptions of their own experiences.

These descriptions were also influenced by how I was perceived as an interviewer. When I was perceived as an impartial academic researcher, the interviews often focused on these medical meanings – particularly among those participants who had not fully claimed medical meanings in their interpretations. At the end of each interview, I asked participants if they had questions for me. Most of them asked about my own experiences with chronic illness, and with religion. For those women who had relied upon medical meanings in our interview, the information that I was raised practicing Black Christianity and that I live with chronic illness changed their perspective of me, leading them to present a new version of the same events. This "second interview" relied upon the personal, cultural, and religious meanings that were important to the participant. The difference in these descriptions reveals that not all participants had integrated medical meanings into their personal understanding of their illness experience.

Women who simultaneously engaged personal and medical meanings in the interpretation of their own illness were more likely to apply medical meanings to their own habits and routines. Those who did not take up medical meanings were more likely to engage care strategically, according to their own priorities – priorities which were often not considered by their providers. For example, they might seek care only when their symptoms became too difficult for them to manage on their own. This choice did not seem to mean that they had rejected medical meanings or medical care, but that they felt that the care they were receiving did not take their personal beliefs and circumstances into account. Participants were most successful in taking up medical meanings when new concepts were communicated in a way that connected with their personal meaning systems and physical experience. Those who had integrated medical information into their explanatory frameworks were able to discuss illness in a way that simultaneously engaged medical and spiritual meaning systems.

> *There are three stages—four stages of cancer. The first one is brand brand new, when, you know, everything has just been found and it's a 98% chance of recovery. Stage two it gets a little bit more serious, chances get a little, maybe fifty-fifty. Stage three it's very very serious. Stage four, it's terminal. But people have come*

> *out of stage four cancer also, so it ain't over until God says it's over.* (Patricia, participant interview)

Navigating Physical Changes

Navigating changes in the body is a significant aspect of chronic illness. Given the range of different diagnoses among the women interviewed in this study, it is not surprising that they described very different physical experiences of chronic illness. Some physical changes were symptoms caused by a disease itself, and some were attributable to the medical treatment of the disease. Participant narratives included descriptions of physical changes including pain, discomfort, fatigue, changing abilities, and changes in appearance. The physical experience of illness directly shapes all other dimensions of illness experience – social, psycho-emotional, and even spiritual.

Across interviews, experiences of pain, discomfort, and fatigue emerged as consistently challenging aspects of chronic illness experience. Although I asked questions in the interview about pain, it came up organically most often when participants were discussing the ways pain limited them in their daily routines. Patricia describes not only how the pain affects her range of movement, but also how she is accommodating her changing physical abilities.

> *You'd be surprised at how all your body works together and just raising my right leg, all this hurts. So, you know, you just kind of take it a little bit slower, use your left side a little bit more, and*

> *kind of try to not to baby it as much. I have to remember, I have no feeling now, and I have this pouch.*

For the most part, Patricia's physical pain is caused by the surgeries she received to treat cancer, including the removal of her bladder. Participants described these physical changes as limitations, referencing low energy and inability to maintain the routines of their lives before diagnosis and treatment. In the words of Nina, "What it means to have chronic illness is to have limitations."

While I did ask direct questions about pain and discomfort, I did not ask about experiences of fatigue and low energy. Most participants referenced fatigue as a major factor in their journey to manage chronic illness. According to Josephine, "I have fatigue but no pain, I still can manage daily tasks. Sometimes I push through my routine." This idea of "pushing through" was present in several participant narratives. Participants expressed feeling that they were constantly battling their own limitations in order to maintain their commitments, meet their obligations to others, and to be able to do things that were important to them. Similarly, there was a common description of illness as something that had changed the pace of their lives. Dinah stated simply: "Illness slows you down, makes you think."

The feeling that illness had required them to "slow down" and "push through" emerged as a prominent theme in this project. In fact, most participants evaluated the effectiveness of medical treatment based on improvements in their ability to manage daily tasks. Some of these tasks were related to their jobs or commitments to other people, while others were activities that allowed participants to maintain a life that reflects who they feel they are as a person.

Social Roles and Relationships

All of the changes that an individual experiences in the course of chronic illness have the potential to impact their social roles and their relationships with other people. For some women in this study, changing physical and emotional abilities made it more difficult for them to maintain their roles in family and community in the same way they did before their illness and treatment.

Most people interviewed were selective about how they represented their illness, and to whom. This type of strategic disclosure was especially prominent in the narratives of participants diagnosed with stigmatized illness, such as HIV. Women living with HIV chose a select few people to tell about their diagnosis. Celeste says that only her sister knows, and she has not told anyone else in her family. Jada told her mother and her boyfriend, as well as one friend who also lives with HIV. Both women named stigma as the reason for their nondisclosure.

> *I don't talk about it. I'm secretive about my medication. I tell my boyfriend they're for my menopause, but they're for my HIV….It's not enough information, or people don't accept it, the information that's already out there. It's like trying to send somebody back to school. If you didn't go to school to 12th grade, how am I going to educate you about HIV? And then when I do educate you about*

> *HIV, there's new studies coming out about this medication, that medication. So I'm just trying not to be stigmatized, or just stereotyped…What I can't handle is the stigma, people saying, "Don't touch my baby."* (Jada, participant interview)

Each of these women altered their daily routines to maintain their own privacy, and to avoid judgment and social exclusion due to the judgments of other people. Imani also expressed anger at the person who had exposed her to HIV, and said that her anger led her to drink more heavily: "I really started drinking then. Because I just couldn't believe that this son-of-a-bitch gave me HIV. And I got it from one of my kid's fathers, because he was fucking around with men and I didn't even know."

Even women who did tell their close family and friends about their diagnosis described managing the perceptions of others throughout their illness journeys. Participants had different options when it came to disclosure, given that some illnesses and medical treatments have visible effects. Patricia describes how she hides her ostomy bag under her clothing choices and frequent emptying:

> *So I have to just kinda—well, I have to change the way I dress, because now I wear sweaters and jackets and things, and I just have to remember to kind of just rub the front, to make sure it doesn't need emptying. Otherwise, it makes this bulge right here. So it's life-changing, but it's not as crazy-making as I thought it was gonna be.*

Figure 3.6
Photograph taken by Patricia

In addition to protecting themselves from potential judgment, participants described a desire to manage the expectations that others may have for them. Particularly when participants were rearranging their lives to accommodate changing abilities, sickness, and depression, they were less likely to be able to meet the needs and expectations of other people. While most participants described difficulty navigating the routine obligations of their social roles, many also described facing new expectations from family, friends, and community in regards to how the participant responded to her illness. Multiple women described that the same people in their lives who offered them support throughout their illness also had specific ideas for how they should behave and interpret chronic illness and its medical treatment. In particular, participants felt that their support networks were assessing their work to recover or ameliorate the negative impact of disease. The people who were most involved in supporting a participant in managing illness were also most invested in her return to what they considered normalcy, which was usually a physical and emotional state similar to their condition before diagnosis.

Participants described feeling pressure to change their behaviors in certain perceivable ways, in order to address the concerns of the people in their lives. Their narratives reveal that a form of a "sick role" was ascribed to them upon disclosing their diagnosis to others, compounded by familiar expectations that they manage new challenges without becoming overwhelmed or "giving up." This combination of social expectations – the sick role and the superwoman schema – has the potential to create a specific set of rules for the emotion and behavior of Black women living with chronic illness. Religiosity added another dimension for these expectations, with participants being expected to demonstrate their faith through consistent efforts to improve their health.

Three participants specifically described a fear of disappointing those people who were supporting them. Patricia recounted her daughter's belief that she had the capacity to do more to accelerate her own recovery from surgery. Her daughter's concern with her health led her to create certain expectations for the pace of recovery, and she became frustrated when her mother was sicker for longer than she had expected. She held her mother responsible for the discrepancy between her expectations of a return to "normalcy" and the reality of her mother's slow recovery. Echoing the movement mandate associated with the sick role, Patricia's daughter insisted that she was not trying hard enough to restore her good health:

> *She felt that I was giving up because she would want me to, to go outside and walk, or you know, just walk the hall, or you know, to do some physical something. And I was telling her, I can't. I. Just. Can't. And you know, then she's telling me, 'We licked the cancer, and now you're just giving up on me.'…And then [my daughter] had lost it, and she walked out, and [my daughter] told me that Dr. – was talking to her in the hall, and you know she was telling Dr. – how she felt that I was just giving up, that I wasn't even trying. And she said, and you know, she was telling me, she says, 'Your mother can't. It's not that she's given up, she just can't do it.' And then she went on to try to explain to her what was going on inside my body, with the organs, and muscles and things, you know, that I just honestly couldn't, I just really couldn't. So, you know, she kind of calmed down after that.* (Patricia, participant interview)

Patricia describes how a provider had to explain to her daughter that she had a limited amount of control over the pace of the improvements in her physical condition. She was not the only participant to describe feeling that they were disappointing people in their lives who held them responsible for their own recovery.

One major factor in this experience was the difference in the concepts of "recovery" and "normalcy" held by a participant and those held by people in her support networks. According to participant narratives, family, friends, and community members who were invested in the participant's return to health often imagined that she would regain the health and abilities she had prior to the onset of chronic illness and the effects of medical treatment. As scholars have noted in their critiques of the idea of a sick role, recovery is different in the context of chronic illness. As participants work to establish new expectations for their own lives in the illness experience, they must also navigate social expectations for their choices that may not have fully accounted for the many changes illness has catalyzed in their lives and their bodies.

Some participants expressed feeling more concerned with meeting the expectations of others and being able to support others than they were with improving their own condition. In these cases, the emotional stress of managing changes in their close relationships was potentially more concerning than the illness itself.

> *Not being afraid, not being afraid to die, but you know, how sometimes, how just—how disappointed people would be in me. Like, Aww man, no she didn't give up. You know, How dare she do this to me. And you know and people are, you are the rock, now you know you are the rock. And it's just, what are they gonna do without me? That's crazy, huh. Not wanting to disappoint anybody.* (Patricia, participant interview)

Particularly for women who routinely prioritize the needs of other people, even before diagnosis, it could be very stressful to become more dependent on others for support in their own journey with chronic illness. Participants experienced needs for new kinds of support – physical, emotional, and spiritual. This potential dependence on other people was a challenge for participants used to their own autonomy, and who had come to identify with their roles of support in other people's lives.

> *Relying on other people. Coming to the realization that now there are some things that I am physically not able to do, and not being embarrassed to tell somebody I can't do that.* (Patricia, participant interview)

The process of learning to recognize and communicate their needs for support emerged as a consistent theme in participant narratives. There were several challenges associated with seeking support, including the stress of possible rejection or disappointment if a participant's needs were not met after requesting help.

For some women, turning to their existing networks of support was a natural choice as they sought support through illness. This was primarily true among women who had strong social supports before diagnosis, within their families, friend groups, and religious communities. It was also more likely among women who were unable to hide the changes in their appearance or lifestyle caused by illness. When participants had disclosed to the majority of people with whom they have close relationships, they were more likely to have relied on the same people for support through chronic illness.

For those participants who had not fully disclosed their diagnosis, or who had disclosed different aspects of their experience to different people, it was more of a challenge to find the right people to ask for support. The women in this study who referenced this particular challenge were women living with stigmatized illness, women with leadership roles in their religious communities, and women without stable resources or social networks. Not only did these women have to navigate socially in ways that protected their privacy, they also had to assess which people in their lives could provide them with the types of support they required. Most of the participants who were successful in establishing relationships and even networks of support acknowledged that they received different forms of support from different people. Some women described reaching beyond their existing social circles to establish relationships with new people who might be able to offer new kinds of support – including forms of support that the participant may not have previously considered requesting.

Support groups were one of the main sources of emotional support for participants outside of their friends and family. Participation in support group meetings offered several distinct advantages. Women who had attended gatherings of people with the same or similar diagnoses learned that the challenges they face in the course of their illness also occurred in the lives of other people. This understanding opened them up to new concepts of normalcy that accounted for their illness. Experiencing affinity with other people who had the same diagnosis could contextualize their illness socially and medically, beyond their own embodied experience.

For the most part, women who had participated in support groups expressed feeling that they had become members in a new community of chronically ill people. The normalization of their illness within these communities was frequently described as a welcome change from other social contexts. The language and meanings that participants were able to access in these affinity groups had the potential to affirm dimensions of their individual experience by naming the social and emotional impacts of illness, and by providing new explanatory frameworks for understanding these challenges. Jada began attending meetings at a well-known advocacy organization after initially engaging them to seek contraceptives: “I started going to get condoms and then started going to meetings every Wednesday; women with HIV, share experiences, check in, support, retreats, speakers.” Dinah cited mandatory chemotherapy classes as her first time meeting other people with similar diagnoses. For her, hearing the stories of other patients shed new light on her own journey and her feelings about it:

> *So I had to go to a chemo class. And just hearing everybody's stories—you know, you always think, I'm the only one, I'm the only one. And then you hear other people's stories. And there was this guy there who had breast cancer, and you know, it was just, I think it just brought everything to a head for me, and everybody was telling their story and, we were all crying right along with that person, and I don't know, I guess it all just—the floodgates just opened. The floodgates just opened, to where I was like sobbing—that kind of crying.* (Dinah, participant interview)

Participants who attended support groups were also able to form new friendships with people who are navigating similar illness experiences. These new relationships provided companionship in an isolating experience, and could offer a participant new insight into the possibilities of life with chronic illness. The consideration of other illness experiences could offer participants new perspectives on what support can look like, and what other forms of support might be available to them.

Interestingly, participants who formed supportive friendships in their religious communities described them similarly to the way participants described friendships made in support groups. Several women interviewed told stories of making friendships based on shared faith – friendships they came to rely upon during challenging times in their illness journeys. In rare cases, women were able to establish friendships with people who shared their faith and had been diagnosed with the same illness (or a similar one).

> *But there's someone in my building that…she's like…whoo. She's like really into it. And I'm kinda glad that I latched onto her. Because it's just like one addict knows another addict. It's like, I asked her, it was just because she's so calm, and she has so much peace within herself, and I just happened to ask her, "Do you chant?" And she's like, "Yeah!" You know, she was just someone that I would, that I would see in my building, you know. From time to time. And we had never spoke but, other than, "Hello," "How are you?" "Have a good day!" Something like that, but we have something to hold conversation about…I'm like, "You chant?" She's like, "Ahh! Yeah! Okay, well, cool!" She's the one who I found out about the meetings. And uh… Yeah. I actually go with her.* (Imani, participant interview)

In these friendships, participants were able to engage multiple meaning systems – social, medical, and religious – as they interpreted their illness experiences. These friendships could support them in making meaning of their illness, creating healthy routines, and managing daily life in ways that other relationships could not.

Although sharing experiences and beliefs made it more likely that a participant could receive multiple forms of support within a relationship, several women also described receiving support from people who did not know about their diagnosis at all. Imani, who had been diagnosed with HIV did not tell anyone in her religious community, but would share with them when she was not feeling well. When she missed a religious service, other members would pray for her and check in on her to make sure she was okay. Stories like hers reveal the way in which women were able to create networks of support that could sustain them without compromising their privacy or leaving them vulnerable to social stigma.

The importance of supportive relationships and social networks echoed across interviews. Still, many participants felt isolated in their experience of illness. Josephine stated that she had no community of support beyond her church, and she did not feel comfortable confiding in other churchgoers as their pastor's wife and a leader in the congregation. When participants did make an effort to seek support from other people, there was no guarantee that participants would receive the help they needed. In some cases, the disappointment associated with requesting support and not receiving it could negatively impact the likelihood that a participant would continue to ask others for what they need.

There were several types of support that participants cited requesting and/or receiving. Physical support included help in navigating changing physical abilities and changes in access to public spaces. Social and emotional support involved assistance through changing relationships, offering companionship, compassion, and empathy. Spiritual support took form through the interpretation of life circumstances according to shared meaning systems, offerings of prayer, and the reinforcement of the tenets of a shared faith.

> *And I would tell 'em, when people would leave, I would say "Just pray for me." And they weren't understanding because at that time I was just so sick—you know you can be so sick that you can't think straight. And I couldn't, I could not even, I had to tell God, 'I know this must really sound stupid, huh?' Just like, 'what is she talking about?' (laughs). I would tell my mother or one of my prayer partners. I guess God is just thinking, "What is wrong with you?" I said you know, I can't—the sentences don't even come out right. And that's when they would just talk to me, and just said that the Holy Spirit is the interpreter. So you know, God knows what you're talking about. Then after that, you know, even if it didn't sound intelligent enough, I figured well, the Holy Spirit will interpret it for me. But prayers just really, it's just what kept me. It kept me. Listening to my gospel music. When I was able to sit up*

> *for a few minutes, 'cause I only have cable in here, to watch some spiritual programs. To hear some preaching. And they would send me CDs from the services, you know that was inspiring.* (Patricia, participant interview)

In learning how to consistently identify their needs and communicate them to other people, participants engaged in a process of determining their own priorities in managing their illness. For many women, this was one of the first times they had defined their needs. For almost all participants, it was the first time they sought to prioritize their own needs as much as they had focused on the needs and expectations of other people.

Particularly when their medical providers did not consider their personal priorities, it became important for women to define them when seeking support from people in their lives. In some cases, the priorities women developed in their illness experience were fundamental to maintaining their lives and routines. They described learning to communicate their limited physical capacities and emotional struggles, especially to set boundaries with loved ones and manage the expectations of those who wanted their attention and support. Even for participants who were relatively accustomed to navigating change and uncertainty, changes in their ability to manage their social roles led them to communicate and pursue their personal needs in new ways. Choosing to assert their own needs created new dynamics in the existing relationships in a participants' life. Reconfiguring these social relationships in order to receive support constitutes a form of self-advocacy.

The priorities women pursued illustrate the ways in which they defined their own health and well-being. These definitions of health changed over time, as participants identified new needs in the course of illness. Women who had succeeded in creating supportive daily routines were more likely to describe routine self-advocacy, communicating their needs even to strangers in their daily lives.

> *Something as simple as going up four flights of stairs. I could do it, but I have to—uh, so stupid—I have to hold onto the rail, and just like pull myself. You know, and I've been in positions, situations where I've had to do that. And if there are people behind me, I just tell them, you know, Come on around me, I'm moving slow. And they see it's obvious that's something's not right, 'cause I'm having to pull myself up. But then once I get on level ground, I'm fine.* (Patricia, participant interview)

This type of confident communication reflects an internal process of acceptance. Patricia journeyed to accept her new reality, after a cancer diagnosis and rigorous medical interventions. She had overcome shame about changes in her abilities and appearance – and fear of the judgment of others – in order to be able to protect her body, her emotions, and her lifestyle by expressing her needs openly. Regardless of a woman's choices about disclosure, her ability to prioritize her own health in various social situations was a key factor in whether or not she was able to maintain networks of support and create new, healthy routines in her daily life. Self-advocacy was also indicative of the extent to which a woman had re-established her personal identity in the wake of diagnosis. In most cases, a participant's ability to advocate for her own needs, even as they changed, reflected her concept of self and its adaptability. Dinah described reinforcing her own sense of self in interactions with other people: "Friends and family keep asking are you okay, reminding you of the crust of illness outside of you, but inside you know you're still you, still full of life."

Identity and Self-Image

Each of the factors that influence the experience of chronic illness among religious Black women have an impact on their personal identity and self-concept. Changes in physical ability and appearance, social relationships, and spiritual meanings all have the potential to challenge an individual's fundamental beliefs, and to transform the way they see themselves. In order to reimagine themselves and accept their new realities, women engaged in a process of reframing and reinterpreting their experiences in light of new information and changing circumstances.

Changes that resulted from illness and treatment challenged the ways a participant had constructed her identity. While changes in physical appearance have an obvious impact on self-image, many women in this study identified strongly with their social roles – wife, mother, friend, church sister. When these relationships changed, participants had to create new identities that accounted for the changes in their social roles.

Consistent with the concept of biographical disruption, women interviewed described the failure of familiar meanings in accounting for the changes in their lives.

When they did not recognize themselves, did not recognize their lives, the stories they told about themselves were no longer fully accurate. When participant narratives referenced depression and social isolation, the changes in their identity were often a root cause of their inability to navigate according to the meaning systems that had previously sustained their interpretive frameworks.

Although the concept of biographical disruption has been significantly elaborated in sociological scholarship, the original theory puts forth several fundamental features. These include an interruption in an individual's construction of her own biography, a disruption in the way an individual imagines and plans for her future, and a process of normalizing a new reality through the utilization of social and material resources (Bury 1982, Querol 2020).

In the wake of biographical disruption, an individual is put in a position to interpret and describe her own life according to new information and experiences. Narrative reconstruction involves the rewriting of personal biographies in ways that account for unexpected change, particularly change that disrupts a person's systems of meaning and interpretation. Participants were describing a process of narrative reconstruction when they explained how they reframed their understanding of illness over time.

Women interviewed in this study had various levels of success in creating and integrating new meanings into their understanding of themselves and their circumstances. This biographical work relies upon access to new information, its contextualization, and its affirmation over time in the life of the individual. Several common themes emerged in participant descriptions of their internal process of reconfiguring their own identities. These themes illustrate simultaneous processes of transformation occurring in the women's perspectives. Each participant was in a different place with regards to each category of transformation, but each of these themes emerged in the majority of their narratives.

A strong majority of participants spoke at length about the impact of their thought patterns and mindset on the quality of their lives. Although almost everyone interviewed referenced periods of depression, many of them were clear that their intention was to consistently focus on gratitude and possibility in their lives. The stories that women told about themselves reflected this orientation.

> *Your head and heart give a lot of impact on what goes on outside.*
> (Jada, participant interview)
>
> *I'm switching my mind to learning how to heal, not focusing on negative aspects of disease.* (Dinah, participant interview)

One of the most prominent themes in accounts of narrative reconstruction was a shift in women's perspectives of their illness. Participants noted that they had intentionally moved away from characterizing illness experience in terms of loss and other negative consequences. Instead, they made the choice to focus on the positive opportunities that their journey had created, and on the positive personal attributes they felt their choices had revealed about themselves.

Participant narratives often referred to their own strength, faith, and survival. In this sense, the experience of surviving with chronic illness had transformed women's view of themselves to account for their management of the difficulties created by illness. The tone of these self-descriptions were not boastful; rather, participants spoke of their survival in a matter-of-fact way, or with a tone of awe. Their survival itself was the measure of their success in navigating illness.

In order to maintain the emotional balance and clarity of perspective necessary to feel gratitude in times of hardship, participants cited a focus on mindfulness and practices that support being consciously present in the moment. Women's illness narratives reveal a transformation in their relationship to time. In particular, participants' illnesses pushed them to confront their own mortality in new ways. The combination of an orientation toward possibility and a focus on the present moment changes an individual's relationship to their own future. Just as biographical disruption changes the way an individual imagines her future, faith influences narrative reconstruction in a way that changes how she relates to it. For participants, a focus on the present moment supported emotional balance in times of uncertainty. It seemed that if an individual could accept that the future is uncertain and unknowable, she could more readily adapt to change. Not all participants, however, had a positive relationship to the future. Even when they maintained routine mindfulness practices, three participants expressed that they did not have a sense that their lives were normal, nor that things would improve.

As all of the women in this study were religious, most of them engaged religious meanings to navigate uncertainty. It makes sense that they would rely upon the same meaning systems in their experience of illness. Religious and spiritual meanings were woven into participant narratives, with spiritual interpretations being the most meaningful to most participants. According to Dinah, "Religion and illness overlap because the illness reminds you that every breath is precious, because you don't have to be alive, so you have to enjoy every breath."

Although many participants in the study had a firm daily spiritual practice, most described ways that their practice had changed or expanded over the course of their experience with chronic illness. No one interviewed had abandoned or limited their religious beliefs or spiritual practices as the result of illness. Some of them had added new practices, while others expressed having increased intentionality in their existing practices – attending religious gatherings more often, creating more time for prayer and meditation, and even exploring new spiritual traditions.

Several narratives also described how new physical routines had impacted them spiritually. Dinah, who is Universalist, began to practice yoga while in recovery from mastectomy surgery. She described how the practice transformed her relationship to her body, which was especially important to her in the wake of major physical changes. Other participants described that they had come to enjoy and appreciate exercise in ways they did not before diagnosis. These stories revealed transformations in how participants related to their physical bodies. Rather than viewing their bodies as sites of pain or disability, they were re-described in terms of survival and capability. Women who had recovered from major surgeries spoke of their bodies in terms of their recovery. Most women described their physical pain in ways that emphasized what they were capable of doing despite limitations.

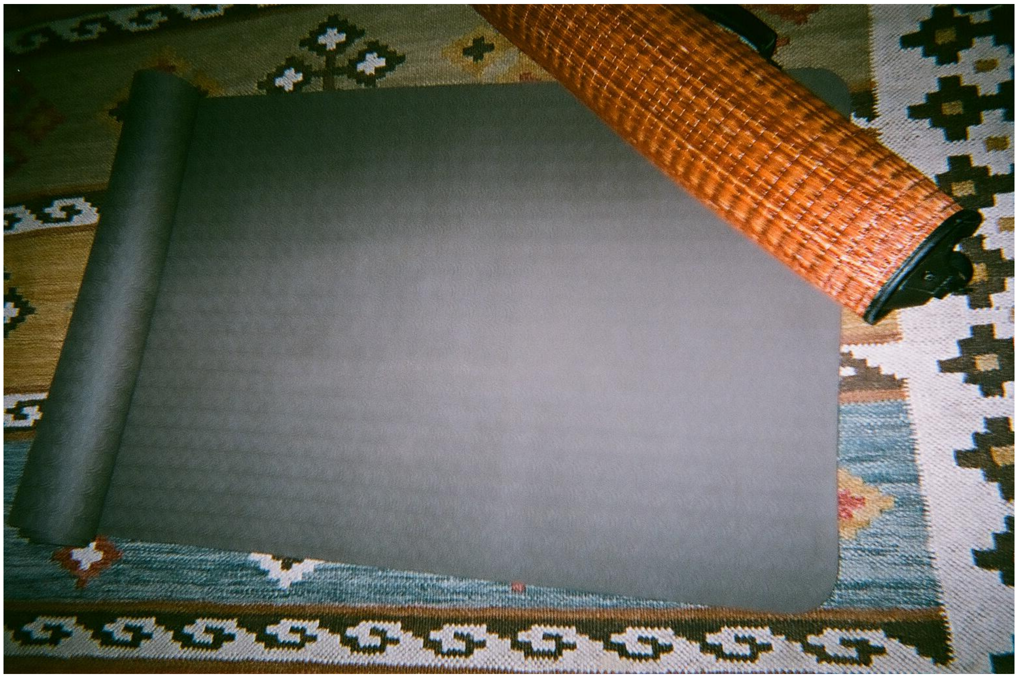

Figure 3.7
Photograph taken by Dinah

"Physical recovery is for the fullness of my life, I'm motivated by honoring all parts of my life and that's totally church for me – honoring that this was part of my journey, for me to learn, for me to grow from."

Perhaps the most surprising theme – one that I did not account for in the structured part of the interviews – was the centrality of a changing relationship to the natural world. Every participant in this study included photos of nature, and each of them told stories of how they related to nature in their daily lives. Their stories ranged from descriptions of gardening as a peaceful practice, to metaphors for life gleaned from observing plants or water.

Figure 3.8
Photograph taken by Jada

"The greenery, the natural environment – they settle with me."

Figure 9
Photograph taken by Nina

"I just thought I'd go over there and just sit…you know how water is peaceful."

Figure 3.10
Photograph taken by Nina

"I think one day I was praying and looking at the sky."

No matter where they found ways to interact with the natural world, each of the women interviewed intentionally included these stories. Their narratives reference the natural world as a source of peace and consistency, sometimes in specific comparison to the nature of illness as arbitrary and unbiased.

> *Illness doesn't care what you look like, it doesn't care. If illness doesn't care, then why should love care? Just as you have chronic illness you should have chronic love. Illness has made me consider things differently – I'm more present.* (Dinah, participant interview)

No one in this study had been recently diagnosed, and most of the interviews reflected a thoughtful attribution of meaning that had likely been developed over time. Still, many participants expressed that they had rarely shared the story of their illness in its entirety. A select few participants felt it important that they use the lessons from their experience to positively influence the lives of other people. This altruistic impulse was most prominent in the narratives of women who had recovered from major medical interventions. Sometimes it was articulated as a religious impulse – the desire to bear witness to the power of faith and the love of divinity. Other times it was presented as the responsibility of survival that they use the lessons of their illness experience to improve the lives of others. The inner transformations that these women underwent led them to seek to share the ways they felt their lives had been improved. In some cases, this meant public disclosure and openly sharing about their illness journey. In others, it meant sharing by personal example, putting the insights they had gleaned into practice, and allowing their choices to speak for themselves.

Figure 3.11
Photograph taken by Dinah

"This is religion in my daily routine, these people are my family and my long-term friends...this is really religion for me. They all have different attitudes, they all have different ways, for me, this is my church. dealing with them, learning to accept them, learning to love them exactly as they are, this is my religion. And its personal, just for me for my spirit. These are the people I love and embrace. This is it every day."

When asked, many participants expressed that they had participated in this project with the intent of sharing information about their experience that might help someone else. An altruistic intent seemed to be tied to a feeling of accomplishment for participants – the sense that they had survived, were still surviving, and had something they wanted to share as the result of their experiences.

CHAPTER IV

CONCLUSION: SUMMARY AND IMPLICATIONS

"Caring for myself is not self-indulgence, it is self-preservation,

and that is an act of political warfare."

– Audre Lorde, *A Burst of Light* (1988)

Reflections on Study Design and Methods

This project opened the door to understanding common themes in the illness experiences of religious Black American women. There were many benefits, both anticipated and unexpected, that arose from the use of photovoice and photo-elicitation in the qualitative interviews conducted for this study. I became familiar with these methodologies in the contexts of community organizing and public policy, as a tool to gather data from community members about the issues that affect their lives. The visual data that these methods generated, as well as the narrative data evoked in photo-elicitation interviewing, facilitate an analysis that takes time and memory into consideration. The visual data further contextualizes the information presented in interviews and gathered in participant observation.

Interviews were conducted in the location of the participant's choice, and many took place in participants' homes. In some cases, I joined participants in cooking a meal or in other routine activities. The interviews that were the most rich in data often felt like two interviews: a first, more formal interview, then a re-telling of the same stories once a participant felt more familiar with me. The visual data and the intimacy of the interview setting supplemented narrative data to further reveal the layers of meaning that participants navigate in their illness journeys. The themes that emerged in this study illustrate some commonalities in experience, even among women in very different social circumstances.

Social Resources and Social Roles

Scholarship on Black American women's health has described the many ways that social inequalities impact their health outcomes, even beyond access to high-quality, culturally appropriate healthcare. This research further illuminates the way social conditions impact the way Black women themselves define and support their own health. Limited social and material resources determine the options available to individual women in their illness experiences, as well as their ability to prioritize their health in their daily routines. Competing priorities, including the needs of other people, often take precedence over the ways women can meet their own physical, social, mental, emotional, and spiritual needs in navigating chronic illness. These interviews revealed the ways individual women choose to prioritize or de-prioritize their own health over time, in various circumstances, and with varying degrees of support.

In addition to navigating access to resources, women must also manage a myriad of social expectations within and beyond their illness journey. Obligations to other people took high priority in the minds of most participants. The vulnerability of having to depend on other people for various types of support was difficult for most women in the study, and their social roles were challenged as a result. In addition to the demands of their daily lives and social relationships, women living with chronic illness described navigating new expectations for their behavior and emotions in responding to the illness itself. These narratives reveal how dominant narratives have shaped expectations of Black women and how they will respond to hardship, including how they interpret and respond to illness. Familiar themes of strength that recall the trope of the strong Black woman arose in multiple interviews. Participants described changes in their definitions of strength and competence, particularly in response to external expectations that they found to be unrealistic or unfair. Over time, more women shared definitions of strength that define it in terms of limitations they have overcome, and that allow their responses to stress to be understood as reasonable. Instead of minimizing or denying emotions like sadness, anger, and overwhelm, several interviewees ultimately expressed pride in their ability to maintain aspects of their lives and identities even while managing these emotions.

Healing Priorities and Self-Advocacy

In negotiating changes in their social relationships during illness, many women interviewed had to advocate for themselves both physically and emotionally. This self-advocacy involved learning various ways to communicate their changing capacities to the people in their lives. In responding to social circumstances and the expectations of others, participants often engaged a process of assessing their own capacities and limitations, defining their needs, and determining their own priorities in their illness journey. This ongoing process of self-reflection became necessary in order for an individual to establish and maintain boundaries with other people, as well as to identify the types of support she needed. This was not always an explicit or intentional process, but participant narratives consistently illustrate changes in communication and self-advocacy over time. It was new for most participants to prioritize their own health and wellbeing in this active way, and assessing their own needs often challenged the ways they saw themselves and defined their health.

Although each participant described different goals and motivations in responding to illness, there were some common themes. I have referred to these as "healing priorities." These priorities indicate which outcomes are most important to an individual in navigating illness experience, and reveal the interpretations that may motivate their choices.

All participants expressed their desire to relieve any physical pain and other symptoms of illness. While this was a primary motivation in seeking medical care and alternative therapies for many women interviewed, they also expressed the desire to minimize the physical impact of medical treatments and medications.

Participant narratives reveal that individual women are concerned with maintaining and managing the perceptions of other people as they respond to the changes in their lives produced by illness. It was most important to most participants to address those physical symptoms that impacted their capacity to meet routine obligations and maintain relationships. The way women in this study prioritize their management of symptoms of illness is connected to their concern with maintaining their social roles and daily lifestyle — another common healing priority. This priority also led participants to address symptoms and treatment effects that impacted physical appearance. Rarely was vanity or unhappiness with personal appearance cited as a reason for this focus. Rather, participants described concern that other people who identify them with their illness, to the exclusion of their other identities. Their concern was due to a desire to maintain their social positions, regardless of social stigma or judgement from other people.

Maintaining social relationships, lifestyle, and appearances were priorities for most participants even at the outset of their illness journeys. Over time, other priorities emerged that influence how individual women navigate illness experience. One of the most prominent themes was the ability of a participant to receive support when they requested it. In the wake of diagnosis with a chronic condition, many participants expressed feeling more dependent on the people around them. While being less independent was difficult for most of the women interviewed, several of them also described feelings of disappointment and confusion when their requests for support were not met within their social networks. Participants with the most well-established networks of support described how they eventually sought distinct kinds of support from different people or social groups. For example, they might ask one person for a ride to the hospital, and ask a different person for emotional support in a time of difficulty. Learning who to ask for various types of support was part of the ongoing process of self-advocacy. For some women, the decision to involve themselves in religious community was partially motivated by the desire for extended networks of social support. Intentionally establishing multiple social networks allowed individual women to seek and receive the range of support they needed from a wider variety of people.

Changing Routines and Perspectives

Whether or not these healing priorities were communicated explicitly, all participants made choices in their lives to support their own goals in responding to illness and the changes it produced in their lives. There were various types of change that individual women engaged to manage illness, including a transformation of their daily routines, relationships, interpretations, and identities. In the wake of diagnosis, most participants altered their patterns of daily life in significant ways, including their diet, work patterns, social activities, and physical activity. While these changes were initially intended to make life manageable by reducing stress and physical challenges, many interviewees expressed that their new routines had also changed their relationship to their own bodies. Particularly in the case of increased physical activity or new workout routines, multiple participants specifically described learning to see their bodies as strong and capable, even in the face of illness and physical limitation.

In addition to altering daily habits, participants also described how they had established new spiritual routines. For most women in this study, these personal rituals centered on mindfulness, an appreciation of the present moment, and a mindset of gratitude. One of the most surprising emergent themes was the ways in which women intentionally developed their relationships with the natural world, making a special effort to spend time outside, near water, and near plants. In some cases, these practices brought new healing priorities into perspective, including emotional balance and inner calm.

Several participants spoke about wanting to include their families in these lifestyle changes. This desire was not only based in the need for support from the people around them, but also because they became concerned with the ways their lifestyle could impact the health of their family members. In this way, the personal healing priorities of individual women were influenced by their obligations for other people, particularly in their social roles as mothers, daughters, and romantic partners. This altruistic intention extended beyond family for women who wanted to use their personal experience to offer support to others going through similar situations. These participants transformed the ways they learned to care for themselves into ways to care for others.

Some of the ways in which participants reconfigured aspects of their lives in response to illness can be considered to support strategies, particularly when these choices were motivated by the pursuit of specific healing priorities. The goals of each participant were specific to their own lives, circumstances, and beliefs — and not all responses to illness constitute a strategy. There were, however, several common types of response to each aspect of illness experience. Participant responses sought to minimize the impact of illness, manage its effects, transform its meanings, and/or create new meanings of health and illness in their lives.

Implications

These responses to illness and the strategies they support underscore the range of meanings that can become important to an individual in her illness experience, and that may shape her priorities in responding to the changes that illness creates in her life. An understanding of personal priorities can help contextualize individual medical and lifestyle choices, which is particularly important in developing effective medical interventions and other supports for people living with medical conditions. In many instances of medical care and social support, providers and community members made assumptions about a chronically ill person's objectives that did not align with the individual's personal priorities. As more empirical data is gathered regarding individual healing priorities, dominant definitions of health and healing can be expanded to include the many ways chronically ill individuals come to define their own well-being.

The exploration of individual healing priorities among the participants in this study opens the door for new understandings of coping and response to illness, particularly in the context of faith, religion, and spirituality. Among participants, several aspects of religiosity emerged as significant in their illness narratives: religious belief, religious practice, and religious community. These elements of religion presented both challenges and supports for individual health. Religious beliefs and practices often shaped the meanings that women engaged to interpret their illness, and religious community potentially offered networks of social support beyond family and friends. Still, religious institutions and communities also reinforced expectations for belief and behavior that participants found challenging as they managed chronic illness.

Even when they experienced supportive religious communities, many of the changes in perspective described by participants were characterized as part of their personal spiritual practices. While religion offered access to shared meanings, spirituality created opportunities for individuals to continuously reconfigure those meanings an interpret them in the context of their own lives and experiences.

In the context of chronic illness, coping can be understood as a nuanced and ongoing process of response to change. Chronic illness creates changes in physical ability, in relationships, and in personal identity. Individuals rely upon meanings available to them, new and familiar, in order to navigate the stress and uncertainty produced by these changes. This ongoing process of re-interpretation and narrative reconstruction is influenced by several factors, including an individual's experience with uncertainty in the past, as well as her ability to imagine different possible futures for herself. Participant narratives engaged faith as an active, even intentional orientation that has the potential to guide choices in the context of uncertainty and facilitates adaptability in a changing reality. Coping in the context of faith was not just a series of reactions; rather, faith provided individuals with tools and strategies to create and act upon new meanings, imagine alternative outcomes, and expand what they believe to be possible in their own healing journey.

As they confronted changes in their bodies and their lives, women in this study developed new understandings of health and well-being. Their priorities in responding to illness often changed as they considered what it would would take to feel like themselves in new circumstances. Their reconfigured identities often had to account for new relationships to mortality, to their own embodied experience, and to other people — including increased dependence on others. For example, one participant described feeling that her independence was a major part of who she was before the onset of chronic illness symptoms. In the beginning of her illness journey, reducing her dependence on other people was a major healing priority for her. Over time, as she accepted the idea that there were certain kind of supports she would need long-term, her priorities shifted from being completely independent to being able to request and receive the support she needs. Although most women interviewed expressed dismay at a loss of independence, several participants used positive language to describe receiving care and support from other people, citing their appreciation for the love they received in the form of support. In patient narratives, a successful system of social support was commonly reframed as a positive expression of love from other people, rather than being characterized solely by feelings of helplessness. For these women, the meanings of dependence were transformed through their illness experience. Instead of interpreting their own need for support according to an independent vs. dependent framework that holds dependence to be morally undesirable, some participants came to value their ability to rely on support from others as a significant positive aspect of their lives. For some participants, the experience of chronic illness was the first time that they had sought support from other people; the gratitude and relief they expressed at receiving it was new to them, as well. These findings underscore the importance of establishing effective networks of support in chronic illness experience, as well as the benefits of being able to assess and communicate changing capacities in order to maintain these networks.

Changing physical abilities was a common challenge among participants, often catalyzing a transformation of participants' relationships to their own bodies. Participant narratives cited new exercise routines, new diets, changing physical capacities, changing appearance, and the experience of pain and discomfort as factors in how they felt about their bodies. Many women described feeling frustration and anger at their body and its limitations during illness, and for some of them, this never changed.

For others, however, their journeys in managing physical changes led them into new perspectives of their bodies. Some women came to view their bodies with gratitude and appreciation for their own survival. Participants frequently referenced how they had to determine when to "slow down" and when to "push through," engaging a process of negotiation with their bodies. "Pushing through" often meant that an individual ignored signals from her body that she needed rest and continued to engage a stressor, usually motivated by priorities other than personal well-being. "Slowing down" referred to changes in lifestyle to accommodate physical limitations and prioritize personal health.

This ongoing process of negotiation characterizes a range of participants' strategies for coping with the changes associated with chronic illness. For this reason, I refer to individual responses to illness as part of a health journey, occurring in the context of continuously changing physical, social, and psycho-emotional landscapes. The ways in which participants defined and prioritized their own health depended on their management of multiple, often competing priorities. The transformations of meaning facilitated by personal faith often meant that participants were more comfortable with the risks they perceived as associated with prioritizing their own health. While many women described fears that their illness would negatively impact their social roles and relationships, those who "slowed down," communicated their needs, and sought support from others found new ways to consider and attend to their own health, even while managing other commitments.

One significant way that participants shifted focus was to increase their attention to mental and spiritual health. While my initial approach sought to understand participant responses to depression and isolation, the interviews revealed that participants themselves were focused on maintaining emotional balance and internal peace at all times, but particularly in times of emotional hardship. This priority was apparent in participants' descriptions of their expanding connections to the natural world, which they viewed as a significant aspect of their spiritual health. Again, these choices and the priorities they support reveal coping to be more than a reaction to circumstance; rather, it can depend on maintaining and strengthening routines of self-preservation and self-care beyond the illness experience itself. It was not only self-preservation, however, that led women to prioritize their own health. While it was common for participants to value the needs of others over their own, those who developed ways to prioritize their own well-being also communicated insights from their illness experience as a way to benefit other people. The themes of testimony and witness describe an altruistic choice to share personal narratives and the useful aspects of individual coping and healing strategies, with the goal of helping people who could usefully engage them.

This project has offered significant insight into how individual religious, Black American women navigate change and uncertainty, develop tools for self-advocacy, negotiate competing priorities, and expand their definitions of health and healing in the context of chronic illness. This research introduces understandings of coping and faith as active, mutually influential processes. The combination of narrative and visual data analysis reveals the meanings that become important to women in times of hardship, and the ways that individuals may transform these meanings to maintain their sense of self. This information is potentially useful even beyond the context of illness, as Black women navigate significant social and structural challenges to their well-being. We can learn to structure systems of social support and medical intervention according to data on what is important to people as they respond to illness.

Individual women develop their own healing priorities and strategies for response to change in ways that depend upon personal and collective meaning systems. The transformations of meaning and identity that characterize Black women's survival in the context of illness represent the manifestation of both inherited and invented cultural cosmologies, survival strategies, and healing modalities. Establishing and maintaining conditions that support Black women's health requires that we honor the creative epistemologies they have engaged and elaborated to survive — in relationship to themselves, to other people, to the social world, to the natural world, to time and memory, and in relationship to divinity.

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9/6/2022
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