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"How Connected is This Heart?": The Religious and Spiritual Lives of Women of Color with Heart Disease

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"How Connected is This Heart?": The Religious and Spiritual Lives of Women of Color with Heart Disease

by
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Dedicated to

Dr. Amy C. Visser

and

Dr. Ibrahim Abdurrahman Farajajé

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“How Connected is This Heart?”:

The Religious and Spiritual Lives of Women of Color with Heart Disease

Megan Visser

Abstract

Religion/spirituality may be as complex a characteristic as race, culture, age, sexuality, gender, or socioeconomic status. Yet, religion/spirituality is not frequently included in sociological analysis with these other factors. For Women of Color who are dealing with chronic conditions, such as heart disease, religion/spirituality is both a health resource and an important facet of daily life. Since nearly one in five female deaths in the US is caused by heart disease, it is important to understand how Women of Color cope with their illness using religious/spiritual resources (CDC 2020). In this dissertation, I used an interpretive phenomenological research design to develop an initial understanding of how religion/spirituality and illness experience shaped one another and changed over time. In multiple in-depth interviews, 13 Women of Color with heart disease and I explored together how their religion/spirituality and illness experience shaped one another and changed over time. I interpreted whole cases to develop a detailed description of how religion/spirituality was embedded in the lived experiences of Women of Color with heart disease and changed as they encountered turning points in their lives, ranging from health crises to progression in their illness trajectory. This interpretation revealed three patterns of being related to how the connection between religion/spirituality and health changed during participants’ lives: relational change, intersectional change, and receptivity to change. (1) *Relational Change*: Religious/spiritual relationships connected to women’s sense of self, God/Higher Power, families, congregations, and faith groups changed as they aged and responded to health crises.

(2) *Intersectional Change*: Religion/spirituality's influence on health was negotiated within the shifting rhythms of access to health care, gendered racism, and other burdens connected to marginalization. (3) *Receptivity to Change*: Women were receptive to offers of support, interventions and new ideas related to the relationship between their religion/spirituality and their health. These three patterns of being hold implications for the fields of sociology, medicine, and religion, including potential interventions and future investigations to support Women of Color who deal with heart disease. Also, this research began approximately one year into the 2020 US COVID-19 pandemic. Thus, my research findings also shine a light on the ways in which the pandemic disrupted the religious/spiritual and care practices of Women of Color with heart disease. These findings suggest that the bidirectional relationship between religion/spirituality and health in the lives of Women of Color with chronic conditions is transported to their health care and may be used as a coping resource when other resources have been exhausted. Dimensions of Women of Color's religion/spirituality and health are best addressed by understanding their lived experiences *on women's own terms*.

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CHAPTER 1: INTRODUCTION

> One of the statements that we use in our practices, is what matters first is the matter of the heart. The matter of the heart is the most important thing over anything else. And for me to be going through this with my heart, I had to make the connection. Yeah. You know, this is my heart that we are talking about! And it's in my practice, telling me what matter most is a matter of the heart. It is the most important thing of all. So, that made my connection stay when I went through the dark night of the soul, as my friends call it. . . . Just imagine **how connected this heart is**, right? (Cherie, Buddhist)

Religion/spirituality may be as complex a characteristic as race, culture, age, sexuality, gender, or socioeconomic status. Yet, religion/spirituality is not frequently included in sociological analysis with these other factors (Padela and Curlin 2013). People may use religious/spiritual experiences to find purpose and meaning in their lives (Pew Research Center 2015). They may also use religious beliefs, practices and support from religious/spiritual communities to interpret challenges in their everyday lives (Harris et al. 2013). Religious/spiritual resources may provide many different functions in crises or everyday life, including providing comfort, meaning, a sense of control, assistance in changing one's own behaviors, and connection with others or with a higher power (Pargament, Koenig, and Perez 2000). Religious/spiritual experiences may have an important role in people's daily lives and how people see themselves. There is a lack of understanding of how religious/spiritual experiences change over time (Park et al. 2008).

Many people use religion/spirituality as a set of resources to deal with difficult life circumstances, or to cope (i.e., successfully adapt) with life issues, such as exposure to trauma or the death of a spouse, as well as stress that can arise in daily living (Conwill 1986; Padela and Curlin 2013; Pargament et al. 2000; Park et al. 2008; Warnock 2009). Religious/spiritual resources are used across socio-demographic categories, such as age or race (Pargament et al.

2000). Religious traditions have practices and beliefs that overlap or serve similar purposes to one another. For instance, Buddhists and Hindus use sitting meditation as a major spiritual practice that involves self-discipline, silence, and repetition. Important days of observance may fall on different days of the week and regular gatherings may have different names, but people from multiple traditions hold attendance at a specific hour of group spiritual practice as central to what helps people feel connected or belonging to a religious community (Juergensmeyer 2003). I was interested in how people across religious traditions use religious/spiritual resources to deal with life circumstances, such as a serious health condition.

Religious/spiritual beliefs may play an important role in a person's understanding of health conditions and help them make decisions about care and treatment (Hunter-Hernández, Costas-Muñíz, and Gany 2015). People have used traditional healers, such as a shaman, or relied on the prayers of other people as forms of complimentary or alternative medical treatments (Levin, Chatters, and Taylor 2011). Religious/spiritual rituals, such as healing ceremonies or anointing a person with oil, have been used for centuries to treat serious health conditions (Aziato and Omenyo 2018; USCCB 2006). Personal religious/spiritual practices may be important healing tools for people regardless of their affiliation or involvement with a particular religious/spiritual tradition. For instance, studies have suggested that spiritual meditation techniques may decrease a person's anxiety or improve their mood (Morone et al. 2016; Wachholtz and Pargament 2005). Researchers have long accepted that religion/spirituality has some influence on health. More research is needed to understand how religion/spirituality affects a person's health, including the role that religion/spirituality plays in the experiences of people with chronic health conditions over time (George et al. 2000; Rippentrop et al. 2005).

In the past 25 years, spirituality and health researchers have taken more interest in studying the experiences of people with chronic conditions (Hall, Koenig, and Meador 2008; Rippentrop et al. 2005). Approximately half of US adults have at least one chronic condition (Raghupathi and Raghupathi 2018). A chronic health condition is a serious illness that lasts a long time and cannot be cured by medication or treatment, nor prevented by some other means (Goodman 2013; Ward, Clark, and Heidrich 2009). There are a variety of ways that a chronic condition can change a person's life: pain, limited mobility, stress on family and caregiving relationships, financial challenges, reduced social activity levels, and the need for specialized support and care (Rippentrop et al. 2005). People may use religious/spiritual resources to cope with their chronic conditions (Unantenne et al. 2013). For example, community involvement, prayer, and clergy visits were found to be positively related to spiritual well-being, remission from depression, and less fatigue for a person with a chronic condition (Hays et al. 2011; Makros and McCabe 2003). HIV researchers found that spirituality was associated with better mental health and fewer HIV-related symptoms (Buttram 2015; Szaflarski et al. 2012). It is not clear *how* religious/spiritual experiences shape the ways people deal with their condition. I was interested in learning how religious/spiritual experiences influence the ways Women of Color deal with heart disease.

Heart disease is the most prevalent cause of death for people in the United States, accounting for approximately one in every five female deaths (Bucholz et al. 2014; CDC 2020). For at least the past 20 years, researchers have agreed that significant racial/ethnic and gender disparities exist among people with heart disease, with regard to mortality as well as access and quality of care (Popescu, Vaughan-Sarrazin, and Rosenthal 2007; Qian Feng et al. 2013; Sheifer, Escarce, and Schulman 2000). Heart disease includes a range of conditions affecting

the cardiovascular system, such as coronary artery disease and congenital heart disease; these illnesses involve narrowing or blocking blood vessels or impairment of the heart's muscle, valves, or rhythm. Symptoms of heart disease are connected with cardiovascular events, including arrhythmias, stroke, myocardial infarction (heart attack), and heart failure (CDC 2020). Living with heart disease may include serious medical complications that can result in multiple hospitalizations during one's lifetime. People with heart disease experience symptoms that impact various areas of their lives and may contribute to increased anxiety, depression, and emotional distress (Jackson, Fox, and Kovacs 2020; Johnson et al. 2011; Tully, Sardinha, and Nardi 2017).

Adults with heart disease may have meaningful religious/spiritual experiences; they also may have religious/spiritual distress or struggle in their lives (Ai, Wink, and Shearer 2012; Clark and Hunter 2018; Fitchett, White, and Lyndes 2018; Koenig 2008). Recent studies have explored how people with heart disease use religion/spirituality to cope with their symptoms and related life circumstances (Koenig 2008). For instance, in a study of Jewish residents of Jerusalem, secular Jews had significantly higher risks for myocardial infarction than the Orthodox Jewish residents (Friedlander, Kark, and Stein 1986). A study of African Americans in Oakland, California with mild hypertension found that Transcendental Meditation sessions were twice as effective as Progressive Muscle Relaxation (a nonspiritual intervention) in reducing the participants' systolic and diastolic blood pressure (Schneider et al. 2001). Few studies have focused on the religious/spiritual experiences of Women of Color dealing with heart disease (Bauer et al. 2017; Blanc et al. 2020; Eichner et al. 2010; Jepson et al. 2012; Misra and Khurana 2010; Sidhu et al. 2016).

Many Women of Color use religion/spirituality to deal with a variety of issues in their lives, including health conditions (Gullatte et al. 2010; Hickman et al. 2013; Mattis 2002). My research assumed it was important to better understand how Women of Color cope with heart disease. My purpose was to understand several Women of Color's common or shared experiences of coping with heart disease using religion and spirituality. A second objective was to understand how religious/spiritual dimensions of a Woman of Color's life change over time as they age and as their illness progresses.

RESEARCH QUESTIONS

I framed the following research questions in order to understand the religious/spiritual experiences of Women of Color with heart disease as well as the bidirectional relationships between religious/spiritual experience and dealing with heart disease over time.

(1) What are the religious and spiritual experiences of Women of Color with heart disease?

(a) What are the religious or spiritual components of daily life for Women of Color with heart disease?

(b) For Women of Color with heart disease, how central are their religious or spiritual experiences in their view of themselves?

(2) How do religious or spiritual experiences shape how Women of Color deal with heart disease?

(a) How do Women of Color use religion or spirituality to cope with heart disease?

(b) What religious or spiritual beliefs and practices do Women of Color with heart disease identify as supporting them?

(c) What do Women of Color with heart disease identify as support that they receive from their religious or spiritual community?

(3) How does the illness experience of heart disease influence Women of Color's religious or spiritual experiences?

(a) How do Women of Color's experiences with heart disease affect their religion or spirituality over time?

(b) Do religious or spiritual beliefs and practices change for Women of Color as they deal with heart disease?

(c) Do Women of Color with heart disease change their involvement in a religious or spiritual community over time?

I used an interpretive phenomenological study design to understand 13 Women of Color's shared experiences of coping with heart disease using religion and spirituality (Benner 1994a; van Manen 1990). I conducted multiple interviews with each participant to draw out and understand the participant's daily life dealing with heart disease as well as the meanings of religious/spiritual experiences, beliefs, practices, and support in their lives. I investigated these phenomena through multiple interviews to reveal their meanings for the participants. In the process of collecting and analyzing interview data, I explored how religious/spiritual experiences and experiences dealing with heart disease shape one another in the lives of Women of Color over time.

OVERVIEW OF THE DISSERTATION

In this first chapter, I will describe the theoretical approaches that shaped this research and review the literature related to the research questions I developed. In the second chapter, I

will provide an introduction to the philosophical foundations of interpretive phenomenology and review the research design and process that shaped this research. Also, I will describe the methodological commitments I brought to this research as well as discuss some strengths and limitations to the trustworthiness of the results. Chapter Three is a window into the religious/spiritual lives of the 13 Women of Color with heart disease in the sample. I introduce each woman to share the religious/spiritual components of their daily lives and explore how central those experiences were in their view of themselves. Also, I provide a brief overview of three patterns of being that I found in the overall sample, and were exemplified by three different participants' full narratives, who are the main subjects of the next chapter. In Chapter Four, I describe in greater detail the lived religious/spiritual, health and daily life experiences of Ayo, Carmen and Mary, who were three paradigm cases. These cases helped me to understand the patterns of being that help explain the bidirectional relationship between religious/spiritual experiences and illness experiences over time. Chapter Five will deepen the interpretive account of these three patterns of being connected to how religious/spiritual experiences changed over time. These patterns include relational change, intersectional change, and receptivity to change. (1) *Relational Change*: Religious/spiritual relationships connected to women's sense of self, God/Higher Power, families, congregations, and faith groups changed as they aged and responded to health crises. (2) *Intersectional Change*: Religion/spirituality's influence on health was negotiated within the shifting rhythms of access to health care, gendered racism, and other burdens connected to marginalization. (3) *Receptivity to Change*: Women were receptive to offers of support, interventions and new ideas related to the relationship between their religion/spirituality and their health.In Chapter Six, I will turn to focus on how the US COVID-19 pandemic and its secondary effects shaped the religious/spiritual and illness experiences of

the women who participated in this research. I will describe how Women of Color with heart disease used religious/spiritual resources to cope with pandemic-related stress and how they adapted these resources to meet new needs and social constraints. The results that address pandemic conditions might help us understand the experiences of Women of Color in dealing with a chronic condition during a global public health crisis, as well as the ways such a crisis exacerbated existing problems in accessing quality health care and the need for religious/spiritual coping resources when other forms of coping are not available or exhausted. In the concluding Chapter Seven, I review the contributions of this research to the discussion of religion/spirituality and health across multiple disciplines. I will provide suggestions for potential interventions and future investigations to support Women of Color who deal with heart disease. I will describe implications for the sociology of health and illness, medicine and religion. Overall, I will describe how my findings suggest that the bidirectional relationship between religion/spirituality and health in the lives of Women of Color with chronic conditions is transported to their health care and may be used as a coping resource when other resources have been exhausted.

Dimensions of Women of Color's religion/spirituality and health are best addressed by listening to their voices. Now, I will turn to the theoretical approaches that helped me design this research with this commitment in mind.

THEORETICAL APPROACHES

Theoretical approaches from the sociology of health and illness and religion shaped this research and the interpretation of the data. In this section, I describe key theoretical approaches to religion/spirituality that helped to develop this research and understand the key issues of importance to religious/spiritual Women of Color with heart disease. The theoretical discussion

helped me to approach the interpretive phenomenological study as well as develop the interpretation of whole paradigm cases and narrative exemplars from the data. Into this journey, I carried my interactionist foundations in sociology,, which I do not take for granted but which I do not cover exhaustively here (Cho, Crenshaw, and McCall 2013). First, I describe three theories connected to religion/spirituality: the relational framework for the study of religion/spirituality, organic multireligiosity, and lived religion. Then, I include theories from the sociology of health and illness that helped me to describe the experiences with heart disease included in my research, including illness trajectories, life course perspectives, and theories of coping. Before describing these theoretical approaches, I briefly address the terms religion/spirituality as a conceptual package, which I used throughout this research.

Religion/Spirituality, a Conceptual Package

Throughout this dissertation, I have used religion/spirituality as one term to describe a multi-faceted conceptual package. In sociology, religion and spirituality have been studied separately and together, or as a specific factor, such as religiosity, religious orientation, or spiritual well-being. Recent studies of religion and health have relied on the work of Émile Durkheim (2005, 2012) directly to ground their research questions and define religion. Durkheim's theory of religion famously separated sacred aspects of life from the "profane," or everyday life. While his ethnographic observations about aboriginal groups have been extensively discredited, Durkheim's ideas about religion helped clarify his views of society (Idler and Kasl 1997a, 1997b). He concluded that religion was a reflection of social integration in society, consistent with his broader project: to understand how the individual fits into society (Collins 1994). He argued that any religion was a mirror of society's structure regardless of its level of sophistication. Durkheim's perspectives had long-lasting effects on interpretations of

religion in the fields of sociology and psychology (Hall et al. 2004; Hill et al. 2000; Idler and Kasl 1997a, 1997b). Over the last 10 years, Durkheim had been a major source in the theoretical background for a number of published articles investigating the relationship between religion and health (Ahmadi and Ahmadi 2017; Argo 2009; Band, Dein, and Loewenthal 2011; Cohen et al. 2012; Cruz-Ortega 2013; Dumangane Jr 2017; Goodman et al. 2013; Kannan et al. 2010; Lim and Putnam 2010; Pargament and Lomax 2013; Petts 2018; Rodríguez-Galán and Falcón 2018; Sasaki, Mojaverian, and Kim 2015; Simonič and Klobučar 2017; Sternthal et al. 2010; Turley et al. 2020).

Durkheim's point of view that religion would eventually fall to secularization in society had staying power in the social scientific study of religion and popular ideas about religion in society. Also, few other theoretical frameworks have been developed to demonstrate if or how well religion supports "social support and integration" (Idler and Kasl 1997b). This leads to an important question for the purpose of this research: has this theoretical trend reinforced the lack of engagement with religion as a social phenomenon alongside other social factors such as race and gender? Newer indicators and frameworks of religion/spirituality had privileged certain components of religion/spirituality. Some focused on religious orientation (such as extrinsic or intrinsic) and religious commitment (such as religiosity, attendance, or strength of belief). More recent studies of religion relied upon Durkheim's perspective to hypothesize that attendance at religious services reflected one's obedience to social norms in other areas of life, such as intimate relationships and health behaviors (Idler and Kasl 1997a). Also, it was suggested that measures of religiousness were just a reverse measurement of secularism, rather than illuminating another aspect of experience (Hall et al. 2008; Pesut et al. 2015). Yet, survey data about the religious landscape in the US showed that religion/spiritual experience had multiple

facets that vary in importance and centrality in people's lives, changing over time (Pew Research Center 2015). For instance, the Pew Research Center (2021) found that Black American adults almost all believed in God or a higher power, regardless of religious tradition; yet Black Americans were evenly split in terms of their view of whether belief in God was a requirement for someone to be a moral person or associated with "good values" and 76% included "opposing racism" as an essential component of what their faith means to them.

Spirituality is a concept that overlaps with religion and emphasizes more personal and experiential notions of "the sacred" (George and Park 2017a; Hill et al. 2000; Hunter-Hernández et al. 2015). Some people may claim to be "spiritual" or to value spirituality, whether or not they identify as religious. In everyday use and some of the literature on religion and health, spirituality and religion were interchanged, and their definitions are intertwined (Unantenne et al. 2013). Both concepts retained a "focus on the sacred or divine, beliefs about the sacred, and the effects of those beliefs on behavior" (Unantenne et al. 2013:1148). I resisted polarizing these two terms based on recent research on how these concepts direct my interests in how religious and spiritual expressions take place in their proper contexts. Unantenne, Warren, Canaway and Manderson (2013) called into question whether one must differentiate religion from spirituality to explore the effects of each or both on people with chronic conditions, such as heart disease. Hill et al (2000:65) argued it is problematic to "speak of either individual spirituality or institutional religion," because religions were concerned with spiritual things and spirituality and religion were socially expressed. They also refuted the idea that "spirituality is good and religion is bad (or vice-versa)" because there are the possibilities of negative and positive (harmful and helpful) instances of either one (65). This discussion leads me back to the

purpose of this study, which is to address *how* religion and spirituality are practiced by Women of Color in coping with their heart disease over time.

As a theoretical lens and to focus on practices, I used religion/spirituality as a conceptual package and honored the language of the participants in my research. If religion/spirituality is a form of meaning-making, then it is appropriate to also observe and honor the understanding of the people who have the experience and shape meaning of such activities for themselves. Therefore, as a theoretical lens, I relied on approaches to religion/spirituality that privilege lived experience over "outsider" Enlightenment paradigms of religion/spirituality (Nyhagen 2017; Spickard 2018). Consistent with my methodological approach and the theories presented here, I acknowledge that participants will self-interpret their experiences with religion or spirituality. During the interviews and in the interpretation of data, l privileged the ways participants name and define their experiences as religious, spiritual, religious/spiritual, or otherwise. Occasionally, a participant would identify things they considered to be spiritual as distinct from their religious affiliation or identity. Some used the word "faith" to describe their religion/spirituality almost exclusively. Two participants, Violet, and Diya, spoke about their lives without distinguishing religious or spiritual activities from other activities, because the patterns of their lives were shaped by their religion/spirituality from morning to night and in all their relationships.

Relational Framework for the Study of Religion/Spirituality

Jacqueline Mattis and Robert J. Jagers developed a conceptual framework for studying the religiosity/spirituality of African Americans in the United States (Mattis 2002; Mattis and Jagers 2001). The relational framework arose from the notion that religion and spirituality are complex and deeply social phenomena, open to change and changing intensity during one's

lifetime. Religious/spiritual relationships are interrelated at different ecological levels (individual, family, institutional, community) and change over the lifespan or based on development. Mapping religion/spirituality across these social locations and transformative times in one's life helped me to understand the multiplicities of religion/spirituality within a person's life. People are socialized religiously and spiritually through their connections to family, peers, or other important relationships in one's life. For instance, with regards to theistic belief, "the very act of believing in God places one in relationship with, and immediately invites reflection on one's connections and obligations to, this Other" (Mattis and Jagers 2001:520). In a relational framework, religious belief is not a static religiosity or simply extrinsically or intrinsically motivated; instead, religious belief (or practices, support, etc.) is woven in connection with relationships (Mattis and Jagers 2001). Mattis and Jagers (2001) concluded that their framework responded to the overly simplified and disinterested look that psychology research had given to African American religion/spirituality with little attention to the diversity of cultural, ideological, and experiential dimensions of religion/spirituality among African Americans. Based on their conclusion, I believed that this framework contained sufficient breadth to be applied beyond African Americans to other communities of Color. Each participant included in this research described relationships (with God, family, institutions, and groups) as a part of their religion/spirituality during their lifetime. From my interpretation, I found some participants described patterns of change that interacted within and shaped key relationships. Also, changes in relationships at key times in women's health journeys shifted religious/spiritual values and activities.

Focused on health issues for African Americans, Mattis and Jagers (2001) also attended to the relational outcomes of religion/spirituality, which becomes activated in mental,

emotional, and behavioral ways through socialization. Mattis and Jagers (2001:521) explained: "We are concerned with the links between religion, spirituality, and such experiences as guilt, anxiety, altruism, hope, happiness, forgiveness, trust, love, the search for relational commitment, the search for personal significance, the construction of a sense of community, and involvement in acts that promote social justice." Through relationships, religious/spiritual experiences connect to feelings and actions that may provoke other life activities or behaviors also linked to one's health or to other domains of experience (in addition to other areas of their social and community experiences). A framework for religion/spirituality in the lives of women with chronic conditions must be able to withstand and account for the intensities of emotions and progressive phases of illness over one's lifetime, which realistically transmits through experiences in community as well as isolation.

Beginning this research as a theological scholar and justice-minded pastor, I was pleased to find a theoretical framework that did not attempt to be morally neutral in its narrative of history and its direct impact on relationships related to religion/spirituality and health. The relational framework helped researchers to take seriously the work of African American theologians who addressed issues of racism, oppression, and "the quest for liberation, love, hope, and justice" (Mattis and Jagers 2001:523). Religious/spiritual experience exists in a web of individual, family, and community relationships; it also connects to (and often necessitates) moral commitments to social action and participation in community empowerment. Religious/spiritual themes, such as freedom from suffering, building Beloved Community and social solidarity, should not be overlooked in the study of religion/spirituality and health. In this research sample, advocacy and justice-making were built upon religious/spiritual foundations and connected to illness experience. Thus, my interpretive work with participants made use of

the important themes and commitments defined in the relational framework of religion/spirituality (Mattis and Jagers 2001).

The relational framework of religion/spirituality fit the research questions I explored for several reasons. A relational framework rejects the idea that religion/spirituality is strictly an individual-level concern or internally consistent across individuals. It turned my attention to the tethers between religion/spirituality and a variety of dimensions of human experience that bring us into contact with others. It helped me to approach religious/spiritual experiences as central (or not) in Women of Color's lives as part of a complex, changeable tapestry of relationships (rather than simply competing priorities or activities themselves). Second, it relates to my aim to understand "how" religion/spirituality shapes the experience of dealing with heart disease, possibly by "activating" or promoting interactions among people. In dealing with heart disease, how do religious/spiritual beliefs, practices, or community involvement lead Women of Color to pursue, assess, or change important relationships? Lastly, the connection between moral commitments or social action and religion/spirituality in the relational framework makes explicit the link between dealing with heart disease and challenging and seeking freedom from oppression as a community. Amid adversity, religious/spiritual resources can support well-being by cultivating self-empowerment, diminishing hopelessness, or encouraging advocacy (Mattis and Jagers 2001:523). Investigating the question, "How does the illness experience of heart disease influence a Women of Color's religious or spiritual experience?" I needed to employ a framework of religion/spirituality that engages directly with the conditions and effects of racism and sexism that permeate the illness experience of heart disease for Women of Color (Barber et al. 2016; Conway-Phillips et al. 2020; Cozier et al. 2006). The relational framework supported my work with participants and interpretation of the data.

> how are the ways in which concepts of nation-state and purity of borders shape how we study religions? what are the interconnections between Religionswissenschaft and the origins of nation-states? If bodies are divided into 'identities' and 'nationalities', each with their discreet characteristics, can they also be divided into 'religions,' which also have clear borders between them? (Farajajé 2012b)

Before his death in 2016, Ibrahim Abdurrahman Farajajé was the fourth member of my dissertation committee; he was a colleague and mentor to me as a new faculty member while Farajajé was Provost of Starr King School for the Ministry, and Professor of Cultural Studies and Islamic Studies at the Graduate Theological Union in Berkeley, California. A Black queer Sufi theologian and improvisational scholar-activist, Farajajé developed a model of organic multireligiosity in an immersive, evolving process that emerged through and infused the school and all who touched it. The term "model" may be insufficient to categorize their work. A better set of descriptors might include: ethos, mystical Sufi order, hip-hop aesthetic, ritual construction, scholar-activism, and pedagogy (Farajajé 2004a, 2004b, 2012a).

Organic multireligiosity rested upon two perspectives: (1) Antonio Gramsci's concept of the organic intellectual,[1] in which scholarship is deeply connected to and emerges from lived experiences within communities; and (2) notions of race, gender, health, and religion/spirituality are always in flux and connected (Farajajé 2004, 2012b). From his note, "Organic Multireligiosity: Counter-Oppressive/Counter-Hegemonic Intersections," Farajajé argued that "our studies of religion, the*°logies, spiritual traditions must include an understanding of the elements of class, gender, sexualities, geographies, embodiment, spiritualities that go into the

1 To date, Farajajé's writings have not all been published. From our personal conversations and faculty retreat lectures, I know Frantz Fanon's work and the "colonized intellectual" were also essential to his development of organic multireligiosity. I continued to locate manuscripts, video lectures, and digital works by Farajajé to support and build this approach in my research (Fanon 2007; Gramsci 1992).

shaping of notions of race" (Farajajé 2012b). As a theoretical approach, organic multireligiosity viewed race and gender among other elements as interlaced and co-constitutive with religion/spirituality. Organic multireligiosity was not value-free regarding the context in which religions and spiritualities exist and are theorized. Farajajé actively rejected "fictions of purity" in the study of religion, which he said, "become an obsession" of those who have rigid categories of tradition and scholarship and "seek monolithic definitions of religions, while others allow for fluidities and diversities." The pursuits of purity in religion threaten the existence of those who live their faith that were not contained by one tradition alone, or live in bodies deemed as disposable, invisible or just "mix it all up," religiously and culturally. He wrote:

> the kind of counter-oppressive multi-religious the@logical education on which i have been working for the past 27 years challenges those fictions [of purity]. it interrupts practices of considering religions as monolithic, rigidly-separated traditions in conflict with one another (as though they could only exist in relations of conflict, but rather understands them as having complex and constantly-morphing relationships in successive generations and in ever-widening geographical and cultural contexts (Farajajé 2012b).

Farajajé's theories are embedded in his decades of teaching in graduate theological schools and in community settings that lived into the "challenges" to fictions of purity in religion/spirituality that he defined in his public scholarship notes. Rather than strictly boundaried religions, Farajajé embraced pluralistic definitions of religion/spirituality and an "interculturality" that valued difference and cultural negotiations among a variety of voices in the field (Farajajé 2004).

From an intersectional and interactionist perspective, I embraced and likely extended the use of organic multireligiosity in order to address the research questions in my study as well as the literature in which my research questions are situated (Blumer 1986). I rejected an additive

approach to engaging religion/spirituality and understood that religions and spiritualities are constantly being renegotiated by those that live them. I was concerned with how religion/spirituality is theorized in studies that attempt to understand the relationship between religious/spiritual experiences and coping with serious health conditions, such as heart disease (Blumer 1986; Cho et al. 2013).

After studying and teaching with Farajajé in that context from 2006 to 2016, there were key features of organic multireligiosity that traveled with me as part of my theoretical approach in this research. Organic multireligiosity enriched and helped to ground my questions in an intersectional perspective that included religion/spirituality and did not emerge from a strictly Western (read, colonializing) and Judeo-Christian understanding of religious/spiritual experience (Cho, Crenshaw, and McCall 2013; Farajajé 2012a). It also arose in the narratives in this research, especially in the ways that women blended religious/spiritual aspects of multiple traditions, shifted their beliefs based on relationships that developed over time, and picked up new religious/spiritual practices based on health crises or parts of their identity that were in "flux." Organic multireligiosity breaks down the colonizing boundaries of religion and religious scholarship that the relational framework for the study of religion/spirituality helped to expose. As yet another theoretical perspective on religion/spirituality, lived religion will help to describe the material realities of religious/spiritual experience, which this research addressed.

Lived Religion

Nancy Ammerman's (2014) approach to the sociology of religion prioritizes the religious/spiritual lives of "ordinary people," and improves upon categories of religiosity that prioritize religious belief or religious service attendance as the important variables in understanding "how much" religion/spirituality is making a difference or present among a group

of people (rather than how it works or how it makes a difference). In developing the literature on lived religion, she wrote that "[l]ooking for lived religion does mean that we look for the material, embodied aspects of religion as they occur in everyday life, in addition to listening for how people explain themselves. It includes both the experiences of the body and the mind" (Ammerman 2014:190). In contrast to classical approaches within the sociology of religion that appropriate binary Enlightenment ideas about religion/spirituality and regular human experience, Ammerman's approach claimed and encouraged the engagement of "our symbolic interactionist heritage" so that they could join with other sociologists to have "conversations about how a variety of symbols and stories, not just religious ones, are shaped" and contribute lenses and tools to those dialogues; she wrote, "[o]ur work in finding *religion* in everyday life must inform and be informed about the *nature of everyday life*" (202). The religious/spiritual conversations in which we participate rise and fall along the winding path of one's life, as opposed to fixed within it or at a distance.

As I described earlier, organic multireligiosity challenged fictions of purity that excluded marginalized peoples from the confines of authorized traditions and refused to authenticate people who do religion interculturally. In the sociology of religion, lived religion was another approach to "finding religion" in ordinary people that provided room for understanding the linkages among gender, race, and religion. These connections were essential for initiating this dissertation research. It defied the theoretical giants of Enlightenment ideas promoted in sociology's early days as a discipline and used persistently in studies of religion and health. Ammerman (2014:192) wrote:

> Writing at about the same time [as Durkheim] Charlotte Perkins Gilman drew a connection between gender and different forms of religion. The lived religion of women, she argued, was built on experiences of birth and growth, while the lived

> religion of men was built on experiences of struggle, conflict, and death. Similarly, W. E. B. Du Bois understood the central role of Black Churches in the formation of African American communities (Du Bois 1989). Each of these early theorists saw religion as a central social reality and built their theories of society to include what they understood about religion.

Religion/spirituality were identified by Gilman and Du Bois as foundational to understanding society as a whole, rather than simply as an aspect of society or special topic. Gilman and Du Bois published on issues of religion/spirituality at the same time as the popular sociological voice on religion, Durkheim. Yet, very few researchers who focused on identifying religion/spirituality in everyday life, included in their samples Black people or women, or relied upon Gilman or Du Bois to shape their conceptualization of religion/spirituality. Ammerman (2014) found that twentieth-century sociology developed methods and theories that relegated religion into what could fit into a survey. She wrote:

> When religion made its way into social scientific research during this period, it was likely to be the sum total of a few survey measures. Being Protestant, Catholic, or Jew; how often one attended services; whether one believed in hell or the literal truth of the Bible—as these survey numbers went up and down, "religion" was said to be appearing and disappearing, gaining and losing influence in society (2014:192).

Religion/spirituality cannot be flattened into singular measures and still called a social scientific study of religion/spirituality; such attempts only showed one part of a religious/spiritual life and would not make the whole person ("Waldo" as Ammerman referred to the elusive religious/spiritual person hidden in plain sight) recognizable to us.

Lived religion as an approach to identifying religion/spirituality refocused attention upon the populations that were neglected or colonized (and misrepresented) by early sociological approaches. To do so, lived religion drew our attention into the "everyday world of material culture and spiritual practice (Ammerman 2014:192). "Indigenous practices" and

"hybrid expressions" were studied with the goal of making religious traditions of many kinds understandable to one another. Lived religion had the potential of making scholarship on religious practice more "globally connected" (192).

Regarding the purity of religious/spiritual categories within lived religion, Ammerman (2014:193) offered:

> Looking for lived religion means that any notion of an authentic pure tradition is probably best left to the theologians to discuss. The lived religion we are likely to find will almost inevitably be a patchwork. . . . The mixing and hybridity of religion as it crosses borders means that pure categories tied to location and tradition are disappearing fast.

I do not know if Farajajé and Ammerman or any of her colleagues ever met, but there were points made within the theoretical approach of lived religion, which I believe Farajajé likely would have celebrated, even if perhaps identified by another name. Organic multireligiosity called into question whether "pure traditions" ever truly existed (as opposed to now disappearing). I believe he would have insisted (and as do I insist) that the marking of some approaches to religion/spirituality as noncanonical others was due to White Christian supremacy in comparison to the secularization debate or preferences for quantitative survey measures (Ammerman 2014; Joshi 2020). Ammerman did address "North Atlantic heritage" as an obstacle, but that colorblind term obfuscates the issue. Interestingly, when developing my literature review on religion/spirituality and coping with heart disease, I discovered a wide variety of research articles published in Iran, Israel, and other parts of the globe from scholars in universities in settings with a predominantly non-Christian patient population. Many of these authors also used quantitative measurements within their cultural context and highlighted popular white and male-authored theories (see literature review for some examples). This qualitative research attempted to understand lived religion as expressions and experiences best

clarified through personal disclosure and interpretation, adjusting the focus to center Women of Color with heart disease.

Illness Trajectories

My study was informed by the theory of illness trajectories in the sociology of health and illness. Strauss, Fagerhaugh, and Suczek (1997) as well as with Carolyn Wiener (1982) developed the notion of illness trajectory that opposed biomedicine's idea that the "course of illness" is a strictly biological process. This put into motion a new constructionist way of looking at illness that values the patient's experience of being ill (from identifying their own pain and seeking care to participating in their treatment) and the impact of that illness on the rest of their lives and social relationships, rather than focusing narrowly on an affected body part or physiological symptoms. This theory helped to differentiate the unfolding of the symptoms and treatments of heart disease from the fuller relationships among different "workers" involved in the management of heart disease, beginning with the individual Woman of Color herself (Strauss et al. 1997:8). It supported my research questions in addressing the bidirectional relationship between religious/spiritual experiences and experiences dealing with heart disease. The notion of an illness trajectory recognized that medical technologies (treatments for heart disease, determinations of "risk") and physiological symptoms (felt experiences of disease) "interplay" with "life-cycle and life-styles" (Shim 2014; Strauss et al. 1997:11). The illness trajectory for people with heart disease and some other serious chronic illnesses included uncertainty and unpredictable losses in abilities or activity levels (Close 2004; Jackson et al. 2000). These changes created burdens as well as shifted meanings in complex ways. Gender and racial/ethnic disparities in access and quality of medical care for heart disease suggest that illness trajectories differ based on a confluence of factors during one's lifetime

(Sheifer et al. 2000). For instance, a large cohort study (Li et al. 2016) found that overall, women with coronary artery disease received worse quality of care, compared to men, when they were discharged from the hospital. Religious/spiritual experiences likely intersected with care-related issues, the burden of illness, and changes in the meaning of illness over time. My research questions called upon the social construction of illness as a trajectory that unfolds in connection with changes in other parts of experience and social context. The results of this research include patterns of being that reflect the shifts indicative of this theoretical perspective.

Some parts of one's life may be continuous, but chronic health conditions, such as heart disease, often create circumstances that cause a person to *have to* respond, even if it is not to seek medical assistance or engage in positive coping practices (Exley and Letherby 2001; Gullatte et al. 2010; Strauss et al. 1997). Thus, living with an illness, such as heart disease, has a "full range of meaning" (Phinney and Chesla 2003:284) beyond what the biomedical view of the illness alone can ascertain. Illness trajectory perspectives linked up with my interest in how Women of Color respond to their heart disease as they live and endeavor (including, perhaps, religious/spiritual striving) along a path of change as their illness progresses.

Life Course Perspectives

My third research question included the elements of change and time. I was interested in how Women of Color's experiences with heart disease change, as well as how these changes influence their religion/spirituality. A life course perspective underscored the relevance of long-term change. Its principles include that: (1) early and later stages of life are connected; (2) the timing of events in one's life can make a difference in terms of meaning-making; (3) humans are interdependent in that what affects one person's life connects to the lives of those close to

them; (4) life is situated and formed by historical and geographical contexts; and finally, (5) people create choices and actions within their contexts and life circumstances (Ben-Shlomo, Cooper, and Kuh 2016; Bernardi, Huinink, and Settersten 2019; Dannefer 2020; Pescosolido et al. 2010:450–453). The relational framework for the study of religion/spirituality also saw people as working out their religion/spirituality in relation to people important in their lives, intersectional factors, and the choices connected to their life circumstances (Moscati and Mezuk 2014). People may have personal responses to their illness that reflect institutional processes, which shape religious/spiritual experience (McFarland et al. 2013). They may also experience disruption in their life course, which would lead them to use religious/spiritual forms of coping (Exley and Letherby 2001). Both the relational framework of religion/spirituality and life course perspectives encouraged me in describing and understanding interpretive accounts of religious/spiritual experiences for Women of Color with heart disease.

Recent studies of health inequities and disparities have shown that there are aspects of life course perspectives that are relevant to how health is produced through social factors over time, rather than sets of risk factors,[2] such as the concepts of latency periods, stress proliferation, linked lives, period effect, sensitive periods, and social pathways (Bernardi et al. 2019; Gee, Walsemann, and Brondolo 2012). For instance, Gee, Walsemann and Brondolo (2012:967) suggested that racism transformed the extent to which different contexts ("asset-

[2] In research articles about religion/spirituality, heart disease and disparities, the authors concentrated on the association of religious/spiritual coping or practices and cardiovascular risk factors. Janet Shim discusses extensively the "risk factor logic" and patterns in epidemiological research that privileged certain risk factors. Other contributors to disparities in heart disease may go understudied or ignored. While the epidemiological study of heart disease was not a focus of my dissertation research, Shim's findings helped to orient my understanding of life course perspectives and the literature review, in which risk loomed large. Shim, Janet K. 2014. *Heart-Sick: The Politics of Risk, Inequality, and Heart Disease*. New York: New York University Press.

building" versus "disadvantaged") contributed to racial inequities in life expectancy or other health outcomes. They also argued that the length of time and intensity of exposure to racism also contributed to these inequities. The life course perspective provided helpful background theory for understanding how "social pathways" of heart disease may be connected to religious/spiritual experiences (2012:968). During the US COVID-19 pandemic that began in 2020, the wide-reaching changes in one's relatedness, health behaviors, and the expansion of racial and economic inequalities particularly harmed heart disease patients of Color (Brandt, Beck, and Mersha 2020; Dorn, Cooney, and Sabin 2020; Zheng et al. 2020). Life course approaches to observing the pandemic's consequences in the context of time and life stages helped me to understand the experiences of the Women of Color who participated in my study and were simultaneously affected by and connected to heart disease and the COVID-19 pandemic (Settersten et al. 2020). Overall, life course perspectives supported the results of my study related to relational and intersectional patterns of change in the relationship between religion/spirituality and health for Women of Color with heart disease.

Theories of Coping

My research questions asked about religious/spiritual coping for Women of Color. Coping referred to how someone deals with an adverse life circumstance, such as stress, and making efforts to support one's well-being (Martz and Livneh 2007). According to the Process Theory of Coping (Lazarus and Folman), coping was a "process that is likely to change over time" (Martz and Livneh 2007:9) and in which someone is trying to manage the internal and external demands upon them, created by illness or any number and combination of hardships. In some cases, religious/spiritual resources were internally focused on a person's inner sense of

peace or struggle; alternatively, religious/spiritual resources were external, related to group activities or social support (Martz and Livneh 2007; Mattis and Jagers 2001).

Religious/spiritual coping theory corresponded to several functions of religion, including meaning, control, comfort/spirituality, intimacy/spirituality, and life transformation (Pargament et al. 2000). Just as any other type of coping, religious/spiritual coping included both negative and positive forms and had been shown to influence the effects of major incidents of stress. People use different types of coping strategies or resources to deal with specific situations or stressors in their life. For instance, some Women of Color with heart disease who were included in this research used religious/spiritual coping to deal with heart disease. A few women also used religion/spirituality to cope with other problems in their lives, which were unrelated to health. Later in this chapter, I will review a set of research articles that addressed religious/spiritual coping, which was particularly relevant to my research questions.

Coping has been shown to be important for living with chronic disease, such as heart disease (Bennett and Boothby 2007; Chan and Ward 1993; Moss-Morris 2013; White et al. 2018). Studies of coping with chronic conditions suggested that coping included general activities, such as sustaining social connections, balancing one's emotional state, cultivating a positive self-image; and illness-connected activities, such as dealing with symptoms, accessing treatment, and connecting with health care providers or staff members. There are many approaches to understanding coping and many different conceptualizations of coping within the social and behavioral sciences (Martz and Livneh 2007).

As I will further detail in the next chapter, the interpretive phenomenological method of qualitative research gelled well with the religious/spiritual theoretical ideas I described in this chapter, including the relational framework for the study of religion/spirituality, organic

multireligiosity, and lived religion. My research design and interpretive process also brought to life the illness trajectories, life course perspectives, and theories of coping. Research on religion/spirituality and health in the past 10 years did not often use a phenomenological approach or conceptualize religion/spirituality as fluid, pluralistic, or in constant dialogue with one's life. I was focused on the "full range of meaning" of what *doing* religion/spirituality meant to a Woman of Color dealing with heart disease, which intersected, shaped, and was shaped by other dimensions of experience in dealing with heart disease.

REVIEW OF THE LITERATURE

The lived experiences of US adult Women of Color with heart disease and the religious/spiritual experiences of people with heart disease have received little attention in the relatively brief history of religion/spirituality and health research. This section addresses my review of the literature connected to my research questions: (1) religious/spiritual experiences in daily life; (2) how religion/spirituality shape dealing with heart disease; and (3) how experiences dealing with heart disease influence religion/spirituality. Lastly, I explore the possibility that religious/spiritual experiences are a "mixed blessing," introducing some contradictions in the literature regarding religion/spirituality's effects on health.

Religious/Spiritual Experiences in Daily Life

My first research question focused on the central phenomenon in my dissertation research: the religious/spiritual experiences of people of Women of Color with heart disease. I hoped to understand how these experiences fit into their daily lives, as well as how central (or peripheral) religious/spiritual experiences are to their lives and to their perceptions about themselves. Daily experiences that are religious/spiritual include anything that they consider

religious or spiritual, because of the nature of the activity, its meaning for the person, or its connection to a religious/spiritual tradition. The activities should be done regularly. Religious/spiritual experiences may or may not be closely connected to a Woman of Color's cultural group (Bauer et al. 2017; Eichner et al. 2010; Jepson et al. 2012; Misra and Khurana 2010; Sidhu et al. 2016). For instance, different cultural and ethnic groups (e.g., Mexican Americans) within the US Latinx population may have very different religious experiences from one another (Hunter-Hernández et al. 2015; Manning and Manning 2014). One of my goals in uncovering the meaning of religious/spiritual experiences within the broader lived experiences of Women of Color with heart disease was to reveal how religious/spiritual dimensions of their lives connect with other dimensions, such as culture, tradition, or community.

My second research question pointed toward, in part, a more detailed description of the religious/spiritual beliefs, practices, or communities important to Women of Color with heart disease. The US Census does not ask Americans about religion/spirituality. The Pew Research Center (2015) sought to fill in the gap of knowledge about the changing landscape of American religion by surveying over 35,000 people residing in the US in 2007, and again in 2014. The Pew Research Center's work offered some demographic understanding of religious affiliation as well as religious beliefs and practices, but it also invited me to ask more questions about the religious/spiritual experiences of Women of Color in particular. In the US, more than 75% of adults identified with a religious tradition (Pew Research Center 2015). Regardless of affiliation status, 82% percent of women said religion is at least somewhat important in their lives; among different racial groups this mostly held true (91% of Black Americans, 84% of Latino/as, 66% of Asian Americans, 79% of people who identify as Other/Mixed, and 72% of whites). Interestingly, only 36% of people attend religious services at least once per week, with only

slightly higher attendance among Black and Latino people, as well as those Pew identified as mixed race or other than white people and Asian people. Sixty-nine percent of women said they held an absolutely certain belief in God. Black Americans were most likely to hold this belief (83%), followed by people who identified as other or mixed (66%), white Americans (61%), Latino Americans (59%), and then Asian Americans (44%). Interestingly, 27% percent of nonaffiliated "nones" stated they believe in God with absolute certainty, while another third do not believe in God. The percentages of people who said they pray at least daily were similar to the findings on beliefs in God across gender, race, and level of religiosity (Pew Research Center 2015).

The Religion in Everyday Life study found that highly religious people were not distinctive from less religious people in terms of how they lived their lives, including how they are satisfied with their health (Pew Research Center 2015). Globally and in the US, the future of religious identity and practice will shift as demographic changes shift. For instance, the Religious Futures project found that the number of Black Americans who did not identify with a religious tradition was increasing but among those who were unaffiliated, most still believed in God and 50% still prayed regularly, even though there were few of the non-religiously identified Black Americans who attended religious services regularly (Cox 2021).

The study of the Pew Research Center (2015) suggested that religious/spiritual experiences are more complicated than simply whether or not someone attends services; such experiences may also be much more common and less understood ways in which people practice their religion/spirituality. Stewart et al. (2013:91) reviewed literature on religious factors among patients with different health conditions and suggested that patients (with different diseases) regularly practice religion and "interact with God about their disease state."

Given the importance of religion in people's lives in the US, it is important to understand the ways in which religion/spirituality may connect to the rest of Women of Color's daily lives as they deal with heart disease.

The relational framework indicated that religious/spiritual orientation and the experiences one engages in daily life might not always be in sync or synonymous. Mattis and Jagers (2001:522) described that "secular spiritual orientation can exist apart from religious beliefs and practices." Using worldwide data from 154 nations and over 450,000 people, a 2011 study found that "spirituality was associated with greater meaning" in one's life (Diener, Tay, and Myers 2011, as cited in George and Park 2017:132). Religion/spirituality could help bolster or "facilitate" a sense of meaning in life, because it involves "a sense of 'transcendence and connection with something larger than one's self" (George and Park 2017:132). It was also easily available as a resource at times when other resources might be more difficult to access (George and Park 2017:132). Researchers attested that religious/spiritual people may experience life to be more than just the "physical, the corporeal, and the ephemeral" as one's "actions, experiences, and existence take on a larger significance and value" (George and Park 2017:132). They may also turn to spirituality, when they are "low on meaning" (George and Park 2017:132) in their lives and thus, meaning itself is a motivator for engaging in religious/spiritual experiences. This research uncovered the meanings of and motivators for religion/spirituality grounded in their proper and fuller contexts in Women of Color's daily lives.

Daily life and the centrality of religious/spiritual experience in shaping how a person deals with their cardiovascular disease may be dependent upon a few factors and relationships. Among the small number of recent studies that specifically addressed the religious/spiritual lives of Women of Color with heart disease, there was some recognition that religion/spirituality

had a cultural role in the lives of people with heart disease. However, neither religion/spirituality nor the role of gender and race were fully investigated in these studies (Bauer et al. 2017; Eichner et al. 2010; Jepson et al. 2012; Misra and Khurana 2010; Sidhu et al. 2016). A few authors took care to mention how religion or spirituality were important to the population or health issues they studied, but still did not explore religion/spirituality deeply in terms of daily life and dealing with heart disease over time (Eichner et al. 2010).

Religious/spiritual experience is often connected to cultural values, and influences family or community life. Also, family or community may shape religious/spiritual experiences (Hunter-Hernández et al. 2015). In order to understand the religious/spiritual experiences of Women of Color, specifically, it is important to also gather insight into how religion/spirituality is connected to other aspects of their lives, including culture, racial identity, gender identity, racism, and sexism (Mattis and Jagers 2001). A recent study concluded that religiosity and racial identity together might interact to cultivate a protective role against the impact of racism on the health of African Americans, suggesting that together, they could play a role in addressing cardiovascular health disparities (Drolet and Lucas 2020). In their critical ethnography about religious and spiritual plurality, Pesut and Reimer-Kirkham (2010:815) found that encounters between providers and patients connected to religion/spirituality could not be separated from other lines of difference, such as race, class, and gender: "(n)egotiating difference was a process of seeing spirituality as a point of connection, eliciting the meaning systems of patients and creating safe spaces for the expression of that meaning." The narrative accounts of my participants held insights into the intersections of identities in relation to the specific narratives explored about their religious/spiritual experiences, and how women's view

of themselves changed over time. The process of negotiating difference is not linear, nor is it finite.

Religion/Spirituality Shaping Experiences with Heart Disease

It has been established that religion/spirituality has some influence on health (Hunter-Hernández et al. 2015; Morone et al. 2016; Wachholtz and Pargament 2005). More research is needed to understand my second research question: *how* religious/spiritual experiences shaped the ways women deal with their health conditions, such as heart disease (George et al. 2000; Rippentrop et al. 2005). As a "culturally enshrined" individual difference, it is appropriate to try to understand the meaning of religious/spiritual coping in the lives of Women of Color from different religious/spiritual traditions or no affiliation, as well as from different racial and cultural backgrounds (Drolet and Lucas 2020; Mattis 2002). Between 2007 and 2016, 12 studies were published that discussed the relationship between "religious coping" and African American women; 6 studies on religious coping and Latina women were found. Other recent studies have been published on other racial groups, including white people with heart disease, that support the importance of religious/spiritual coping across identity groups. Two studies focused on both African American and Hispanic women (Curtis, Morgan, and Laird 2018; Fatone et al. 2007). Curtis, Morgan, and Laird (2018) found that among US mothers of Color with depression, religious/spiritual coping themes emerged in "narratives of distress" intertwined with "stories of survival, persistence, and beauty" (293). Also, the women in the study used words to describe their experiences that blended with themes in Latina/African American women's theology. Fatone et al (2007) examined views of quality of life among Black and Hispanic women with breast cancer. They found that 50% of the Hispanic women in

the study described faith as a central way that they coped with their condition (Fatone et al. 2007).

My second research question drew attention to how religious/spiritual beliefs, religious/spiritual practices, and involvement in religious/spiritual communities are involved in religious/spiritual coping. The limited recent research on religious/spiritual coping among Women of Color or among people with heart disease suggests that these activities may be resources for dealing with serious health conditions (Allen et al. 2014; Arnette et al. 2007; Blanc et al. 2020; Bryant-Davis et al. 2011; Mattis and Jagers 2001; Molina et al. 2014; Sheppard et al. 2010). Religious/spiritual coping may include prayer, church attendance, relationship with God or a higher power, among other activities (Baldacchino et al. 2013a, 2013b; Banerjee et al. 2013). Among people living with coronary heart disease in Palestine, Salah et al. (2020) found that religious practices were the most commonly used complementary/alternative medical therapy (CAM), and that the participants attested to using CAM, incuding religious/spiritual coping, to address other problems in their lives other than their heart disease (Salah et al. 2020). Recent research on religious/spiritual coping among people with heart disease also has found that church attendance or other group spiritual practices (fasting, pilgrimage, religious dance) were frequently used coping resources (Al Hamid et al. 2017; Baldacchino et al. 2013a, 2013b; Sabado et al. 2010; Sidhu et al. 2016; Weathers et al. 2009; Wingood et al. 2013).

As I described in the previous section of this literature review, religious orientation or affiliation does not sufficiently tell the story of how people use religious/spiritual coping or have religious/spiritual beliefs, practices, or communities that are meaningful in their lives. Culture may also play a strong role in how religious/spiritual coping shapes experiences with

heart disease. Overall, recent studies concluded that cultural factors played a role in how Women of Color cope with their life circumstances and/or illness (Arnette et al., 2007; Curtis, Morgan, and Laird 2018; Fatone, Moadel, Foley, Fleming, and Jandorf 2007; Molina, Beresford, Espinoza, and Thompson 2014; Sabina, Cuevas, and Picard 2015). Several studies recommended that providers consider cultural values or competence in their interventions or therapy with patients who are Women of Color (Arnette et al. 2007; Curtis, Morgan, and Laird, 2018; Molina, Beresford, Espinoza, and Thompson 2014). Likewise, women of some racial/ethnic groups or religious identities may use religious/spiritual coping more intensely than others (Blanc et al. 2020; Caperchione et al. 2011; Fatone et al. 2007; Hemmati et al. 2018).

Religious/spiritual coping may also be connected to cardiovascular health outcomes. Recent studies agree that religious/spiritual coping may have effects on both spiritual well-being and health outcomes related to dealing with a serious health condition, such as heart disease. Providing religious/spiritual coping training or programs might have a positive effect on complaints about symptoms or reduce stress-related hormones (Gholami et al. 2017; Moraes et al. 2017). Engagement in religious/spiritual coping before or following heart surgery may have a longer-lasting positive effect on posttraumatic growth or quality of life (Ai et al. 2012; Trevino and McConnell 2014). Baldacchino (2011) found that as time passed following a critical heart disease event, people shifted from making huge lifestyle and attitude changes to periods of less concern or awareness about the connection between their daily lives and their disease. She suggested that religious/spiritual forms of coping may help extend coping strategies beyond the first few years that a person is coping with heart disease.

Research examining other noncardiac health issues among Women of Color found that positive religious/spiritual coping was related to well-being (Arnette et al. 2007; Bryant-Davis et al. 2011). Increased religious belief was found to be connected to lower levels of anxiety or dread about death (Soleimani et al. 2018). Personal religious/spiritual practices can be important healing tools in dealing with challenging life circumstances, including illness; for instance, studies have suggested that spiritual meditation techniques may decrease a person's anxiety or improve their mood (Morone et al. 2016; Wachholtz and Pargament 2005).

Involvement in a religious/spiritual community may provide "collaborative coping" and "logistical assistance" as well as emotional coping support by providing social support programming to people with serious health conditions (Sabado et al. 2010; Weathers et al. 2009; Wingood et al. 2013). How someone deals with their life circumstances, including how they cope with serious medical conditions, is linked to important relationships in one's life (Bennett and Boothby 2007; Dalteg et al. 2011). In a chapter on coping with cardiovascular diseases, Bennett and Boothby (2007) predicted that the use of religious/spiritual coping to address heart disease outcomes would receive more research attention in years to come (Martz and Livneh 2007). Existing research on religious/spiritual coping has shed light on psychosocial outcomes, such as resilience, acceptance and adaptation of one's situation, changes in treatment decisions or improved well-being (Allen et al. 2014; Baldacchino et al. 2013a, 2013b; Sheppard et al. 2010). Religious/spiritual coping may help alleviate depressive or anxious feelings related to life circumstances, including health conditions. Religious/spiritual coping, such as prayer or meditation, has been shown to have resilience-related outcomes, such as a reduction in sleep disturbances, acceptance of and adaptation to their illness, better treatment adherence, or a sense of responsibility for one's health (Baldacchino et al. 2013a, 2013b; Blanc et al. 2020; Stewart et

al. 2013; Unantenne et al. 2013; Warner et al. 2019). It has been suggested that religiosity might also be a protective factor against the cardiovascular health effects of everyday racism for African Americans (Drolet and Lucas 2020; Mattis and Jagers 2001). It is important that religious/spiritual coping with heart disease be explored from the perspectives of those who use such resources to cope, exploring how religious/spiritual coping connects with their culture, life experiences, relationships, and other experiences that shape their illness experience.

Heart Disease Shaping Religious/Spiritual Experiences

As illness progresses and time marches on, symptoms of heart disease can become more disruptive or severe. Recent studies have found that people with heart disease find ways to adapt to the losses and disruptions they experience in their daily lives as a result of heart disease (Bennett and Boothby 2007; Martz and Livneh 2007). They make adjustments and changes within their family relationships, practice self-care coping, seek social support (Bennett and Boothby 2007), and use humor or positive thinking to deal with their heart disease (Bennett and Boothby 2007; Dalteg et al. 2011; Karademas et al. 2012; Li, Chang, and Shun 2018; Martz and Livneh 2007; Östman, Ung, and Falk 2015). People with heart disease may also try to make meaning of their illness, and ask "Why me?" and other existential questions, especially after serious events, such as myocardial infarction (Baldacchino 2010).

Women, including Women of Color, become more religious as they age (Manning and Manning 2014). Studies of religious/spiritual experiences, including beliefs, practices, and coping strategies, have indicated that over time, religion/spirituality may be a protective factor in dealing with serious health conditions, including heart disease. Given that survey data indicates religious/spiritual experiences change as people age, it would make sense that religious/spiritual experiences change as one's illness progresses. However, it is not clear how

the experiences of dealing with one's condition shape religious/spiritual experiences. As religious/spiritual relationships change based on development or life circumstances, they continue to be interrelated to one's health or illness, as well as experiences in health care (such as a relationship with providers, access to interventions, as well as racism and discrimination) (Drolet and Lucas 2020; Mattis and Jagers 2001). My research addressed this bidirectional relationship and approached new understanding of the ways in which being ill and dealing with heart disease shaped religious/spiritual experiences of Women of Color.

Some recent studies indicate that illness experiences may shape or reshape a person's religious/spiritual experiences. For instance, in studies examining the association of religious/spiritual coping with progression of heart disease, the direction of the relationship is not always clear. In other words, quantitative analyses of the relationship between these factors does not always indicate if being ill and dealing with heart disease is changing religious/spiritual experiences over time (Baldacchino et al. 2013b). One qualitative study of the perceptions, experiences, and responses of African American women and Hispanic women who had survived breast cancer observed such a change (Fatone et al. 2007). Fatone et al. (2007) found that most of the African American women in the study experienced a change in their religiosity that was good following their diagnosis. The authors concluded that the study indicated a need for culturally tailored health-related quality-of-life interventions. If quality of life has a religious/spiritual dimension, then surely, dealing with heart disease could have an effect on this dimension (Ransome 2020; Soleimani et al. 2018). In a recent systematic review of instruments measuring spirituality in clinical research specifically, Monod et al. (2011) found that there were too few instruments that were designed to measure a patient's spiritual state at

the time of measurement, and very little data on those measurements that would lead toward appropriate spiritual interventions.

Aspects of religion/spirituality also interact with one another, in addition to being interconnected with other aspects of our socialization and development. In a study of suicidal African American women survivors of intimate partner violence, higher levels of positive religious coping predicted religious well-being during the study period (Arnette et al. 2007). These findings suggest that the bidirectional relationship between religious/spiritual experiences and dealing with heart disease is dynamic and potentially co-constitutive, even multidirectional.

Recent studies have shown that there are many different possible circumstances that would have an impact on religious/spiritual experience over time. If a woman has fewer supportive family members and needs social support for dealing with her health condition, she may access religious/spiritual coping strategies that would involve a community group or practical religious/spiritual support (Weathers et al. 2009). Programs connected to education about coping or providing treatment of their illness sometimes contain a religious/spiritual coping component, which may have an effect on religious/spiritual experiences, such as increasing "religious social capital" or re-casting religion/spirituality as a resource in a person's life (Sabado et al. 2010; Wingood et al. 2013). Recent articles on religious/spiritual outcomes among those with heart disease and other serious illnesses illustrate that there is a bidirectional relationship between religious/spiritual experiences and experiences dealing with heart disease ready to be explored and developed.

Mixed Blessings?

There are many studies that show religious/spiritual coping to be a mixed blessing, associated with both positive effects and negative effects in the same sample or having contradictory results over time (Al Hamid et al. 2017; Bryant-Davis et al. 2011; Fatone et al. 2007; Gullatte et al. 2010; Hickman et al. 2013; Krägeloh et al. 2012; Sabina, Cuevas, and Schally 2012; Wells et al. 2015). People may increase their religious/spiritual coping activities over time, but those activities are not always linked with improvement in health or well-being (Bryant-Davis et al. 2011; Hickman et al. 2013; Wells et al. 2015). People who find themselves in a new health crisis may also continue to use the religious/spiritual practices that had worked for them prior to a serious incident. For instance, recent articles have observed a paradox in the study of racial/ethnic differences in the utilization of clergy: Despite greater attendance at religious services, researchers appear to agree that African Americans are less likely than Whites to seek out clergy for counseling for serious issues in their lives (Chatters et al, 2011; Mattis et al 2007). Chatters et al. (2017) found that this difference was mediated by the fact that African Americans in their sample were more likely to have closer existing ties to clergy through attendance at a religious setting than to seek them out in another setting (such as a hospital). People of Color continued to rely upon the religious/spiritual support that was in place before the serious issue came up. More investigation into these relationships is important to understanding how best to support people experiencing challenges as their illness progresses.

The relationships between religious/spiritual experiences and dealing with health conditions may also take a cyclical shape or have both negative and positive relationships at the same time. For example, religious beliefs may influence health decisions, which in turn affects how health care providers navigate support for social/religious norms and balance such norms

with other personal health needs. Depending on the particular convictions and the forcefulness of religious belief, religious/spiritual belief could grow to have a stronger impact on medical advice, thereby changing those religious/spiritual experiences (Dilla et al. 2020). In a qualitative study of people with heart failure in Kenya, Kimani, Murray, and Grant (2016) found that their patients relied upon the resources of spiritual beliefs and practices, such as praying and attending services. The patients' (Christian) spirituality could offer comfort, but also bring distress, especially among younger patients. The participants also described "feeling abandoned" by members or pastors who did not understand or try to provide support related to their heart condition (Kimani, Murray, and Grant 2016:5). A relational framework for religion/spirituality considered the importance of individual, community, and institutional relationships in studying religion/spirituality. My study might offer new insight into how using religion/spirituality to cope with heart disease could be a mixed blessing.

In the past two decades, the research community has debated and expressed confusion over the effects of religious/spiritual coping on health and well-being (Koenig 2008). There has been widespread agreement that religion/spirituality includes resources that people choose to rely upon when coping with major life disruptions or illness (Miller and Thoresen 2003). However, there has been significant disagreement about the degree to which it independently affects health and how to measure religion/spirituality (Hall et al. 2008; Koenig et al. 2020; Szaflarski et al. 2012). There is also a lack of understanding about the ways in which dealing with heart disease influences religious/spiritual experiences over time, or the nature of the general relationship between the religious/spiritual experiences and the illness trajectory, in general. For instance, among their participants with chronic diseases including heart disease, Warner et al. (2019) found that being a Woman of Color was related to positive religious

coping, but also to more loneliness and depression. For Women of Color with heart disease, life disruptions may be expected or occur suddenly, causing a range of effects on the lives of people dealing with heart disease. Some Women of Color may experience such disruptions as intensely challenging and others may find that not much in their lives changes immediately after a disruptive event. Because there are so many possible influences in play for individual Women of Color over time, it is worthwhile to create deep interpretations of the shaping and changing of the relationship between one's religion/spirituality and dealing with heart disease over time. My study design allowed for deeper investigation into the nuances of how the relationship between religious/spiritual experiences and illness experiences is activated.

CHAPTER 2: METHODOLOGY

My literature review scratched the surface of the multiplicity of religious/spiritual concerns, experiences and practices among people dealing with serious health conditions, such as heart disease. An interpretive phenomenological method offered the opportunity to uncover and explore lived meanings *on the terms* of Women of Color with heart disease (van Manen, 1990; van Manen, 2018; Benner, 1994). In using this person-centered method, I set aside ascribed definitions of religion/spirituality and does not rely solely upon accepted models and measurements of religion/spirituality, religious/spiritual coping and cardiovascular risk or outcomes. I explored what concerns or challenges are central to the Women of Color participants in my study in shaping how they deal with heart disease as well as how they view themselves and what is important to their lives (van Manen, 1997). The interpretive phenomenology method helped me to address the gap in knowledge about the religious/spiritual experiences of Women of Color with heart disease, present "initial understanding" of these experiences as they are *lived* (Phinney, & Chesla, 2003, p.28). In this section, I describe the nursing tradition of interpretive phenomenology, upon which my study relied, and make the case that this method is an excellent fit for my research questions and the aims of this study.

PHILOSOPHY OF INTERPRETATIVE PHENOMENOLOGY

The interpretive phenomenology method has an underlying philosophy and a set of assumptions, all which demonstrate this method's appropriateness for the study of religious/spiritual experiences of Women of Color with heart disease. In preparing the research design, I reviewed exemplar research articles in interpretive phenomenology research and discussion of interpretive phenomenology research methods written by Patricia Benner, Catherine Chesla, Alison Phinney, Victoria Leonard and Max van Manen among others. A

German philosopher writing in the early twentieth century Martin Heidegger, developed a philosophy about what it *means* to be a person. His thought forms the theoretical basis of interpretive phenomenology, sometimes called Heideggerian phenomenology (Leonard 1994). The aforementioned interpretive phenomenology authors describe the philosophical growth of interpretive phenomenology from Heidegger's ideas illustrated in his work *Being and Time*, first published in 1927 (Benner 1994a; Heidegger 2008; Leonard 1994; Phinney and Chesla 2003). Heidegger argues that we, as humans, care about what we do and how we do it. Our existence and our actions are significant, not just in the interests of one person or another, but in the nature of being alive (Kesselring, Chesla, and Leonard 2010:5). Our lives are embedded in contexts that shape our understanding of ourselves and our actions. In Benner's discussion of interpretive phenomenology, she wrote that interpretive phenomenology research begins with a "preunderstanding of human action and engagement," recognizing that humans are "situated within meaningful activities, relationships, commitments and involvements" (Benner, Tanner, and Chesla 2009). My study design, participants, and data flowed from acceptance of this premise: describing religious/spiritual activities and their relationships to Women of Color's daily living with heart disease will uncover lived meanings of these activities in their proper contexts.

Three foundational assumptions about human experience aligned with my research questions and theoretical approaches. First, Benner, Tanner and Chesla (2009) wrote that everyone develops in at least one social and cultural context that infused some ways of seeing, doing, or believing into their lives and makes other ways of thinking and acting inaccessible to them. Our socialization shapes our worldviews, our understanding of ourselves, as well as what we fail to notice, or may not be presented to us. Each person is shaping and forming practices,

not always intentionally or unconsciously, but rather in "situated freedom and agency" (Kesselring et al. 2010:5). Religious/spiritual experiences were also embedded in the social or cultural context in which a person lived (Farajajé 2012b; Fatone et al. 2007; Johnson et al. 2011; Mattis and Jagers 2001).

A second assumption in interpretive phenomenology methodology was that human activity is "engaged" and "practical," insomuch as each person moves through the day taking some ordinary things for granted, occasionally responding to an unexpected event or circumstance, and reflecting on one's life and activities (Benner et al. 2009). One's "being-in-the-world" (how we are "always already situated") is conveyed through both implicit, inner experience and the language employed to name how it changes one's experience (Leonard 1994:46–47; Phinney and Chesla 2003:284). Also, "embodied habits and practices" shape what we do as well as how we live as humans (and how we change) (Leonard 1994:51). Heart disease and other health conditions include symptoms or hospitalizations that disrupt or re-shape activities in one's everyday life (Jackson et al. 2020; Schneider et al. 2001). According to interpretive phenomenology philosophy, practices are repeated over and over as a way of maintaining and caring for what is essential and worthwhile in being alive (Kesselring et al. 2010). Religious/spiritual experiences may include daily practices that change and have new meaning when there are unexpected changes in one's life (Chatters et al. 2011). Embedded in regular everyday practices, there is "more to the story" of religious/spiritual experiences of people who are dealing with life issues. Through interpretation, I uncovered the everyday practices in the lives of Women of Color with heart disease that have meaning connected to religious/spiritual experiences.

The third assumption was that people's engagement in the world around them is structured and constrained by "what matters to them;" in other words, one's interests or concerns affect how they respond to a particular situation (Benner, et al., 2009). Illness experience can introduce a person to practices and institutional entanglements that are common to heart disease management or related in some way to other aspects of one's life or relationships (Leonard, 1994, p.46-47). To make choices about their illness, people may have religious/spiritual interests or they may use a completely different set of criteria (Fatone et al. 2007; Gullatte et al. 2010). My research explored what mattered to Women of Color who also deal with heart disease, and the degree to which religion/spirituality is important among those priorities.

The philosophical foundation of interpretive phenomenology gelled well with a patient-centered view of illness, an organic multireligious and relational model of religion/spirituality, and evidence-based spiritual care practice (Farajajé 2004; Fitchett et al. 2018; Mattis and Jagers 2001). Yet the research on religion/spirituality in the past ten years has not often used an interpretive phenomenology approach. In the past ten years, there have been a handful of research publications that use an interpretive phenomenological method and address religion and spirituality intentionally in their research questions (Dalmida Holstad, and Dilorio 2012; Minaye, 2012; Noorris, Jones, Kilbride and Victor 2014; Manning 2014; Mawaka 2017; Tolvoonen, Charalambouos, and Suhonen 2018; Khazaeipour et al 2018; Mwaie and Simuchimba 2019). In addition, a few recent articles found religious/spiritual themes in their data collected to address research questions unrelated to religion/spirituality, but in which religion/spirituality was important to the context.

Interdisciplinary spiritual care research (also called healthcare chaplaincy research) does not regularly engage with interpretive phenomenology research methods to study religious/spiritual experience. Interdisciplinary spiritual care research as a still-emerging discipline has been increasingly interested in quantitative methods; at the same time, there has been a push for more case study research, conducted by chaplains based on their own practice of spiritual care (Poncin et al. 2020). Between 2000 and 2018, chaplains and theologians along with other types of scholars published articles on chaplains' practices, spirituality, research, impact of chaplaincy, and health care professionals' practices of spiritual care. Less than half of the research included in the review by Poncin et al (2020) was empirical and 24% was qualitative (predominantly, interviews and case studies). None of them used interpretive phenomenological methods.

RESEARCH DESIGN

I developed a research design that I hoped would bring forward the religious/spiritual experiences of Women of Color with heart disease, specifically focused on religious/spiritual experiences, practices, and beliefs that Women of Color describe as supporting how they cope with their disease. Also, I was particularly interested in how the relationship between religion/spiritual and their health was connected to other aspects of their lives, and changed over time.

Research Questions

Kesselring, Chesla and Leonard (2010) recommend that interpretive phenomenology research questions be framed to invite the participant's "experiences, skills and practices in a more holistic, less reductionist way" (Kesselring, et al. 2010:15). Theoretical approaches or

concepts were kept in mind, but I was interested most in the participants' views on themselves and their experiences. For this research, the research questions were developed to bring forward the religious/spiritual experiences of Women of Color with heart disease with a focus on practices. The first question helped me to cultivate a rich description of religious/spiritual experiences as well as how central they are to the participant's view of themselves and their life as a whole.

My second and third research questions sought out the bidirectional relationship between the illness experience of heart disease and religious/spiritual experiences. By focusing on change, I invited in another important element in the interpretive phenomenology view of experience and practices: time. Leonard (1994) wrote that in interpretive phenomenology the "view of person or being-in-time that differs radically from more traditional Western notions of time. Our traditional view of linear time is of an endless succession of nows…this 'snapshot' view of time presents us with the problem of conceiving continuity or transition" (Leonard 1994:53). The current "time" in which I was asking participants to reflect, is a combination of both what their past was like (their "having-been-ness" as Leonard describes it) and the future they anticipate, in relation to what they care about (Leonard 1994:53–54). My interview guide engaged with the issues of time and change, in order to understand in fullest relief how each Woman of Color participant views themselves in relation to the changes in their health along with the changes in their religious/spiritual experiences.

Sampling and Recruitment

The data for this study was gathered primarily from interviews with Women of Color with heart disease who considered themselves to be religious and/or spiritual or have components of their daily lives that they consider to be religious or spiritual. With the goal of

developing an interpretive account, I recruited 13 Women of Color (ages 24-60) who were living with a diagnosis of heart disease for at least a year (Benner 1994b; Phinney and Chesla 2003). My hope was to interview Women of different religious/spiritual traditions and include Women who did not have a religious/spiritual affiliation but have regular religious/spiritual activities. Given that the size of this population is unknown, I was not confined interviews or sampling to a specific geographic area of the US. Participants were recruited through religious/spiritual networks, as well as through social media (Instagram, Facebook), and electronic medical record recruitment facilitated by the Participant Recruitment Program at the University of California San Francisco's Clinical and Translational Science Institute (CTSI).

Data Collection

Between April 2021 and March 2022, participants were interviewed. Data interpretation was ongoing. Eligible volunteers for the study continued to be screened and due to the number of interested volunteers, screening was ongoing between March 2021 and February 2022. Due to the unknown size of the population and the addition of the recruitment method using electronic medical records, there was a higher number of initial contacts that needed to be screened for eligibility and a higher number of ineligible initial contacts, mostly due to miscoded diagnoses. Second and third interviews were scheduled with participants based on initial reviews of interview transcripts. One participant could not be located following the first interview and so, did not follow the recommended collection process for interpretive phenomenology. However due to the depth of the first interview, she was included in the final sample.

One-on-One Interviews

I conducted multiple interviews with 13 participants to follow developing lines of inquiry and shape a thematic description of their religious/spiritual experiences as I interpreted the growing text. Each interview took place for 30-120 minutes on Zoom, an online video conference program. Given the pandemic, often participants were in their homes. I was located either at home or in a private office near my home. Interviews were video-recorded and audio-recorded as well as live transcribed using software. I recorded fieldnotes and observations mostly by hand. Also, all participants completed an electronic questionnaire with demographic questions as well as some questions about their physical and mental health. Lastly, each participant (except Kay, who could not be reached) selected their own pseudonym. For some the pseudonym had a personal meaning or reflected an important symbol or person for them: a spiritual object, a favorite color, a Marvel character or "runner up" name for their child.

Setting. All the interviews were held via Zoom and ranged from 30 minutes to 2 hours, based on the participant's schedule and need for breaks due to job-related or health constraints. I found that Zoom allowed a disclosive space to develop over the course of the interview(s). Most of the participants spoke to me from their homes. Whereas in-person we may have met in a neutral space, the setting for the interviews invited me into a glimpse of the participant's home, and the spaces within their home were the most comfortable for them. Due to the COVID-19 pandemic, some participants' homes were also their remote workplaces, places of worship, provider tele-offices and child's playrooms. From the view of their space on their web camera, I was able to observe sacred objects, altars, faith-related phrases, cultural items, or religious icons visible in their space, as well as of course, ordinary signs of home.

My interview guide (see Appendix A) structure created a space where the participant and I meet to explore the project's central questions and to bring forth the participant's lived realities as they see them. I asked participants about their daily lives and ask that they turn to the religious/spiritual parts of their lives as they identified them. I invited them to tell me about specific experiences they have had with a religious or spiritual community as well as any other religious/spiritual experiences that were important to them. My role was to listen, gather as much detail as possible, and let the participant guide the conversation.

In the first interview, participants were guided to offer narrative information about things they did that they understood to be religious/spiritual experiences and the instances in which any religious or spiritual communities. When it came to discussion of religious/spiritual beliefs, probing questions invited a narration of the full context in which a belief takes hold in their view of themselves or of their disease as well as what it meant to them. The goal of the interview was to situate the sharing of the experience as well as the participant and myself, in a text, which can be read later and revisited later in the first interview or in follow-up interviews.

Interpretive phenomenology research is grounded in a commitment to the integrity of the practices being studied and regard for the lives of the Women of Color involved. Thus, the number of interviews with one participant will also be determined by the extent and speed in which "background understandings, which arise from local (cultural) worlds become visible" and the participant's disposition and wishes (Kesselring, et al. 2010:14). Between interviews, I listened to recordings and identified initial lines of inquiry. Follow-up interviews served to review transcripts with the participant in order to make sure I've understood them correctly and to hear more narratives or descriptions of relevant experiences.

DATA INTERPRETATION

In entering the process, I immersed myself in the data, reading thoroughly multiple times in order to get a full sense of the relationship between individual statements made by participants and the broader context. I watched and listened to recordings to make corrections to the transcript, remove identifying information, and document my observations of non-verbal communication and expressions. This supported me in developing initial interpretations (Cohen, Kahn, and Steeves 2000; Phinney and Chesla 2003). Contained within the text and the lines of inquiry, I hoped to uncover the meaning that "goes unnoticed" in the everyday but becomes explicit as I work with the data from my interviews as well as observation of the adults who participate (Leonard 1994:58-9). Analysis began at the same time as the initial interviews were held and continue throughout the collection process, using initial analytical categories and maps to identify themes and questions for follow-up interviews with participants. As the data collection continued, I read raw data side-by-side to identify thematic areas of similarity and difference (Phinney and Chesla 2003). I wrote detailed interpretive notes and identified exemplars of themes, which highlighted and illustrated meaning in the construction of a final manuscript.

With regards to the variety of types and severity and staging of heart diseases among the women in the sample, I focused on what the condition meant to the person, as they described it. I trusted in their description of medical facts, accepting that for the purposes of my research questions, my task was not to describe for the reader "what was really going on with their health." Instead, my task was to present how each woman viewed themselves considering their illness, and how religion/spirituality shaped, supported, or influenced their health and well-being over time.

Interpretive Partners

To uncover lived meanings in the texts, I reviewed transcripts with two research analysis collaborators of Color in a role defined as "interpretive partners." Jiaying Ding, a chaplain researcher, and QuianaDenae Perkins, a religious education professional and advanced Master of Divinity student joined me as interpretive partners in the analysis of narrative exemplars. I trained them to conduct "initial coding" based on the guidelines provided in Max van Manen's *Researching Lived Experience*. First, I send them a reading from van Manen's chapter on coding along with a process sheet that described how to code the narrative pieces, including examples of quotes. Then, I met with each interpretive partner individually to "live code" a short section of interview text together and share initial feedback on the quality of the coded fragments. Then, we met as a group three times for collaborative analysis sessions. Each interpretive partner reviewed nine narrative exemplars from 8 participants and both partners reviewed the same transcripts in order to create a dialogue among the three of us about the same material. The narrative exemplars I selected were from text that I had identified as strong cases or sections about which I had questions and hunches that might benefit from review with religious professionals. solicit their perspective on themes emerging from the text as clinical spiritual care providers.

Before each collaborative session, Ding and Perkins completed two "passes" reading and coding three narratives for the upcoming session's discussion. The first pass focused on their general reflections, emotional responses, resonances with their own experiences, and any clarifying questions on the narrative. The second pass included descriptive comments about the participant and their relationships or practices; metaphors or repeated ideas; and conceptual ideas, such as ideas about religion/spirituality in the story and summarizing the overall message

of the narrative. Coded documents were shared among the three of us, and the collaborative sessions were recorded and transcribed.

Collaborative partnerships in spiritual care research are not unusual, and involving chaplains in interdisciplinary teams of researchers may bring important strengths (Kestenbaum et al. 2015; Poncin et al. 2020; Powell et al. 2015). In fact, the lack of collaboration between social scientists, health scientists, and religion scholars has caused a divide in how religion/spirituality is conceptualized, especially in relation to the realm of the supernatural or "what is *real*," and a persistent academic perspective that these social phenomena "cannot be measured" (Levin and Vanderpool 1987:591; Mattis, 2001). The interpretive phenomenological method helped me to address the gap in knowledge about the religious/spiritual experiences of Women of Color with heart disease and present an "initial understanding" of these experiences as they are *lived* (Phinney, & Chesla, 2003, p.28).

PARADIGM CASES

I developed paradigm cases to support the presentation of my interpretation of the data. After extensive memo-writing and analysis of the interview text as a whole, areas of commonality or resonance among the participants began to emerge. The process of discussing specific participants with the interpretive partners provided me with a conversational tool to be able to say "her experience was more like this person and less like someone else." With a manageable number of samples, I was able to develop a strong sense of each woman's text and important patterns related to religion/spirituality and health that they embodied. Then, following discussion with interpretive phenomenologist Catherine Chesla, a few paradigm cases began to take shape. Three women who "bear a family resemblance" (as Dr. Chesla said) to a subset of other whole cases or exemplars from the sample. These particularly strong narrative accounts

started off a conversation about religious/spiritual experiences within my own analysis and it continued, with the two interpretive partners, along with mentors and colleagues. Through dialogue with the full text and other related accounts, my initial understandings of ways of being or life activity among my sample became fuller and more complex.

The paradigm cases helped me to uncover this pattern as I moved between re-reading the entire interview texts and the issues and concerns about religion/spirituality and illness, which were so often discussed in one breath. I presented three paradigms as whole cases to provide the "opportunity to engage in the practical world of the participant and come closer to the lived experience, […and] a particular way of being in the world" (Benner 1994b). After reading and re-writing each whole account of each of these three women's interviews, I developed a within-case analysis and a cross-case analysis.

METHODOLOGICAL COMMITMENTS

The first step in my IP methodological approach is to reflect upon my preconceptions and my social positioning as a researcher. I am a white, queer cisgender woman and ordained Unitarian Universalist minister and sociology doctoral student. This social location may have shaped the nature of my relationship with my participants in a few ways. As a woman interviewing women, my gender might have be an advantage in developing rapport with a participant. As a Unitarian Universalist minister, I found myself moving between sociologist and chaplain researcher, who bridges a research self with a pastoral self; even without knowing if I was a clergyperson or not, some participants may have found speaking with a clergywoman made them feel more comfortable sharing about the religious/spiritual aspects of their lives; others may have found it less comfortable or would fear some form of religious judgment. Most of my recruitment materials did not specific that I was "Rev. Megan." During the interview

itself, I did not volunteer the information about my own religion/spirituality or that I was a minister, but if asked, I would have told them the truth and answered any questions they might have. I hoped to support the participant in feeling comfortable to discuss whatever they consider religious or spiritual, by clarifying that "when I say religion and spirituality, I mean all the beliefs, practices or activities that you might call religious or spiritual." Follow-up interviews invited the participant to revisit previous narratives or share additional details if they feel more relaxed.

"To Hold These Women Well"

Reflecting on the interview process with others, including mentors, colleagues and the interpretive partners, helped me to continue to grow in my self-awareness as I collected data and interpreted text. At the close of the final collaborative analysis session with the interpretive partners, one of them reflected on the process of coding and discussing narratives about some of the most traumatic and sensitive moments in the participants' lives. She said, "I hope that we held these women well. I think we did." All three of us nodded, before signing off for the last time in the project.

Participants of Color may not have shared as openly or comfortably as they might with an interviewer who holds the same or similar racial and cultural background as they do. There is a long history of abuse, coercion and mistreatment of communities of color by white researchers (Cruz 2008; Denzin, Lincoln, and Smith 2008). Patterns of extractive research have also relied upon people of color for research participation without collaboration or meaningful engagement. Racist violence and oppression were actively present in the social context in which this project and each interview took place; this would have been true at any time in history, but the racial justice uprising of the Summer of 2020 and the turbulence of the 2020 US presidential

election season, coinciding with the rollback of voting rights and emboldening of white supremacist and state violence formed a poignant backdrop to the interviews. I have a methodological commitment to inductive learning and critical reflection on the power dynamics of my research process. Even after this project closes or moves in new directions, I have an obligation to continue to evaluate the impact that my words and my work have upon individuals and communities and identify areas of needed reflection or uprooting related to the biases or presumptions I made due to my own religious/spiritual experiences, eclectic as I may think them to be, and my own racial and class privileges. I hold firmly to being in a mode of "white listening and a call to the particular" as a religiously-grounded and persistent commitment as a white researcher engaging in researcher-participant and researcher-collaborator or student-mentor relationships with individual People of Color (Vigen 2006). Part of this commitment has been to be in relationship with scholars of color throughout my graduate school career; I am grateful to the American Academy of Religion's Western Region, the Black Church Studies and Womanist/Mujerista leaders at the Graduate Theological Union, the Emerging Scholars network of the Unitarian Universalist Association, and of course, the Social and Behavioral Sciences Department at UCSF, including my committee, for giving me opportunities to share think pieces, receive feedback and address problems in these early stages of my academic career.

I entered the individual interviews with participants knowing that I was a learner and had limited presumptions about what I would hear or what would become relevant or irrelevant in the scope of the interview and interpretation. Reviewing data with participants also allowed me to engage a participant as a collaborator in developing the text and the interpretive account. Lastly, in meeting with interpretive partners, I had the opportunity to improve my own listening skills and improve the credibility of the text. I read and reread multiples over simply for

comprehension before forming my own interpretations following the phenomenological approaches modeled for me. At the close of this project, I have strong respect for interpretive phenomenology as a method. Women of Color with heart disease are using religion/spirituality in ways that may be important to their coping and deserve to be asked to share their experiences.

TRUSTWORTHINESS

To my knowledge, this is the first qualitative study to explore the religious/spiritual experiences of Women of Color with heart disease during the COVID-19 pandemic. The sample size (13 participants) fit the recommendations for preliminary studies using interpretive phenomenology. In the process of developing my interpretation of paradigm cases that bring the reader into close contact with the participants' direct experiences, early re-readings brought out my own assumptions. Through the process of working through the case by writing and re-writing, I was able to check those assumptions as my interpretation developed and as I discussed my interpretations with the participants and interpretive partners.

Most research on religion/spirituality and health includes women who are considered older adults (over 60 years old). My research included only participants who dealt with heart disease and were younger adults to middle-aged adults. Their narratives might add to the insights about how religion/spirituality and health change over the life course and as people age.

The study also had some limitations that are worth noting. The sample included participants with different religious/spiritual belief systems, practices and connections to religious/spiritual community. Many of the world religions were included among the women's religious/spiritual lives in this sample, but one glaring omission is that there were no Muslim

women included in the sample. According to Pew Research Center's projections, between 2010 and 2050, Muslims are expected to be the fastest growing religious group in the United States.

This study's findings were also limited by the range of type of participants' heart conditions, which was by design due to the expectation of low response rates to the recruitment process. However, because the volume of interested volunteers for research was so high within the MyChart recruitment process, eligibility requirements could have been narrowed to include participants with specific diagnoses. Nevertheless, crises such as myocardial infarctions and sudden hospitalizations, were present in the life stories of all the participants and revealed religious/spiritual practices. Lastly, future research on religious/spiritual coping should sample for an economically diverse sample, including more people who are underinsured or do not have a financial safety net as their narratives would improve insights from this research on health equity and the use of religious/spiritual resources.

The interpretive phenomenological approach I have described in this chapter required that data analysis be on-going. I drew upon qualitative data that I collected through semi-structured interviews with 13 Women of Color with heart disease who engaged in religious/spiritual activity regularly or considered themselves religious/spiritual. The interpretive account included in the next few chapters deepened as follow-up interviews were conducted, and as participant were interviewed.

CHAPTER 3: RESULTS

"Experience, affectively reconceived, constantly cuts escape hatches in the constricting enclosures that scripture, tradition, and reason perpetually threaten to become." (Karen Bray and Stephen Moore, *Religion, Emotion, Sensation*)

When we include spirit as part of our understanding of what it means to be human it can shine a light on who is human, where our policies, practices, and discourses support, enhance or deny that humanity and how experiences of disability may intensify and shape the life journey of human beings." (Deborah Stienstra and Terri Ashcroft, "Voyaging on the seas of spirit")

I interviewed thirteen Women of Color with heart disease who considered at least one weekly activity to be religious and spiritual. Religion/spirituality was expressed in glowingly different ways from person to person, and sometimes, which I discuss in later chapters, from interview to interview. In presenting the whole sample, my goal is to provide a rich description of these 13 women's lives on their own terms, as well as "light up" my understanding of their religion/spirituality's influence on their daily lives and illness experience. Also, I wanted to let each account of beliefs, practices, and communities shimmer in-context to bring myself and readers one step closer to how each person "embodied" their way of being and what's to be learned from that understanding (Dreyfus 1991:18).

SETTING AND SPACE

I interviewed each participant at least twice, except for one participant who was unable to be reached after the second interview was scheduled. Most of the participants spoke to me from their homes. Whereas in-person we may have met in a neutral space, the setting for the interviews invited me into a glimpse of the participant's home, and the spaces within their home that were the most comfortable for them. One participant described her room where we met as the "eye of the storm" – it was in the center of the house and was a sanctuary for her to study, rest and have some solitude.

CASES, PARADIGMS AND PATTERNS

Each participant's narratives involved changes in religion/spirituality and illness experiences. Understanding their lifeworlds supported my interpretive work and led to the development of paradigm cases that shaped how I interpreted the patterns of being-in-the-world revealed by the data. Three patterns of being are described in more detail in the chapters to come, through the lenses of paradigm cases (Chapter Four) and then in the deepening of my interpretation (Chapters Five). These patterns were not mutually exclusive of one another and "showed up" in almost every participant in some way, but some participants revealed the pattern more brightly. These patterns reflected changes in the relationship between religion/spirituality and health over time in Women of Color's lives as they deal with heart disease: relational change, intersectional change, and receptivity to change. The method of interpretive phenomenology provided the opportunity to focus on change and time.

OVERVIEW OF THE SAMPLE

The women with heart disease in my sample varied greatly across categories of identity and sociodemographic characteristics, as well as disease severity. Participants were invited to self-identify their race, ethnicity, culture, religion, and health conditions. Some selected characteristics of the sample are provided in Appendix B. Despite the diversity within the sample, data interpretation offered an opportunity to conduct within-case analysis, cross-case analysis, and thematic analysis. These activities drew my focus to the commonalities among the women, features of their regular religion/spiritualty, and patterns of being related to how religion/spirituality fit into their lives. Each of the women point a spotlight upon how living with heart diseases under different circumstances influenced their beliefs, practices, and communities. They ranged in ages from 25 to 69 years old. Four participants were in their 30s,

and seven participants were in their 50s. Five of the participants were Black; five identified as Latina or Hispanic. One participant identified as Asian; one woman was Filipina American, and one woman identified herself culturally Hindu. Most, but not all participants had health insurance and saw a regular health provider and a cardiologist during the study period. Only two participants were retired. Three had periods of unemployment between recruitment and the final interviews. Two received disability benefits. Most participants said they had at least a couple people with whom they felt close.

Each participant had one or more types of heart disease and experienced a major hospitalization or surgery. Two women had heart conditions that began in childhood or at birth. Three had conditions that arose when they gave birth to their first child. One woman had undergone a heart transplant, and another was awaiting a new heart during our interviews. Two women had experienced cancer as well as heart disease; one had multiple strokes and at least two participants had an autoimmune disease. Five participants rated their health as "excellent" or "very good;" three participants rated themselves as "good." One participant rated their health as "fair" and two rated as "poor." For some women in the sample, their major symptoms of heart disease were largely resolved and the crucial incidents with their heart a distant memory (Diya, Sloane, Cherie). For others, dealing with heart disease in their daily lives was an anticipatory experience, for they were not feeling sick or disabled by their heart disease in recent memory, but they knew that their illness was progressive. Some day they would have symptoms that would affect their daily life. This outlook was often coupled with anxiety and religious/spiritual searching (Vera, B, Kay, Ayo). For some women, the challenges of fulfilling basic needs was so great that religion/spirituality was first applied to those realities, of which their heart disease was one aspect (Carmen, Diane, Denise). For several women, their

experience of heart disease itself was a religious/spiritual experience (Mary, A'huva, Violet). These were not mutually exclusive groups of women, but they represent different ways of understanding the influence of illness experiences upon religious/spiritual experiences of the women in this study.

THIRTEEN WOMEN'S LIVES

Here I present the sample as a set of 13 whole cases of Women of Color with heart disease who used religion/spirituality to deal with their illness. First, I describe the lives of 10 women whose religious/spiritual lives changed over the course of their illness and endured other changes in life circumstances. Their narratives helped me to identify major patterns in the whole sample. At the same time, each woman experienced their own challenges, produced their own relationship between religion/spirituality and health. Then, I provide a short summary about the lives of the three women featured as paradigm cases in this dissertation, including a general interpretation based on my analysis of the whole sample and the whole individual. I close this chapter with three cases that I will take up in future chapters. I developed these texts into paradigm cases, representing key themes and patterns of how religion/spirituality and health change over time.

Diya

"Whatever I'm doing for my religion, I want to focus and to focus, I have to do something different to find out."

Diya* was 54 years old and an immigrant from India. She had congenital heart disease, which was discovered a few years after she was born. She lived with her husband in a joint household of multiple adults, including siblings of her husband and their families. Many aspects of her life are shared responsibilities in the household, from the businesses they own to housework and childcare to involvement in the same temple community. Diya was a dedicated volunteer at her Swaminaraya temple in addition to all her responsibilities in her large joint family home and her family businesses: “My life is temple, temple and home, or if I'm not home, I'm at the temple. If I'm not at the temple, we have a business. So it depend, when they need where, and if it's something comes up at the business, it's also priority. So I work around that area. So if I'm free and I don't have to be there [at the business], I don't need to go there, I just volunteer myself over here at the temple.” Contributing her time at the temple was a spiritual practice, in addition to her prayer, meditation, and reading of sacred Hindu texts. Diya lived her beliefs through hospitality, welcoming and feeding and listening to guests of the temple. She also deepened her spirituality through reading sacred texts, namely the Vachanamrutam, which outlined core teachings through detailed dialogue between the founder Bhagwan Swãminãrãyan and his earliest devotees. She carried her copy with her always in order to catch up with her reading while traveling. As part of Diya’s responsibilities as a host for her temple community and the extended network of families and other joint households of which her own joint household was a part, Diya often provided emotional support to distressed members, often individual women with family or emotional concerns, who came to the temple for the first time. She said: “It is a day-to-day life. Everybody’s so busy. People really want to

* Pseudonyms were selected by 12 of the 13 participants. Kay was unavailable for follow-up and so a pseudonym was assigned to her. Other identifying details have been changed to protect women’s confidentiality (business names, for instance).

share their experience. People really wanted to talk to somebody, but nobody has time to listen. So, we should give them our ear and listen to them." Mutual support and providing emotional care to people who were younger than Diya was an informal way in which Diya lived her religion.

During our first interview, Diya shared how she came to be diagnosed with congenital heart disease as a seven-year-old. Living in a small town far away from any large cities in India, the diagnosis process was arduous. She eventually traveled to Bombay in the care of an uncle and her mother to see a heart doctor, who found a life-threatening leaky valve that required open-heart surgery. Her family did not expect her to live, but she survived. Her parents were informed that she should not become pregnant, and this had ramifications for them in the process of finding her a husband. However, before she married, her now-husband was informed of the problem and agreed to marry her anyway. Later, just after Diya and her husband moved to the United States, she did become pregnant unexpectedly, and despite the medical advice she received to slow down, she did not want to be a "hassle" to her family and experienced serious complications during the pregnancy. She gave birth to a healthy child, but needed to have another open-heart surgery following the delivery. While her heart problems resolved following surgery for many years, in the past few years, she felt more stressed and depressed. She shared that she needed a break soon from the pressures upon her leadership at the temple and in the hotel businesses she ran with her family. She also had lingering feelings of grief from not being back in India with her mother when she was ill and dying:

> I feel guilty that, because I was too far from them and I constantly feel that my mother took care of me so good, and now my time to, it's my turn to, to do, you know, to serve them but unfortunately, I was here. I'm enjoying family, they were in India.

Recently, when she noticed that her mental health was suffering, she reached out to a friend in her temple who had dealt with her own depression, who suggested Diya pursue mental health care:

> "I keep forgetting stuff and my behavior, my behavior is I'm really aware of what I think, but my mind is keep thinking negative that 'this person is not taking care of me, this person is not thinking me.' And I, when I go to the hotel, I become really like irritated and little mad, or like a little anger, which is not normal."

She found that her mood had improved after adjusting to antidepressant medication, but she still felt overburdened by the pressure and workload of her various responsibilities. She wanted to gain skills to prioritize herself: "I need to learn to take care of my soul, my body. And how can I not say yes to everybody?"

With the blessing of her guru and husband, she accompanied her niece on a meditation retreat at a meditation center not affiliated with a particular religious group. Engaging in meditation outside of the Swaminaraya tradition was rare in her community. I met with Diya after the retreat to hear what it was like and continue our discussion of her religious/spiritual beliefs and practices in relation to her health. She had a few concerns about her participation. First among her concerns was that she had to go away for 10 days, which was the longest she'd been away from her family household. Second, she was asked to leave her phone at the door. She was worried but felt it was a good idea: "I feel like, you know, I want to be... I want to get away from everything, right? So, if you have a phone, no matter where you are, you are in the world." She found that the tenets of the meditation retreat were largely compatible with those at her temple, except the retreat did not have a guru, or role model, but they left it up to her as to how she would want to "cure" herself. When she told her husband about the retreat's format, she said "I want to, whatever I'm doing for my religion, I want to do really--I want to focus and to focus, I have to do something different to find out." The retreat did offer "something

different" to Diya - space and time to think. She also befriended a white woman at the retreat who was studying to become a therapist. The woman offered her guidance, not as her therapist, but "its just I feel like its my guru, my heart was inspired to talk to her." She took away the advice that she could accept her unhappy mood some days and just let it be. They left the retreat as friends and began to text one another. Diya reflected that the woman held her accountable by text in applying what she had learned during the retreat to her daily life back at home.

Diya came to new conclusions about her family life and how it affected her ability to do things on her own terms and support her mental well-being. In a joint family, there were always a lot of people who had their own divergent opinions about what she might want to do. During the retreat Diya realized that the result of her bringing her initial ideas to each person seeking approval, was that often Diya abandoned any new ideas that might make her happy. When she returned home from the retreat, her relationship to her responsibilities at the temple had changed. Diwali, a major festival celebrated by Hindus (as well as Buddhists, and other groups), was approaching and typically Diya would become very focused on the preparations, specifically wanting them to be pleasing to other people. Following the meditation retreat, she had a change in perspective, "I have more clarity that why do I have to wait for somebody's opinion? I still do what I like to do. I have to keep myself happy."

Though Diya felt deeply changed by the retreat experience, service was still a key religious/spiritual activity. She also believed she would need to return to the retreat another year to volunteer to cook and then be able to attend the retreat as well to continue to deepen her own well. When I asked Diya to select a pseudonym for this research, she selected the name "Diya," which is the word for the deep bowl in which candles are rooted in homemade ghee and lit during the festival of Diwali.

Cherie

"How connected the heart is!"

Cherie, 58 years old and African American, had been raised as a Christian, and 30 years ago, she found her way to Buddhism while deep in Christian prayer during the height of her health problems:

> I didn't start off as a Buddhist, I started off as a Christian, and then all these other different things. And I actually became a Buddhist because I got on my knees and pray. And I asked God to help me find a practice that I can utilize, and I can just feel they can help me grow and develop as an individual and be the core that was missing in my life.

At first, she felt the message she received to pursue Buddhist meditation was "blasphemy!" given her childhood brought up in a "Christianity world." As she listened to the call toward Buddhism from her prayer, she found herself growing internally in ways her spirituality had not produced prior to finding Buddhism. She realized that:

> I was always putting the blame outside. It's like, Oh, I can't do this, you know, it's not the Lord willing. And then I realized that I had to take the responsibility, you know, and had to actually—that's when I started understanding the Bible, and then my practice, because I started realizing: if God says he made us in His own image, then the same abilities that he's been given we have it already [in] us. So He already gave us the wisdom and knowledge, it's up to us to use it. And I felt in doing the regular Christianity way was not allow me to, you know, build out that and actually practice what I was just saying.

Cherie worked in financial services for a university and was in relatively good health at the time of our interviews. She experienced heart murmur and blockage problems, which she has mostly kept out of her way in the past few years, in part due to the meditation and chanting practices that she identifies as protecting her. During the pandemic, Cherie added TikTok (social media platform) to her spiritual repertoire, joining in dialogue with spiritual leaders from around the world. She formed a friendship with a meditation practitioner who shared his practices on social media and together, they began leading spiritual discussions and practice sessions on Zoom. These conversations and connections expanded Cherie's spirituality during a period, in which

social isolation was prevalent and religious/spiritual communities had become dormant. Cherie felt that her spirituality had flourished between our interviews, which took place during serious waves of the pandemic. Her resilience and flexibility contrasted with the serious financial, health and social support challenges faced by other women in the study.

Violet

"Lord, I know you're working on me."

Violet was a 59-year-old Black woman living in California, and a survivor of multiple long-term serious health conditions. When she first got sick, she retired from 29 years of service working for the state. During our first interview, a colorful art piece sat atop a high shelf behind her, in rainbow letters spelling out "REJOICE." As a devoted leader and member of an Assembly of God church, the work of the congregation filled her schedule and her soul on a daily basis through activity groups, individual study, family prayer, worship services and volunteer service. Her strong belief in God had begun when she had experienced marital issues when her children were young. Faith restored her marriage, and in many ways, life in her church community reconnected her and her husband. In June 2017, her belief in God and her devotion to her church intensified when she was given only six months to live, following diagnosis of amyloidosis, a heart condition in which there is a build-up of amyloid proteins in the heart and other organs. Each year that she lived longer than her doctors had anticipated, her gratitude to God increased. She was diagnosed with multiple myeloma (a cancer that forms in plasma cells in bone marrow). Later, she was also diagnosed with congestive heart failure and then, in early 2018, with breast cancer.

Violet was one of the several participants in this research who had multiple long-term health conditions. She also isn't alone in needing to request a second opinion after receiving recommendations that limited options for treatment. Her oncologist had told her that she was "not going to make it" through a mastectomy and recommended she just "leave well enough alone and live her life." Violet could not abide by that recommendation and proceeded with surgery and treatment anyway. At the time of our interviews, she was in cancer remission and experienced symptoms associated with amyloidosis, but getting by each day through "diet changes, exercise, positive thinking, and the Lord."

Over the course of her many treatments, side effects of treatments, periods of uncertainty regarding her survival, and battles with pain, Violet found comfort in the story of Job from the Hebrew Bible, in which Job suffers greatly:

> it just like blows my mind—all the pain and suffering and the losses. There's a part in there where it says Job prayed for his friends…. and I realize it's not about me. It took me a while to get to that, but I get it now. It could be this journey that I'm learning could be for my kids, you know, to strengthen their faith. I don't know who it's for. I mean, I'm, I'm in it, but it could be for somebody else. It's not about all about me, I guess is what I say.

Violet hoped that there was meaning in her own suffering, that somehow it had a purpose. The lessons from Job and Psalm that her cousin gave to her that read, "I shall not die, but live and declare the works of the Lord." For Violet, this did not mean that her "earthly shell" would not die, but that she would "live eternally with God" and that she would be able to turn to God in times that life took a "detour" from her expectations. She referred to herself as a "work in progress," and that while her beliefs did not always bring her out of her sorrow and periods of painful symptoms or treatments, her husband and her community helped her to remind her

about God's plan for her life. Violet made sure to clarify for me a part of her belief in God's role in her health: "I don't believe God made me sick. But I do believe God got me through." She is one of several participants who made this distinction in how they understood God's relationship to the origins or outcomes of their illness.

Violet also found her sense of purpose in life through serving her church community. As her health conditions caused her to need more rest at home or to adjust her busy lifestyle, Violet was uncertain of how her life might change and reluctant to admit it might limit or affect her emotionally or spiritually. There were challenging emotional days in dealing with her health conditions and treatments that she and her husband called "being in the bucket." She recalled testimonies of people in her church, persevering through challenging times, with God at their side. During the pandemic, Violet continued to be heavily involved in leading church groups and participating in online services or groups. Her involvement was a regular practice, as part of her devotion to God and her church community. Service was an opportunity to give back and do good as repayment for how much good God and her faith community had done for her life. Saying "yes" to activities, and leadership was not necessarily related to the content or activity of the groups. Part of Violet's religious involvement was being open to being changed by, and even surprised by, what would present itself to her through study and participation with God. For instance, in 2021, Violet co-led an online summer "sister circle," a group of women who would select different Bible-focused curricula about aspects of living a Christian life. she was skeptical about whether the topic was a good fit for her. She stayed in the group because she had committed to participating in the program. The focus of the program was on the theme of

"beauty," which wasn't really a topic that had interested her. She ended up being glad that she stuck out the course, as she learned more about herself than she expected. She said:

> I learned so much about, you know, all the scars and all the imperfections that I think I have. It's beautiful. And so, in that healing time, you know, it talked about anytime, like you have a scar, you hurt your finger, you have serious surgery, or you scrape your knee and it heals, that's a sign of, that is, God that heals us, right? And that is Him that is showing you that through the scars, 'I'm still here,' and that He's the one that heals, and that I don't have to feel some kind of way about how I dress.

In exploring the program, she felt God was encouraging her to stay in the group, despite her early misgivings. One of her major beliefs supporting her in staying in the course was: "Draw near to God [and] He will draw near to you." In other words, if you participate in something for which initially you may not know the full benefits, God will reveal something greater than what you expected. Violet found new spiritual meaning for her scars from medical treatments and reassurance about her own style of dress. Also, she found her relationships with the women who stuck with the entire curriculum formed stronger bonds.

Groups were a major part of "drawing near" for Violet's religious/spiritual life, participating in groups almost seven days a week, from Bible study classes to prayer groups to women's ministry and helping out with Vacation Bible School. She kept up with all of them that went online when the pandemic started. Also, outside of her local congregational community, Violet also participated in prayer by conference call with friends and family who were scattered across the country. During her chemo treatment, they created a prayer time via conference call to pray aloud together for her health. They continued the prayer calls, after she recovered from major periods of illness or treatment and prayed for other people who needed

spiritual support, especially during the COVID-19 pandemic. Also during the pandemic, Violet pursued new activities, such as guitar lessons so she could play and write praise music. Violet and her husband also participated in an international online Bible Study Fellowship that connected people across the country online for chapter-by-chapter study of the Bible. Also, as another participant, Kay, did, and other women in the sample, Violet used the Holy Bible app regularly as a tool for her Bible study.

When I met with Violet for our follow-up interview, she had been diagnosed with glaucoma and had been experiencing unrelenting cramping and muscle stiffness in her legs, which had affected her ability to walk or sleep well. She hadn't missed any services at church due to her pain, but she had to miss or cancel other events with friends or family. Her support network had been understanding about her and it had not kept her from making a new friend, who needed some support with errands and companionship, with whom she prays or shares scriptures. She helped the new friend because Violet believed that

> there's so many people that just need help, they just need a smile, they just need a handshake. And when I say that, it's just little things, too, sometimes not so much. Now she's [the new friend] a believer, but, you know, just because you're a believer, doesn't mean you have somebody in your life to help you. Right? And so, a lot of times people just need--I call them little angels--you know, like, I've had so many in my life.

Violet relied upon her strong beliefs in God and the power of mercy to get through her own medical problems and to show that mercy to other people through acts of service to other people in her community.

By February 2022, Violet was really pleased her church had reopened to in-person services following the pandemic. However, she was concerned about the fact that many people were not wearing masks inside the church. Also, she feared that the lack of people returning to the congregation's in-person Sunday services would harm the congregation as well as those members who didn't attend as they did before the pandemic. She didn't waste her time comparing herself to others, because God was "part of my day, every day." She recognized how her husband had become quite disciplined in his study and prayer practices and said:

> I don't beat myself up over it anymore. I said, 'Lord, I know you're working on me.' And I've come, not, nowhere have I achieved the goal. But I have grown a lot throughout the years. So to give Him time. I do strive to do that in my day.

She knew that the things she was facing often she had to face with God; "nobody, not even my husband could fix that" situation with her health. She said, "I do believe if it wasn't for Father God, I probably would have lost my mind."

A'huva

"Don't put a question mark where God put an exclamation point!"

A'huva, 55-year-old, identifies as a Person of Color and Latina. When we scheduled our first interview, she was waiting for test results related to a recent scan to determine if a mass on her heart was cancerous. By the second interview, she had received news that the cancer had recurred and underwent more surgery. However, she took a different treatment route than her earlier experience with cancer and heart problems. In 2014, A'huva had a resection of her heart, after removing a tumor. Following that procedure, she had seven years of "clear scans" and a strong functioning heart. She said she suffered greatly through chemotherapy, and her self-image changed dramatically during that period of time. She said, "I really felt that I felt like my youth was gone….that picture [pointing to her zoom photo]. No wrinkles, happy, you know, strong. And somehow, six months later, not so much." In that six-month period, A'huva was diagnosed with cancer. She also lost her job and was in legal battles to get her job back. She had reached out to people of faith close to her for support and did not find their support comforting. She then became more disconnected from her Roman Catholic faith:

> I even got more disconnected from God because I felt like I was not protected. I didn't understand what was happening. I tried to talk to a priest. And I told him I was in crisis. And if he could, you know, talk to me for a little bit. And he said he was his day off. And he did not offer another priest or anything. And there was another priest I went to that was my longtime pastor at church and he had gone to this one house to retire until he got re-assigned and he didn't call me back. And again, those are all people. Yeah, you know, but I looked to them to help guide my spiritual walk and they were not there. And so, yeah, for a long time, I felt disconnected. I stopped even going to church.

She felt that she was not protected by God, though she said she doesn't think she's ever truly been "away from God." Looking back on that period in her life, she told me that she had felt wronged to deal with cancer and heart surgery, followed by job loss that God was not in "first place" in her life. She felt she wasted a lot of time trying to resolve conflicts with her previous employer, which she said she had incorrectly assumed were parts of "God's promises." Now, she felt closer to God and had been praying multiple times per day, seeing the blessings in her life. She had not returned to church, in part due to the pandemic, but also because had been receiving a lot of comfort and support from watching televangelist and megachurch pastor, Joel Osteen's services on television.

During her first experience with cancer treatment, A'huva had an important message come through to her in the hospital. She had begun to feel emotionally "unglued" and could not stop crying, when suddenly she heard a verbal message in her ear say: "that would be a shame." She said, "I don't know if it was an angel, or God or my dad, but it was definitely something from the spirit realm to tell me." She interpreted it to mean that she should not lose control but "grab a hold of yourself" so you can move forward and get stuff done. For A'huva, losing control due to her medical conditions would be a way of separating from her spiritual beliefs or trust in God.

In another incident, A'huva described, the "electrical system in her heart totally failed." She was seconds away from being intubated when her heart was stabilized with medication. She remembers the doctor calling the resolution a "miracle." This word became an important part of

her religious/spiritual identity from that day forward, and a frequent part of our interview conversations.

During our second interview, A'huva shared with me that she had received yet another cancer diagnosis and a tumor was removed from her heart. Determined to avoid chemotherapy treatments, even with her oncologist urging her to treat the cancer following surgery, A'huva tried to remember that she "was a miracle" from the experience in the hospital several years ago. Despite her stronger spiritual practices to "put God first" in her life during the years since those first health crises, A'huva had received another cancer diagnosis. She said, "later on, they say I have a tumor in my heart, again. I'm not feeling miracle, you know?" In the first cancer treatment experience, she did not tolerate the medications and treatments well. She decided that "God already saved me from chemo once." She felt she couldn't go through chemotherapy again and survive it. Instead, A'huva pursued multiple different opinions on her case from medical centers. She also began to have a plant-based diet and tried to reduce the cancer remaining in her body after surgery. The diet change ended up being successful, and when A'huva's test results showed no cancer in her body, A'huva recalled the doctor's words to her. She recounted that the doctor said "miracle like 15 times." Her family members were not as convinced:

> My sister still doesn't get it, and even when I told her about the zero reading on the last blood test, she's like, 'Oh, I think you need a second opinion to make sure.' And I thought, 'What? That's when you get a negative one. When you get a positive one, you go, 'Hallelujah. Praise God. Amen to that.' And that's it. You don't put a question mark where God put an exclamation point. You don't do that.

> But I do believe, for me, I'm grateful that I've had a lifetime of believing, but I definitely am no theologian, or no zealot or anything like that. I just have had that respect and belief and openness for it to come to me. Because at the end of the day, when people blame God for all that's bad, you have to realize they're not giving him any credit for all the good.

"You don't put a question mark where God put an exclamation point" was a Joel Osteen-ism. In a few instances during our interviews, A'huva quoted back to me popular phrases from Joel Osteen's programming. To her, "Pastor Joel" was offering in his services things that were so relevant to her life without having to spend time on her own looking this up or trying to figure out the scripture. She also felt him speaking directly to her circumstances, in times when Roman Catholic priests or other people in her life didn't offer her the kind of presence she desired. During a visit to Texas for a second opinion, she visited Osteen's Lakewood Church, which is a stadium seating thousands of people each service. A'huva sat near the front, close to where Osteen stood, but her relationship with Osteen primarily was with his message. She didn't have a pastor-parishioner relationship in a direct sense. By March 2022, she had begun taking her grandson to Catholic mass but still felt a deeper connection to Osteen's message for her personal spirituality. A'huva did not base her connection to a particular kind of tradition due to her changing religious/spiritual beliefs, but where she felt like her own story was reflected back to her, and her needs were met. Osteen's congregation in Texas and televangelist programming did not offer A'huva the opportunity to have a direct dialogue with clergy, receive individual prayer for her situation, or take part in the more intimate connections in smaller brick-and-mortar congregations. She had poor experiences requesting care from a Catholic priest or spiritual leader that turned her away from the faith of her childhood. Her connection to Osteen's

congregation did not provide any opportunity to have those personal contacts, nor, I suppose, any risk of being disappointed.

Denise

"He'll make a way out of no way."

Denise, a 51-year-old Black woman, and I met for interviews in her car on Denise's lunch break at the mental health facility where she worked. Prayer was a main religious/spiritual practice in Denise's life. She said, "just in the course of a day, will call on my higher power to give me strength." She had been attending church services before the pandemic, but since the pandemic she hadn't returned to them, even after they re-opened. However, occasionally, she would watch weekly church services on Zoom. In 2009, Denise was diagnosed with cardiomyopathy, congestive heart failure and "a bunch of other stuff." She had experienced a few complications, including a blood clot in her lung and more severe heart failure symptoms. She had been "bedridden" for several months, unable to walk downstairs from her bedroom or make food for herself. The time she spent resting gave her time to research her health condition. She found out about how dire her situation was through her own search for information. She learned that most people with cardiomyopathy who progress to heart failure, die within 10 years:

> So, I'm in like year 12 now. And so, I firmly believe that my higher power is sustaining me, you know? Because I was rooted in the Church and brought up in the Church and taught to believe that, you know, my God is my strength and my salvation, that he'll take care of me. And so, I remember when I was really, really sick around that time, I used to pray and say--you know, I asked the Lord to sustain my life.

Denise's prayer each morning is one of gratitude to her higher power for keeping her alive and supporting her children. She said she "talks to him" whenever she needed "to be strengthened," which left her feeling more peaceful in ways that were difficult for Denise to put into words. In terms of what "higher power" or God mean to Denise, she said her sense of what the terms mean had evolved over time, that she had come to believe that it was possible to ask questions and have doubts about what she read in the Bible or how some religious traditions interpreted texts or explained certain life events. She said:

> I just kind of feel like, you know, there's someone there that I can depend on, especially, with me going through so much and coming out of it. What is, what is the explanation for a diagnosis that I was supposed to be dead two years ago and I'm up here making plans and working every day and taking care of my kids and trying to buy a house and--you know, what's the explanation for that? Is that a miracle?

With or without an explanation for what she experienced, she had fears about her future, because her mother, who was her best friend, had died of cancer at 59-years old and she had just started a new business. She said it doesn't make sense to her that her mother had died, she was sick and people like Donald Trump, killers, or other terrible people were "healthy and thriving." She thought to herself, "At that point, I really started to question, like, is this all bullshit?" She accepted that she had confusion about why some people received long and happy lives and others, such as her mother, died.

People in churches had not always been a positive influence in Denise's life. She had a negative experience with the church where her mother and she were members. When her mother died, the congregation had a change in leadership and Denise felt that the newer leaders didn't know her family as well and "turned their back on us". Based on that experience, when Denise

was diagnosed with heart disease, and in another instance when she lost all her income from closing a business she owned, she didn't reach out to anyone at a church community for support. She also struggled to contact her family members or other people for help, as she had pride in herself for being an independent woman and she wasn't sure "any of those people would have came through anyway."

Denise summarized her belief that there were some things that she would be able to control for her health, or do to improve her well-being, and at the same time, there were things that she could not control or change. She said that having heart disease had made it more difficult to feel like she had control. She knew she would not have control over her ability to do physical activities and while she had "a better grip on my mortality because of my illnesses," her experiences with disease also gave her much more empathy for other disabled people in her community. She believed that she could always return to God and to prayer, since she believed as her mother had told her growing up: "He'll make a way out of no way."

Sloane

"God is not a genie in a bottle."

Sloane was a 37-year old Asian woman who just moved from New York City to the Bay Area. When she was pregnant, she became short of breath just prior to the birth of her child and following the delivery of her child by C-section, they could not resolve her shortness of breath and fluid backed up into her lungs when her heart was struggling to pump. After additional testing, they found a heart condition called mitral valve regurge that needed to be addressed with heart surgery. Sloane remembered being extremely angry and frustrated during her

hospitalization. It was really challenging for her to accept the change in her birth plan, and she felt that her care team was highly disorganized, delaying her discharge to be home with her new baby. She had worked in the medical field, and admitted that if she had not been familiar with how things worked in the hospital, she would probably have been there for another week. She was able to be a strong advocate for herself.

Since the birth of her first child, she had not experienced significant challenges with her heart, but she did have concerns about what would happen should she become pregnant again. Eventually, she did become pregnant again, and was able to have a vaginal birth. She had preeclampsia and gestational diabetes this time, but no further complications with her heart, except for some additional appointments. Over the years, she had bouts of anxiety regarding her heart condition and her risk for hypertension. She was able to share her anxieties with her husband: “But no one knows except me and--I believe--God because He was there or--He was overseeing it.” As a Christian, Sloane’s principal beliefs included a trust in God’s plan and that God was not a “genie in a bottle,” able to grant our wishes just as we would like them. Prayer was a time Sloane felt she could be most honest about her fears and anxiety, as well as her desires, such as for the vaginal birth in her second pregnancy. She said, “I mean, I just think I was like--God, yeah, really listened to my prayer. And answered.” Sloane also received visitors from the congregation when she was at the hospital as part of the church’s pastoral care efforts. She appreciated the thoughtfulness of the church coming in larger groups at one time (versus individual friends showing up all the time), which she didn’t think she would have considered to be helpful if she didn’t have a church. Sloane related the nature of pastoral care over secular groups of friends to be relevant in how the care she received felt. She was able to give back in

an organized manner, by joining others at church to do the same for other people, when they were ill or had a baby, as part of the broader church community.

Other than prayer, Sloane had not been in touch with her religious/spiritual practices with the same regularity or depth since leaving New York City. In NYC, Sloane had a strong church community of people the same age as she and her husband, who participated in evening activities and were her main social group generally. She also had a Life Group that would reflect on devotionals, check-in about daily life, and pray for one another via text message chains. The Life Group was still including her after she had moved to the Bay Area, especially during COVID, but it wasn't the same as when her whole social life was embedded in her congregation. After moving to the West Coast, Sloane church-hopped a bit with her husband to try out different communities but didn't find the same sense of welcome and like-minded community as she had hoped. Also, now with children, she wasn't available to attend weeknight gatherings, where strong bonds were formed. When the pandemic began and congregations no longer held in-person services, she did not find the worship services on Zoom to have the same sense of connection she desired, and it was too challenging to feel out possible church friendships. Without a community, church and religion/spirituality generally just "hasn't been on the forefront" of her mind; although, her personal religious/spiritual practices remained largely the same.

During our second interview, Sloane shared that her husband had become increasingly disconnected from God, since church had stopped being a strong force in their lives. She said:

> "The times I feel disconnected, I still have enough faith to be like, you know, this is just the season of my life, that this is like how it is and I just need to keep persevering. I do get nervous, and maybe I don't give him [my husband] enough credit that, you know- Anyone else who's not as strong as a believer or has doubts would be like, 'Okay, you know, I'm not hearing Him, because He's not- He does not exist.' So we [me and my

> husband] talked about it. I'm like, well, that's what faith is, right? You like, you don't hear Him, but you have faith and the idea is you'll hear Him again. And we talk very lightly about it. That was probably the extent of it." Aside from her husband, the pandemic and the lack of a congregation she felt she belonged, she felt "more isolated. I feel a bit alone."

The friends she had made were not Christians who practiced their faith, or not religious at all, which made her feel strange or like an outsider. She felt hesitant to create deeper bonds with newer friends in which she might share her faith with them: "I love sharing my faith, but I don't want to come across as those people who are pushing their faith."

B.

"This is my calm place in the eye of the storm."

B., 31, described herself as Latina and Hispanic and spent a great deal of her life in Texas before being with family in California since she had needed significant medical care. B faced perhaps the greatest number of chronic conditions among the women in this project. Her heart conditions were a subset of several chronic diseases she faced, including lupus, kidney disease, and rheumatoid arthritis. B also recovered from two strokes, one that occurred around the same time as she developed congestive heart failure, and the other a few years later. After B gave birth to her first child, she developed a urinary tract infection that persisted and led to her developing sepsis, followed by an infection in her brain and heart. She had to have her aortic and mitral valves replaced, but the ordeal concluded with a major stroke. While she was recovering from the stroke, she lost custody of her child, because she was unable to travel out of state while on IV medications to be at the court date and the court would not reschedule despite her and her doctor's pleading. She later gave birth to a second daughter, and it was through that pregnancy that B learned a great deal more about her conditions and their medications.

Over the course of her experiences dealing with chronic conditions, family support has been inconsistent and due to her family members' own health problems, B said that many caregiving and emotional support responsibilities fell to her. During our second interview, B wore a Zio patch, or a home heart monitor, as she had just established care with a new cardiologist and had been curious about some irregular heartbeats. However, she also said it could be emotional, because she found herself under so much pressure from her family dynamics at home: "I'm going, going, going like fight or flight mode over here, because it's just like chaotic sometimes."

Before her rehabilitation took her to California, B had been an assistant manager of a large retail store. She began to receive disability benefits after her second stroke, and at the time of our first interview was taking courses to become an Xray technician. Also she was moving through the process of applying for Section 8 Housing for her daughter and she to begin a new chapter. Yet, for now, she called the room where she sat for our interviews the "eye of the storm." It was a room to herself in the center of her parents' home where her multigenerational family was constantly in motion and asking things of her. At times, B resented her caretaking responsibilities and felt like her family did not realize that she had health challenges that were ongoing. Behind B. in our Zoom window, there was an altar and a portrait of Marilyn Monroe on the wall of the room. She described herself as having an eclectic spirituality; though there have been periods of time in which her health was less stable following her first stroke, and she was attending a Christian church with her family. More recently, she did not have a dedicated time of week or day in which she practiced her religion/spirituality. Rather, she took up specific activities to prepare for exams, comfort her when family stress is high or cleanse and clear the energy of her space. She also relied upon mind-body techniques, such as biofeedback,

aromatherapy, and chakra healing, for relieving pain, grounding herself or investigating the sources of tension or discomfort in her physical body or mood. She found gardening and listening to music had a spiritual quality.

Rather than adhere to the tenets of a particular tradition, B described herself as being on a spiritual journey. Following her open-heart surgery, she remembered being in the hospital and "felt like there was—there was God, and, you know, He was there for me, but I felt like there was something more." Later, B found a close friend with whom she shared her spiritual beliefs and practices. Together, they processed what is going on in their lives through shared interests in crystals, biofeedback and metaphysical practices, as well as their shared experiences of chronic illness. Especially during the pandemic, their bond deepened and was tested when B's friend had a serious COVID infection and moved to Florida, but they continue to support one another.

Kay

"Sometimes [my Bible App] will be right on the dot with what's going on in my life."

Kay is a 25-year-old Latina (Salvadoran) who was a mother of a three-month old baby and identified as Christian. When she was 19 years old, Kay underwent heart surgery, but she said that she did not have a full understanding of what "a surgery like that does to your body." She said she had a heart condition since birth, but said she was still learning the potential complications or risks. Kay was the youngest participant in the sample. Kay had "a heart problem with [her] valves," which began while she was delivering her daughter in the hospital. She had fluid in her lungs. It resolved before she was discharged, but then a few days after, she had to return to the emergency room to deal with the liquid. Due to COVID-19 pandemic-

related restrictions on hospital visitors, she had to deliver her baby with only her partner present and no other family in-person support, and she had to return to the hospital alone when she had fluid in her lungs.

At the time of her interview, Kay had been waiting to see a cardiologist to get a fuller understanding of her diagnosis and how to prevent "flare ups" of what happened to her when she gave birth. She experienced significant anxiety and fear when she was hospitalized, away from her newborn child and alone for many hours per day, fearing that she might not see her daughter again. She said:

> On a day-by-day basis, I was worried. Also, I felt like I wasn't gonna make it out of the hospital, and I have this beautiful baby, and I'm gonna leave her alone. So, I was very appreciative as you know, during the time there, for every minute I got to be with her.

While hospitalized, she turned to God to offer gratitude for her healthy pregnancy and child, and to pray that her health issues resolved as well as that she would survive to be a part of her daughter's life.

In addition to praying to God, Kay observed and deciphered "signs" during her hospitalization that gave her hope that she would be survive and recover. For instance, her boyfriend's grandmother died just the day before Kay was induced to give birth. She was worried that in his grief, her boyfriend would not be able to support Kay through the birthing process. However, Kay felt he was able to stay strong in way that must have been through some divine intervention and the spiritual presence of the grandmother: "it has to be coming from a higher being, because I don't know how he does it…we just imagine his grandma, like, guiding our baby to us, and like, meeting us in some way in that in-between realm." Her boyfriend's grandmother had lived with Kay and her boyfriend, and had a strong evangelical Christian spirituality that inspired Kay to explore outside of Roman Catholicism. Kay's religious/spiritual

relationships were interrelated to her connection with important people in her life, from her boyfriend and his family to her newborn child and God.

When she became hospitalized and spent many hours of the day alone, Kay started used a Holy Bible app to help her calm herself and find distraction. She found it on her own by searching in the "App store" on her phone for "Bible" and it was the first application available. She found it was relevant for her, due in particular to how its features resembled an "Instagram story" and was fairly intuitive to use as a social media user. Following her discharge, she continued to use the Holy Bible app on a daily basis for her spiritual practices. She said:

> Sometimes it will be right on the dot with what's going on in my life. And sometimes, it kind of something that happened in the past, but it still gives me that time to just look over that and think about that situation and implement what I'm reading into those particular situations.

She used it to help her manage her emotions during conflicts with her boyfriend. Her morning routine included using the app's devotional tools and, then, practiced a few yoga poses from Youtube. As a result of using the Holy Bible app, she felt that God had spoken to her through the experience and allowed her to "feel seen" by God.

In terms of religious/spiritual community, after the birth of her daughter, she had begun to "transition out of Catholicism." She said she didn't feel that she wanted to raise her daughter with the strict beliefs that she experienced growing up as a Roman Catholic. She had recently decided she wanted to wait rather than baptize her daughter as an infant in the Roman Catholic Church. Instead, she had decided to invite her daughter to make a choice about whether to be baptized. For a while, she had enjoyed the practice of leaving flowers for the Virgen de Guadalupe ("I just feel that's an LA thing"), but she had abandoned that practice, when she began to learn more about the Christianity her boyfriend and another friend practiced. For now,

she was not attending worship services in any tradition. Instead, she was relying upon those personal spiritual practices that helped her to get through her hospitalization. Most recently, her battle with anxiety had resurged following her hospitalization and illness. She had several experiences with fluid retention. Her anxiety persisted because she felt like she couldn't do anything additional to prevent the fluid retention that had prompted her to go to the hospital a few months prior to our interview. Following prayer to reduce her anxiety in the evenings, she decided to "leave it in God's hands and hope for the best," even if the anxiety would return again shortly.

Vera

"Holding it together."

Vera, 37 years old and Filipina, was still connected with her Roman Catholic roots and family practices, but in the past few years, had found an interest in reiki, crystals, as well as videos of people with near-death experiences and mediums on Youtube. She generally viewed herself as a pessimist, with regards to the future. She described her belief that things don't always work out for the best. At the time she participated in this research, Vera said she was one of the healthiest people her age with pulmonary arterial hypertension (PAH), a progressive illness affecting the lungs and the heart with no known cure, usually advancing into heart failure. She also had Sjogren's disease, an autoimmune condition. Vera's anxiety and emotional struggles emerged from her fears about the future, especially the future for her child who might not always have Vera to care for her. Vera was the main financial provider in her immediate family, and she was aware that she wouldn't be able to work as much as she worked now indefinitely, because her disease would eventually become more symptomatic. During our two 2-hour interviews, she also shared many of her struggles at her job, working in the business

administration side of a medical office. She felt she was stronger and more skilled than her coworkers and supervisors appreciated, even as they were willing to give her more work to do without the recognition. She struggled with anxiety and found that the Holy Bible app, used by several other participants, helped her to feel calmer. She preferred the app's activities to a group "live" Bible study. She believed she could not get anything out of the group study experience, because she did not know enough about the scriptures, specifically the meaning of the language and context of Biblical texts.

Diane

"Breaking the Cycle"

Diane, 50, is Mexican and Portuguese, and had been preparing to leave her job of over 10 years when we met for our first interview. She said that when the big change in her life really "hit her" that she reflected on God's blessings in her life, especially at the lowest points with her health: "I just felt it, I felt in my heart, what a big change this is, for me, and then I always just think about God and how blessed I am. Especially because after my transplant, like I always call myself, I'm a miracle because I really was saved at the very, very last minute." Over the course of our two interviews, Diane shared with me how her strong meditation practice supported her along her journey to find the right workplace and cope with the end of a long-term relationship. Diane had meditated for over 20 years, following a long meditation retreat. Following her heart transplant 13 years ago, she began to practice more consistently to gain the health benefits of meditation. Also, she felt more connected to God in gratitude for her recovery from her terminal condition through the transplant, and meditation helped her to "hold onto that feeling" of gratitude that she survived her illness. She saw the "evidence" supporting her faith in God

through her life. Diane was one of a few participants who did not have a connection to a formal religious/spiritual community. She did not grow up going to church, and while her mother and a few cousins that do go to church, she feels like her "family doesn't really understand" her meditation and prayer practice.

Just before our second interview, Diane had left her newer job because it wasn't a good fit. She said it was a leap of faith because she had no other job prospects at the time and during the pandemic, she was concerned about not having income. She ended up becoming infected with COVID, which was especially frightening due to her heart condition as well as not having health insurance at the time. Luckily, she did not have serious symptoms and was able to recover, while continuing her job search. During her period of not having a job, she had to ask her relatives for a loan to help pay her mortgage and other expenses. During COVID, her regular meditation routine practice lapsed, and she went to a "dark place" in her mind for that period. She said:

> "I hadn't really been meditating because I had just been feeling so terrible. And I always feel like I don't want to meditate unless I'm like, in the right space, mentally and physically, you know, I think I had probably had already been maybe like, a week since I had stopped meditating. But you know, I was still praying and I was still kind of, like, you know, trying to reassure myself that everything was going to be okay. But I think you know, it was just a combination of things to COVID and then I had bills coming due and I didn't know how I was going to pay them. Yeah, it just, it just kind of started out bad, but then I, you know, but then it just kind of got worse as the morning went on. And then, then I had to really like, just stop myself because I was starting to go into, you know, just a dark place in my mind, you know, and it's not good. It wasn't good. And I just hated feeling that way."

This period of feeling "helpless or hopeless" was something she had not felt since her 20s when she was a single mom and struggling financially and was sick "but didn't know it" or when she first had her transplant, and the recovery process was slow and arduous. With the help of her sister-in-law, she reflected on the times when she had felt worse and survived. She said she knew that she had "broken the cycle" of dysfunctional family dynamics (domestic violence, putting "up with BS," alcoholism, etc) and relationships. Some family members had felt bad for her not being married, but she believed most of them felt they could look up to Diane, "showing the younger generation that you don't have to get pregnant and get married, you can go to college, you can have a career, and you can buy a house by yourself." She tried to share her meditation space and be available to answer questions about spirituality or the benefits of meditation for her younger family cousins.

Ayo

"God's heart breaks with mine."

Ayo was a 30-year old Black woman and Jehovah's Witness with peripheral pulmonary artery stenosis and pulmonary arterial hypertension, two rare and progressive heart conditions. At the time of our first interview, Ayo was living with her parents, who were also her main caregivers. Before the COVID-19 pandemic, she was working per diem as a cardiac sonographer; she returned to work in late 2021. Ayo pursued many hobbies, such as Polynesian dance and beauty pageants, in addition to participating in the traditional spiritual practices common among Witnesses. During most of her childhood and young adulthood, Ayo had surgery almost annually. In addition to frequent procedures to support her heart and lungs, she

also used at-home and portable oxygen. Even though she noted the benefits of the oxygen treatment, especially with regards to her energy. Ayo was active in patient advocacy organizations and groups for other people with heart conditions and disabilities. She had a moral commitment to sharing her story, especially with other Black disabled young women.

Later in this dissertation, I discuss in greater detail Ayo's interview texts as a paradigm case essential to my interpretation of the whole sample.

Carmen

"Listening for small voice of God."

Carmen is a 57-year-old Black woman living in Texas, who was experiencing housing instability. Seven years ago, she had a mild heart attack and while hospitalized, the hospital found that one of her valves contained a small leak. Carmen relied upon the emergency room for medical care, but said she delayed seeking care many times. At the time she participated in this research, she did not have a clear picture of how her heart disease was progressing, but she knew that she had felt symptoms of concern, such as becoming short of breath or feeling fatigued.

Carmen used prayer and a Bible app to connect to her faith as a Christian and find a way to "leave it in God's hands." At the time of her heart attack, she had received pastoral care from a minister at a local congregation, but she no longer participated in an in-person religious community. Occasionally she would listen to Joel Osteen's services on television because she found he "kept it real" by staying close to the Biblical text when he would share his message. Allowing God to inform her choices had saved her life when she was spending time with people who were a potential bad influence on her life. Still, she longed to be able to implement the

instructions that the "small voice of God" offered her, so that she could stabilize her housing, financial situation and healthier eating habits. In addition to traditional Christian practices, such as prayer and Bible study, Carmon enjoyed jewelry-making as a spiritual practice. She used the practice to "check out" from the financial and health concerns that followed her, and "be out of her body." This practice served a second purpose as she would sell her jewelry pieces to help her contribute to the expenses she shared with her spouse, who held jobs outside the house. Sometimes, she prayed to God for someone to purchase some of her jewelry so that she could pay a bill or fill the gas tank.

Later in this dissertation, I discuss in greater detail Carmen's interview texts as a paradigm case essential to my interpretation of the whole sample.

Mary

"Spirituality is meant to be shared."

Mary, 43 years old and a Brazilian immigrant, described herself as a medium (a skilled communicator with the spirit world) and as a good storyteller. She was raised Roman Catholic, and still felt a connection with her childhood faith, but now practiced Kardecism (Spiritism), Umbanda (Brazil), and Candomblé (Brazil), which each have a syncretic connection to Roman Catholicism. Her wall has a small altar and sculpted image of Oya Yansan, an orixá or goddess, who is connected to the wind and storms in Yoruba. Several years ago, Mary had suffered an aneurysm, followed by a coma and two brain surgeries. This near-death experience had long-lasting spiritual importance to Mary and would shape her she responded spiritually to her current heart condition. About two years ago, Mary had a heart attack while she was training as a bodybuilder and developed heart failure. During each of her health crises, she received

support from her various religious/spiritual communities and babalorixás who conducted healing rituals, offered prayers, and other forms of religious/spiritual support to Mary and her family. Mary discussed her tendencies to go to extremes with things she enjoyed, whether it was her job, drinking wine, or even spiritual practices that drained the reserves of her energy while ill. Mary had hoped to develop more balance in her life while she adjusts to a new way of life as a heart patient. As we were talking during each interview, I was acutely aware that she was expecting a very important call — she was awaiting a heart transplant. Each time, the phone rang while we talked — I stopped recording our conversation and held my breath. *Not yet.*

Later in this dissertation, I discuss in greater detail Mary's interview texts as a paradigm case essential to my interpretation of the whole sample.

CHAPTER 4: PARADIGM CASES

In a community empowerment project many years ago, a wise trainer shared with me his facilitation technique for learning what's most important about a complicated high-stakes issue from a group of people with their own lived experiences and perspectives. He instructed that it was best to allow one person in the group to throw a stake down and then bring in others to help you move it around, contributing nuance, challenging assumptions, and providing important contextual details. Eventually, this would allow an interpretation to be shared and verified by the group. We used such a process to create a pool of shared knowledge in that community project. In the process of analyzing my "pool" of 568 pages of interview data from 13 participants, I found that paradigm cases in interpretive phenomenology can operate in a similar way to the community dialogue. This chapter offers a presentation of these shared understandings through paradigm cases.

Religious/spiritual experiences influenced how Women of Color dealt with their heart disease. Also, dealing with heart disease had an influence on their religious/spiritual experiences. Paradigm cases helped me to uncover this pattern as I moved between re-reading the entire interview texts and the issues and concerns about religion/spirituality and illness, which were so often discussed in one breath. I presented these paradigms as whole cases to provide the "opportunity to engage in the practical world of the participant and come closer to the lived experience, […and] a particular way of being in the world" (Benner 1994b). Here, the reader and I can engage participants' ways of being on their own terms.

Through reading the 13 individual sets of interview texts multiple times and writing many interpretive memos exploring the relationship between sections of text and "whole cases" of individual participants, I found that three participants (Ayo, Carmen and Mary) expressed

strong perspectives that brought forward a range of important aspects of religious/spiritual experience's influence on health. I shared narrative exemplars from those cases with the interpretive partners in our collaboration meeting, along with others who discussed similar issues. My experiences listening to (and then reading multiple times) the narratives of Ayo, Carmen and Mary led me on divergent and equally valuable paths to understanding the phenomena I wanted to explore in this research. By interpreting these "whole cases," comprised of 1.5-6 hours of interview data per case, I developed an interpretation of each woman and a presentation of their whole text to acquaint readers with their direct experiences as closely as possible. After reading and re-writing each whole account of each of these three women's interviews, I developed a within-case analysis, interpreting each narrative piece in terms of her whole interview text. I responded to the question: how the qualities of one specific experience intermingled with other parts of her life shared in the interviews? Then, I developed an analysis of each case's contributions to an understanding of religion/spirituality's influence on how she dealt with her heart disease. I invited the interpretive partners to weigh in on an exemplar section of text from each case, which furthered my sense of the paradigm cases as influential in interpreting the overall phenomena.

This chapter also produces a dialogue between the three cases that does not force their individual texts to "live in the same world" as one another. Ayo, Carmen and Mary were very different people from one another, in age, identity, religion beliefs, and invited crosstalk among their experiences and senses of themselves in terms of their religion/spirituality and their health. Yet, they each connected to one of the three patterns of being, related to change and time that shaped my interpretive work and the discussion to come in Chapter Five.

Patterns of being revealed the journeys by which the relationship between religion/spirituality and health travel during participants' lives. In each pattern, I found embodied, non-dogmatic and unending religious/spiritual experiences. Also, each participant described soul-stirring events, in which their lives were upended, their health declined suddenly, medical care was substantially burdensome or traumatic, or they received a new religious/spiritual message that redirected their health and their life forcefully. These life-changing moments were religious/spiritual and connected to their heart disease in some way; they often set off important changes to their ways of being-in-the-world (Dreyfus 1991). These patterns were not mutually exclusive of one another; rather, one of the three pattern of change was strongest in one of the three paradigm cases presented in this chapter. (1) *Relational Change*: Religious/spiritual relationships were connected to a sense of self, their families, congregations, and other key relationships that changed as they aged or responded to health crises. This pattern was observable in nearly every participant, which I expected based on the relational framework that fed the theoretical approach and design of this research. Ayo's paradigm case helped me to uncover this pattern and connect it to the relational framework of religion and spirituality described in Chapter One. Ayo's religious/spiritual practices changed over time as she gained independence from her parents and then, as she felt distanced from her Jehovah's Witness congregation when she began to need at-home oxygen 24-hours-a-day. Her relationship to God was a strong connection that provided her an opportunity to periodically reflect on her understanding of herself within her congregation, within her family and within the broader disability community. (2) *Intersectional Change*: Religion/spirituality's influence on health was negotiated within the interwoven realities of access to health care, experiences of gendered racism, and other burdens connected to marginalization. Carmen's religious/spiritual

practices surged and receded based on her housing instability, financial problems, use of the emergency room for primary and urgent care, and revisiting memories of drug addiction. Her anxiety was so immediate and insurmountable that she found herself "leaving it up to God" to keep her doctor's appointments after months of not showing up to them as scheduled. God's "intervention" in times that she was near people who were a bad influence on her, had on multiple occasions ensured her survival. It was her prayer that God would do the same for her again, by bringing her out of her immediate financial troubles, inspiring her to have healthier eating habits, and establishing more regular health care. For Carmen, she also had a spiritual practice of making jewelry, which doubled as a small business to help her contribute to the household rent, gas, and groceries she shared with her husband who worked outside the home. In this pattern, the influence of a religious/spiritual practice over time could only be understood within the broader context of social conditions and inequalities taking place simultaneously and shaping her health and view of herself. (3) *Receptivity to Change*: Women with heart disease in this sample were receptive to support, interventions and new ideas related to the relationship between their religion/spirituality and their health. Each participant shared stories in which the relationship between their religious/spiritual beliefs and practices and their heart disease experienced a turning point. Each turning point revealed the malleability of the bidirectional relationship between religious/spiritual practices or beliefs and support in dealing with heart disease. Sometimes, receptivity was a positive pattern in women's lives offering the possibility of better support and fewer feelings of fear or anxiety. At other times, women were susceptible to messages that might cause them further emotional pain or inflict shame. The receptivity I observed in Mary, along with other whole cases of women's interview data, illuminated how religious/spiritual influences, such as the spirit guides and priests Mary regularly consulted,

shaped the actions she would take related to her heart disease. Mary worked with her goddess and spirit-guide, the Orixá, Yansan, each day to direct her life. When she felt she could not trust her own judgment or choices related to activities she wished to pursue, she would consult her religious traditions and conduct religious/spiritual practices to gain insights as well as fortitude to follow a path of balance. For some participants, a single statement from a religious or medical professional, expanded its impact over time, and for others, religious/spiritual practices were integrated into the medical care they received for their heart disease. These three patterns of being reflect important implications from this research for the fields of sociology, medicine and religion, including potential interventions and future investigations. A thorough discussion of these patterns follows in Chapters Five and Seven.

Here, I first present a within-case analysis of each paradigm case and include a stand-alone summary of key issues and meanings as described in the whole interview text. Then, I offer an interpretive summary of the patterns I found in the case.

PARADIGM CASE #1: AYO

Ayo sat on her couch at home where she lived with her parents, who are also her main caregivers when she needed more assistance for symptoms related to symptoms of two congenital heart diseases. Ayo had peripheral pulmonary artery stenosis, in which the one or more of the branches of pulmonary arteries narrows restricting blood flow from the heart to the lungs, as well as pulmonary arterial hypertension, another rare disease in which pressure increases in the blood vessels in the lungs and the right side of the heart. Ayo was a seasoned public speaker at 30 years old; though she also told me she was more of an introvert during our first interview. For the purpose of this research, she chose the pseudonym “Ayo,” which was the name of the second-in-command female warrior and protector of Wakanda in the Marvel

Comic, Black Panther. The character was known for her loyalty to Wakanda, impressive athletic skills, and sense of humor. The Ayo with whom I spoke had similar traits. She was dedicated to her community of Jehovah's Witnesses, was an accomplished Polynesian dancer, and had a wonderful sense of humor. Also, she was developing a platform that she hoped could be a way to support young BIPOC women with health problems and possibly, become a source of passive income in the future when her health would decline. For instance, in early 2022, she told her story and shared her expertise on disability at a large tech company event for Black History Month. She also had a strong social media following on two platforms.

Ayo spent some of her days at work staring at *other* people's hearts, or at least images of them. She worked as a cardiac sonographer on a per diem basis, a career she enjoyed and had missed when she had to take a medical leave during the pandemic. Ayo's parents were concerned about the risk of COVID-19 infection for Ayo, given her cardiovascular conditions. However, Ayo put great faith in the science of vaccines and use of protective equipment. In our first two interviews, when a vaccine against COVID was not widely available yet, she looked forward to being able to return to work and dance groups and other activities as vaccination became more prevalent.

By the third interview, she had returned to work, despite her parents' protests, and worked more hours than ever before, due to staffing shortages. She continued to work during the Omicron variant's surging infection levels in her area. Ayo's supervisor allowed her to work in more predictable conditions, where she could sit more often, and allowed her to pass off patients who were known to be infected with COVID-19 to other staff in her position. Working gave Ayo a sense of purpose, but it also made her more tired than usual, so she had not returned to her dance group, and it was challenging to connect to her individual spiritual practices.

Passage from the Religion of Her Parents to Her *Religion*

Ayo described her religious/spiritual sense of herself *as a part* of her family and her tradition, as well as *distinct* from her family and *independently motivated* as an individual Witness. As a member of a Jehovah's Witness family, many of the religious/spiritual activities in which Ayo participated were oriented around her family life. Mid-week meetings were a group Bible study, and each Sundays was the main meeting that corresponded to the section of the Bible reviewed earlier in the week. Witnesses were formally encouraged to also practice and read between meetings alone and as a family. When I interviewed Ayo for the first and second time, her twice-weekly congregational meetings were meeting exclusively online. During our third interview, she said that other Jehovah's Witness congregations had re-opened for in-person meetings, but her particular congregation had not yet done so. Ayo's baptism at age 17 was a critical moment in her faith development as a Witness in her own right: "I took it on as like, 'this is what I'm now doing,' what I choose to do, rather than 'this is what my family does.'" Her baptism was a public declaration before a district convention (an assembly of many congregations, including her own) and the passage between the religion of her parents and *her* religion.

Ayo had religious/spiritual components of her daily life that were connected to her family's practice, but she also had her own personal religious practices. She said, "I try to have my own personal --I'm a Christian--so, I try to have my own personal Bible study." These activities were expected parts of individual spiritual practice as a Witness among baptized adults. Unlike older generations of Witnesses who had relied on print study materials, Ayo used Witness phone/web applications, to apply her religion/spirituality to her daily life and illnesses to her religion in concrete ways. Her personal Bible study was more self-guided than the lessons composed by

her congregation and comprised two different activities. First, Ayo would have a question come up on a given day, or take interest in a specific topic. She searched for the topic using her smart phone application. Ayo researched topics that interested her by searching the large body of materials published by Jehovah's Witnesses online. Often Ayo found that the examples in the entry on the web application connected directly to her own experiences at the time. For instance, both her two dogs had died in a short period of time, and she had been feeling quite depressed as a result. Using the Witness phone application, she was able to look up "depression" and "loss of a pet" in the index. She found an article on the loss of a pet, which helped her feel more "normal" about her grieving process. It helped her to recognize that she was "getting back into old habits" related to depression (14:40 ¶ 507 in 101.Ayo). Also, she located and read articles on the app about the topic and clicked on links to scriptural readings that corresponded to her own chronic illness. She said, "It talked about other Witnesses who have chronic illnesses and how they feel. So, it was very relatable to me— and like what they've done in certain circumstances to help them when they're depressed" (14:40 ¶ 507 in 101.Ayo). The app put her illness into a religious/spiritual context and helped her to feel less alone with her condition. Unlike her parents and able-bodied Witnesses, as a young adult, Ayo needed to connect the Witness spiritual practice material available to her with issues that reflected her specific experiences.

The second aspect to her personal Bible study was journaling. She used a Witness Bible study aid, called "How to Remain in God's Love," directed at baptized adults, which included personal reflective questions as part of a discussion of a scriptural reading. The study tool helped Ayo to take notes on the current topic and find ways to apply the lesson to what is happening in her life. Over the course of our interviews, Ayo had several examples of times in

which her Bible study helped her to address things going on in her life. However, she also said she was participating in personal Bible study and journaling less frequently than she would prefer: “I have a goal of doing it once a week, but it's infrequent.” Also, she admitted that she was sometimes distracted during weekend meetings on Zoom. More than once, she asked “I don’t know if this makes me a bad Christian, or not” to describe a way in which her behavior or opinions differed from the traditional norms of Jehovah’s Witnesses. Later, when the topic of “being a bad Christian” arose again, she expressed a lot of grace for herself instead of internalizing the label of “bad”: “I have to also be considerate of myself.”

Following our first interview, Ayo did not speak about her Witness-related spiritual practices in much depth. Instead, our discussion focused on how her age, disability and racial identity shaped her relationship to her Jehovah’s Witness community and her other interests. Ayo did not say explicitly that her age, disability, or race influenced her motivations to be consistent in her Witness-based personal practice. Given her statement about being “considerate of myself,” I interpreted that the reduction in frequency of her personal spiritual practices was another part of being “considerate of herself,” combined with her reduced energy level after she participated in other activities that were bigger priorities for her personally (working as a sonographer, for instance). Ayo presented herself as someone thoroughly connected to her religious identity in her daily life, even if the religious tools did not meet her needs exactly or she ran out of energy at the end of a busy day to engage the individual spiritual practices common to Witnesses and part of Ayo’s spiritual practices, especially using the phone applications.

Not “Pretending” to Be Sick

Technically, Ayo had heart problems since birth, but she didn’t receive a diagnosis of heart disease until age four. Doctors found a large hole in her heart, which was repaired with surgery

and her heart health was expected to be uneventful. However, following her recovery, Ayo's mother noticed she was still fatigued more than any other kids her age. Her doctor referred them to a psychologist, writing off Ayo's physical symptoms as "pretending to be tired" or "doing it for attention." Her mother did not accept this response and pursued other medical opinions. Testing eventually revealed that 7-year-old Ayo had peripheral pulmonary artery stenosis and pulmonary arterial hypertension, which she had since birth but had gone undetected. In the next few years, Ayo's mother became a nurse, inspired in part by having to teach herself a high level of technical and medical knowledge about Ayo's condition to make sure providers were treating her daughter appropriately. She taught Ayo how to explain her heart defect, her lung problems, and medications to other people, as well was explaining the reasons behind the accommodations she needed or the restrictions on her activities.

> She taught me all this stuff really young. And she said she did it because she was like, 'just in case there's an emergency and I'm not there, you're gonna have to advocate for yourself.' So I guess that's why I'm just used to it, I guess?"

Ayo became accustomed to explaining her conditions and advocating for herself, but having to repeatedly prove herself as having a disability was frustrating and sometimes, dangerous. There were other instances in which Ayo's symptoms were not taken seriously, from physical education teachers in grade school who didn't believe her when she presented a doctor's note dismissing her from an activity to more serious incidents, such as when she had a pulmonary embolism that was repeatedly dismissed as pneumonia.

Ayo said it was a "common thread" for her to not be believed, delaying accurate diagnosis and treatment of her symptoms. She said, "I was diagnosed misdiagnosed for so long--my mom decided that she needed to educate herself, so that wouldn't happen with her other kids." Forced

to prove herself as sick to providers for so long, Ayo had learned to assess quickly if a provider was listening to her, and if not, find another provider right away. Her mom and she talked about racism and ableism often now, looking back on her and Ayo's experiences, as well as what her mom sees as a nurse, which included mistreatment of other patients and families similar to what Ayo's family faced.

Ayo recounted a day when she found her medical records from her birth and early open-heart surgery. Looking at them with her mother, they found racist comments in the report about her mother at the time of Ayo's birth:

> They said that she was dirty, that she had lice in her hair. And she's like- I've literally never had- My mom is not a dirty woman. She's very clean. She's like, 'I've never had lice. Ever.' She said they were probably talking about- She's like, 'I might have had some dandruff? And they thought it was lice?' But it was just so weird how they like talked about her in the report. I mean, she was a young mom, she was 21. And she looks really young like me. So she actually looks like she's 16. But she's 21. But she was just kind of, taken aback at how they were talking about her in the report, you know?...But she read my report while we were there, and they didn't say anything like that about me [as a baby having open-heart surgery].

Ayo felt as though her mother had experienced more direct, actively racist behavior from providers than she had when she was growing up. However, the experiences of having to prove herself and being misdiagnosed stay with Ayo, which she has come to categorize as a mix of ableism and racism. She said:

> I think that I went misdiagnosed for a while, and because of that experience, it kind of traumatized me. Because now, I feel like every time I bring up like a new symptom, or I'm experienced something, it's my automatic default that they're not going to believe me, and I'm going to have to prove it. So, that's definitely had a lasting impact on my life.

Ayo has also observed her mother's treatment by health care providers for her own medical problems and pain. Her mother had kidney stone problems and though she is a nurse herself, still has been treated as if she is "drug-seeking" or not taken seriously for her pain symptoms

until diagnostic imaging affirms her complaint. Ayo's other relatives with sickle-cell disease told her similar stories about their treatment from providers and during hospitalizations.

Ayo felt the Witness community had some challenges understanding her illness or recognizing her experience as a Black woman. She took solace in the fact that even when other people didn't understand what she was going through, God did understand. She also used different tactics to live with integrity with her fellow Witnesses than she would with people she met outside of her faith community. She discussed her time at the Kingdom Hall (the space where Jehovah's Witnessed gather for their meetings twice weekly, at least prior to the pandemic shutdown) as being in the "Witness Bubble."

Ability and Race "In the Witness Bubble"

Ayo described interactions with members of her tight-knit congregation that she characterized as being "in the Witness bubble." In other words that there were some interactions, in which people would behave in such a way they would not outside of their religious community and that she believed would provoke a different reaction if Ayo herself was not with this group of people who shared common beliefs and values. She shared a few different examples from the "Witness bubble" during her life. They connected to her identity and lived experience as a Black disabled woman. During adolescence, Ayo had to defend her appearance and style of dress when other Witnesses made comments about how tight-fitting they believed her clothes to be, commenting on how she should wear looser clothes more often. She said that if it were someone *not* in the congregation hall, she probably would have rolled her eyes and rebuked their comment. However, because it was someone from her congregation, she had "a bit more grace":

> I think grace would also be, like, if I heard somebody say something ignorant [about race or racism] or if they made some kind of remarks that made me uncomfortable in the past, if they were somebody who wasn't in the Kingdom Hall, I would probably stop interacting. Like I wouldn't really give you another chance. But if you are in my congregation, I'm more likely to give you another chance.

She said she offered more grace to other Witnesses in her congregation, but also had higher expectations for them in terms of their knowledge of "race within the Witness bubble". She mentioned situations where something comes up from the news in a casual conversation among members of her congregation:

> if something happens in the news, right, like, let's say, George Floyd, and people are talking about that-- typically, everybody's like, 'I can't believe that happened. That's disgusting.' But if somebody says something that is anti-black, I cannot help but to correct that. Because I do--most of my congregation is white. So, I do feel like I kind of have to--but I don't mind in the same breath--But I also am not going to waste my energy on somebody who just chooses not to listen as well.

She described her feeling that she was willing to educate white people about racism or able-bodied people about disabilities when they were members of her faith community. However, this "grace" would only be offered to a certain point, especially if the person in the conversation wasn't willing to listen: "There are people who actually listen, and they're like, 'Wow, like, I never got that. But now I see it. Thank you for explaining to me.' And then there's other people who just like don't want to listen." She is more likely to give her time to a Witness who is willing to listen and learn from her, as opposed to someone outside of the Witness community.

In Ayo's congregation, these conversations would take place in reference to public events in the media or the Movement for Black Lives, as well as a family experience with police violence in October 2021. Her brother was pulled over by a cop and arrested in a racially-motivated traffic stop, after driving home from dinner at a friend's house with his wife. Discussions with family friends from the Witness community following her brother's release, included a "colorblind"

response dismissing the incident as non-racist. Ayo recounted the conversation with one friend of her brother:

> My mom was like, 'Well, you know, there's definitely documented evidence about how police, they are particularly, clearly targeting black men, and there's usually like, interactions between them do not go well.' And she was just stating all these things. And he just was not listening. And then, at one point, I think he said, 'Well, Christians, all Christians are persecuted, too.'
>
> And I was like, 'What? Come on, in America, right now, currently, tell me *Christians* who are being persecuted? None, as far as I know.'

It pained Ayo for someone she had felt was a good friend of her family to defend the fiction of race-neutral policing upon the premise that Christians in the US were somehow more oppressed than Black Americans. Ayo hoped that other Witnesses could understand that what happened to her family or to George Floyd was not a "one-off thing." Later in our conversation, I said having to educate other members of her congregation both about race and disability sounded like a lot of work to do in a place that is supposed to feel like a spiritual home; I asked her how she managed it. She responded with an experience that had reminded her of how she might have it better than other disabled BIPOC women. Through her involvement in the broader disabled community, she had found other disabled people who had left their churches in other faiths because the church had told them that they're disabled because "they don't have enough faith." She said that every time she is having a procedure, members of her congregation are notified and respond with support and volunteering to offer her meals, but never judgment:

> They've all been really supportive. They've like all, 'thank goodness,' and everybody believes in--at least as far as I go--the science that keeps me going, in the healthcare that keeps me going. Everybody believes in that. So I think that's one thing that I've come to appreciate, because it would be really hard for me to maintain my faith when people are telling me that-- you know. But I think that's just an experience of me being a disabled black woman. Like, I have to do that within my congregation. I have to do that at work. I feel like I have to do that everywhere.

Ayo said that thankfully, her issues with racial bias or ableism among members of her congregation were infrequent, usually "when something in the world happens." In terms of which communities she feels most like herself, she said she felt best in smaller friendship circles within the pulmonary hypertension community and with her Polynesian dance community, because the physical activity makes her feel happy. Life in the "Witness Bubble" often required dealing with responses to her presence in one respect or another.

Ayo valued the use of her own "conscience" in making decisions about other behavioral values important to Jehovah's Witness community culture, such as modesty and bodily appearance. She recounted several instances in which she discussed with peers, activities, such as getting a tattoo, or definitions of modest dress, that might not be popular among older generations of Witnesses in her community. She felt confident about her use of her moral conscience in making decisions about these lifestyle choices based on what she had read in her Bible study on conscience and her own reflections. In these moments, Ayo did not seem wrapped up in the question of her "goodness" as a Christian; instead, she described how her choices or preferences were amenable to her faith, even if they might stir a response from her peers or elders who took a more traditional view.

"Nuggets of Encouragement" When Anxious

Major health-related events in Ayo's life caused Ayo to experience anxiety, which seemed to become more intense during health crises, and affect her when she was anticipating potential poor test results or experiencing new symptoms. Ayo's Witness community played a supportive role during crises, and in between those experiences, she also relied upon her religious beliefs and practices to deal with the feeling that she was always awaiting another health challenge. To cope with anxiety, Ayo's spiritual friendships would help her access the spiritual practices she

knew were important tools for dealing with her anxiety, such as prayer. In Ayo's congregation, there were people she considered to be "spiritual mentors" for her, which helped to shape how she dealt with her health problems and heart disease at critical moments. In the summer of 2010, when she was 18, Ayo had some small infarctions in her brain, or small strokes. She had not experienced anything with her brain before; her eyes widened and she looked intently, recounting the story as if it were just yesterday:

> They were thinking that maybe they [headaches] weren't migraines, that they were strokes. And I can handle bad news about my heart and everything. But I was--this is my *brain*. You can't mess up your brain. Your brain doesn't just back bounce back as easy, you know? So, I was totally freaking out. I called [someone]. In my congregation, I have like friends that are kind of like, spiritual mentors.

Her conversation with her mentors offered her a "sense of calm" from their attention and presence with her that helped her throughout her month-long hospitalization to assess and treat her small infarctions. It also offered her a reminder to return to her personal spiritual practices, such as prayer. During her hospitalization, she followed the suggestion to continue to pray to God for calm when Ayo was admitted to the hospital, despite the hospitalization feeling "totally chaotic."

Prayer reassured her, particularly when outcomes of medical procedures or other events were not in her control. She was in the hospital for a month for the brain infarctions, and over the course of that hospitalization, she experienced short periods of sadness followed by a longer sense of calm when a friend would happen to visit from her congregation just at the right time, or "a text would come in" that encouraged her. Ayo had grown accustomed to hospital stays since childhood, but the month-long stay had included repetitive neurological tests taking place during the day and night, which "drive you crazy":

> "I felt right at the right time, something, somebody, would pop up. I would just get some little nugget of encouragement that would give me just enough to just keep on chugging along" (14:34 ¶ 421 in 101.Ayo).

For Ayo, her relationship with God (including her prayer practice) and supportive visits or messages from other people that improved her mood were causally linked: "I think He has the power to use other people to help me when I need it" (14:33 ¶ 397 in 101.Ayo). The arrival of people to support her was not a matter of chance, but divine intervention into her emotional health.

As Ayo dealt with her heart disease as an adult, she needed new things from her religious/spiritual practices and from her relationship to God. In addition to small strokes, she also had gynecological issues linked to her heart disease that disrupted her life. Most of her life she expected that she likely should not become pregnant. The news of a possible hysterectomy made it real in a new way, bringing on anger and grief. Then, more recently, after nine months of heavy menstrual bleeding and anemia, she was hospitalized to resolve it. When her gynecologist mentioned the possibility of a hysterectomy, she was devastated. She summarized the situation:

> From a very young age, I was told that I probably shouldn't have children, which that's something that was really hard for me because the one thing that I knew I wanted to be was a mom. So, that was a really tough pill to swallow. But after working through it with therapy, and my mom's really great about it, you know, I had accepted that fact that I can't carry kids, but I can still be somebody's Mom. You can always adopt somebody. But in that moment [upon hearing about the possible hysterectomy], though, it felt like the choice or me even having room to think about it have been taken out. And, afterwards, I felt very angry because, you know, what did I [do]--there's mothers who are ---there are people who are terrible who have kids. And I'm a good person so, why is it me, you know? (101.Ayo)

Her prayer practice supported her in this challenging moment by providing a direct conversation with God that she believed moved God to the point of presenting her with a person in the flesh who could relate to her experience:

> I had a prayer. And I vented all of those frustrations. And it just so happened that I ended up having, a conversation with a friend who's not a 'heart person.' But she has had the same, or similar issues. And it was just, perfectly timed, where she was like, 'You know what? it's okay to feel like it's not fair because it's not fair.'…I think the way that I link it to God is that He knew exactly what I was feeling at that moment, and how frustrated and like, heartbreaking this was.

Sometimes, God would present her with another person who understood the specific circumstances of her illness's progression. Other times, the relationship to God himself filled in that gap in her human relationships. Ayo described the quality of being understood that she felt from God and could be absent to her in relationship with other people, even those closest to her, such as her parents:

> I live with my parents. And just because— I need their help some days. And there can be certain times that even though they've lived with me my whole life, it's hard to realize, though. There's just certain things about my life that they will never understand. And I personally believe, with my relationship with God, that He— even when they don't understand [as] the people who are the closest to me--He understands what I'm going through. And that can be validating. (14:39 ¶ 471 in 101.Ayo).

Members of the Witness community tried to sometimes say that there was a meaning and even a purpose for her suffering with heart disease. She recalled conversations when she was younger:

> When I was younger, you know, when I had the first heart surgery, a lot of people—and this isn't my family members—but people would say, "Oh, God gave you this for a special reason." And I always found that to be like, incredibly disturbing as a kid, because I was like, how can a *loving* God--why would a loving God make this happen to me? I personally don't believe that I have a special purpose with this. I believe that we are imperfect. And yeah, that's how this happened. So I believe God can give you the tools to endure it, but I don't think *He bestowed this upon me*. (14:44 ¶ 1054 in 101.Ayo).

Ayo's tools (such as belief, community, or prayer) were both ones from her faith and others that connected to other parts of her life, but she did not believe that there was a reason she was provided an opportunity to suffer.

Life's Difficulties are Temporary?

Ayo shared how her religious belief that life's difficulties are all temporary did not always resolve her feelings about her progressive symptoms. Incrementally, her health challenges were changing her lifestyle in ways that would then be with her the rest of her life. When Ayo learned that she would need to wear oxygen full-time, Ayo's religious belief from her Jehovah's Witness theology supported her through the hurt of the grief. She recounted her belief to me:

> God will restore the earth to a paradise and all humans will then be perfect…I always have this belief that someday in the future, I will become perfect. So that makes everything hard that I'm dealing with, it's temporary, like, it'll go away. So, while I remember that, it's still, like, It still sucks to hear bad news. It still hurts.

Her religious belief about the temporal nature of her illness experience did not resolve her feelings about various progressions in her illness, such as the first time she heard she needed oxygen full-time. She recalled her experience in the provider's office that day:

> 'What do you mean that I have to wear oxygen now?' [she said to the doctor]. I literally went to a Zumba class, you know, during the week before this. 'Right now, I have to do this?' I was just wrapping my brain around how am I at 20 [years old] going to be able to navigate my life with an oxygen tank? I think I actually asked that out loud to my doctor, and he had a resident at the time and the resident was like, 'well, you'll meet a nice guy and everything will be fine.' And I was like, 'Meet a nice guy? I have oxygen strapped to me! Like how am I-- I'm not even going to want to go anywhere with this!' And I will say like the first month with oxygen, I probably-- I didn't leave the house.' (101.Ayo)

At the time she was informed of her need for continuous at-home oxygen, her family was concerned about Ayo's emotional well-being. They tried ways of cheering her up that had been successful after prior procedures:

> My mom knew that I was really sad, so she was like, 'why don't we go to Disneyland?' And I said no…I was not yet ready to face the world with oxygen. I was still very sad about it. I don't know if it was because I was so sad. But I feel like that was probably the longest angioplasty recovery I've ever had. And I do think it's partly because I was just like, so crushed…So, she knew it was really bad. I think she was really, really nervous. I don't know, it was just like a really slow process.

There was one incident when Ayo wore “Bella” around an elder in the congregation who said seeing her with her oxygen “made them feel encouraged.” This surprised her and it helped her feel more comfortable. She said:

> When I see these older Witnesses, I kind of feel like they have a lot of wisdom; they're well-seasoned. Like, there's nothing I can really do to like, encourage them really. So, to hear that I can and it's not even me doing anything that I consider like to be super amazing, it's also encouraging to me. (101.Ayo)

Ayo was able to see elders in the congregation who were participating in spiritual community with their disabilities. I believe she was able to see a reflection of a possibility for herself at an older age. While Ayo displayed significant wisdom gained through her experiences in leadership and with her disabilities, Ayo was aware of what she was living through and found these “older Witnesses” inspiring and encouraging.

Ayo described her recent relationship with “Bella” the Tank, her oxygen tank that was with her during each of our interviews. When she first was instructed to wear oxygen at all times, she avoided wearing it in some parts of her life, including when she first started training as a cardiac sonographer and when she was with her Witness community.

When she first began training as a cardiac sonographer she would return home from the classroom so tired, because she had not worn her oxygen all day:

> I probably made some moves that weren't the smartest. I would physically bring the tank with me, but I wouldn't actually wear it, because I was worried about what people would think. But then, like, the next day, I would be completely wiped out because I didn't wear it. So I would do dumb stuff like that. (101.Ayo)

Ayo realized she needed to wear her oxygen during the school or workday and she found a creative way to explain the sudden presence of her oxygen tank to her fellows students by standing up and asking to make an announcement on the first day she brought it with her. She introduced her oxygen tank to the class: “Her name is “Bella” the Tank. I will be wearing it.

Thank you very much." In her Polynesian dance community, Ayo had custom dance clothing created for her to allow her to carry "Bella" while dancing with her group. However, she had yet to introduce "Bella" in this way to her Witness community. It is possible that within her religious community, which include people who had known her most of her life without oxygen and would be newly shocked and people she had not met before who might judge her. My interpretation of her decision to not wear oxygen among her congregation members was to avoid interactions in which other Witnesses comment on *why* she had to wear oxygen or respond with overbearing concern. Now that it had been years since she started wearing oxygen full-time, broaching the subject also risked other Witnesses feeling she was ashamed or wished to deceive them about how sick she really was.

"Bella" marked the loss of some of Ayo's agency regarding the conditions under which she would share with another person her disabled status. The presence of the oxygen tube changed the public appearance of Ayo's heart disease from private or invisible to public and visible. She said:

> I've had other bad news and complications and all that before. And I've been living with this [disease] my whole life. But the big difference with that was up until that point, it had been up to my discretion who I told I had this-- was living with these health issues, right? Once I had to wear this all the time, it was announced to everybody that something is wrong with me. And that that was hard to deal with. (101.Ayo)

Ayo found some comfort in her spiritual belief that God was as heartbroken as she was about her need for the oxygen. She said:

> He truly understands the sense of loss that I had at that time. He knows it. And He feels that with me, because I can't always find the words to express it in their time. I know that He was feeling what I was feeling. And that it's just as devastating to Him as it is to me.

This belief helped Ayo to feel God's presence as suffering alongside her as afriend during the most dire of challenges. Rather than asking "why me?" Ayo could feel God experiencing the

pain and loss with her as an "us." This relational sense of God-with-us was a religious/spiritual resource.

After Ayo competed in a pageant competition for women with disabilities, she described the experience as a "180" with her regards to her heartbreak over her use of oxygen at home:

> If you would have told me, like, when I was first put on oxygen full time, that like, 'Oh, yeah, you're gonna do a beauty pageant with your oxygen and, like, win.' Like, I probably would have laughed in your face, you know? Because at that point, I didn't- I didn't want anybody to see me with my oxygen. So like fact- like, I've- Just this like, huge— [pause] (103.Ayo)

Ayo had grown in her acceptance of herself wearing oxygen. She also said that she felt like other people, especially other young disabled Women of Color needed to be able to see themselves in the media, which her image could offer. There were so few other Black pageant contestants, and she said it was important for people to see disabled people of color with stories that were not tragedies. Traveling to pageants and being active on social media with "Bella" the Tank gave her a sense of purpose. She saw herself as an advocate for other BIPOC women with heart disease and disabled young people, especially other disabled BIPOC women.

"Distanced from God"

Over the past year, Ayo felt increasingly "distant" from her religion/spirituality, including feeling separated from her friends in the congregation and "distanced from---God in a way." She paused before saying "God," and shifted her weight in her chair as her eyes looked down slightly, after an hour of consistent eye contact. Her change in expression indicated to me that she might feel self-conscious about her distance from God or discussing her distance from God with me, nearly a stranger during our first interview.

When Ayo's Witness congregation (and all other Witness communities around the country) went into "lockdown" due to the pandemic, the distancing-from-God coincided with feeling depressed as her many activities were canceled and her immediate world narrowed. Then, Ayo felt it more profoundly when her two dogs died. Over the course of our three interviews, Ayo was clear with me that she meant that *she* had personally withdrawn from God, as opposed to God withdrawing from her. Withdrawing from God did not stem from an idea of being apart from God's presence, but it was connected to the devotion with which she practiced or paid attention to the congregational meetings. Additional anxiety or worry in her life, especially during the pandemic, made it more difficult to maintain her personal Bible study and prayer time. She did not pinpoint a reason why it felt harder to access, but the lack of regular prayer practice and a feeling of being distanced from God seemed to reinforce one another during the first year of the pandemic. She said:

> I'll say up until December of last year [2020] I wasn't praying as often as I normally do. Just stuff like that, which normally I would pray to Him. If anything, just to vent out what feelings that I do have. I often pray just to have like a sense of calm. I'm naturally a little bit of a worry wart. So, I pray for just to be calm and not worry about things and stuff like that. And I wasn't doing that as often. (14:28 ¶ 337 in 101.Ayo)

Later, when Ayo returned to work, she also had more difficulty maintaining those practices, because she was extremely busy with work, pageant-related events, and her advocacy work. Nevertheless, when I asked what she made of her distance from God or how her irregular spiritual practice schedule influenced her health, Ayo emphasized God's closeness *to* her, as well as God's heartbreak over what she was going through, and feelings that God might "get her" (read, understand, and accept her) better than her parents or her congregation did. With her health challenges as a young adult with heart disease and in part, due to her hobbies and interests, she did not conform to some of the traditional expectations for a young adult Witness, especially able-bodied Witnesses, nor did her hardships correspond to those of many of the

Witnesses her age (or, in some cases, Witnesses much older than her) in her congregation. Yet, people were not God. Thus, others' expectations or knowledge of her illness or times of suffering might be narrower than how God perceived or understood Ayo's experiences. Perhaps, except for seeking her mother's approval for certain everyday activities, generally Ayo had to strike out on her own to make sense of her disability in relation to her faithfulness. Sometimes, Ayo's congregation's members would reveal their lack of understanding about disability as well as race and intersecting oppressions through casual conversation.

Vaccination and Mask Hesitancy as Ableism

During our first interview, vaccines against COVID-19 had not fully distributed, but Ayo was very hopeful about the potential for the science to help activities open back up. Her national faith organization supported the science, promoted the use of masks and vaccines among Witnesses, and persistently warned against the risks of COVID for their community around the world. As the pandemic raged on over the year, some individual members of her local Witness community did not get vaccinated and promoted dangerous myths about vaccines and masking. Ayo found there were views on COVID protections that were "surprisingly apathetic." These views would also put Ayo at added risk at the Kingdom Hall or cause her family to become more isolated from their faith community. While by the third interview, Ayo's specific Kingdom Hall had not reopened for meetings in-person, she was not looking forward to the day they reopened. She imagined she would be needing to confront a few people there who were not willing to get vaccinated to protect people among their community members who are more at-risk for COVID-19 due to illness, such as herself. This upset Ayo. Given these debates in her congregation, she had become more reluctant to share the details about her life or her

illness (including using her oxygen in front of them) with others in the Witness Community. She said:

> This feels really bad to say, but I feel like you don't get a right to know about me if you don't think that this is real, and you think like, 'Only sick people should be worried-- I'm going to continue to live my life.' And I'm one of those sick people. You want to know how I'm doing, but you don't care about the sick people- people that you don't know? Like, it just feels very weird to me.

Previously, Ayo had expected that the vaccines were going to be successful in bringing the congregation back together. The reality of Witnesses' lackadaisical perspectives on things that were life-or-death for Ayo also affected her sense of connection to the congregation overall. She became deeply distracted by her awareness of individuals in her congregation who would prioritize their opinions about the vaccine or who can contract COVID over her health. Even as most were vaccinated, the few members of the community who did not take the pandemic had soured Ayo's anticipation of returning to in-person meetings. COVID-19 revealed what insensitivities to disabled people or those with weakened immune systems had already existed in her congregation.

Risks and Safety Nets

Ayo's choices about what kinds of risks she was willing to take for her health during the pandemic, such as traveling to a pageant or working at a medical clinic, came under scrutiny for coworkers. When she returned to work at her job as a cardiac stenographer, she received a work modification for her disability, so that she did not have to scan known COVID-positive patients and was able to see slightly fewer patients per shift to allow herself time to rest. Quickly, she faced some backlash from peers about the accommodations, especially as staffing shortages in the hospital increased. When one coworker learned she had traveled out of the area to compete

in a pageant, one coworker complained about Ayo to a supervisor and other colleagues, making the work environment tense and "weird." Other coworkers came to say they supported her and the modifications she needed. Still, Ayo felt like she was "being watched" by her colleagues at work, which had made the work experience less appealing. Her mother, a nurse, took similar precautions at her own hospital job, given her daughter's condition. She had to switch floors to have her requests fulfilled. Ayo was considering leaving her job or working less due to the poor treatment she received from the coworker, related to her disability accommodations. She did not know if it was worth it to go to the workplace if she was walking on eggshells around her colleagues.

Ayo's parents were willing to financially support her, but she wanted to continue to work while her heart condition's level of severity and oxygen treatments allowed her to do so. However, these recent comments from coworkers had made the environment at work increasingly hostile and unpleasant and with staffing shortages, Ayo had been spending more and more time at work. In our final conversation, Ayo mentioned that she had a recent doctor's appointment in which they "noticed that some of my numbers are higher than they would like--not scary high, but higher nonetheless--and my doctor kind of alluded to the fact that it might be [due to the fact] that I worked a lot." It was a challenging trade-off; Ayo knew that there would come a time when her progressive disease would simply not allow her to be employed in the medical field or other occupations, so this was her best opportunity to take full advantage of her physical abilities now. The test results made her anxious. For previous stresses and dilemmas, Ayo had used spiritual practices to help her find peace. In this instance, awaiting the further

tests regarding her illness's progression, she did not use those practice to help herself find more peace:

> I feel like that should be my first instinct, like, to pray. Not necessarily, like, make my anxiety go away, but in the past, I would just pray for a sense of calm, and that would make me feel better. And I haven't done that yet. Makes me feel, 'Mmm, you could be doing better, kid.'"

Ayo knew there were religious/spiritual resources available to her that she was not using and working more hours than she needed to work to keep her position. I deduced that her reluctance to pray on this dilemma revealed that she was fearful of having to stop working or slow down earlier than she wished. She wanted more time to participate in life outside her room or her symptoms. The pandemic had stolen some of that time and now, she was facing another setback or potential procedure. She said:

> I always have people like, 'Why don't you want to get a benefited position where you get solid hours?' And I'm just like, realistically, I know that I'm not going to be working this job my whole life. And not because I don't like doing it, I just know that physically I'm not going to be able to do this job my whole life.

She wondered about what would come next. She called back up the Witness belief that God will restore earth to a paradise that gives her hope. She said:

> It might sound far-fetched, but I do find that [belief about the earth restoring to paradise] to be comforting, because it makes me feel like this is temporary. And like if something is temporary, then you can kind- if you know it's going to be over--I don't wanna say soon--but it's not going to last forever, then you can like kind of cope and deal with it if that makes sense.

In her plans to "retire early," she knew she may be financially dependent upon her family for a long time, which her parents were prepared to do. Ayo already had to rely upon her parents significantly to pay for monthly prescription medications. Even with insurance, one of her medication's co-payment cost her family $3,000 for a month supply. She had friends with heart diseases who did not have a family member who would be able to put the medication on a credit

card or await reimbursement from insurance, and went without medications for months at a time, because of their cash flow and waiting on additional support. Ayo recognized that she was in a privileged position in comparison to other disabled people or chronically ill people who did not have a safety net of support.

In part because Ayo had a stable financial and medical support system in her family, she was able to pursue her passions and life goals independently. Nevertheless, she was confronted with her grief, especially after receiving news about the realities that her life may limit some of the other goals she had for herself. Wearing oxygen full-time as a young person was one such blow. Another: the official recommendation that she should not ever become pregnant, something she had wished for herself in becoming a mother later. There's a sense of anxiously awaiting when the other shoe will drop when things are going well, and she feels good. There have been several times in which her illness had progressed, or she needed a procedure, even at times she was physically active and had more good days than bad with her symptoms. Based on those memories, she dreads test results: "oh, you feel fine, but you're not *actually* fine." After learning her blood pressure had increased and she needed more tests to determine the severity of the changes in her health, Ayo took herself to the movies the next day. She wanted to "treat herself" to assist in distracting herself from the anxiety of awaiting results. The combination of the stress at her workplace, the pending test results, and world events (namely, the early days of the war in Ukraine in 2022), coalesced to become overwhelming: "It's all wrapped up," Ayo said.

Anxiety and uncertainty about how long she would lead a physically active life did not stop Ayo from having big plans for herself and pursuing goals. During 2021, Ayo competed and won a national beauty pageant, geared toward disabled women. Since the competition, she has been

surprising herself with her advances in her confidence wearing her oxygen (who she named "Bella* the Tank"). She said:

> If you would have told me, when I was first put on oxygen full time, that, 'Oh, yeah, you're gonna do a beauty pageant with your oxygen and win.' Like, I probably would have laughed in your face, you know? Because at that point, I didn't want anybody to see me with my oxygen. Just this huge [pause] self-growth, I guess, and acceptance.

At the pageant, Ayo was surrounded by other talented contestants, but she was the only contestant wearing oxygen. Therefore, winning the national title spurred new awareness of her public image when she posted in her social media wearing oxygen. Her other creative endeavor was writing a manuscript about a disabled Woman of Color and her dating misadventures; its "a romance story, but she doesn't die at the end, because that's a really common trope, right?" She referenced the popular plotline of movies featuring disabled main characters, such as *The Fault in Our Stars,* in which the main character was disabled or had a terminal illness and falls in love, but the romantic intensity depended upon portraying the disabled person as tragic or dying. Ayo planned to take her project all the way, even to Hollywood. After she won a national beauty pageant, created a social media brand, and became a sought-after public speaker on her experiences with disability, all by the age of 30, nothing would surprise me.

Interpretive Summary of Ayo

Ayo's life story presents important information about the possibilities of living a life with heart disease and religion/spirituality. Living with heart disease on her own terms and living as a young Black disabled woman on her own terms was a process of intentional choices that reflected overarching religious values, including living with integrity, extending grace to others, and using her moral conscience to guide her. Over time, Ayo's religion/spirituality influenced her health and her view of herself in a relational pattern of change through

socialization, community support, her connection to God, and in connection to her broader moral commitments. Ayo's religion/spirituality as a Jehovah's Witness was an important part of her family; and vice-versa, her family was deeply connected to her religion/spirituality. Her baptism symbolized her transition from being a child socialized and raised in a Witness family to adopting and fully embracing her Witness identity as an adult. Her Witness community provided spiritual and practical support to Ayo and her family during periods in which she was recovering from her many surgeries. It was impossible to talk about her choices about her health and choices about how she lived her life without mentioning her closest relationship, which was to her mother. Her mother was a strong supportive presence in Ayo's life and her confidante in discussing issues of identity or medical problems. Yet, at times, Ayo's mother took up an "overbearing" presence, from under which Ayo attempted to climb out by asserting her individuality through Tahitian dance, public-speaking and pursuit of her own medical career.

Ayo also experienced events that were soul-stirring, altering the image of herself and her perceptions of her community members and colleague (or at the very least her perceptions of those perceptions). When Ayo first was required to wear oxygen and then, when she received a physician's confirmation that she should not become pregnant, these were soul-stirring events in her sense of herself, her faith, and her health. Her view of herself as a future dating partner and as a future mother changed dramatically. Ayo had major medical incidents or procedures nearly annually during her formative years, and they became more emotionally burdensome and spiritually-involved as she aged. She held tightly to sources of strength, such as the knowledge that God was "heartbroken" with her. She believed God was present with her in her pain and uncertainty about her health conditions, and understood her unendingly, including the periods of time in which Ayo herself felt disconnected from God or lapsed in her home practices.

The bidirectional relationship between her religion and her heart health over time was also *intersectional*, in that power relations of race, class, gender, and disability all affected how Ayo experienced her religious/spiritual community and her heart disease, including the complexity of managing her experiences with biases within the Witness community (Crenshaw 1991; Collins and Bilge 2016). Ayo valued the important role of her congregation members in her life and in her family, so much so that she had high expectations for their understanding of racism and implicit bias, and also, was willing to educate them when necessary. The willingness to model and expose her somewhat-insolated Witness community to shapes of difference in identity, extended to helping them to understand her as a young woman with heart disease, with one significant exception – she would not wear her oxygen around her fellow congregation members. From our conversations, it seemed easier for Ayo to respond to incidents of unconscious bias directly with members of her congregation than it was to present her illness via wearing oxygen, even if it did not require words or confrontation. In a relational framework of religion/spirituality, feelings can provoke other actions that are linked to one's health and social experiences (Mattis and Jagers 2001). When Ayo decided to wear her oxygen to her training classes for sonography, she made it into an announcement. Her oxygen tank even had a *name* – "Bella": relationship was truly everywhere for her.

Ayo readily agreed to invitations she received to share her story more publicly in the past few years. Not only did she want to be of service to young women who (like her) deserved to see people who look like them wearing oxygen or pursuing their interests (such as dance), these moral commitments helped her feel an overall sense of hope, purpose, and direction in her life. Likewise, the COVID-19 pandemic was its own forceful shape in Ayo's context. Ayo's illness was progressive, in that her symptoms would continue to worsen. At some point, she

would not be physically able to be involved in the level of group physical activity that she deeply enjoyed or work long hours in a career that was important to her. Ayo's relational pattern through which her religion/spirituality and health changed over time, also gave shape to various moods in her life, which could be contradictory in lived time. For instance, Ayo showed a mix of optimism and anxiety about the future, or as another example, she had shifting desires about the question of showing up with oxygen to one important relationship and not others.

PARADIGM CASE #2: CARMEN

During each of the three interviews, 57-year-old Carmen was either packing to move or had just moved from one apartment to another with her "common-law husband" who was her major support person. He had been laid off from his job, and then, their landlord had decided to evict them. The COVID-19 pandemic had made it more difficult to find financial and housing stability in their southwestern Texas city. At the beginning of our third conversation, she smiled cleverly and turned her phone camera around to show me what made her most proud those days: several pairs of dangly earrings in several bright colors. She had been making jewelry to sell at the local farmer's market near her home in Texas, but it was also something she considered a spiritual practice. It helped her cope with her concerns about her finances and her health; it also had kept her from making "bad decisions" regarding drug use.

Seven years ago, while trying to conquer her drug addiction, she had a mild heart attack and during that treatment, a small leak in a valve was discovered. Since that incident, she had attended a drug rehabilitation center but had not received much in terms of consistent health care, except for other visits to the emergency room. She usually had to leave the hospital early to take care of things at home before being able to complete the diagnostics or treatments. She

was quite self-critical, calling herself a “procrastinator” and yet, she felt God was an angel on her shoulder to help steer her clear of bad influences in her life. In addition to crafting jewelry, she had a daily Christian prayer practice, using the Holy Bible application on her phone to study and pray. Since the pandemic began, she was not connected to a formal religious/spiritual community but had friends who were dedicated church members she would call when she needed more specific religious advice.

Christian Spiritual Practices – The Holy Bible App

Carmen grew up as a Christian, raised by her parents to attend church on Sundays. During her teenage years, she was going out Saturday nights to dance clubs, but her parents said that if she had enough energy to go out, then she had enough to energy to get up the next morning and attend the church service. When she had her heart attack, she had been offered prayer and laying on of hands (a ritual of blessing in the face of great challenge or rites of passage) led by a pastor at a church she attended. She said:

> I do believe in my higher power. Most definitely. I've gotten through I believe in prayer. I believe in the power of prayer. I believe that [when] more people gather together praying for one thing, it elevates the prayer of a person or a group. I do like to go to church. I haven't been to church, probably in about a year because of the pandemic. But I do like to go to church.

At the time we met, the church she had been attending had shut down due to the COVID-19 pandemic, and so she would sometimes watch televised worship services, including nondenominational televangelist Joel Osteen’s messages, which are broadcast from Texas to the live audience of 47,000 attendees and then millions by television and YouTube every week from Lakewood Church in Houston (Miller and Carlin 2009). Carmen shared this practice of

watching Osteen's televised church services with her husband. "I like him," she said, "I like how uplifting he is. And I like how his message is just straightforward…He keeps it real." By "keep it real," Carmen meant that Osteen relates his message directly to the Bible, which gave his message credibility and allowed you to go to the Bible reference and see "exactly what he's saying." Osteen leads the largest church in America and according to sociologists, functions as a cultural self-object projecting an image of success and "seeker-sensitive symbolism," such as accessible Biblical references. Osteen and his spouse, Victoria Osteen, professed a theology of abundance through their message of "you can have what I have, too" and "God is on your side and can fight your battles with you" (2009). While Osteen reflected an unattainable level of wealth and prestige for most of his attendees, he also shares his empathy for people experiencing "brokenness," rejecting individual blame and instead blaming society for making people feel like "losers." He also provided people with a reflection of a piece of themselves that they want to know themselves to be successful, loved by God, and not a victim of their life's story. His church had a strong following among communities of color, and had BIPOC church leaders on staff at every level of leadership.

In addition to watching Osteen's services, Carmen had a strong prayer practice. She believed in the power of prayer to lift people out of their situations or offer forgiveness. She also read the Bible using the Holy Bible phone application (Holy Bible App), which also included a devotional and journal exercises, often running in several day-long programs related to a specific topic or part of the Bible. She described for me the process of using the application as a spiritual practice:

> I open up the app, and you know, they have different devotionals that are specific topics that you can choose. And I do choose certain topics to read. And they go on for like,

> some are five days, some are seven days, some are 10 days. And then they have some that are like the whole year where you can use you can read the whole Bible in a year. And every single day you go and they give you what to read. And they'll direct you to the Bible. Of course, they have the Bible, where you can, you can bookmark the verses that you that stick out to you the most. And I do that a lot. And sometimes, you know, if I forget to do it, then I'll open up the app and do it immediately when I remember.

> There's questions that you can that you can write in a journal, and go back and refer to them. There's certain of them that have guidelines, where you can write down certain questions and they'll ask you certain things about how you feel and write it down and write put affirmations up to make you feel better. Yeah, there's all. It's a really nice app. I like it. I've been doing it for a long time.

She used to put the affirmations she found on the app up around her mirror, but they had fallen down. Some reflections in the app stand out to Carmen more than others. In one practice session with the app that was focused on "letting go":

> It was actually yesterday, it was about letting stuff go and stop worrying so much, and stop putting so much stress and worry about worrying about tomorrow. That was a Bible, a Bible verse that I read about saw putting so much emphasis on what's going to happen tomorrow, because it's not even here yet. So yeah, that's something that really kind of stuck out to me when I read that…

> It kind of put things in perspective, you know? I try my best not to worry not to stress about things. I tend to be a procrastinator, you know, and I tend to worry about what's going to happen and how it's gonna happen. And I try my best to get out of that element of myself. I try to get out of my own way. Sometimes I get in my own way. And I put more, I read more into things, and then I actually should. [The message of this devotional was] stop worrying so much and leave it in God's hands.

Carmen sought out relief from the stress of her worries about the future through her spiritual practices. After the lesson on "letting go" from the phone application, Carmen said she "felt a little relief" as it helped her reflect and return her to a more calming head space. It helped her to

let go of some of the concerns she carried, namely about her finances and her health. On a regular basis, she also used the Holy Bible app twice daily. Except on days she forgot, she read the Bible verse of the day and did a devotional, which is a prayer connected to the sacred text. The days she missed were often days she had more fatigue or pain, or days in which she had to do something to address her basic needs.

Religious/Spiritual Beliefs about Forgiveness

Carmen described her religious/spiritual beliefs as connected to Jesus Christ, forgiveness and sin, which connected to events of the distant past in which she had hurt people she loved with her drug addiction as well as a few events in which God reached her just in time to save her life. At first Carmen summarized traditionally evangelical Christian beliefs about certain rituals and their relationship between evil in the world. In particular, she said that she did not believe in other religious practices that sought out spiritual communication from horoscopes to "witchcraft and Voodoo." However, she did believe that people could become "evil spirits in your home." She explained:

> I definitely believe in Lord Jesus Christ, I believe in heaven and hell. I don't believe in witchcraft—well, I believe that there's evil in the world. I'll take that back. I know there's a devil. But as far as like astronomy, and witchcraft and Voodoo, and all that other kind of stuff—horoscopes. I don't do anything like that--Ouija boards, tarot cards, somebody reading my palms or going to a psychic. And I think that's all of something else that I don't want to get into. So I believe in the Bible, I believe in the Lord Jesus Christ up above. I believe that there are demons in this world that are set out I believe that you know, that you can get in, I believe that some people can be evil spirits into your home. I believe in stuff like that, you know? Yeah, I do. I do believe in that. But as far as practicing anything else other than the Holy Bible, and praying to God, I don't do anything else like that.

She also believed children were born sinful and that sin is "just a part of us as human beings." She was convinced that people know the difference between right and wrong, but they might

not always follow that guidance. She said, “I believe if you pray to God, and you really ask for forgiveness, and you believe that you're forgiven, and you let it go, that God forgives you. And will he give you peace and he'll give you a sign that you've been forgiven? I do believe that.” In this view, Carmen believed that if she sinned against God by doing wrong in your life, and believed in God’s ability to forgive sins, then she had an opportunity to ask for forgiveness and based on that request, a message from God would return to help sustain her. She said:

> There's been lots of instances, you know, where I've done things that I know aren't right. He'll put a calming effect on me, letting me know that it's okay. And just to let it go, and that it's been that I've been forgiven. And, and, it does say in the Bible that once you've asked for forgiveness, leave it in God's hands and let it go. And don't keep going back and asking. That once you've been forgiven, if you truly know you've been forgiven, to leave it alone, and not go back and ask for forgiveness [again].

Carmen’s comments about not requesting forgiveness for the same thing more than once, seemed to be an idea with which she struggled. She said that she would often “get in her own way” or the “devil would put [me] in a trap.” I interpreted some of her comments about “letting it go” after God had forgiven a past action, to be related to the guilt she continued to feel about things that she did wrong a long time ago.

Crafting Jewelry – Spiritual and Financial Sustenance

Aside from prayer, Bible study and journaling using the Bible App, Carmen enjoyed making jewelry as a spiritual practice and she shared with me some of her pieces via the webcam on Zoom and her Etsy shop. This crafting practice provided her with spiritual and some financial sustenance. Crafting came into Carmen’s life slowly over time. About 30 years ago, she had been working for Dillard’s department store, which is where she first learned how to make

jewelry. She had begun to make jewelry regularly on her own about 10 years ago. Around the time she was getting clean and had her heart attack, she had begun to sell her pieces. She said:

> I used to see stuff in stores, and then I used to see the beads and I used to try to copy what I saw. And so I would do that and I would wear it and then people started asking me, 'Where did you get that? 'and I will say, 'I made it,' and that's how I started making money: people wanted me to make or sometimes I'd be in stores and I've had a couple of times where people just bought what I had on. That's when I realized that I really had something going on there. You know, so it was a great moment.

When Carmen spoke about her jewelry, she gleamed with pride. From her expression, it was clear how emotionally grounding she found the practice of making jewelry, in addition to the pride of being able to provide for herself with things she made. What made this practice spiritual? She explained:

> We can, you know, we sit down and you see all these beads in front of you that are just laying there and you actually make something out of what's just laying there and you make something look really, really nice by putting all these pieces together. It can be uplifting, you know, it can be really satisfying. So, yeah, Ah [sigh], that is a spiritual moment.

Carmen spoke of the practice of making jewelry in a manner that resembled how others spoke of their meditation practice, with an important distinction. For meditators, spiritual practice was an opportunity to connect with the body, to feel centered internally. For Carmen, she said crafting was a way of disconnecting from her body. She said while making jewelry, she was able to check out and "be out of her body." It did not seem like she would completely dissociate from reality while working on a piece of jewelry, but for the moment, she was able to live outside of the pain she felt in her body and her financial concerns. Not only did the creation of jewelry pieces for the market offer her some hope for financial gain, but it also required her focus enough to ignore the things in her life that troubled her for a short time.

Occasionally her health problems would get in the way of trying to make crafting a daily practice:

> I get up every single day and make something, unless I have something else to do. If I'm at the doctor's office or I'm not feeling 100%. Your hand-eye coordination has to be in what you're doing. And, a lot of times my, my health will make me a little slow or to make me a little absent-minded. And then I get clumsy. And that's when a disaster will happen, where you'll drop beads all over the floor. And that's not fun. Need to sweep up the floor. So if I feel a little off center, or more shaky, because I know I have medication sometimes that makes me feel a little weird.
>
> …That was not a good time [when the beads all fell], because that'll make me more irritated. If I have if I started something and it doesn't come out, right because I'm not in the right frame of mind. So I've learned that already. I've learned my lesson trying to do that. Because if I'm not in the right frame of mind, I'll end up putting something on [the jewelry] wrong. And then I have to take it all apart and start all over. And I don't like to do that! Once I start a project, I like to finish it. I don't like to start over. So yeah, I've learned to know when I'm not in the right space.

Unlike other personal ritual practices, jewelry making required her to have the ability to focus and the fine motor dexterity to do detailed work. Also, while selling her pieces was a part of the motivation, she continued to try to craft for her own satisfaction as much as her health allowed. When she was able to focus and make it regardless of the circumstances, she felt a relief from her stress: “I’m still making jewelry regardless [of my health or sales] because it’s going to get better.”

Some religious/spiritual communities provide opportunities for people to sell handcrafted goods among members of the community as a way of providing more support to people. Carmen’s business reminded me of such forms of ministries, even if she was organizing and promoting the sale of her items created through a spiritual practice. The COVID-19 pandemic had disrupted her sales of her jewelry:

> Once the pandemic struck, nobody has, nobody's going anywhere. So why don't I put on a piece of jewelry to sit at home? So my business slowed tremendously down within the last year.
>
> …It's gonna pick up so I'm still I'm still rooting for it. And I still have my website and everything going. I have a Facebook page and Instagrams and all that other kind of stuff.

While God and Bible reading urged her to "let go" of worry-shaping habits, making jewelry brought her out of her immediate sensations or worries related to her heart problems or concerns about her finances, and into a space of hope and forward momentum with her life. She shared an incident in which she ran into someone from her past who was inviting her to do drugs.

> I just went to Walmart just to buy some beads and supplies, some supplies. And I ran into somebody from my past and they were trying. They were--of course, you know, the devil all put other people in your way to try to convince you to do wrong. And this person was exactly that. And I got out, I got out to my car. And believe it or not, my car wouldn't start. So I had to rely on this person to give me a jump in order to get me home. And the...this person actually followed me home to make sure I got home. And of course, he wanted to come upstairs, and he wanted to get high. And I you know, it just it just like kind of like a domino effect. It's like everything. And I have my [craft] supplies. So, I told him, I said, "No, that's okay."
>
> And, you know, I came upstairs and I immediately sat down at my workspace and got all my materials out. And he gave me his phone number, it took me a good, took me a good 30 minutes to finally get that out of my head, you know, to fight that, that, um, that kind of wanting, knowing that I shouldn't, but kinda trying to get that out of my head. It took me a minute, but I did. And once I started crafting, I realized it was like, five hours later, and I had totally forgot about it. And by that, I mean had passed.

The plan to do some crafting was motivating eenough to make a better decision for herself, and then, the process of making jewelry herself loosened her attention from the temptations to lose her sobriety. Regardless of whether jewelry-making would be considered a traditional spiritual practice, it served as a critical spiritual and emotional purpose in her life.

Casting Out Past Demons – Guilt over Drug Addiction

In our discussions, Carmen spent the majority of her time grappling with the multiple stressors that were unyielding, longing for the still small voice of God to fulfill the promises, clearing away the "demon" on her shoulder for good. That demon seemed to be embodied in her past drug use and the effects of addiction on her life. At first Carmen referenced to the period of her addiction as "*before* I got into a better headspace." Then, tearfully, she shared with me about her what she meant by "before":

> Five or six years, I've come from being in a really dark place to finally being in a better space. I might as well just go one and tell you, I am a recovering drug addict. And a lot of things. And the reason why I have so many health problems is related to that. A lot of reason why I have so many heart problems are from drug use. And I've been clean for, in December, it'll be six years.

We both teared up from the happiness of her triumph and the pain that still trailed behind her obstacles from the past, including the origins for her heart disease. It had been over 30 years that she tried to get clean and finally she had success after numerous attempts to recover:

> I tried many times. I've been to rehabs. I've been in detoxes, I've been homeless…it's easier knowing that I worked really hard to get to the space that I am now.

Part of the religious/spiritual struggle facing Carmen was related to her view of the origins of her health issues. She believed that that her heart problems were due to drug use. My personal interpretation of her overall story is that her heart problems were likely not *only* due to drug use. Drug addiction is itself a health problem. I do not distinguish Carmen's heart disease on its own from heart problems of other etiologies. However, in exploring how religion/spirituality influenced Carmen's life and health over time it is essential to consider the full story of her heart disease from her perspective and her own interpretation as well.

Receiving Medical Care Triggered Older Traumas

Carmen experienced several hospitalizations for severe medical problems that echoed into the current problems she faced accessing medical care and understanding the status of her heart condition. Seven years ago, Carmen began seeing a cardiologist after a mild heart attack that she had thought was indigestion or heartburn. When it didn't resolve, she stayed in the hospital for a week of tests and her providers found that a valve contained a small leak. It was an already stressful time in Carmen's life. She was trying to get clean, but at the time she went into the hospital for the heart attack, she was still using drugs:

> At the time when I actually went to the hospital, I had drugs in my system and they were going to put me on a certain medication, but because of my addiction, they couldn't. They had to hold off.
>
> So, I've kind of been really hesitant about keeping my doctor's appointments. I'm really a procrastinator. I must say, I'm not, I'm not good with doctors. I've been in the hospital so many times…Because every time I go, I went to the hospital probably about, I'd say probably about a year ago, about a year ago and I just went in for just a routine check and they ended up admitting me for another seven days.

Entering the hospital with a minor concern and becoming admitted for a heart attack is itself a traumatic event. Carmen did not mention specific discrimination or how she was treated by the medical team at the hospital. However, it is my interpretation that simply the experience of not receiving a medication that would have helped her should she not have had drugs in her system, would only exacerbate the trauma and the feelings of guilt she internalized. The stigma attached to drug use, along with racism in health care and poverty, further contextualize Carmen's experience. Carmen shared repeatedly her hesitancy to follow through with further treatment of her heart symptoms, and previous research showed how stigma contributed to the reluctance

and fears about seeking healthcare among people who use drugs. A stigmatizing experience is not just the actual experiences of discrimination, under-treatment or criminalization as someone who uses drugs, but it is also the anticipation of future bias and the internalized stigma or negative self-image a person may carry within them (Mays et al. 2017; Muncan et al. 2020). She shared a long list of different procedures she had over the years, which had exhausted her and caused her to be indecisive about medical appointments or delay care:

> So, I've kind of been really hesitant about keeping my doctor's appointments. I'm really a procrastinator. I-I must say I'm not, I'm not good with doctors. I've been in the hospital so many times. I've had a gallbladder removal, I've had three C-sections, I've had stitches, I've had some broke limbs, I've had all kinds of stuff happen, you know, and hospitals are just not, I mean, I had my thyroid removed, I've had just all kinds of things that put me in the hospital. I've actually been in the hospital three times because of my heart within the last five years, and that's a lot.

In addition to being concerned about experiencing additional trauma when seeking care, Carmen was concerned that if she sought health care for something routine, the providers would admit her for something else, and she would unexpectedly be hospitalized for a long time, preventing her from addressing basic needs at home, such as housing problems.

> So me going to the hospital and keeping my doctor's appointments, I'm not good with that and my cardiologist really gets on me because, um, I haven't even had a mammogram or, or a pap smear because I am just *so not* wanting to go to the hospital.

> ...because every time I go, I went to the hospital probably about, I'd say probably about a year ago, about a year ago and I just went in for just a routine check and they ended up admitting me for another seven days. And so, every time I go to the hospital just to have a checkup or anything, they end up admitting me because my EKG is always abnormal. So, in order for them to make sure that nothing else is wrong, they have no choice but to admit me. 'Cause the minute they check me, they're gonna find out, you know, that there's something wrong. You know, maybe I shouldn't think along those lines, I should have a little bit more faith, but with my, my past history, I can't help but think like that.

On some occasions, Carmen needed to leave the hospital prior to coming to resolutions or a treatment plan. She recounted one instance, she left earlier than advised:

> My blood pressure was like, through the roof. And they- they decided to keep me overnight for observation. I was there for maybe two days, because my blood pressure just wouldn't go down. But then I really started breathing and I started relaxing and my blood pressure finally started dropping. And the doctor just told me to make a follow up--they really actually wanted to keep me longer. And I told him--I said, 'I can't I have things to do. I mean, I have to move, I have to pack.'

I found that the uncertainty of her housing and the uncertainty about her health were strongly connected. She had experienced several traumatic hospitalizations, which now had caused her to be reluctant to keep medical appointments and follow-up according to provider recommendations. Hospitalizations involved challenges with her health, but also came at times when she was facing other difficulties and had to address her basic needs at home.

Carmen and her husband experienced a high degree of precarity related to their basic needs, including housing, health care access, food and employment. Carmen did not have a regular job or health insurance. The second and third time we met, they were about to be forced to leave her current housing situation. At the second interview she had just learned that her landlord was evicting her and her husband, who had just started a new job but not collected a paycheck yet. Additional COVID-19 related rent protection had kept them from eviction, but when that expired, they had to make other plans quickly. At the third interview, her husband and she had their food stamps cut off and she had considered taking a job hostessing at IHOP in order to help them get a new place to live. She knew her health would suffer, but the stress was already a challenge, and it was what they just might have to do. She had been unhoused during periods of her addiction and then when trying to get clean; the shelters nearby her and her

husband were not ones they would let themselves re-enter. The process of packing up and moving and unpacking was wearing on her body and energy level. In our last conversation, she was concerned about having to pack up all her belongings quickly.

Especially during our last conversation, Carmen reiterated her wish that she could just do what she knows is right to do for her health. She had a phone call with a friend who was "doing really well" and did not have serious issues that Carmen was facing today, such as housing issues and financial trouble, despite the fact that her friend and she had "both partied really hard in their 30s." She had not expected her friend to be so successful and became tearful describing her happiness for her friend, which was mixed with a feeling of jealousy. Carmen wanted *that* life. She felt impatient about the situation in which she found herself, and once more, turned on herself regarding her procrastination, as well as her impulsivity. While her ability to be patient had improved over the years, she knew the root of her impatience was her addiction:

> Addiction is selfish, so you want what you want when you want it and that's something that you have to work on and being in that frame of mind for so many years and you have to retrain and regroup, you have to retrain your frame, your line of thinking.

When I asked Carmen how it played out when she heard the small voice of God within her tell her to get care for her heart, she paused and said

> right now, my mind is telling me that I need to go to the hospital. I need to get, there's something that's just not right. I can't put my finger on it, but I-I feel it in my body and I, and my head is telling me, and I've been thinking this for the last two weeks and I've been putting it off and my husband is off tomorrow and he already told me that I'm gonna, he's gonna take me to the emergency room just so I can get my blood pressure checked and get an EKG.

She said was realizing that he had been putting off going to the emergency room because she was worried about having elevated blood pressure. Her husband was at work, and so she decided to go the following day when he had the day off and could take here to the ER. We ended the conversation shortly thereafter so she could rest and consider options to go seek care earlier. When I spoke to her later, she had been to the ER for stress and other symptoms related to circulation in her legs, but she had not gone to her follow-up appointments. However, she said she did have a cardiologist appointment and had been praying for God's guidance to keep the appointment. She said:

> This'll be a first, I haven't seen a cardiologist. I've seen one in the hospital, but now she's gonna be my actual cardiologist. So they'll probably do a lot of blood work. And I probably have to fill out a whole bunch of questions and stuff like that. So it'll be something good.

Family Support System Challenged

Carmen's family support system had been challenged by the long history of addiction and its impact on her and her family, especially her relationships with her children:

> I lost my child, lost my youngest daughter to adoption because of my drug use. My brother, my brother stepped in and adopted her so that she wouldn't go into the system. So I do know her and she knows me. And that's a good thing.

> I burned a lot of bridges. You know, I have friends and family members that still even to this day, won't talk to me and won't acknowledge me. You know, and that's kind of hard, even though I worked hard to get to where I am. They're not as not as forgiving as I thought they would be. You know, once I got clean, you know, I thought everything would go back to normal. And it didn't, you know, so that was hard to deal with. And it's still hard sometimes. But um, I know that I've been forgiven. And I know that my hard work paid off. And I can't wallow in that, and I have to move on. And that's what I'm doing.

Carmen's belief in God's forgiveness for sins, which I introduced earlier, was a part of how Carmen viewed her relationship to addiction and to the "burned bridges" of relationships that she worked to repair from her side. She felt that she should not be feeling as guilty for those times as she sometimes did.

> There's days where I started getting to my I get in my own way. That's what I'm talking about getting in my own way. And I start thinking back to things that I did and things that happened, and then I start feeling guilty. And then I'll call...I have a friend that's real good with the church, and we'll get into the Bible. 'That's what [that attitude is] just nothing but the devil. That's the devil trying to convince you to feel guilty. And the devil will put you in a trap in your head to where you'll go back to doing those bad habits, just to try to make yourself forget about what you did wrong. And then that'll just start putting you in the same trap that got you in the trap in the first place.

I interpreted Carmen's statements to mean that she was concerned she might return to using drugs, if she let the guilty feelings over the past ensnare her. She recalled friends that she could call for support. Her husband was also a recovering addict who she had met in one of the rehab centers, and she considered their relationship to be the strongest supportive relationship in her life. She considered their bond to be life-saving and somewhat of a "miracle":

> Something like addiction by yourself is hard. And it's even hard to--believe it or not--it's even harder to go through it with somebody that's an addict also, because you'll play on [each] other's addiction in order to get what you want. But we learn not to do that. And we've been together for over 20 years. So for us to still be together and go through everything and still be clean together is really a miracle. It is a miracle that we are still together and we're still in love. And we still, you know, work hard. We still laugh, we still go out. But it's just so much better right now. It's so much better now that we can do things together that are fun. And still like each other.

Carmen celebrated the work that she had done to change her life and longed for other family relationships to be repaired. She said:

> I've worked really, really hard to get to this point and I guess me expecting everybody should forgive me and everything should be okay is not realistic because not everybody is going to be easy to just let things go and my older son is one of them.
>
> It's really hard sometimes. You know, I struggle with that sometimes because I know a lot of the things that he says are true, a lot of things I don't wanna hear…Its real hard for him to let things go, so I try not to bring up things and I try not to ruffle his feathers. But, um, I just, you know, I just pray about it and, you know, I leave it in God's hands.

Despite the estrangements, when Carmen had her heart attack a few years ago, Carmen said she had slightly more support from her family at that time. Her brother and his wife, along with one of her sons came to visit her in the hospital. Carmen's other family members had not always been in close contact with her. She described the improvements in the quality of relationships with her family, since she was in recovery:

> Within the last five or six years, my family has really, really been there for me. There was a time when they didn't wanna talk to me at all, you know? So, now I have relationships with all my siblings, with my kids, with my cousins and all my other relatives. So, everything right there is pretty good, you know?…I remember when it was just terrible, terrible, terrible.

Her husband and she were quite isolated living far away from relatives and limited given their housing situation, but Carmen lit up when she talked about her children. She had many regrets about how her drug use and instability earlier in their lives affected them and their relationship with her. Her daughter lived close by and she was in touch with often. Her younger son lived with his father, who was estranged from Carmen and would not allow her son to travel to see her when she was hospitalized. Recently, they had just started talking, after 8 years of separation. She described her youngest son as "fragile" and knew that because they were at the beginning of reconnecting, he didn't want to put all of the details of her health problems and

other “baggage” onto him, while they’re just starting to have more contact. “I'm sure he's probably not sure 100% if I'm still okay.” Her older son is in his 30s and “he’s toughened up” and “knows everything” about Carmen’s life. Sometimes, “all kinds of things from the past will come up,” and her son would become angry and this pattern frightened Carmen, so she tried to keep things positive. She was afraid she would “feel guilty” and hear things that she knew to be true, but of which she didn’t want to be reminded.

“Little Small Voice” of God Saving Her Life

Carmen’s faith in God was strengthened by incidents in which God’s “little small voice” became large and loud, saving her life on multiple occasions. Carmen appeared to focus her mind on the small voice of God to become more attuned to her body and the symptoms she experienced. Multiple times during our interviews Carmen brought up how she doesn’t listen to the small voice enough; that she made a lot of mistakes lately and needed to act upon the advice that God had offered her. She narrated aloud her prayer to me:

> So, say like the devil getting in, that's like when you're feeling disconnected from from God and I'm just feelin' like, Oh God, I'm just doing all this praying and as soon as one thing gets really good, all the sudden, as soon as you take three steps forward, you take 10 steps back, you know? Yeah, there are times, there are times when I feel like that like it's all for nothing and then something wonderful'll happen like, you know, somebody'll just call me and say, ‘Well, Carmen, I wanna buy some jewelry,’ or something like that and I'll get money and then that, you know, to put towards something and then that, that, that, that's when it all comes back at your perspective, that, that's the sign I was looking for and don't ever, ever give up my faith.

Carmen’s favorite scripture is from the Gospel of Matthew, Chapter 21: “If you believe, you will receive whatever you ask for in prayer.” Its from a parable in which Jesus curses a fig tree without fruit that it will never bear fruit again, and it withers before his eyes. The strength of

your belief can even move mountains, is what the gospel writer depicts Jesus saying to his disciples. To Carmen, this means, “Let go and let God,” let her belief in God be enough to do what is needed to stabilize her life. That aphorism is also a popular 12-Step slogan about the power of one’s higher power to intervene when we find ourselves powerless over addiction. I asked her what “leaving it in God’s hands” or “let go and let God” meant to her. She said:

> It means just having faith, just leaving in God's hands knowing that prayer and knowing that time and knowing that God always has the best, everything that happens, happens for a reason and a lot of times, you have to know or you have to believe that there's a reason behind it that God has his way, that God has his way of putting you in your place or he has his way of showing you the right way 'cause a lot of times, God'll do things for you or he'll save you from things that you don't even know that you're being saved from. Just certain things that you know that if it wasn't for God, you wouldn't have gotten through it.

She described situations in which she would be in a place with people who were a bad influence on her and the only reason she escaped before something worse happened was just the voice of God pulling on her to leave the situation:

> I’ve been in places, around people that have done some terrible things and a lot of times, God'll put it in my heart or put it in my head, ‘Well, I think it's time for you to get up and leave,’ or, ‘I think it's time for you to get out that situation,’ and as soon as I get out of the situation, something bad will happen to where if I would've been there, I would've been in that bad situation also, do you know what I mean? Like God'll get me out of a situation. He'll keep, get me out of a dangerous situation that if I wouldn't have listened to him, I would've been in the situation. So yeah, there's been lots of times like that where I know it was nothing but God.”

For example, she shared a situation in which she was at a friend’s house doing drugs for a couple of days, and then the voice of God told her to get up and leave. A few hours after she left, a good friend of hers who was at the house was killed. She recounted the story this way:

> I’d say probably about, um, about five years ago, well maybe a little bit longer than five years ago, I was at a friend's house and I had been there for a while doing drugs and,

> just in the wrong place at the wrong time and I had been there for maybe about two days and something just told me, a small voice in my head said, 'Carmen, enough is enough. Get your butt up. Get yourself together and go home and regroup,' and I did. And maybe about a couple of hours after I left, somebody got killed in that same house that I was in. Yeah, and it was a good friend of mine. And if, and if I would've been there, I probably would've went to jail or who knows, it might've been me that was in the situation. So, that was one of the times where, you know, I listened. I don't always listen to that little small voice.

The "little small voice" of God was something that came to Carmen's aid in multiple situations over her life, in which "God [was] telling me to go because if you don't go, it's gonna get uglier than it already is." She believed that everyone has that voice:

> We all have that little, you know, we have the good [angel], you know, like you have somebody sittin' on one shoulder, the angel on one shoulder and the demon on the other shoulder whispering one thing in one ear and something else in the other ear and a lot of times, we don't always listen to what's in the right ear.

Carmen laughed and said that there were times where she had listened "to what's in the wrong ear" and things had gone terribly wrong for her, staying somewhere and

> I ended up going to jail or ending up kicked out in the middle of the night with nowhere to go. If I would've just left and went home, those things wouldn't have happened. So yeah, I've had those things happen too to where I didn't listen, and something awful happened.

Carmen's voice of God in her ear was one that she hoped would inspire her to seek out medical care and keep her appointments with specialists. Over the course of the interviews, when we revisited these beliefs, Carmen's past actions seemed to haunt her, and cause her to not put her best interests or her health first. While other people in her life, such as her children, had forgiven her and reconnected with her, Carmen had yet to fully forgive herself for the past: "I had to forgive myself before anybody else to forgive me. And I am still working on that."

Interpretive Summary: Carmen

Carmen incorporated religious/spiritual practices into her life in heart disease in ways that were traditional yet unsatisfying in delivering her the calm or self-love she sought as well as creative and non-traditional, which offered her an escape and a practical tool for dealing with financial stress. She used Bible study, prayer, and devotional reading to engage with Christianity; she also made jewelry as a way to make money, but also as a spiritual activity to "check out" of her body and the stress of her life. As a paradigm case, Carmen demonstrated my interpretation of an *intersectional* pattern of change, in which religion/spirituality and health change over time according to the ways in which forms of system oppression shape the lived experience with heart disease as well as lived experience in religious/spiritual communities. Carmen faced challenges to her mental, physical and emotional health from almost every direction, without adequate social support or basic resources. These challenges increased during the pandemic and influenced her sense of the future. Carmen's relationship with God was one in which God was an angel on her shoulder or higher power with the ability to compel her to take action for her health or to change the direction of her and her husband's struggles to fulfill their basic needs. Carmen avoided thinking about the things that troubled her relationship with her children and feared rejection and guilt from her children. She struggled to keep doctor's appointments and had a pattern of avoidance of dealing with things related to her medical care for fear of receiving bad news and having to be hospitalized for a longer period of time. Not only did hospitalization trigger memories of her first hospitalization with a heart attack while she was still using drugs, but it would also take her away from the things she needed to do each day to get basic resources together to survive and stay housed.

At times, Carmen appeared to feel punished by God for her years of drug addiction and the things she did in the past (constant presence of the devil on one shoulder). Mattis, et al. (2017) suggested that "theological messages that represent God as punitive and that position individuals as outside of the boundaries of divine grace and forgiveness may impact the optimism of African American believers." In each interview over the course of a year, Carmen revealed more details to the religious/spiritual practices she engaged, the beliefs she found useful or confounding, as well as what they meant in terms of her relationships, health and basic needs. For Carmen, "life becomes an effort to hold onto what keeps unraveling" (Ahmed, 2017:238). I believe our conversations moved quickly from health to God to housing to money to crafts and back again, because again and again, she was trying to pick up lost loops of yarn to place them back onto their skein.

It is not a surprise to me that Carmen found appeal in messages of Joel Osteen, in which the central argument is that changing your belief about yourself could change the way you live (i.e., big success is attainable to all who love God). This religious/spiritual message replaced the punitive theological messages as Carmen watched Osteen more often as the pandemic continued. However, Osteen's "audience" was not a congregation, but a TV program and so did not give her the social support or tools with which to overcome her pattern of avoidance. Looking back upon her life, she saw the ways in which she listened to the angel or the demon on her shoulder, and the task before her during our conversations was how to remember to only listen to the Angel, and not just to avoid bad situations but to seek out the changes she needed to make for her health. Yet, she seemed to be increasingly frustrated with herself as one setback after another, pandemic-related and otherwise, presented itself.

Listening to a Prosperity Gospel message might help someone transcend their pain momentarily. For Carmen, perhaps Joel Osteen's worship services were similar to the experience she had while making jewelry of setting aside the worries of the world and focusing on the hope inspired by the activity. Yet, outside of the practice, the intersectional pattern between her religion/spirituality and health persisted. The health care activities, which she believed would alleviate the stress in her daily life, were out of reach as she dealt with daily tasks of finding enough money to put gas in their car, buy food and secure housing.

Aside from Osteen's message, "Leaving it up to God" was a common principle for Carmen, which has different meanings in people's lives. For Carmen's way of being, I interpreted this belief as a holy reluctance to ask for more specific help, and her last hope being pinned on God to remove the deadly combination of crushing adversity and internalized guilt and shame. Carmen would benefit greatly from expanded access to basic resources and a relationship with a community of religious/spiritual practice that had strong networks of social and practical support for its members. Carmen's case exemplifies the ways that programs to bring families out of poverty and provide approachable health care without stipulations would benefit her heart condition as well as her spiritual view of herself and her capacity to make sure of religious/spiritual coping resources.

PARADIGM CASE #3: MARY

Mary, 43 years old and a Brazilian immigrant, described herself as a medium (skilled communicator with the spiritual world) and as a storyteller. She grew up Roman Catholic, and still felt a connection with her childhood faith through her religious/spiritual life now. She defined herself religiously and spiritually through three syncretic traditions, connected to West African (Yoruba) traditional religions and blending other beliefs and practices, including Roman Catholicism. These included Spiritism (derived from Allan Kardec among French middle-class), Umbanda (Brazil), and Candomblé (Brazil). She practiced each of them in combination with each other and alone, depending on the period in her life. Spiritism or "Kardec-ism" was the tradition her husband brought with him into the marriage, which she fully claimed, and she described Umbanda as her "roots." Her wall had a small altar and sculpted image of Oya Yansan, the orixá or goddess known for her connection to wind and storms.
At the time we spoke, Mary was awaiting a heart transplant after being diagnosed with heart failure a little about two years ago. Heart failure and waiting for a transplant was not the first serious health condition that Mary had encountered. In 2017, she had a brain aneurysm, followed by two brain surgeries and was in a coma for 17 days. This near-death experience offered Mary important insights into the purpose of her life. She recovered and continued to live a busy life and carry on with spiritual practices in each of her religious traditions. Then, about two years ago., she had been pursuing bodybuilding, but the exertion overcame her heart, and she was diagnosed with heart failure and informed she would need a heart transplant. For most of our interviews, she was upbeat, smiling and shared stories with bubbly enthusiasm. However,

there were moments in which the exhaustion of her progressive illness and effects on her family were palpable amid her hopes for a new heart and a future.

Daily Connection with the Divine

Religion/spirituality began and closed each day for Mary. Just after waking, she spent a few minutes in meditation and breathing practices to "connect with the divine." She sat in front of her orixá, Yansan, to give thanks, while lighting a candle and incense. She described the purpose of the other elements in her morning ritual:

> The candle is just to bring light, you know, to my Orixá and to my head, saying that I'm alive, I'm here…And the incense helped to clean up the energy. And then I meditate to calm everything because our mind goes [wild at night]. And I believe that when we woke up is harder because we lose control. When we are sleeping and our minds go whatever they go, sometimes when we wake up, we wake up angry--so I like to concentrate in my body, in the feelings, try to get better and feel better. And then I go about my day.

In the evening, she also did a meditation before going to bed to "ask that my mind goes to a nice place while I sleep, and to please help me sleep as well." Sometimes she had difficulty falling asleep, holding the concerns about her health and prognosis.

Mary also had religious/spiritual practices that she engaged on a weekly basis. During one evening per week, she gathered with her husband and three daughters at a table to sing, share in prayer, and read a sacred text from Kardecism. The family ritual time then opened to discussion about the meaning of the passage. Typically, as the medium in her family, she would also open up a spiritual space for connection and conversation between her family and the spirit world (deceased humans and other entities) in order to help the deceased "go to light" or interact with them, if the spirits were interested.

During the COVID-19 pandemic, as a family they added additional practices to help the "massive number of spirits that are dying suddenly with no preparation." They talked to the spirits who have died, helped them to "go to light" and opened up through Mary's mediumship for any messages they had for them or for the living. Mediumship required significant stamina and expended a great deal of energy from the medium, as it engaged her whole body and spirit. As Mary's own health declined due to her heart failure, she felt too weakened to open herself up to spirits for mediumship, and as a family, they decided to stop opening conversation with the spirits of those who have died. She enjoyed that practice and sharing it with her family, but reluctantly agreed it was too taxing on her body in her current condition. There were other religious/spiritual practices that Mary valued and were physically demanding. Singing, capoeira, and other rituals were activities that Mary would do them all every day if she was able, but she had to let go of some of these during the past year. She became tired quickly from going full-throttle into an activity, often ignoring signs of exhaustion, even though she had difficulty breathing or losing her voice.

Through family ritual practices, Mary wanted her children to understand that "spirituality is shared." Also she shared charity work with her family:

> Another thing that is not really spiritual--but I believe it is--is doing charity work. So we try to go to this homeless camp and give them food. So we prepare the food and then, or buy it or something, and we energize the food and go and talk to them. Once a month, that's what we do right now.

She believed that through giving and spending time with people on the streets that she was receiving a lot more than what she gave. She said that this "unconditional love is helping me to

evolve." She also believed that spending time volunteering with her children helped them to cope with her illness and to understand the role of generosity in spirituality. Another example of the spiritual charity work included providing some financial support for another woman's initiation rites with Yansan (the same orixá as connected to Mary). Initiation rites within Umbanda communities required some financial commitment. So, after Mary had completed a small fundraising campaign online to help her and her family manage the costs of her heart transplant and recovery period, she donated some of the additional funds to the initiate in Brazil.

Near-death Experiences Changed Meaning of Life

Mary described her 2017 aneurysm as a "near-death" spiritual experience, in which she chose to remain alive, and reflected on her legacy as well as the meaning of her life. She said, "It was clear for me that I am here for a purpose, and I do have a mission." She described her memory of the experience in positive terms:

> For me, it was good. You know, it was a peaceful feeling. It was something like, I was- wow, I was levitating. I was going. I was happy. I was feeling good. It was like [motions upward] and then when I kinda look back for a second, I saw my family. And I chose to be here. It's clear to me that it was a choice that I make. I had to be here for my family, with my family right now. But I have to fight to stay here. I have to fight for my life. And I thought [it was fast]. It was 17 days. To me, I woke up after 2 minutes. But then I was into surgery. And I only wake up after 17 days. And it was- I struggled to be back, you know. And then I'd be fighting things then because and then I got better.

Inside the near-death experience Mary felt as if time slowed down and she was making conscious choices about whether to live or die in a short period of time. In fact, her family had been instructed to begin to make arrangements for her death, but then she got better slowly over the course of 17 days.

Mary believed that the intensity of religious/spiritual practices at her bedside, at her family's home and in different religious groups contributed to "helping me to come back." During the coma, multiple religious communities near and far from the hospital performed rituals and prayed for Mary's survival. From Buddhists to Catholics and Presbyterians, along with the Kardec church and from Umbanda, people were praying for Mary to make it through her coma. Her family also continued the weekly family rituals, which rippled out among the hundreds of people praying for her to recover. Members of her spiritual community was at her bedside, as was her husband who would read sacred texts to her in the dark. It was recounted to Mary later that the visitors who came to be at her bedside and offer spiritual practices while she was in the coma began to be noticed by the medical staff:

> I had my babalorixá [priest] doing all the works, and I had my cousin going to the hospitals and doing the Jin Shin Jyutsu [an energetic practice for releasing tensions in the body there. She was doing the Jin Shin Jyutsu there, and every time she went there, like my heart—I was in coma, but my heart was like 150 [beats] per minute. She would go there, do the ritual, the prayers. She would put stones, like crystals, on me. When she left, I was at 90 [beats per minute] and the nurse was like, 'What are you doing? I don't care what you're doing but keep coming back.'

Later, when Mary was awake and recovering in the hospital, a nurse asked her, "Do you have a religion?" and Mary responded, "I have many." It is possible that the nurse asked this question because of the number of different types of rituals from a variety of healing traditions had been brought to Mary's room. Mary's nurse also called Mary a "miracle." Mary also needed two surgeries following her aneurysm, for which she had significant religious/spiritual experiences.

Spiritual Preparation for Surgeries – "Go Be with the Good Spirits"

In her religious tradition, surgeries are paired with spiritual preparation, as the cultural traditions surrounding Umbanda and Candomblé, in particular, integrate conventional medicine with spiritual practices directed at healing. However, after her aneurysm and before her first surgery, Mary did not want to do the spiritual preparations that her priest and husband wished to do for her to become ready for the physical surgery: "And they said, 'you need the physical surgery, but we did everything that we can to minimize [the challenges of having brain surgery].' But before the first brain surgery following the aneurysm, she refused the opportunity to undergo the spiritual practices that leaders in her communities were suggesting: "I didn't want to do a prayer before, and I was in a bad place returning from the anesthesia…I was crying all the way through [the surgery]. I went, 'Oh.'" Mary reenacted her dumbfounded face at the time of her recovery from the first surgery. The gesture indicated to me that she had realized with her pain and tears waking up from anesthesia that spiritual preparations might have relieved of some of the discomfort.

For the second surgery, 8 months later, she knew what would happen to her physically and wanted to do the spiritual preparation recommended to her:

> And then by the second [surgery], I need to prepare myself for the second, which was about eight months after. And then in the second, I'm like, 'Let's do everything. Let's do the prayer, and let's do…' I did the Jin Shin Jyutsu [an energetic practice for releasing tensions in the body] before my surgery with my cousin to help me to prepare my body for anesthesia, so I could come back better, in a better position, and prevent my spirit to go to the dark place. I want to go be with the good spirits, and [the first surgery] was a dark place in my mind and my subconscious.

Mary recovered from the second surgery with less pain and discomfort. She went onto experience several years of improved health until her heart attack and heart failure diagnosis a little about two years ago.

Sharing the Heart Failure Prognosis with Her Family

After recovering from her brain surgeries, Mary had become very interested in becoming physically fit and attaining a strong physique. She began body-building and lifting weights, but was unaware that "she had something in her health that I couldn't do it." Mary had been body-building, but did not know that she had a pre-existing vulnerability that would cause her to have a heart attack while attempting this lifestyle. She then learned she had heart failure and would only survive five years without a heart transplant. She quit bodybuilding, left her high-powered job in marketing, and reduced other time commitments she had.

When Mary first learned of her diagnosis and prognosis if she did not get a new heart, she told her daughters the news and recounted that they felt assured that she would pull through this illness. Mary imagined that given what her children had already withstood watching their mother go through the coma and brain surgeries, they had become prepared for this time in their lives, just as Mary's near-death experience had prepared her. Briefly, Mary described how her children were coping with her illness and waiting for her heart transplant:

> People asked me, 'How are your kids coping?' I say, 'They're great.' And they *are* great, because somehow in preparing them from that [near-death experience], you know, and they know, it's fine. You know, what- If she has to go, she will go and she will be connected with us. And we will meet later. So they are good with both ways. And if I get through this, like, Yay! You know, I still here. I have a mission. So, yes.

In interpreting Mary's family dynamics, it was challenging for me to imagine Mary's children being "good with both ways," or feeling equally satisfied by the outcome of their mother's survival or death awaiting a transplant. Mary's remarks about "they know, its fine" and the casualness with which she spoke indicated to me that Mary had felt some certainty that she was going to receive a new heart and survive. She did not express certainty of her survival explicitly to me, but rather offered calm references to feeling content with this illness process, despite its challenges and painful moments. Her statements indicated to me that this was a perspective shared among the members of her family, giving them strength through their religious/spiritual beliefs and traditional practices.

Heart as a Gift from Yansan, Cleaning the Soul through Illness

Mary explained her religious traditions understanding of waiting for a heart transplant as cleansing the soul – her own and that of the universe. She then described two religious/spiritual activities that helped her to process the waiting period for a new heart and maintain hope in the face of grave illness. Here is the general perspective from her religion:

> Now I have to go through a heart transplant. I'm waiting for someone to give me a phone call. I know it's hard, but I am glad that this is happening with me. Because in my religion, I am cleaning the soul. And I'm also being able to help- to help other people. Because what I am experiencing- me, I believe that I am like a sponge. You know, so and I'm helping to clean, to channel and that, you know, with my body. I'm gonna need a new heart. You know, and it's a- it's a sacrifice. But it's good. It's also a gift of life.

She said the process of cleaning the soul was channeling through her body certain life forces in need of healing that then, become changed, washed or renewed as they move through her. This

healing process was not only coursing through her own physical body, but supported by and supporting the healing process of the universe.

Messages from Yansan and the spirit world were the first set of religious/spiritual activities that helped her to process the waiting period for a new heart and maintain hope. These messages focused on the purpose of her illness for her own life and for the universe. Regarding one such message, she said:

> the new heart is a gift from Yansan, from my goddess, you know. And she's saying, 'Everything is fine. You need this new heart. It's a gift for- from me to you. So don't worry, everything good.' That's why every day I go and say a prayer to her, you know.

Mary also described her larger mission in going through this part of her illness journey. Yansan had never let her down before; she had supported Mary throughout her life and was connected to the entire world of goddesses and spirits that constructed the most sacred entities of her tradition. Mary had her own feelings about how the situation might resolve, but said that "I trust my guts, but my guts put me in bad spots before." Better to ask the Orixás.

Another message came through contact with another spirit and was focused on the connection between her illnesses and the brokenness in the world: "I am using my body to heal the world. And that's why I keep getting this many diseases." From this message, Mary believed that her illness experience had a purpose — a function in her own life ("cleaning myself from bad things that I've done in the past lives") and a function in "healing the world." When she first received this message, she felt that this was a great honor and it was a good thing. She clarified this

"point of view" as one that did not think of the cleaning process as transactional – a lifetime of bad deeds being cleaned by a lifetime of bad illnesses:

> I prefer to think that way. You think, 'Oh, my God, it must be pretty bad (laughs) in the past lives that I have so much that I have to go through.' But they say that it was a different point of view. Maybe the first experience [of cleaning her soul] I pass through really well…

> you don't need religion if you do something bad or if you do something that has a bad energy, you attract things that are bad. I don't believe that what I am experiencing now is because of bad thing. I did in the beginning.

The second religious/spiritual resource she engaged to help her cope with her waiting for a new heart was more self-directed than offered to her following her consultation with Yansan or spirits. Recently, Mary decided to write down more details about what she could remember from her near-death experience during the aneurysm and coma in 2017. She wished to call back up for herself the feelings she had during her near-death experience with the aneurysm to help her sense the meaning of her life more deeply during the wait for her new heart, which is a different kind of near-death experience. She said, "I try to connect. And I'm writing everything [down] to try to remember my mission here." Mary wished to feel more fully and make use of the life's purpose that was revealed to her during her time in the coma, the liminal space between our living world and the world of the spirits. She wrote to return to the world of her aneurysm, the dreamscape of near-death to "see if there is a story there." It was helping her to cope and understand the connectedness of her whole life. Another way in which she said she gained support from remembering her near-death experience was that it "didn't allow myself to be in depression" on a daily basis.

Dealing with Depression and Self-Blame

Mary tried to project a happy image to most who saw her going through her medical challenges. She said:

> Even though I'm sick and I'm about to do a heart transplant, let's see the good part of it. Let's see the cup half full. So I think this is the charity that I can do. So when I show my pictures, yes I am sick, but I am alive. And what is life? It's love.

On her Facebook or GoFundMe page, Mary would be raising money to support her family without her income upon which to rely now. She described her Facebook pictures and attempts to share her happiness:

> l see pictures are happy and nice, and with me and my family. And well, they don't see me sick. And then I start looking at my pictures in the hospital. I said I'm going to do an album, and I noticed that even my pictures in the hospital are happy. I wrote and said, 'Happiness is the best medicine,' And then #gotransplant*.

> Saying that you don't have to be in pain when you are in a hospital, you can be happy. It is important that you are happy because if you are happy, you will get better sooner. And even if you, I don't know, I had that, I think I already told you that my nurse used to say like, 'I mean, you must be in so much pain. How are you making fun? How are you making jokes?' I said, 'If I'm not happy, what's the purpose?'

She believed sharing her image as a happy sick person was an act of charity, to remind people about the important things in life and to find the laughter and love throughout. She also did not want to waste her time with her family being tearful or always just saying "Oh, I'm dying." She continued: "Come on. I'm not dead today. So, this is important in my daily life." Mary believed that the sad or depressed feelings she had were temporary, and that the next day might be better. This was a message she tried to remind herself and she wanted to share with other people who might face similar life journeys with illness.

Although Mary had found a sense of purpose and reasons to persist in joy within her experiences with disease, she was not wholly positive about the challenges she faced with her health. She admitted that when she woke up in the morning, she felt exhausted and sad about the state of her health, unable to return to her career and not feeling positive about how she looked.

> That's why I try to do my morning ritual, and I think it's so important because every time that I wake up and I'm like, 'Oh man, this is tough. I feel tired and I cannot do my things. And I have this huge scar here, and I don't feel pretty. And how come I cannot be working'…I stop and do my meditation. When I connect and I breathe, and I try to don't get anxious. And I talk to Yansan and I say, 'Thank you for one more day. And I'm here.' And I need to be grateful, and I try to feel that in my heart. I can't allow myself to be depressed because I'm here, that's the biggest gift. I'm here one more day.

Despite her morning rituals, Mary admitted that sometimes she experienced life as "in the bottom" emotionally. Occasionally, she didn't feel like doing spiritual things, and felt depressed about her condition and the limitations on her life. She said:

> Because when I am in the bottom, I don't want to pray. I don't want anything, I'm like, 'Don't.' Sometimes. When I am, not too often now, maybe because of the medicine, but before. Then my husband would come, 'Come here. Let's do different [practices]. Let's read the Bible.' I'm like, 'No, get away. I don't want that.' I was like, 'Do it downstairs and send that energy to me.' I don't want to do it.

She saw a psychiatrist and found her mood improving since taking anti-depressants. While she wanted to enjoy fully her time with her daughters, she didn't always feel up to the cause of her spiritual practices. My sense was that with her immediate family, Mary seemed able to temporarily remove the happy exterior she showed to the rest of the world on occasion.

Performing happiness and only expressing her love for life in front of others was a double-edged sword.

Bad Choices, Finding Balance

Mary guided me through her self-reflection about her life choices and how these were connected (or not) to her health conditions over time. Sometimes even something that seemed as if it would be a positive action had a negative effect on her health. For instance, I shared above about how the projection of a happy positive heart patient could be a "double-edged sword" for Mary, not just building her strength and perseverance, but also preventing people from understanding the severity of her illness. First, Mary reflected on the ways that her appearance of happiness could prevent her from addressing problems with her health quickly, misleading a provider, or sometimes deceiving herself. Then, she discussed the choices she had made that were bad for her, and led to medical problems.

Mary would go to the hospital but the hospital would see her happy disposition and not treat her right away. She described the situations in which she had been very sick but putting on a shiny face when she tried to receive care:

> If I get to the hospital, they look at me and I look happy and I look alive, and they said, 'You don't have anything. Go home.' But I know that I'm not feeling good. And then I start, 'Okay, don't send me home because I'm feeling this, and this, and this, and this, and this.' And they said, 'Oh my God. Something is happening. Let's do the exam.'

> And then I start feeling down, and then I get worse. And then I end up staying one day, two days, one week. And then I decide, and I start feeling happy again, and then I'm getting better and now I can go home. I'm like, 'Am I doing this to me again?' And then they find something, they're like, 'Okay. I'm glad we did this exam because you

> have 80% blockage.' Even though I'm feeling positive, sometimes I hide symptoms that are important.

Mary assured me that it was not intentional for her to try to mask her symptoms or only use religious/spiritual practices when she was feeling a physical symptom. The outcome of her self-deception or appearance as healthy was often detrimental to her health or resulted in a longer process of receiving care. Sometimes she delayed because she assumed a heart-related symptom was just her anxiety and the result of a panic attack. She would try to do all the spiritual and meditation practices she had in her toolkit:

> Before I actually go [to the hospital], I'm like, 'I'm feeling good.' I meditate. I put on Chopra—Deepak--and then I do the whole-body scan and the whole chakra balance. And then I do Jin Shin Jyutsu [ancient healing art of harmonizing body with acupressure points]…the meditation, and then I breathe and then I call my babalorixá [priest].
>
> And then I say, 'Okay. Call 9-1-1.'
>
> They come and they take me, and I usually have to stay. And usually there is something [wrong], usually. But the first impression, because I always have 'this positive thing,' is that I'm okay. But then if I start going down, it's hard to pull me. I have to, my mind has to come first as well…My heart, my mindset have to switch.

Mary realized that sometimes her sparkling presentation in the physician's office or to others around her "that she was okay" masked the problems she was experiencing with her health now. She did not use the word "denial" to describe her delays in seeking help for heart symptoms but admitted that she may have prevented the problems if she had agreed to consult her Orixá for a reality check about a decision before her. As an example, she recalled an earlier experience in which she made a bad-faith financial arrangement, and the Orixá did not mince words with her:

> So, I did something, 'I want to go right now and do this.' And this was a bad choice. I knew it was bad, I lied, and I do something bad and something that I knew it was a bad thing. And you do things here [in this life], you get back...So, I understand that.
>
> And the Orixá said to me, 'This is happening because you made a bad choice.'
>
> And I said, 'I know. I had a feeling it was a bad choice.' 'You didn't ask me,' [message from Yansan]. So we have the free will to do whatever, they're [Orixás are] not going to say no, but…

When Mary began bodybuilding, there were some signs that she ignored about whether that hobby might not be the best fit for her or be harmful to her. However, she didn't listen. She said, "I was lifting weight because I wanted to feel pretty. And I wanted to look strong, and nice, and sexy, and I don't need [that], not in this lifetime. This is not my mission. So I was doing for the wrong reasons." However, she did not believe her participation in that activity was in and of itself a bad thing, but if she had consulted her spirit-guides, she would have learned that she had a pre-existing condition that put her at risk for this level of sport and it might have prevented her from having a heart attack and needing a transplant.

In her tradition, she always has a way to consult her spiritual guides and seek clarity through her religion in order to make the best next choices in her life, especially when those choices had such important possible consequences. Right now, for example, she was awaiting a message from her babalorixás, or her pai-de-santo (priest) regarding the decision of whether to use her long-term disability health insurance or to return to work while she awaited the transplant and after it. She had a hunch she should go onto disability benefits, but did not want to do anything without consulting them. The ramifications are critically important, not just for her but for her family since she was the primary financial provider. She said, "So, maybe if I go back to work again, my full salary, but I know that I can also harm my heart. Because I got

stressed. I overwork. I like to talk and talk and talk, and this is not good for me." As in weightlifting, Mary felt she wanted to return to work now for the wrong reasons. On one level, she knew that she wanted to go back "because of pride, because I want to feel important." She believed she could not keep her work or a hobby or even a spiritual practice in balance with other parts of her life; balance had always been a struggle for her. She described the way she moved through extremes:

> My problem is overdoing. And then putting aside many things that are important to me as well. And closing my eyes for things that are important for me as well. So I have things that are like addictions, and work is one of them. So everything that, even water can kill you if it's too much. So that's the problem, I have to find my balance. And some things I am addicted to, so I have to stop drinking.
>
> Wine is good. But if I drink, I drink too much. So, that's the first thing that I had to stop.
>
> Well, first thing was body beauty. It's good for me but I did too much. I wanted to be in competitions. That's too much.
>
> I want to win in competition and be the best. Why? Pride.
>
> I can do body beauty, but now I can't. Why? Because if I get to, I do too much.
>
> I had to stop drinking, was the second thing. Why? Because I did too much. I would drink a bottle of wine a day, and I would drink every day.
>
> And the last thing was, stop working. Why? Overdid it.
>
> I want to be the best, I want to do all. I want to be in magazines, I want to be doing podcasts and being for videos and being in the stage, the biggest stage. So, balance—I can do everything but in balance. Finding the balance is my mission.

Even though she knew she had overindulged, Mary admitted she missed those activities and her job. However, as she had focused on working on herself, she had seen how "balance" continued to be the goal for her, even within her religious practices. For example, if it were up to her alone, she would become a mãe-de-santo (female priest) which was a long process that could not be rushed or pursued by the eager believer alone. "Balance. Why do I want to be a mãe-de-santo?" That's the focus of the first chapter in the book she had been writing about her life, entitled: "Resiliency is my superpower. Is my superpower my kryptonite?" These failures to find balance even in the process of engaging resilience practices worried Mary and were a form of religious/spiritual struggle for her. It seemed to be a lifetime journey, one that religious/spiritual practices were only able to partially solve and through great suffering in the process.

Perhaps, attuned to this tendency to go to the extremes, Mary had received several instances of spiritual guidance to reduce the number of different traditions she was engaging while she was coping with heart failure. On one evening when Mary was doing a Kardecism session, she was instructed by an entity who arrived in her home through mediumship to return to focus on the practices of her "roots", that is, in Umbanda. After her aneurysm, she was told that she needed to go back to the physical practice, dancing and singing of Umbanda rituals to "put everything out to filter that energy and go down, and actually give back to the universe." This important spiritual process helped her in her recovery from the first set of major medical incidents in her life. Then, a year ago, a group of people were engaged in a ritual with a medium at their house, it was brought to her attention that the physical exertion of mediumship and energy-releasing practices was too costly for her body and health. In effect, she had to rely on

mediums and guides other than herself more often and follow the advice to "go back to Umbanda":

> I stop [mediumship and other traditions] about a year ago, because now I'm, like, 'Okay. Too much energy went out and now I have to preserve my energy.' But at this moment, I don't think I am. Sometimes I do feel just connected, and I feel that I want my entities [i.e., Orixás and other spirits]. I want to talk to them. But then they come, and they come, and they say, 'Wait, we are here.' But it's just the mediumship that I kept [trying] to hold on. 'Right now, you pass through this.' But it's hard for me because I want to feel them in me and expressing through me. But I understand that there's time for everything, and the time is not now.

Mary spoke of the longing for her communication with the spirit world as if it were a best friend who had moved away and not left a phone number. Her disconnection from some spiritual practices is something she had chosen, based on instruction from her pai-de-santo (priest) and her own communication with her orixás, but she missed those practices greatly. Perhaps, she is right that even the best of things, such as powerful spiritual gifts—must be taken up in moderation.

Interpretive Summary of Mary

Mary's life story with heart disease included daily connection with the divine through consultation and family spiritual practices that spanned multiple traditions. Mary's illness trajectory had multiple critical events, including a near-death experience that shaped her sense of purpose in life going forward, including how she responded to the more recent critical event in which she received a heart failure diagnosis and was waiting for a heart transplant. Mary's case demonstrated a common theme in the life course of Women of Color with heart disease: soul-stirring events in a person's life that holistically changed the relationship between their religion/spirituality and their health. Mary's near-death experience and her prognosis of five

years to live without a heart transplant all had an influence on her beliefs, spiritual practices, and view of herself.

I learned from Mary how the relationship between religion/spirituality and dealing with heart disease can have a "before" and an "after" due to health crises that shake up the person's entire life in an embodied way. Living a life with heart disease after a crisis, such as a major surgery or receiving a traumatic diagnosis, can require different things from one's religion/spirituality, prompting a shift in belief, practice, or religious community, making some ways of being no longer accessible. In summarizing Mary's case, I find it useful to point out the embodied changes that signal a soul-stirring change had taken place. Some of the shifts are facts Mary described and viewed in herself; others are things that I learned from listening and re-reading her whole text to form a new interpretation.

Before Mary had either the near-death experience or heart failure. There was a "before-before" in which Mary was relatively able-bodied. Mary consulted the Orixás or her babalorixás (priest) for support in making decisions about her life and her health whenever possible. Mary shared in religious/spiritual practices with her children and husband on a weekly basis, which included mediumship, in which Mary helped her family to communicate with the spirit world. Mediumship is a central activity within Kardecism, or Spiritism, and one that Mary really enjoyed. Mary appeared quite confident about receiving a new heart. Mary knew her new heart to be a gift from Yansan and believed she was cleansing the soul through her illness. Recently, she inquired about returning to work, and for spiritual preparation related to procedures and medical decisions before her.

Mary's daily religious/spiritual practices only shifted slightly when she was diagnosed with heart failure and began to have trouble sleeping. She began to ask Yansan, her Orixá, for

help to sleep better. Otherwise, Mary continued to wake up and say prayers of gratitude to Yansan and then also prayed and connected with her before bed. Her weekly religious/spiritual practices with her family changed after her heart failure began to drain her energy more quickly. Before Mary's diagnosis of heart disease, their time around the table in ritual was more extensive. Mary's mediumship provided support for souls of the deceased and received guidance and messages from other entities who showed up. She continued to offer mediumship during the early parts of the pandemic, in order to help the souls who died of COVID in high numbers and sometimes without family or ritual, to go "into the light." Even when Mary was feeling her best, mediumship used a lot of energy and when she had heart failure, together the family decided to stop opening up conversation with the spirits of those who had died. She also had to stop doing other religious and spiritual practices that she loved: capoeira, singing, and other rituals.

At one point, Mary admitted she wanted to be the best at anything she does, from spiritual activities to her job and even the bodybuilding. She couldn't *just* be a marketing professional, she needed to sell the most, be the best at her job. Before the heart failure and then before the near-death experience and brain surgeries, Mary often wanted to go full throttle into an activity and ignore signs of exhaustion. After her heart failure diagnosis, Mary did not want to slow down, but she listened to messages from her priest and from the spirits about what types of choices she needed to make for her health.

Mary's 2017 near-death experience was a soul-stirring event that shook up her whole life. She chose to remain alive at the brink of death, and it became clear to her that she had a purpose and mission in this life: to help heal the world through her body and her illness. When she recounted the experience, it felt peaceful and beautiful. Her family even said she looked

more beautiful and could notice a change in her. Her new mission in life shaped how she viewed her life and her connections with other people. Later when she was diagnosed with heart failure, Mary began to receive messages from Yansan and other spirits regarding her mission. The new mission for her life contained two different functions – a function in her own life ("cleaning myself from bad things that I've done in the past lives") and a function in "healing the world."

From Mary's story of her near-death experience, I formed the impression that she was grateful to have had the opportunity to choose to return to her family and life. Also, she could not recall the specific details of the experience and perhaps, she longed for the feeling she had when she was inside the near-death experience, in the liminal space where she felt weightless and peaceful. Mary wanted to be fully reminded of the purpose she felt. Especially after now being in a very different type of near-death period, which was much slower and anxious, I found that she wanted to call back up the embodied feeling of the near-death experience in order to feel some relief from the stress and the anguish of waiting for her new heart.

I learned from Mary's experience that there was a happy, smiley image of someone waiting for a transplant that Mary wished to share with the world, and sometimes share with me. However, there was also a part of Mary that was sad and even experienced some feelings of guilt or shame around the events leading up to her heart failure. I can imagine that living with heart disease and moving through spiritual rituals every day could support a Woman of Color in bouncing back emotionally each day from the fear and discomfort that accompany these health conditions. Mary was advised to narrow down how many different types of religious practices she was doing and not to perform mediumship any longer. The fullness of Mary's spiritual routine likely served as a good distraction from the waiting process, particularly those practices

that helped other people and deceased souls. So, when she had to do *less* of those practices that were so life-giving (even if taxing), she found herself having more depressive feelings and sadness, even less purpose. Writing might serve as a good replacement for things given up that women with serious health crises have faced.

LIFEWORLDS OF WOMEN OF COLOR WITH HEART DISEASE

The paradigm cases presented in the narratives of Ayo, Carmen and Mary uncovers how religion/spirituality matter to Women of Color who are dealing with heart disease. They engage the reader in the practical world of the participant, in which religion/spirituality, heart disease and daily life mingled and intertwined. These texts were meaningful presentations of ways of being not well-described by other means (Kesselring et al. 2010). Ayo, Carmen and Mary establish concrete patterns of how religious/spiritual beliefs and practices supported them in dealing with heart disease.

Ayo, Carmen and Mary all lived in a world that "can be described, talked about" and revealed. Interpretive phenomenology takes the stance that participant lives are "livable," which is a disability justice stance, even if unintended (Benner, 1994). In a society permeated by ableism, disabled and chronically ill people's lives are livable, and their lived experiences are breathing proof of having purpose and direction as well as belief and practice with a non-curative spirit. At times, their embodied experience included becoming separated them from God or the spirit world, and at other times, it brought them into a more intimate relationship with non-human (at least non-exclusively human) entities of their religion/spirituality. Each case presented how these practices and beliefs changed over time in relation to her illness experience, contextual factors, and what her initial religious/spiritual experiences provoked or nurtured.

Ayo, Carmen and Mary described their heart conditions in religious/spiritual terms, but their life stories were very different from one another. Each had a new kind of story unlike the previous case, and yet, narrative exemplars in the rest of the sample share some types of stories. Reading and rereading the source material and presented cases, each description of their experiences of religion/spirituality and heart disease spoke from full and distinctive lives. Their reflections described ways-of-being; thus, the text makes the most sense as a whole, experiences extending from their own specific social and economic contexts, life histories and connection to different types of support, including medical care, family ties, and religious/spiritual communities.

As Patricia Benner wrote about paradigm cases, "through their different concerns and eyes we more fully see the practical world of both [or all three]. One naturally occurring practical world sheds light on another" (Benner, 1994:114-115). For instance, Ayo's description of her choice of whether to share her illness with others, even if it caused her to be without her oxygen tank at times she needed it, sheds light on how Mary made the choice to display herself as positive and happy, even if it had negative ramifications with providers. Mary's desire to avoid hospitalization by moving herself through several embodied spiritual practices shed light on Carmen's difficulty keeping her medical appointments and leaving it in God's hands to protect her from waiting too long or to remove her from a dangerous situation. In some scenarios, the broader context of the woman's life determined the relationship between the uncertainty, pain or hardship they had in their lives, and the degree to which they wanted or sought out religious/spiritual support. For Mary and Ayo, their religious/spiritual community included their family members, and rituals, practices and beliefs were shared components of daily life for them. In this way, religion/spirituality reflected a cultural context as well, in which

they navigated their disabilities, health problems and personal practices. Carmen felt a lifelong connection to Christianity, but her family relationships did not shape the ways in which she practiced religion/spirituality or used it to deal with her illness. She had to maintain that connection herself, which is much more of a challenge. It also influenced how often she was able to access religious/spiritual practices to cope with her circumstances.

COMMONALITIES AND DIFFERENCES IN PARADIGM CASES

Religious/spiritual beliefs and practices were embedded into the lives of the three paradigm cases in ways that each deserved individual attention. In working with sections of their interview text, each whole individual began a conversation with a few other cases. As if at a cocktail party, they might each listen to what matters to each person, and then, inquire with others, "What would happen in the context were different?" (Kesselring, Chesla and Leonard, 2010; Benner, 1994:114). Despite their differences, there were commonalities and patterns among their experiences and the practices of dealing with heart disease using religion/spirituality.

Religious/Spiritual Experiences

Religious/spiritual experiences were central components of daily life for Ayo, Carmen and Mary, even if *how* these experiences influenced their lives were different case to case. They each grew up with religion/spiritualty in their lives as children. For Ayo, religion/spirituality guided her sense of family connection, strengthened the circles of support around her and her family over the years, surgery after surgery and treatment after treatment. Experiences filled her schedule and connected her to her family, but also were key resources for her when anxiety or uncertainty arose (though not the only resources she took up). The Witness congregation was also a multi-ethnic space in which she planned to be when it was available to her. Mary's

traditions and practices permeated her days from morning until bed. Parts of her life that some participants might not define as religious/spiritual were fully connected to her spirituality. In every area of her life, there was nothing that Umbanda, Kardec/Spiritism, or Candomble did not touch.

In contrast, for Carmen, religion/spirituality seemed both apart from her (leaving it in God's hands) and at her side or on her shoulder, linked to decisions Carmen must make. Carmen watched Joel Osteen's services on television, professing a non-denominational Christianity to over 10 million viewers in the United States weekly. Carmen believed that Joel Osteen's messages were one in which he "kept it real" in the Biblical sense, of staying close to what the Bible said and could be verified verse by verse.

Religious/spiritual practices were embedded in the daily lives of the Women of Color in this research. Common among them was the experience that religion/spirituality was a connection to God (or higher power, spirit, etc) "versus physically going into a church" (¶5 in 201.Kay). Religious/spiritual practices, such as the Bible app reading, was a tool that Kay felt "seen" both by God and by herself: "God is sending me this message. And now like, I'm taking it in and seeing it from like, an outside perspective. And I can move forward with how I see it on the outside and just choose to like, remediate the situation." (¶101 in 201.Kay).

God was participating in their understanding of themselves, and religious/spiritual practices served to further that connection. For instance, Ayo described the contrast between how God understood her even when the people closest to her may not fully understand what it is like to live inside her body with pulmonary arterial hypertension and congenital heart disease. People may not be able to identify with, acknowledge or be supportive to Ayo with her heart symptoms, but "God was as heartbroken as she was." Women described their connection to a

religious/spiritual belief was practiced but also shown to them, especially in critical moments in their illness progression, such as hospitalizations. In times where Ayo said to herself, "Why me?" she felt God be as devastated as her, which was comforting.

Using Religion/Spirituality to Cope

Religious/spiritual experiences were an important part of how Ayo, Carmen and Mary viewed themselves and coped with heart disease. Each of them had multiple health conditions that affect their lives on a daily basis and were life-threatening. Their religious/spiritual experiences were also shaping and being shaped by how much their experiences with heart disease and other medical conditions shaped their lives. For example, when they had serious health complications, such as long hospitalizations or surgeries, they had a large network of people praying for them; this prayer support helped them feel calm and connected them more deeply to their religious/spiritual community.

All three women consulted or reached out to a higher power to deal with a challenging incident related to their disease or their daily lives. They each defined this connection in slightly different ways. Ayo found God offered her tools when she is faced with a hardship so that she can "endure" it. Her God is a background resource that can be relied upon, particularly in times of suffering. Mary worked with her multiple forms of spiritual practices to allow God to flow through her in healing herself and the world. She consulted the orixás or her babalorixás for support in making decisions about whether to return to work, and for spiritual preparation related to procedures and medical decisions before her. Carmen would leave challenges in "God's hands" and hope that she would listen to God's messages for her. Her God was reliable, but she herself was only variably reliable in accepting his help.

Challenges Seeking Help

Carmen, Ayo, and Mary each described ways in which they had difficulty seeking help early enough to make the most use of support for their heart disease symptoms; this reluctance, in turn, would influence how they used religion/spirituality to deal with their heart disease. Ayo said lately she had difficulty feeling connected to God, but she knew that was related to her, and that God had not become distant from her. Mary and Carmen both described problems with addiction or "going to extremes" and making poor choices for their health. For Carmen, she said her history of partying and drug use prevented her from getting the medication she needed in her first hospitalization for her heart disease, and also led to a thyroid condition going untreated for a long time. Mary discussed needing to stop drinking because she could not drink in moderation, part of her overall habit of taking an activity to a point of "overdoing it." She had also been involved in the more extreme exercise habits when training to be a competitive bodybuilder, which led to her diagnosis with heart failure and being informed she needed a heart transplant to survive. Mary and Carmen expressed complex feelings about how their actions might have contributed to their heart condition. Mary resolved to feel and to project a positive, upbeat self-image relying upon her belief that her illness was "healing the world" by moving energy through her body to "clean" and recycle it. Carmen hoped for God to intervene and help her to stabilize.

The concrete patterns in the cases showed the organic ways in which inconsistencies and modifications in religious/spiritual practices emerged over time; some practices stopped satisfying a need, the practical activity became inaccessible, or a religious/spiritual belief was disrupted or disputed. For some participants, religious/spiritual pain was wholly intractable. For others, their religious/spiritual beliefs helped them in one area of their life but shed a light on

other problems. Ayo shared in our third interview that there were (mostly white) members of her congregation who didn't understand how she would be affected by racism there and didn't understand her disability. In Carmen's case, hoping God would help her leave a bad situation, such as when she needed to go to her medical appointment, called up traumatic events in which God pulled her out of a terrifying incident saving her life in the past. Another type of pattern is more challenging to describe, but necessary to unpack, because all three unearthed something similar. Each paradigm case illustrated contradictions regarding her religious/spiritual beliefs and her sense of self. There was a flip-flop, or possibly a spiritual struggle, between hope and trust and lack of feeling in control. To explain, I quote and paraphrase from the cases to show the tension:

> Carmen: God will *have my back. . . if* I don't *forget* to pay attention.
>
> Ayo: "God will *restore me* to paradise eventually" and this is *temporary. . .* this is an *incurable* disease and I *will lose* more abilities over time.
>
> Mary: "I am using my body to heal the world". . . "is my resilience my kryptonite?"

As part of a person-centered research process, the text spoke about the whole case through these kinds of concrete events that helped me to understand simultaneously *how* religious/spiritual beliefs may support and frustrate Women of Color with heart disease in their daily lives. For Ayo, the community played a critical role in grounding her experience as a Jehovah's Witness, even when she had been too relaxed in her personal practices or prayer time for the expectations of her.

In the cases of Ayo, Carmen and Mary, there was some evidence that the ways they have viewed themselves and their disease was strongly connected to their religious/spiritual

experiences. For most participants in this research, religious/spiritual experiences influenced how Women of Color dealt with their heart disease. Also, dealing with heart disease had an influence on their religious/spiritual experiences. Over time, these changes shaped how central or peripheral religion/spirituality was to their illness experience and the support they received. Among the participants, there were common forms of changes that women experienced. I identified three patterns across the sample, which revealed how the bidirectional relationship between religion/spirituality and health changed over time. Changes that took a relational form connected to the ways in which religion/spirituality shifted due to shifts in relationships or ways women were socialized. experiences with religion/spirituality and heart disease co-constituted a way of being that was relational, intersectional and receptive to change. There were practical ways in which these dynamics played out, such as being able to have the stamina to be involved in religious/spiritual leadership work or acts of service within their tradition. Divisions among family members that came about because of dealing with their heart disease and other health conditions also disrupted the religious/spiritual practices of individual women. In addition to the everyday ramifications of having heart disease, participants also found that their religion/spirituality was shaped by crucial medical events, such as near-death experiences, hospitalizations, surgeries, and other incidents. Occasionally, beliefs changed, and as their daily lives changed based on symptoms, uncertainties, awaiting test results, and other factors, their religious/spiritual beliefs and practices shifted to support their new realities. Alternatively, their religion/spirituality became less stable or consistent in their lives.

These paradigm cases helped to develop the three patterns of change that I discuss in greater detail in the following chapter.

CHAPTER 5: DISCUSSION

Overall, this research revealed religious/spiritual practices that shaped participants' experiences of major incidents related to their heart disease and overall health. Through the interpretation of thirteen women's interview texts, I uncovered how religion/spirituality's influences changed over time in a few patterns; namely, patterns of *relational changes, intersectional change, and receptivity to change*. These patterns presented ways of being with important implications for sociology, as well as medicine and religion. Chapters 3 and 4 displayed the religious/spiritual experiences and illness experiences of each woman within her lifeworld. They revealed the strongest illustrations of being in the world, three of which I explored more deeply as paradigm cases. Through deep re-reading and re-writing, as well as comparison among the paradigm cases, I developed a sense of the patterns, which could be meaningful for Women of Color with heart disease, and the providers and religious/spiritual communities who care for them as their illnesses progress. This chapter discusses those patterns in dialogue with other narrative exemplars from the sample, alongside the related literature and theoretical approaches.

Women of Color's experiences with heart disease affect their religion/spirituality over time; likewise, religious/spiritual beliefs, practices and community support influenced how Women of Color dealt with heart disease. Patterns were formed by examining the connection between the lifeworld of the paradigm cases and the analysis of the whole set of interview texts. As the forms of change in the relationship between religion and health took shape, they continued to be developed by tacking back and forth between specific sections of analysis and the texts as well as discussion with the interpretive partners. Ayo, Carmen and Mary, the paradigm cases, illustrated these forms of change and were connected to other narrative

exemplars in the sample that shared similar forms of change. I also developed an interpretation of narratives by paying close attention to what was missing or unsaid in the coded case files. Benner (1994) recommended that interpretations also identify the "silences" or those "stories that we expected to hear and did not." In some cases, participants demonstrated a counterpoint, contrasting experiences that also illustrated the same theme.

Patterns of change were not mutually exclusive, nor are these three exhaustive. Other patterns of ways of being could be present as well. Several participants demonstrated more than one form of change. Each participant demonstrated a greater intensity of one form of change than the others. Most of the participants demonstrated more than one form of change, with relational changes being the most common. The paradigm cases offered the best examples of what qualities such a pattern presented. A counter-point case for each pattern illustrated a distinctly different set of phenomena connected to the same way of being. Other narrative exemplars helped to clarify my interpretation of the pattern and way of being.

"LIVED TIME"

For some, patterns of change were a matter of life circumstances and temporality or what van Manen (1990) also called an existential (i.e., a fundamental theme of being-in-the-world) of "lived time":

> lived time is our temporal way of being in the world—as a young person oriented to an open and beckoning future, or as an elderly person recollecting the past, etc. Here again, when we want to get to know a person we ask about [their] personal life history and where they feel they are going—what their project is in life. The temporal dimensions of past, present and future constitute the horizons of a person's temporal landscape. Whatever I have encountered in my past now sticks to me as memories or as (near) forgotten experiences that somehow leave their traces on my being …and yet, it is true too that the past changes under the pressures and influences of the present (1990:104).

As I interpreted these patterns of how religion/spirituality and illness experiences change over time, "lived time" became an important gauge. In re-reading text, I listened to "what stuck" from a participant's religious/spiritual past and past health crises that helped me to "get to know" her. On occasion, it was the "having-been-ness" (Leonard 1994) or the loss of the important experience that showed me what was most important to the person. In these examples, current religious/spiritual components of her daily life produced a silence, a longing, or a remembrance that made clear that their religious/spiritual experiences were quite central to their view of themselves (per my research questions) because of how they described the lack of that experience in their current life along with the grief or the hope that accompanied that loss or lack. Sometimes, a counterpoint case became important, especially in considering how the results of these research might inform spiritual care for variety of different expressions of a pattern.

Lived Time versus "Dying Time."

Some participants knew that their illness would progress, and they would eventually die from it, or for participants who had waited or were presently waiting for a heart transplant. Is it possible there was a "dying time" as well? Van Manen describes young people with "open, beckoning futures," but for participants in this study, the future was not certain. In their discussions of their unique and bold, physically-demanding hobbies and passion for writing, Ayo and Mary reminded me of an Audre Lorde quote from her diary as she was dying from cancer and continuing to write:

> I want to live the rest of my life, however long or short, with as much sweetness as I can decently manage, loving all the people I love, and doing as much as I can of the work I still have to do. I am going to write fire until it comes out of my ears, my

> eyes, my noseholes—everywhere. Until its every breath I breathe. I'm going to go out like a fucking meteor!

Grasping to life in every direction, they did not give up on themselves or their passion projects, because tomorrow was not guaranteed. If that's not religion/spirituality, what is? In their own and very different ways (and on different illness trajectories), they moved beyond the confines of their traditions. Long-term chronic conditions may require spiritual creativity to cut through anxiety and the fear of death that loomed in our conversations.

PATTERNS OF CHANGE IN RELIGION/SPIRITUALITY AND HEALTH

Relational Change

Religious/spiritual components of daily life were composed of relationships with family, friends, communities, institutions, and God or a higher power. These relationships were aspects of religion/spirituality that were central in how women viewed themselves and how they used religion/spirituality to cope with major health crises, anxiety or other struggles related to their heart disease. They were also subject to change. As relationships shifted, intensified, or fell away, religion/spirituality's influence on a woman's health tended to change as well. Sometimes, these changes were slow and over time, such as Ayo's growing feeling of distance from her congregation. Other times, they happened swiftly, such as Denise's departure from her church after she felt the church turned their backs on her family, following the death of her mother and amid a church leadership change. My findings extended the relational framework of religion and spirituality to Women of Color beyond African American and Judeo-Christian communities, from which the framework was developed (Mattis 2002; Mattis and Jagers 2001). Based on the interpretation of the bidirectional relationship between religious/spiritual experiences and experiences with heart disease, the relational pattern of change takes in consideration the illness trajectory as co-constitutive with changes in religious/spiritual

practices. In other words, relational patterns of change in religion/spirituality and health account for the ways that Women of Color with heart disease navigate important relationships in their lives as their religion/spirituality causes changes to their health, responds to changes in their health, and is subject to further change based on those interactions.

Ayo presented a strong example of a pattern of relational change. Over time, Ayo's religion/spirituality influenced her health and her view of herself in a relational pattern at different ecological levels: through socialization as a Witness, community support during her surgeries, close relationship with her mother, presence of God, and in connection to her broader moral commitments. Ayo's religion/spirituality as a Jehovah's Witness was an important part of her family; and vice-versa, her family was deeply connected to her religion/spirituality. Her baptism symbolized her transition from being a child socialized and raised in a Witness family to adopting and fully embracing her Witness identity as an adult. Her Witness community provided spiritual and practical support to Ayo and her family during periods in which she was recovering from her many surgeries. In contrast, Ayo had become frustrated with some of her congregation members who were reluctant to mask or promoted misinformation related to the vaccines against COVID-19. Because Ayo is a person in that community know to have a vulnerable immune system and serious chronic illness, she was frustrated by fellow congregants' failure to note the potential impact of their personal choices on her health or survival. She had grown in feeling disconnected from her congregation and at times from her relationship to God, due to the people who don't understand her illness.

Ayo's relationship with her mother helped Ayo to make meaning of her medical history and issues of racial/gender discrimination from providers, such as challenges having symptoms treated appropriately. The evolution of their relationship as Ayo grew older and more

independent while living at home caused some strain and frustration for Ayo, particularly during lockdown periods of the pandemic. At times, Ayo's mother took up an "overbearing" presence, from under which Ayo attempted to climb out by asserting her individuality through her hobbies - Tahitian dance, public-speaking, and pursuit of her own medical career. There are multiple potential interpretations of how Ayo balanced the relationship with her congregation and family with her growing commitments to her hobbies, as well as advocacy for other young Women of Color with disabilities. While Ayo did not state this outright, it is possible that pursuing such a variety of passions and working in medicine herself were opportunities for Ayo to assert her independence from her mother and from the somewhat-insulated Jehovah's Witness community. Ayo discussed her development of a social media brand and public speaking as opportunities for her to be financial independent or at least self-sustaining in a few areas of her life, instead of dependent upon her family. Involvement in the disability community and heart disease communities had also been sources of compassion and solidarity when her own religious/spiritual community fell short of her expectations for their understanding of her illness and her identities. Other participants, such as Violet with her international Bible study community, and Cherie, with her TikTok spiritual community, found secondary religious/spiritual communities who fulfilled specific interests of theirs in ways that their primary community did not provide. However, the relational pattern of change takes in consideration the illness trajectory as co-constitutive with changes in religious/spiritual practices.

Another plausible interpretation is that both of Ayo's conditions might progress, limiting her physical activity level, and so, she had been saying yes *now* to activities that were life-giving and gave her a sense of purpose and meaning in her life. As she experienced patterns of

relational change in "lived time," Ayo's perceptions of her future were also shifting, and in some cases narrowing. The latter interpretation echoed through other participants' reflections about their lives, particular among participants in a similar age category as Ayo. For instance, B could not work outside the home, due to her disabilities, but in 2019, as her reading comprehension and writing skills began to return after her second stroke, she decided to go back to school. Many of the "metaphysical" spiritual tools, such as crystals and essential oils, B used helped her to focus, cope with pain and alleviate her anxiety for the purpose of studying for exams:

> [For] one of my online classes, what I did was--there's like this one [holds up an essential oil to the camera], it says for protection, and so I went and sprayed all four corners of room, and then I had like the fluorite with me… And so when I did my test that day-- a small, 10-question one--but I actually passed in, like 100% that day.

> I was not even expecting to get like 100%, but it was a little like 'I remember this, I remember that.' And it was just at that level of peace, like 'Oh, I know this,' you know? And so, since 2014, and then moving back over here from Texas. I feel like there's so much pressure on me. And I wanted to get established, you know? My own place with my daughter and everything. So, when I did that, it kind of was like a calm, where you know, my shoulders now I can actually drop them a little.

B. felt the pressure to get herself established, which motivated her to push herself toward career and financial goals, despite the challenges with her heart failure, stroke recovery and autoimmune disease. Vera felt a similar sense of pressure to earn money, advance her career and gain recognition at work fast, because she did not know when her pulmonary arterial hypertension would become debilitating:

> "My health could start finding like in five years and what am I going to do? I'm going to need oxygen. I'm going to need possibly a heart and lung transplant. How am I going to afford all of this? Do I stay in my job because of my insurance? So, that goes on

> in my head all the time, and I think that's why I pray a lot because I have no answers and I have no one to lean on, but I want everything to be okay."

Vera tried to balance her own desires for a career she enjoyed and the need to continue to earn more to support her family, especially if she were to die from pulmonary arterial hypertension. Research on living with heart failure found that positive life meaning, and religion/spirituality improved depressive symptoms, potentially alleviating anxiety about death as well (Sacco et al. 2014). Sacco, Park, Suresh and Bliss (2014) found that over time social support (in other words, relationships) was an available psychosocial resource, but related to higher levels of anxiety about death. My findings illustrated the supportive aspects of having a sense of meaning in life. The narratives also pointed toward a pressure over time that could cause Women of Color with heart disease to over-exert themselves in a short period of time or need specialized kinds of social support from important relationships in their life to be able to manage the pressure and anxiety about the progression of their illness and concerns about their life's purpose. Ayo, Vera and B were all around the same age (early-to-mid-30s), an age range in which employment and family responsibility are normalized but disability justice frameworks have helped to illustrate that for sick and disabled people are not realistic or sustainable expectations (Piepzna-Samarasinha 2018). Diya and Denise all discussed times in which they over-extended themselves or "didn't slow down" when family care responsibilities were high, and their heart disease symptoms were active. Research on the sense of meaning in life, religion/spirituality, and social support for patients with serious long-term conditions studied older patients. Ayo, Vera and B show how relational patterns of change connected to their life stage, might influence their use of religious/spiritual resources as well as shift how they find meaning in life.

Women of Color with heart disease who believe in God or a higher power placed themselves in relationship with "this Other," experienced changes in the dynamics of the

relationship with God (or higher power) as their illness progressed or as they felt closer or farther from the Other's presence (Mattis and Jagers 2001). In addition to changes in her relationship to her congregation and her mother, Ayo's relationship to God changed over time. When Ayo had a pulmonary embolism, and small infarcts in her brain, she was very anxious in the hospital. She was able to pray and calm herself to get through the long and arduous hospitalization. She found that God brought people to her bedside when she needed relief from her anxiety. However, at the time of our third Interview, she said she had been feeling "distanced from God" and yet, never felt that God distanced Himself from her. She felt God was with her in every challenge she faced, feeling her heartbreak with her as she received discouraging medical news or experienced increased anxiety about the future. My sense was that as her relationships to other people and groups, including her parents, her coworkers, and her congregation changed, she relied more heavily on her personal relationship with God as a stable presence in her life. Ayo spoke passionately about her activities outside of her congregation, such as dance, beauty pageants and working in medical care. However, she did not identify any of these activities as religious or spiritual in and of themselves, possibly given her Witness community's clearly defined set of religious practices. Mattis, et al. (2017) published results of their study on the link between the relationship with God and optimism. They found among African Americans, that the "consistency of God's love" could drive the relationship between subjective religiosity and optimism.

Counterpoint. If I were to consider Sloane as an individual case, I might not immediately recognize the power of the relational changes in her life. When I asked Sloane about how religion/spirituality fit into her life, she immediately spoke of the strong church community she had when she lived in New York City before moving to California. In the past

year, she had not found a church in her new city that she felt would offer her the same kind of community. The lack of a religious home for her and her family was connected to other changes in her relationships at different ecological levels (Mattis and Jagers 2001). With young children, it was going to be difficult for her to become as deeply embedded in the social activities in a new congregation. In the past year, Sloane and her husband had been feeling more disconnected from God and each had stopped praying on a regular schedule. Overall, her religious/spiritual beliefs, practices and congregational life were on the "backburner" for her now, and more at a distance from the practical flow of her daily life or her health. She said, "I still feel strongly about who is really leading our lives and everything, but just going through the day to day, God has, unfortunately just- He's on the periphery now." Before the birth of her second child, Sloane addressed her anxiety about her heart condition through a regular prayer practice. Sloane's heart condition had not been an area of concern for her in the past few years. Simultaneously, she moved away from the religious/spiritual community that had come to encompass her and her husband's social life and major support systems.

The relationship between Sloane's faith and key relationships in her life may have seemed unexciting on their face; yet, when I considered her way of being in relation to other participants whose examples of change are punchier, it is possible to see the power of her situation more clearly. Thirsting for religious/spiritual community long enough can cause a person to lose touch with their desire as other activities or concerns take hold. As a complement to Ayo, Sloane illuminated how patterns of change in religious/spiritual experiences for Women of Color with heart disease may be toned down and connected to ways in which certain relationships have become diminished. Sloane's life is not "secularizing," because her heart condition isn't as much of an issue, or religion is not important to her any longer. That

conclusion would ignore the relational frameworks in which Sloane lived as a religious/spiritual person.

By identifying and interpreting relational patterns of change among Women of Color with heart disease, there was an opportunity to name the ways that the loss of a religious/spiritual community is accompanied by grief and diminished social support, which limits the ways in which otherwise important religious/spiritual beliefs or practices might be used for coping with illness. For Women of Color who might rely upon religion/spirituality as a resource when other resources are unavailable or insufficient, it is important to understand how changes in religion/spirituality disrupt a person's current reality, but also a sense of the future.

The relational pattern of change helped me to interpret the life worlds of both Sloane and Ayo, even if in terms of the power of changes in relationships over time, they differed greatly. Ayo's relational ways of being were also in flux and involved times of disconnecting from religious/spiritual practices, but the changes and varying intensities were more immediate than they were for Sloane. Sloane valued religious/spiritual community support in the past during crises and had a strong Christian view of herself and her health. For Ayo, some of the changes were also still incomplete, the "shape of which we suspect as a yet secret mystery of experiences that lie in store for" her (van Manen 1990:104). In some ways, the relational pattern of change is un-ending. If Sloane or were to face future complications with her heart or health in general, how would those changes shift her religious/spiritual beliefs and practice once again?

Intersectional Change

Inadequate access to health care, experiences of gendered racism, and other forms of adversity were interwoven with one another and with other realities of systemic oppression

among the lives of the Women of Color in this sample. Intersectionality has contributed to and generated key insights into the power relations among race, class and gender, along with other social realities. At its core, it investigates how these realities shape one another, and explains how "power relations influence social relations across diverse societies as well as individual experiences in everyday life (Cho et al. 2013). Women of Color with heart disease faced two different domains of power that over time influenced the relationship between religion/spirituality and health in their lives: (1) "structural domain of power refers to the fundamental structures of social institutions," including housing, employment, and health care, structures in which capitalism and policy shape the options and opportunities for broad populations; and (2) "interpersonal domain of power refers to how individuals experience the convergence of structural, cultural and disciplinary power," including identity categories that assemble social interactions. This second type includes "perceived group membership" which shapes how people encounter bias, including incidents of bias within the first structural domain, causing these two domains to build upon one another. Women of Color with heart disease experienced adversity (such as discrimination in health care, poverty, drug addiction, and losing custody of a child) and unmet basic needs (such as eviction, under-insurance, loss of food stamps). The intersectional pattern of change brings together ways in which power relations shift and are negotiated over time, influencing how religion/spirituality and health change over time.

Within-case, intersectionality can help to name cycles of power relations and risk. Carmen had struggled to hold regular employment, and she had faced long periods of housing precarity during and following a period of drug addiction. During the pandemic, financial and

housing stress increased for Carmen. When stress related to meeting basic needs applied more pressure, it may be more challenging for Women of Color to gain the benefits of religious/spiritual practices that otherwise helped them, because major structural forms of support were lacking. After the first interview, Carmen no longer mentioned her formal connection to a congregation, and the interplay between her religious/spiritual beliefs about God, forgiveness and responsibility became more and more detailed.

Sara Ahmed discusses how racism and racial capitalism cause an "unequal distribution of bodily vulnerabilities." The external resources, such as housing, food, gas, and a job, are those that are needed to support one's living:

> And then, of course you are deemed responsible for your own ill health, for your own failure to look after yourself better. When you refer to structures, to systems, to power relations, to walls, you are assumed to be making others responsible for the situation you have failed to get yourself out of.

Carmen piled a lot of blame and guilt onto herself for her inaction in treating her heart disease, and her painful past. Yet, she had moments where she was clear that she knew she had been trying her best. Ahmed called "you should have tried harder" a violence, a sentencing. Carmen had internalized that sense of shame since her initial heart attack. As the pandemic worsened the basic living conditions for Carmen and her husband, this viewpoint and feeling of stuckness deepened. "You should have tried harder" was the message sent to B. when she lost custody of a child when the court system would not reschedule her court date despite B. having had a stroke just weeks before and still needed the use of IV fluids.

Financial concerns were common among women who lived through an intersectional pattern of change. Carmen's religious/spiritual practices surged and receded based on her

housing instability, financial problems, use of the emergency room for primary and urgent care, and revisiting memories of drug addiction. Her anxiety was so immediate and insurmountable that she found herself "leaving it up to God" to keep her doctor's appointments after months of not showing up to them as scheduled. God's "intervention" in times that she was near people who were a bad influence on her, had on multiple occasions ensured her survival, and it was her prayer that God would do the same for her again, by bringing her out of her immediate financial troubles, inspiring her to have healthier eating habits, and establishing more regular health care. Jewelry-making also doubled as a small business to help her contribute to the household rent, gas, and groceries she shared with her husband who worked outside the home. Vera was the main financial provider for her daughter and this fact was indivisible from her anxiety regarding future symptoms of pulmonary arterial hypertension she anticipated limiting her ability to hold full-time employment. In this pattern, the influence of a religious/spiritual practice over time could only be understood within the broader context of social conditions and inequalities taking place simultaneously and shaping her health and view of herself. For Diane, after leaving her job, she had a period in which she did not have health insurance. She ended up contracting COVID-19 and feared for her life and her ability to provide for herself. Diane did have financial safety net in that she was able to ask a relative for some help paying her mortgage, while she was unable to earn money or look for work.

Ableism influenced Ayo's relationship to her congregation in ways that changed over time. She was willing to tolerate biases or ignorant questions from other members of her congregation, as she had high expectations of them but also a lot of room for grace. However, Ayo drew the line at putting her at risk with poor masking habits and spreading misinformation

about vaccines just before the congregation planned to reopen. Another example of bias against people with chronic illnesses or disability, A'huva lost her job during one of her periods of medical crisis and tried for over a year to get her job back through legal battles.

The COVID-19 Pandemic. During the collection of data for this research, COVID-19 was a consistently unwelcome house guest of a theme, piled atop existing racial disparities in heart disease and quality of care, and new shapes of old adversities related to women's caregiving responsibilities. Unequal social conditions for Women of Color with heart disease existed before the COVID-19 pandemic and shape the broader historical context in which Women of Color with heart disease find themselves seeking out religion/spirituality to cope with the pandemic (George and Park 2017; Garcini et al. 2021). Popular theories of lived religion/spirituality have explored how religious/spiritual practices can inspire resilience and well-being in the face of adversity. The pandemic may serve as a strong example of an intersectional pattern of change influencing the relationship between religion/spirituality and health. Bowleg (2020) writes:

> Intersectionality, a critical theoretical framework, provides an indispensable prism through which to examine the intersectional effects of COVID-19. Intersectionality highlights how power and inequality are structured differently for groups, particularly historically oppressed groups, based on their varied interlocking demographics (e.g., race, ethnicity, gender, class).

> Intersectionality troubles the notion of a collective 'we' and 'all' with the harsh and inconvenient truth that when social injustice and inequality are rife, as they were long before COVID-19, there are only what intersectionality scholar Kimberlé Crenshaw calls 'specific and particular concerns.' (Bowleg 2020)

Chapter 6 addresses the "specific and particular concerns" that Women of Color with heart disease described in their narratives about religious/spiritual coping during the pandemic.

Receptive to Change

In each pattern I observed, the ways in which religion/spirituality was embedded in women's lives was evident in each participant. Women of Color with heart disease changed their religious/spiritual beliefs or practices as well as their involvement with religious/spiritual communities based on new criteria and information presented to them. Some women recalled a situation in which someone or something caused a shift in how they understood themselves religiously/spiritually and how they understood their illness in religious/spiritual terms. Women with heart disease in this sample demonstrated a pattern of receptivity to change and were open to support, interventions and new ideas related to the relationship between their religion/spirituality and their health.

Each participant shared stories in which the relationship between their religious/spiritual beliefs and practices and their heart disease experienced a turning point. Each turning point revealed the malleability of the bidirectional relationship between religious/spiritual practices or beliefs and support in dealing with heart disease. Sometimes, receptivity was a positive pattern in women's lives offering the possibility of better support and fewer feelings of fear or anxiety. At other times, women were susceptible to messages that might cause them further emotional pain or inflict shame. The receptivity I observed in whole cases of individual women illuminated how religious/spiritual influences, even a single statement from a religious or medical professional, expanded its impact over time. For Denise and B., just receiving new instruction on a spiritual practice or a new perspective on a religious belief from people they trusted made a lasting impression that reshaped their practices and beliefs over time. A'huva and Diane both shared a turning point experience in which each of them was called "a miracle" by a

health care provider following their near-death experiences. This label had a sustained effect on their understanding of themselves as people of faith and as survivors of a major heart incident. For A'huva the label of miracle not only had an influence on her view of herself as a spiritual person, it also impacted her choices with regards to cancer treatment this past year. She quickly latched on to non-invasive treatment options for her cancer despite the warnings of her oncologist and the concerns of her family, citing the challenges of her previous chemotherapy treatment as well as her status as a "miracle," extending from the first heart attack she experienced in which a physician told her repeatedly that she was a miracle. For Diane, she was a miracle because she was saved at the last possible moment by her heart transplant. This was evidence that helped her to come out of financial challenges "at the last second," following a period of unemployment in which she contracted COVID-19 and did not have health insurance. At that time, she had had felt significantly more depressed and had difficulty keeping up with her usual meditation practice, which only worsened her struggle at that time. Recalling she was a miracle helped her make sense of this "dark period" in her life, because she felt God once again had saved her just at the last moment from death or ruin.

Diya's narrative exemplified this receptiveness to a new opportunity. She had known something needed to change in her mental health and stress before she would expect it to have ramifications for her physical and heart health as well. Her niece's invitation to go to a non-Hindu meditation retreat broke her out of a religious/spiritual "rut." This experience shifted her priorities with regards to caregiving, overextending herself and caring about what others' thought of her. Often, just as Diya exemplified, Women of Color with heart disease were receptive to a new form of coping based on the invitation from someone they trusted or someone with authority. Cherie responded to the invitation from the spiritual group leader on

TikTok to convene an interfaith meditation group on Zoom, which took off and helped Cherie to flourish during the COVID-19 pandemic.

Becoming receptive to a new way of being was not always connected to positive coping. A'huva had negative experiences with a priest from a Roman Catholic Church, which was the religion of her childhood, in which she requested pastoral care and an anointing of the sick at her home. She felt the priest did not take seriously how ill she was, and therefore, was less responsive to her requests for ritual and prayer. This experience set A'huva apart from a religious/spiritual community important to her during a critical time in her life. A'huva also had the incident in the hospital in which she felt like she could not fall apart or become emotional despite how frightening it was to be hospitalized. A'huva found herself drawn (as Carmen did as well) to Joel Osteen's televised messages, which offered her the message that God could take away her problems if she found the strength to let him. Osteen's message affirmed A'huva's attempts to keep it altogether rather than ask for help. It also became her main source of religious/spiritual sustenance during her last cancer treatment in which she took an alternative food-based approach and did not accept chemotherapy or radiation, due to how intolerable it was. Participants who had strong formalized connections to their religion/spirituality, such as Violet and Ayo, might not be receptive to new practices or beliefs outside of their faith.

Smart Phone Applications – "God is sending me this message". The women's narratives demonstrated how they practiced religion/spirituality in their daily lives, including with the use of a smart phone application (app). These apps became a handheld tool that held a lot of potential among the participants who used it, upon which fears and anxieties could be addressed by searching for relevant articles or reflection questions, as well as giving one's attention to the Scripture of the Day or a prescriptive multi-week program of material. Ayo used apps that were

designed for Jehovah's Witnesses. The phone application that was most frequently described was the Holy Bible App created by a church network that provided daily Scripture and commentary, as well as an index of devotionals and posts about different topics. It follows the Christian liturgical holiday calendar, providing additional content during major holidays, such as Easter and Christmas. The content is frequently updated and previous content can be searched. Kay offered a strong narrative about her use of the app as a practice:

> Religion and spirituality is more, like, my connection with God versus like, physically going into a church capacity or like, going to Mass. So, what I've been doing lately is, like, I have like a Bible study app, and I'll read it like, every day, um, and just kind of, uh, reflect on, you know, what the lecture is…I really liked how it looked like an Instagram story. So it's very relevant, like, to people that are using social media, like it's something to easily easily maneuver.

She identified religion/spirituality as being connected with God through the Bible study app on her phone every day as opposed to going to religious services regularly. She didn't have a reminder on her phone or anything that routinely prompted her to practice in this way, but it was a conscious part of her morning routine: "I really wake up with like a different perspective. And it's just like a grounding practice for me at this point" (06:50 ¶77). The use of the app helped Kay to process things on her mind, and she found that occasionally, the app would be "right on the dot" for what was going on with her at the time, with what she really wanted God's help. For example, after an argument with her partner, she used the app to help her deal with the situation and recounted her mood and sense of her self following the interview:

> I felt seen, in a sense, like, this is God is talking to me, I'm like, this is how God wants me to proceed with this situation. And it just, it felt good, because I could let go that anger. It kind of made me check myself and be like, 'Okay, this is right.' Like this is something I can let go of, and move forward and just bring back peace.

Kay believed when using the app, "God is sending me this message," which then allowed her to take it in as an outside perspective on her situation and move forward to address the problems she was facing. Kay also used other forms of technology to access practices she believed to be spiritual. For instance, she also used Youtube to search for yoga or meditation instruction.

Other participants, including Carmen, Violet and Vera, used the same application as Kay. Vera described the different "Plans" included in the app:

> They have all these topics that you can do. They have a whole section of plans for people with anxiety, but they're all different, like finding peace, seven things the Bible says about anxiety, anxious for nothing, breaking anxiety's grip. There's a whole bunch in that, and then there's new to faith, marriage, dating, work, leadership, prayer, worship, forgiveness, faith. So, they have all these sections and all these different plans per section. I like it. They give you a rundown and then they reference the Bible, how it's connected to the Bible and you read the passage of it and then that's it. It's really easy. (2:60 ¶ 54 in 1201.Vera).

Vera preferred using an app over attending a group bible study because she said often she was concerned that she did not have enough familiarity with the Biblical texts to participate:

> I also do my own Bible study because I don't have a group to go to and I feel really stupid going into a group because I don't know much, because they're so active and I'm just like, 'Oh, okay. Who? What? I don't even understand that sentence. I don't even know what's happening. What are you guys talking about?' But I'm very curious with what the Bible means, what it says. So, I downloaded my own app and there's Bible plans. (2:62 ¶ 8 in 1201.Vera).

Similar to how Ayo used the app to work through depressive feelings and grief over losing her dogs, Vera had been using the app to help her address a life issues. Recently, she was experiencing greater stress at work and feeling undervalued in her current role: "the one that I'm actually reading right now is 'Finding Your Calling Without Changing Your Job.'" She tended to pick up the application when she was in need of hope for a change in her outlook after a particularly unfulfilling experience at work and given her generally realistic outlook ("I'm not really very positive"). She said:

> I'm just hoping for hope. It's just hope. Hope. Maybe what I read will change my mindset. Maybe what I read in the Bible is somewhat of a prayer to God to help me with this feeling and my situation. What am I supposed to do? Do I wait? Do I keep going? Is there a purpose for this? Yeah.

The app was a tool to help interpret the Biblical text, but women felt God was intending what that message meant for them. In cases where the actual app message or scripture was predetermined by the app creators or displayed to the user in a chronological order, God was thought to be sending them that message for a reason. Not every woman who used an app to read Scripture or find relief through looking up their issue in the Bible, used the app as a solitary activity. For example, Violet shared the daily Bible app chronological reading with her husband each morning, whereas other religious/spiritual activities are often things Violet and her husband engage separately.

INTERPRETING THE INTERPRETATION

In the multi-disciplinary space of the study of religion/spirituality and health, there have been challenges in conceptualizing and measuring religion/spirituality and answering questions about the influence of religion/spirituality on health and patient outcomes: (1) *Mixed results* - Some studies demonstrated that religion/spirituality had a negative influence on health outcomes. Others would demonstrate it had a positive influence on health outcomes. (2) *Lack of adequate representation of underserved communities* - Women of Color, particularly women under 60 years old and women who are not Christian, have not been adequately represented in research on religious/spiritual coping and health outcomes. (3) *Contradictory results over time* - It is unclear how and for how long, religious/spiritual experiences change following a critical event such as a hospitalization. In the first chapter, I discussed the so-called "mixed blessings" of incorporating the study of religion/spirituality into research on how Women of Color cope with heart disease over time. The interpretations I offered in this dissertation, presented here as

patterns of change, address these problems by naming the influences of religion/spirituality on health based solely on the perspectives of those who experienced their effects, centering the experiences of Women of Color under 60 years old with a variety of religious/spiritual affiliations (including no formal affiliation), and focusing on how the relationship between religious/spiritual experiences and illness experiences change over time.

To answer the question of "what is really going on" when Women of Color use religion/spirituality to deal with their heart disease is not cryptography. Relational, intersectional and receptive patterns of change help to appreciate the bidirectional relationship between religious/spiritual experiences and illness experiences among Women of Color with heart disease over time. Though surely, these patterns are not a cipher; the patterns may help draw out important relationships, interstructured realities and traumatic health care experiences that build the possibilities for living a life with heart disease as a Woman of Color who is religious or spiritual.

CHAPTER 6: "HOLDING IT TOGETHER," THE COVID-19 FACTOR

"Where is religion going in the twenty-first century? Where is public health going? Are the two on a collision course, or will they open up new pathways for each other?" (Ellen Idler, *Religion as a Social Determinant of Public Health*, 2014*)*

"We're *not* all in this together." (Lisa Bowleg, 2021)

COVID-19 has disrupted community ties and regular social activities, leaving individuals to seek support in new ways. Coping resources for heart disease patients, the structures of individual religious/spiritual communities, and nearly all social relationships have experienced dramatic changes (Garcini et al., 2021). Long-standing structural racism in society (including health care) is also a fundamental cause of racial inequalities during the pandemic (Garcia et al., 2020; Laster Pirtle and Wright, 2021). Social distancing and social isolation, which are preventive measures for COVID-19, increase the risk of cardiovascular symptoms. For Women of Color with heart disease who use religious/spiritual practices to cope with their illness, COVID-19 presents a storm of connected challenges: major life disruptions related to COVID-19, experiences of unequal treatment in medical care, and disruptions to religious/spiritual communities. Given the mental health effects secondary to the COVID-19 pandemic and undue burdens upon women and certain racial/ethnic groups, religion/spirituality may be a relevant source of social support (Collins et al., 2021; Garcini et al., 2021). It is important to understand how individual Women of Color with heart disease used religion/spirituality during the COVID-19 pandemic.

The present analysis may help shine a light on strategies to mitigate the intensity of social effects (e.g., loneliness or anxiety) in a global public health crisis. Yet, unequal social conditions for Women of Color with heart disease existed before the COVID-19 pandemic and shape the broader historical context in which Women of Color with heart disease find

themselves seeking out religion/spirituality to cope with the pandemic (George and Park 2017; Garcini et al. 2021). Popular theories of lived religion/spirituality have explored how religious/spiritual practices can inspire resilience and well-being in the face of adversity. In earlier chapters, I described the embedded religious/spiritual practices of 13 Women of Color with heart disease and how religious/spiritual experiences as well as illness experiences changed as each woman dealt with their illness and other life circumstances. The open-ended interviews offered participants the option to speak for themselves about disruptions caused by the spread and damage of the COVID-19 pandemic. This chapter returns to discuss a few narrative exemplars from the sample, who described their religion/spirituality and health in relation to COVID-19.

I collected data approximately one year into the COVID-19 pandemic. Participants disclosed how contextual factors and critical events during the pandemic connected to life events and narrative moments of their experiences with religion/spirituality and heart disease. They used religious/spiritual resources to cope with the pandemic's effects on their lives as well as how they adapted these resources during a pandemic. Sometimes, adaptations or continued use of religious/spiritual beliefs, practices and community support were adequate to buoy themselves (again). In other cases, the pandemic greatly reduced or blotted out the support a woman had from their religious/spiritual practices or religious/spiritual community.

During the data collections and ongoing process of coding and summarizing data,I also coded for COVID-19 pandemic topics. I created coded case files of participant texts, and interpreted paradigm cases and other examples related to the research questions designed into my dissertation project. Then, I simply noted the relationships between the COVID-19 context and the changes that I observed in religious/spiritual beliefs and practices. In my follow-up

interviews, I asked about the influence of COVID-19, pandemic conditions, lockdowns, health risks, and changes in caregiving responsibilities. However, in many instances, such topics arose organically.

COVID-19, a texturing theme

The COVID-19 pandemic presented as a theme in the interviews consistently. The pandemic textured dialogue about everything from religious/spiritual communities to accessing medical care to supportive relationships. All interview narratives based on the past year and a half, were experiences containing explicit references or contextual features of the pandemic. some experienced changes in religious/spiritual beliefs and practices due to their evolving emotional and social needs during the pandemic, as well as the needs of their family members. For instance, two participants reconfigured their work situations and decided to go on a meditation retreat to help alleviate stress. For other participants, religion/spirituality was an aspect of their lives in which they experienced a loss when religious/spiritual community and practices were no longer available or insufficient to them. Two participants could no longer access their usual spiritual resources due to extended childcare needs in the home. At least four participants revealed they faced new economic pressures due to job losses, family childcare needs and COVID-related risks preventing them from working outside the home. One participant was being evicted at the time of the second interview after both she and her spouse lost their jobs at the start of the pandemic. These pressures challenged women's routine religious/spiritual practices. Participants described how the pandemic disconnected them from existing religious/spiritual relationships or practices; whereas the secondary effects of the pandemic connected some women to new religious/spiritual communities or inspired them to take up new religious/spiritual practices in the absence of previous routines.

Pandemic daily life

The data collection process took place at different stages of intensity in the COVID-19 pandemic globally, nationally and in the state of California where most of the participants lived (except Carmen, who was in Texas). Depending on the participant's social and relational context, the ways in which the pandemic affected the participant's daily life different greatly between participants, and sometimes between interviews with the same participant.

As the participants described their religious/spiritual lives, most described things they did "before" the pandemic and activities that emerged "during" the pandemic. Religious/spiritual experiences changed during the pandemic, and the support the received from their religious/spiritual community also changed shape. In follow-up interviews, some women had returned to previous religious/spiritual commitments in their lives. Others described their religion/spirituality and their daily lives being forever changed – for better or worse.

A Range of Influences

The COVID-19 pandemic influenced the participants' religious/spiritual lives and health along a continuum. Participants described changes in religious/spiritual practices, daily life and coping with their heart disease along a range[DM1] : (1) *flourishing and adapting* – women changed religious/spiritual practices to fit the new patterns of their lives during COVID; (2) *maintaining and longing* – women engaged in lower-satisfaction religious/spiritual activities while waiting for their religious/spiritual communities to return to pre-pandemic activities; and (3) *struggling and scanning*– women experienced higher stress due to family dynamics, economic pressures, and social isolation that led them to search for religious/spiritual reassurance and test fresh sources of religion/spirituality. Individual participants in the study exemplified the qualities in this range through the incidents they explored with me.

Struggling and Scanning

Some participants described themselves as struggling during the pandemic, due to higher stress in their lives during the pandemic. Stress was not only due to the risk of COVID-19 itself. Moreover, they attributed the stress to family dynamics, economic pressures, and social isolation. Twenty-five year old Kay gave birth to her first child during the pandemic, which preceded her first serious incident with her heart. The hospital allowed her partner to visit during the day, but they did not allow overnight visitors: After 5pm, he had to go home. So, the night shift was like, me and her. So it was really scary. There were times where I would cry, like when time was coming for him to leave. Just because it's, like okay, now it was just us two. So it was very worrisome. Prayer was always a part of her life. During the pandemic, it became an essential resource for Kay, as she was often alone or with her child. Sometimes, the struggles connected to the pandemic's role in a participant's life led participants to scan their surroundings for spiritual messages or for fresh sources of religious/spiritual practices. On the day Kay was discharged from her extended hospital stay, she came upon a sign from God that she recounted as spiritual reassurance that her baby would be OK during an anxious time for her.

> When we left, we left on a Sunday. And there were like people outside the hospital that day like clapping every time in, a worker came out, just thanking the essential workers. And then we came out and I guess they asked my boyfriend like what the baby's name was. And so when we came out, they're like, "we're praying for you, Luna! Welcome to the world!" So, her first time out the hospital was a group of people calling her name and clapping for her.

> It was just so beautiful to just have a group of people outside, like welcoming her into the outside of the world, you know, outside of the hospital, and like saying, you know, we're here praying for you. Like it was it was really sweet. And I just, I felt like my baby was, was protected…I felt like a sign like, you know, of like, it's going to be okay…There's just so many things that has to had to align for that to occur.

Kay experienced a major trauma hospitalized to give birth during COVID and the "alignment" of the gathering at the hospital exit arrived at just the right time. She placed a high value on being seen by others and seen by God to help alleviate the pain and uncertainty she experienced after giving birth. Cardiovascular complications brought her back to the hospital not long after her and Luna's discharge. Connecting to God through the "signs" she observed helped her deal with the fear she might not survive.

When the pandemic first hit, Carmen's spouse lost his job, but they were able to stay in their small rental apartment in a city in Texas, because of the regulation preventing landlords from evicting tenants during the pandemic for failure to pay. However, through another method, the landlord was eventually able to remove them from the property. Previously homeless and with a weakened immune system, Carmen was reluctant to return to the shelter system in which her husband had she had previously lived. Carmen moved three times during the year in which we had our conversations due to evictions or non-payment. Carmen's independent jewelry business came to a halt as people stopped buying new pieces of jewelry because they no longer were going out. Before the pandemic, Carmen shared that she felt things were beginning to finally work out for her, following 30 years of trying to beat a drug addiction, and beginning to take better care of her health. Carmen delayed treatment for symptoms of her heart failure, due to the risk of infection at the emergency room where she would normally be seen as she had no health insurance. Also, some days she and her husband had to choose between whether to use their very limted funds on gas, food or a medical appointment. Carmen used the Bible App to help her center herself in the morning and ask God to help her get to her cardiologist or other health appointments and that someone would buy a piece of her jewelry today.

Maintaining and Longing

Some participants used religion/spirituality to offer them hope in dealing with family, caregivers and loved ones within the home. From the participants' perspectives, the pandemic brought new conflicts with family members, especially inside the home. For some participants, these stressors were present prior to the start of the COVID-19 pandemic. Religion/spirituality is a central source of hope during the pandemic, including when "knocking heads" with family and caregivers. Participants described ways in which the pandemic exacerbated stressors at home or with family, even as maintaining those relationships felt essential. The inability to work outside the home and other job-related problems provoked conflict and distress. Religious/spiritual beliefs provided several participants with support to maintain their sense of self during long periods of time inside their homes and in long periods of close contact with family members.

Several women described conflicts or other challenges being at home with family and caregivers all the time during the pandemic. Ayo, 30, lived with her parents and had to stop working due to COVID risks at her medical technician job. Her narrative shows how the pandemic intersected with existing dynamics as a younger adult with a serious medical condition. She struggled to set boundaries with her mother who sought more control over some of Ayo's daily habits during the pandemic. This extract from Ayo's second interview shows her comparing her experience to other "kids" with heart problems and their relationships with their family members:

> I've met other kids who had heart problems and like, you know, we're in and out of hospital all the time, and they're very spoiled and like their whole family revolves around them. Like they're the sun. And while I do feel like I get a lot of attention, I don't feel like I'm the sun. So yeah, but I will say it's pretty good. We have our issues and biggest one is setting boundaries, especially during COVID. Because I did some research because I was struggling. My mom was driving me crazy one day. And

> they're like ‘try setting boundaries.’ So I set boundaries because there's little things that like, we kind of knock heads on. She'll tell me to do something and then, I'm not doing that. And she's like, “You're so stubborn.” I'm like, “So are you -- I got it from you!”

In multiple instances, Ayo discusses her use of phone App resources from her religious/spiritual community to address life and relationship issues in a proactive way. During our second interview, she recounted her attempts to cope with the long periods of time at home with family. Ayo’s parents are her primary caregivers for her routine medical and personal care needs, such as meals and daily nebulizer treatments. However, during the pandemic, she has been spending almost all her time at home, which has led to power struggles and searching for new ways to cope. She describes how she sets boundaries with her mom during COVID, and how COVID exacerbates the ways she is “not treated like I'm 30 years old”:

> Last year during COVID., my mom kept insisting -- she's like, “you got to go to bed early. You need to do this.” She tried to implicate a bedtime. And I was like, “I'm 29, you're not telling me what time to go to bed. Sorry. And like, she would come and just argue her points: “it's better for your health,” and all this stuff. Whatever. And I'm just like, “At this point, you're just wasting your energy, because we're not--I'm not going to do what you're telling me to do right now. That stuff-- that's done. I just -- No.”

Another time in which Ayo “knocked heads” with her mother is regarding Ayo’s return to work at a cardiac ultrasound facility. Her mother does not support her returning to work yet, due to the risks of COVID. In defense of her recent decision to return to work, Ayo reported she is vaccinated, and her supervisor has helped her to take additional precautions working at the clinic. She feels panicked that she was “never gonna be able to go outside again. Like, I'm gonna have to quit my job. And I'm going to be able-bodied, but housebound, because I'll never be able to go outside.” By the third interview, Ayo was back to work despite her mother’s concerns about infections rates in the area. One coworker had resented and began to gossip

about the disability accommodations Ayo received, which allowed her to pass off patients that were known to be infected with COVID-19 to another sonographer. While her primary concern in the first interview was whether she would be able to ever return to working in-person before her illness would incapacitate her, during the final interview, she now questioned whether it was worth it. Inconsistent or apathetic mask usage and the strife among her coworkers made the opportunity to work in the medical field less appealing.

Sloane revealed that online religious/spiritual community was a mixed blessing and she soon dropped off of trying to find a spiritual home for her family via the internet. Her husband and she had not found a congregation on the West coast that was as good a fit for them as their congregation in New York City. On the one hand, the pandemic made it even more challenging to connect locally to religious and spiritual community and form new supportive friendships in her new local geographic area. On the other hand, it made it possible for her to stay connected to her friends from the congregation in New York, and participate in its "Life Group" by text message. The following extract describes her struggle to connect to religious/spiritual community:

> And then we moved to San Francisco. And since then, it's actually been really difficult to find a church community, and we haven't been able to, and then the pandemic happens. And so right now, in terms of like, how [religion/spirituality] play into my life, I think it's really just prayer. Prayer, and then somewhat speaking to my husband about it sometimes --where we think God is leading our lives. And then also, I still keep in touch with my Life Group [from NYC]. So, from there sometimes, you know, we talk about what God's plan for us is, in terms of like, what like, you know, if we're have big decisions coming up or anything like that, and we're sharing with each other and just trying to like, give each other advice. It's very God-centered in that way with that group.

The life group provided a way for Sloane to stay connected to God through a religious/spiritual group, but she reiterated later in the interview that it did not have the same level of positive

influences on her life, wasn't the same as when she was living in New York City before the pandemic. In New York, her social life aside from work colleagues was predominantly members of her religious/spiritual community in her age group. The pandemic caused shifts in religious/spiritual community life from in-person to online that appealed to some participants and hindered others' involvement.

Adapting and Flourishing

Some participants shared memories of the past year in which they changed their religious/spiritual practice routine drastically. A few developed new religious/spiritual practices to support their religious/spiritual beliefs and cope with the stressors during the pandemic. One salient example was a narrative from Diya. Diya shared in a "joint family" household with other relatives who all are members and leaders within the same Hindu temple. Work, family, and religion are closely related within her tight-knit community. Her family ran a hotel franchise, but the pandemic caused staffing issues, leading on one occasion for her to need to clean guest rooms herself in addition to her other responsibilities. These were stressful experiences that would take a toll on Diya's well-being and mental health. She felt depressed for several weeks following the staff problem at the hotel. Earlier in the year, she had been treated for depression following the death of her father. Her religion was a source of inspiration to take care of herself in miserable situations: "somehow we will make it there, he will take care of me. God will take care of me." She made plans to go to a non-Hindu meditation retreat to rest and take better care of herself, after the turbulent times managing hotels during COVID. According to Diya, attending a non-traditional spiritual event was out of the ordinary for her and for other women in her community. She negotiated with her husband to go on the 10-day meditation retreat with her niece who was a volunteer at the retreat center. Her husband, with whom she runs the

business, took some convincing to support her going to the retreat. Diya described the recognition that she had been feeling burnt out: “I think he saw me, that I'm really tired. And I worked really hard for many years. And he realized probably.” An extract from the second interview describes how the retreat experience came together:

> I went with my niece because she's been there before and she was volunteering this time. So she asked me to come and I said normally ten days away is too many for me. I never expected I can go somewhere 10 days, but I told my husband that I really want to go I need a break. I'm tired. And so he said, ‘Okay, it's okay. If you think you feel good, you can go that's okay. Everything will be fine.’

The retreat experience provided a break from the work and family responsibilities, which had intensified during the pandemic. Diya’s typical spiritual practice does not involve long periods of sitting meditation. Her usual meditation practice involves a belief in a role model, or guru, to follow in meditation. The 10-day retreat she attended did not have a guru leading, but she felt she could bring her traditional practice and role model there:

> I realized that whatever I am doing for my religion, I really want to focus. To focus, I need to something different to find out [how]. And so, I realized I really wanted to do a great job, more than what I am doing right now. And it really helped me.

New spiritual practices, such as retreat participation, brought participants into new relationships or reconfigured existing important relationships. Diya also met a fellow retreat attendee, who was a therapist, and asked her for some time to meet individually to share about her depression and ask some questions to get “clarity” about her mood at home and the stress she feels. Diya made a strong bond with the therapist, who continues to check in with her by text message several times a week. Her relationship with her niece deepened after sharing the retreat experience, allowing the two women to share more deeply about losses they had experienced in their family. Diya typically had close relationships with her fifteen household members, but

following her traditions means that she does not share some of her more depressed feelings with those closest to her. Her responsibilities to her family and the temple still take up most of her time, but the time away has inspired her to attend other retreats in the future to reset and focus upon her religion.

Most participants shared memories of the past year in which they searched for new spiritual practices to support their religious/spiritual beliefs and cope with the stressors during the pandemic. For Diya, the retreat experience provided a break from the work and family responsibilities, which had intensified during the pandemic. Diya's regular spiritual practice did not involve long periods of sitting meditation. Her usual meditation practice involves a belief in a role model, or guru, to follow in meditation. The long retreat did not have a guru leading meditation, but she felt she could bring her traditional practice and role model there. "I realized that whatever I am doing for my religion, I really want to focus. To focus, I need to something different to find out [how]. And so, I realized I really wanted to do a great job, more than what I am doing right now. And it really helped me." Diya blended her own traditional practice into the retreat format in order to pursue her religious/spiritual goals and personally honor her own tradition.

Most participants used online resources, such as Zoom and group text messages, to connect with religious/spiritual group activities that might mimic the in-person activities prior to COVID. The integration of online resources helped participants who used them to stay connected to religious/spiritual communities, which were important to them as in-person members prior to the pandemic. Involvement in a religious/spiritual community online required women to adapt their religion/spirituality to respond to a new modality. Violet, 59, with heart

failure, loves praise and worship music. Listening to a full choir was no longer available when the pandemic started. Violet found ways to participate in music ministry in new ways:

> I love music. My husband bought me an acoustic guitar for Mother's Day, or anniversary or something. I think it's Mother's Day. Its been really hard getting lessons, and I finally signed up for some lesson. Then they canceled the class but I am going to learn to play that guitar! I really am. I've been doing some tutorials on Youtube. But I love music. And so, that's another daily thing from him: it is "can you turn it down?" I did love praise, worship music. I love jazz. I love different types of music, too. So that's in my day, for sure. Every day. Yes, yes, indeed.

Violet remained hopeful that the fuller choir at church will come back some day, but in the meantime, she is content to maintaining her connection to music on her own and is inspired to eventually learn to write a song one day.

For some participants, the online resources gave them access to religious/spiritual communities new to them in the past year. Cherie taught herself to use Tiktok, a social media platform with video and interactive content, and found spiritual content creators that connected to her Buddhist faith, even though they were not Buddhist specifically. She dialogued with one creator for almost six months through Tiktok and then, they decided to meet on Zoom. He taught her breathing practices, which are not usually part of her religious/spiritual tradition, which mainly uses chanting practices. Together they decided to host regular Zoom calls on spirituality, in which she is the only Buddhist but among a diverse group of people of Color. She discussed how the "people don't know you from Adam. They just know you through a screen," but are willing to share deeply with one another about mental illness, abuse, and other sensitive topics. Her narrative described a transformation that the online involvement has created in her spiritual life:

> So I'm turning into this individual, that its like unbelievable. I'm about to cry. I'm going through some kind of bigger spiritual awakening in my life. I know I am. But the

> connection that I'm going through [in this group]and the people that I'm connecting with.

According to Cherie, this "awakening" experience would not have taken place without the pandemic's effects on Cherie's daily life and typical community interactions in Buddhism alone. Her religious/spiritual community and overall self-understanding expanded as a result of her online resourcefulness and curiosity during the pandemic.

Cherie described her concerns about her cholesterol as exacerbated by fears about the COVID-19 pandemic. She said:

> This pandemic kind of scared me because then we came to the heart. Because that's all we was hearing was, 'it affect the heart! It affect the heart!' So that kind of scared me and the point there is: OK, you know? That's when I really started to really focus on it [my heart problems and cholesterol] because I felt like okay, I still got one life to live and things to do, so I need to start working on my health.

Solutions to dealing with life in lockdown combined typical religious/spiritual practices with trying to prevent future health problems through lifestyle changes and finding hope in scientific advances. For instance, Ayo discussed the fear of being stuck inside the house forever and said she believes that the "flicker of light at the end of the tunnel – that's all because of vaccines." For several participants, they mentioned praying to God for support in eating healthier, going to doctor's appointments as scheduled, exercising and losing "COVID" weight. Often, participants' COVID-related narratives mirrored the ways in which women in the sample described their religion/spirituality more generally; their religious/spiritual beliefs were incorporated into their health behaviors and other ways of coping with heart disease.

Summary

The present analysis may help shine a light on religious and spiritual strategies to mitigate the intensity of social effects (e.g., loneliness or anxiety) in a global public health

crisis. Unequal social conditions for Women of Color with heart disease preceded the COVID-19 pandemic and shape the broader historical context in which Women of Color with heart disease find themselves seeking out religion/spirituality to cope with the pandemic (George and Park 2017; Garcini et al. 2021). This pandemic investigation into the layers and interactions of disparities and catastrophic global events for individual Women of Color can inform future research efforts to understand the interactions between the COVID pandemic and health disparities. These findings add dimension to how Women of Color with heart disease use religious/spiritual coping resources in their daily lives to mitigate stress and where they might need additional support. Participants in the study described their lives in terms of the relationship between COVID-19 infections and their "high-risk" pre-existing conditions, such as heart disease. Some aspects of the pandemic that changed their daily lives were connected to the social conditions in which they lived prior to the pandemic. Participants who worked outside the home experienced job loss or required medical leaves. Participants who were on disability, in school or worked from home, found their homes were busier during the pandemic and included multi-generational families. Retired participants described less overall daily life disruption due to the pandemic and had more opportunities to pursue adaptive solutions to the losses of religious/spiritual community, or experiment with new religious/spiritual practices. According to the relational framework of religion/spirituality, health disparities are also forms of religious/spiritual suffering (Mattis and Jagers 2001; Laster Pirtle and Wright, 2021). Social solidarity and group resilience are two relational responses to critical life events, such as a global public health crisis. Several participants described ways in which they participated in religious/spiritual community service, serving as Zoom hosts for gatherings (Violet), preparing food for temple events (Diya), feeding the homeless (Mary), and checking in on other people

with multiple medical conditions (Cherie). Such acts of community service are relational religious/spiritual activities specific to the COVID-19 pandemic (Modell and Kardia 2020).

Implications of a COVID Analysis – We're Not All in This Together

> My irritation with the ubiquitous phrase 'We're all in this together' quickly ensued. Although seemingly innocuous and often well intentioned, the phrase reflects an intersectional color and class blinding that functions to obscure the structural inequities that befall Black and other marginalized groups, who bear the harshest and most disproportionate brunt of anything negative or calamitous: HIV/AIDS, hypertension, poverty, diabetes, climate change disasters, unemployment, mass incarceration, and, now, COVID-19.

> 'We are all' is socially distancing to flatten the curve, public health officials tell us. But cognitive, social, physical, and moral distancing from groups marginalized by structural inequality is perpetual (Bowleg 2020)

These findings show how Women of Color with heart disease use religious/spiritual resources to cope with the pandemic's effects on their lives as well as how they adapted these resources during a pandemic may help shine a light on tools to mitigate the intensity of social effects (e.g., loneliness or anxiety) in a global public health crisis. More research is needed to understand the social effects of adapting religious/spiritual coping during a pandemic. For instance, in this sample, Women of Color who adapted their religious/spiritual practices to meet their needs and reached out to form new religious/spiritual relationships had not sustained their new practices for a long period of time. It is also possible that adaptation of religious/spiritual practices is always an ongoing process.

Religion/spirituality became embedded in people's lives through connections to family and loved ones, participation in groups or communities, and making commitments inspired by morals or role models. In a relational framework, religious/spiritual beliefs, practices, and forms of support change as relationships change and critical events in one's life take place. During the

COVID-19 pandemic, religion/spirituality exhibited a complex relationship with other social factors. For instance, some religious groups promoted community precautions, testing and vaccinations, and other religious groups did not adjust their programs to prevent the spread of the virus or openly spread misinformation (Boddie and Park, 2021). Participants in this study found themselves at times in sync with their religious community's regulations, and at times underserved by the resulting programming, and at times, disconnected from their community because of the precautions they needed to take for their health.

Changing pandemic restrictions have changed interpersonal contact in important relationships, interrupted everyday forms of psychosocial support and caused people to delay accessing emergency or routine care for their symptoms (Guzik et al., 2020). US COVID-19 prevention guidelines have changed how people access religion/spiritual practices, support, and communities (Weinberger-Litman et al., 2020). Some religious/spiritual organizations shut down all activities; other groups moved in-person activities to online formats. Congregations that have remained open without instituting any COVID-related precautions or social distancing guidelines in their religious/spiritual communities have received some media and research attention (Boddie & Park, 2021).

Intersectional patterns of change in the relationship between religion/spirituality and health reveal how the COVID-19 pandemic's effects on social conditions and basic resources for people experiencing poverty served to exacerbate an already fragile situation. Religious/spiritual resources, such as the Bible App and prayer, served as a small buffer, but its effects were limited when other forms of support were not present. Among the women who were retired or had significant financial support, they tried out new religious/spiritual practices and used technology to stay connected to their faith communities or access forms of

religious/spiritual support. Women who were sharing space with family twenty-four hours per day due to the pandemic lockdown found themselves providing more caregiving and struggling to maintain their religious/spiritual practices. For women living in poverty or providing financially for children, concerns about finances caused them to take risks with their health to receive care, ride public transit, or work in a densely populated setting, in ways they might not have done if they had the means with which to take additional precautions for their health. The high stress levels for participants, such as Denise, Carmen and Vera, limited how much their religious/spiritual beliefs and practices was a source of resilience. Religious/spiritual communities and leaders should avoid the rhetoric of "we're all in this together," and instead direct attention to the specific needs of disabled people in their congregations and organizations. rather seek out ways to support community members who are dealing with chronic illness and unmet basic needs, such as stable housing. As the shape of the pandemic continues to change for people without heart conditions or other "high-risk" illnesses, the secondary effects of the pandemic will continue to may have longer lasting effects on the religious/spiritual resources available to Women of Color with heart disease. For instance, Ayo's congregation had not yet opened up to in-person meetings in their Kingdom Hall and when it does open, she anticipated having to make difficult decisions about where to be and who to be with, given that some members of the congregation had decided not to be vaccinated or wear their masks.

Modell and Kardia (2020) explored how religion/spirituality may be a "health promoter" during the COVID-19 pandemic as religious organizations may provide hope as well as services to broader communities. For some Women of Color with heart disease, participating in religious/spiritual community online put them in touch with their existing religious/spiritual community more consistently (not having to cancel when they feel sick, because they could hop

on Zoom from bed) and opened up new possibilities of connections with other religious/spiritual groups or groups of other Women of Color over a geographic distance. As COVID-19 shutdowns become a distant memory (for now or forever), maintaining opportunities for people to participate in religious/spiritual community online, will provide Women of Color with heart disease and disabled Women of Color opportunities to continue to connect with religious/spiritual support on a regular basis.

The body of literature on the social and religious/experiences of historically marginalized groups, such as Women of Color, during the pandemic is relatively small and early in its development. This research provided opportunities to understand the intersectional pattern of change that took place for Women of Color with heart disease and their religious/spiritual lives during the pandemic. Invitations to interpret the religious/spiritual experiences of Women of Color "holding it together" during the pandemic provide insights into how religious/spiritual coping may be a protective factor for Women of Color dealing with their heart disease in a public health crisis. This sample of women scratched the surface of how financial stress, housing precarity, reduced access to health care, job loss and other intersectional effects of COVID-19 effectively reduced the effectiveness of women's usual religious/spiritual routines, sent them out to scan for alternatives, or in religious/spiritual struggle. Interpretive phenomenology, the relational framework of religion/spirituality and qualitative research, in general, are poised to contribute observations of the intersectional pattern of change across other populations of underserved communities who practice religion/spirituality.

CHAPTER 7: CONCLUSION

Religion/spirituality continues to be investigated in various disciplines because religion/spirituality matters to people. Another reason it continues to be investigated, is due to how confusing religion/spirituality can be! Whether calling themselves religious or not, most people have a story that involves a belief, ancient or contemporary, or a relationship with a loved one who tethered them or members of their family to a tradition. For Women of Color in the US with heart disease, religion/spirituality may be a coping resource, especially when other resources may have been exhausted (George and Park 2017). I conducted this research to be able to understand how individual Women of Color used religion/spirituality to deal with heart disease on their own terms, and to explore how religious/spiritual experiences and experiences dealing with heart disease shape one another in the lives of Women of Color over time.

Using an interpretive phenomenological design, I investigated these phenomena through multiple interviews with 13 Women of Color and interpreting them as whole cases, as well as developing themes that represent three important patterns of being. My second chapter on methodology summarizes the design of the study overall, including the use of a collaborative coding and analysis process, aided by two religious professionals who served as interpretive partners with me. In this final chapter, I review the major findings of my research and propose implications of this research for the three disciplines I've invoked to understand the lives of the 13 women I interviewed and what aspects of religion/spirituality and health my interpretation presented. Finally, I propose a few potential directions for future research.

SUMMARY OF KEY FINDINGS

This interpretive phenomenological study found that Women of Color with heart disease who consider themselves to be religious/spiritual, use religion/spirituality to deal with a variety

of experiences connected to their disease as well as their daily life, ranging from health crises to everyday impacts of their illness progression. Religion/spirituality interlaced and shaped important relationships, life events and daily routines. In Chapter 3, I presented detailed descriptions of all 13 participants, focused on how their religious/spiritual practices influenced their daily lives and their illness experience over time. Interpretation of the data revealed three patterns of being related to how the connection between religion/spirituality and health changed during participants' lives (Strzempko Butt and Chesla 2007). Each of these patterns had common attributes, namely that in each pattern, the relationship between religion/spirituality and health were embodied, non-dogmatic and unending. Also, they were not mutually exclusive of one another; rather, one pattern was often stronger in a participant's narrative than the other patterns. These patterns reflected three kinds of change to the relationship between religion/spirituality and health:

(1) *Relational Change*: Participants' religious/spiritual relationships were connected to their sense of self, their families, congregations, and other key relationships that changed as they aged or responded to health crises. This pattern was observable in nearly every participant, which I expected based on the relational framework that fed the theoretical approach and design of this research. My findings extended the relational framework of religion and spirituality developed by Jacqueline Mattis to Women of Color beyond African American and Judeo-Christian communities, from which the framework was developed. Almost all participants were socialized into a religious/spiritual community during childhood. Due to important relationship shifts over time, some women felt periods of disconnection from their religious/spiritual practices or a change in their religious/spiritual beliefs. These important relationships included relationships with deities or non-human spiritual entities. A relationship with God/Spirit shaped

some women's reflections on their connections and obligations to their faith and to their health (Mattis, 2001:531). For instance, Ayo's religious/spiritual practices changed over time as she gained independence from her parents and then, as she felt distanced from her congregation when she began to need at-home oxygen 24-hours-a-day. Her relationship to God was a strong connection that provided her an opportunity to periodically reflect on her understanding of herself within her congregation, within her family and within the broader disability community. She built her relationship to the broader disability community through online patient discussion forums and social media platforms. In this pattern of being, belief was not just a static declaration of conviction; for Women of Color with heart disease, religious/spiritual belief in a higher power was active and fluid – a living bond that helped sustain them, when other relationships were not always as affirming or warm.

(2) *Intersectional Change*: Religion/spirituality's influence on health was negotiated within the interwoven realities of access to health care, experiences of gendered racism, and other burdens connected to marginalization. Carmen's religious/spiritual practices surged and receded based on her housing instability, financial problems, use of the emergency room for primary and urgent care, and revisiting memories of drug addiction. Her anxiety was so immediate and insurmountable that she found herself "leaving it up to God" to keep her doctor's appointments after months of not showing up to them as scheduled. God's "intervention" in times that she was near people who were a bad influence on her, had on multiple occasions ensured her survival, and it was her prayer that God would do the same for her again, by bringing her out of her immediate financial troubles, inspiring her to have healthier eating habits, and establishing more regular health care. For Carmen, she also had a spiritual practice of making jewelry, which she used to check out and "be out of her body" and the worries she experienced related to her

basic needs and heart condition. Jewelry-making also doubled as a small business to help her contribute to the household rent, gas, and groceries she shared with her husband who worked outside the home. Financial concerns were common among women experiencing an intersectional pattern of being. For Vera, being the main financial provider for her daughter was indivisible from her anxiety regarding future symptoms of pulmonary arterial hypertension she anticipated limiting her ability to hold full-time employment. In this pattern, the influence of a religious/spiritual practice over time could only be understood within the broader context of social conditions and inequalities taking place simultaneously and shaping her health and view of herself.

(3) *Receptivity to Change*: Women with heart disease in this sample were receptive to support, interventions and new ideas related to the relationship between their religion/spirituality and their health. Each participant shared stories in which the relationship between their religious/spiritual beliefs and practices and their heart disease experienced a turning point. Each turning point revealed the malleability of the bidirectional relationship between religious/spiritual practices or beliefs and support in dealing with heart disease. Sometimes, receptivity was a positive pattern in women's lives offering the possibility of better support and fewer feelings of fear or anxiety. At other times, women were susceptible to messages that might cause them further emotional pain or inflict shame. The receptivity I observed in whole cases of individual women illuminated how religious/spiritual influences, even a single statement from a religious or medical professional, expanded its impact over time. For Denise and B., just receiving new instruction on a spiritual practice or a new perspective on a religious belief from people they trusted made a lasting impression that reshaped their practices and beliefs over time. A'huva and Diane both shared a turning point experience in

which each of them was called “a miracle” by a health care provider following their near death experiences. This label had a sustained effect on their understanding of themselves as people of faith and as survivors of a major heart incident. Recalling they were miracles helped to make sense of this “dark period” in her life, because she felt God once again had saved her just at the last moment from death or ruin.

These three patterns of being reflect important implications from this research for the fields of sociology, medicine and religion, including potential interventions and future investigations. However, they are not mutually exclusive nor are they likely exhaustive as the lives of the women in my study were each richer and more complex than the issues covered in this dissertation. I found that Women of Color with heart disease use religion/spirituality to deal with a variety of experiences connected to their illness as well as their daily life, ranging from health crises to everyday impacts of their illness’s progression. The interplay of religion/spirituality with important relationships, events and life circumstances was dynamic. Interpretive phenomenology provided the opportunity to focus on change and time, because the phenomenological view of the person was one in which time was not “an endless succession of nows.” Instead, each woman’s reflections were a combination of their past (“having-been-ness”) and the future they anticipated, in relation to their priorities and practices at the time of our conversations (Leonard 1994:53-54). By engaging with the issues of time and change, I attempted to understand in fullest relief how each participant viewed themselves in relation to changes in their health, daily life, and religious/spiritual experiences. Through the analysis of three paradigm cases and exemplar narratives contained in the other 10 participants in the sample, I conclude by sharing implications for three fields engaged in this research (sociology, medicine, and religion).

IMPLICATIONS FOR SOCIOLOGY

Sociology as a discipline has always been interested in religion/spirituality and the connection between religion/spirituality and serious health conditions, such as heart disease. Historically, the social sciences considered religion/spirituality to be an optional part of social life, which was thus, less foundational, or reliable than other aspects of experience (Hall, Koenig, and Meador 2004:388). Hall, Koenig, and Meador (2004) describe popular "Enlightenment paradigm approaches" to religion as a "'frosting' that may or may not be applied to the 'vanilla cake' of generic, secular human experience…Religion is thus perceived as a type of knowledge that may be added to the foundation built by reason and empiricism—but because it is not universal, religion is considered both optional and less trustworthy" (Hall, Koenig and Meador, 2004, p. 338). Overall, my dissertation research advocates for the abandonment of the "frosting-and-cake" approach to understanding religion/spirituality in the lives of Women of Color. The theoretical and methodological perspective mobilized in this study promoted an alternative approach, eliciting narratives and participant interpretations of the bidirectional relationship between their illness experience and their religion/spirituality. My investigation probed old paradigms of religion/spirituality in sociology and set out in the direction of understanding Women of Color's experiences on their own terms through eliciting narratives of formative experiences, critical incidents and turning points in their lives.

Results of my study hold implications for sociology and the sociology of health and illness. These findings suggest that the relational framework of religion/spirituality proposed by Mattis and Jagers (2001) extends to the beliefs, practices and communities important to Women of Color who are non-African American and non-Christian. The embeddedness of spirituality and spiritual practice in the lives of the 13 discussed here, revealed the importance of looking at

religion/spirituality and health as an inherently social dynamic. Additionally, sociology of health and illness ought to consider the role of culture in measuring or addressing religion/spirituality's influence on health. Particularly among participants whose religious/spiritual traditions have origins outside the United States, healing and coping with illness includes religio-cultural practices that are embedded in women's lives and may be overlooked or misunderstood by sociologists.

My findings suggest that Women of Color's experiences with racism, sexism, poverty, housing instability, and ableism are interstructured with religious/spiritual experiences. Sociologists concerned with the effects of multiple forms of systemic oppression ought to avail themselves of the important history of religious/spiritual activism in support of equity and justice. They should also understand the ways that systemic oppression, including ableism, are perpetuated in religious/spiritual communities or institutions. These intersectional realities suggest that religious/spiritual beliefs and practices may be obscured, uprooted, or altered for Women of Color due to simultaneous experiences of bias, discrimination or exclusion within their religious/spiritual communities, as well as within their medical care. This research indicates that sociologists should take great care for how categories of religious/spiritual experience and categories of identity and inequalities have intertwined or influenced one another. Disability justice frameworks "understand that all bodies are unique and essential, that all bodies have strengths and needs that must be met" (Patty Berne, in Piepzna-Samarasinha 2018:21). Also, scholars of intersectionality would benefit from including religion/spirituality as areas of investigation along axes of oppression.

Collaboration and Partnership in Research

In general, my conclusion is that religion/spirituality must not be ignored in research of all disciplines that stand to make a difference to Women of Color with heart disease or other complex or chronic medical conditions. The narratives I interpreted and gathered were provocative and reflective of patterns of change worthy of further investigation in medical, sociological and religion research. Still, what I don't know and what went unsaid or unnoticed here may be a key to supporting Women of Color to cope with serious illness. Future research of this kind would benefit from a team-based approach of clinical, pastoral, and sociological leaders with lived cultural knowledge (related to race/ethnicity, nationality and religion/spirituality) from the earliest stages. The support of the interpretive partners in this project was invaluable and yet, underutilized. Women of Color with heart disease themselves should be included as collaborators as much as possible. In this research, interpretive phenomenology relied upon open-ended questions that allowed women in the sample to guide the shape of the results and interpretations. Notably, at least five participants had worked in or were pursuing careers in the medical and health care fields. Future research should consider taking this partnering further and include disability justice movement leaders, Women of Color with heart disease who work in health care, and patient advocates as major stakeholders. Remember the story of the community organizing group throwing down one stake (interpretation) and then soliciting others to help move it around from Chapter 4? This dissertation research further impressed upon me the need for the most affected to throw down the first stake.

IMPLICATIONS FOR MEDICINE

My findings illuminated ways in which Women of Color who have a long-term chronic condition, such as heart disease, used religion/spirituality as a health resource as well as an important set of beliefs and practices operating in their daily lives. Biomedicine has generally considered religious/spiritual concerns to be distinct from the treatment of heart disease and the coping mechanisms for dealing with its symptoms. However, for Women of Color in this sample, religion/spirituality influenced how Women of Color approached their treatment options, dealt with persistent pain, made sense of bad medical news, evaluated their risk and quality of life, and found support during treatments and procedures. My research findings strongly suggest that religion/spirituality's relationship to illness experiences with heart disease changes over time, and is sensitive to the context and other life circumstances taking place in a person's life.

Health care providers have an opportunity to play a role in improving the "psycho-spiritual wellbeing" of Women of Color who are religious/spiritual by being willing to talk about the relational changes that have influenced the connection between their patients' religion/spirituality and health. Prior research has established that there are barriers in the biomedical health care system to addressing religious/spiritual needs, such as personal biases, fear of using the wrong words, or belief that society is secularizing (Büssing and Koenig 2010). My findings with regards to relational patterns of change, for instance, suggest that providers could include religious/spiritual care inquiries in regular conversations about caring for their illness at home and the different kinds of support and resources available to them. Participants, such as Sloane and Vera, demonstrate how asking *once* is not enough, and the overall sample

suggested that it could be fair to assume that when a health crisis takes place, Women of Color should be offered spiritual care and be asked about the meaning of their heart disease for them.

Research on religious beliefs and coping with serious illness suggested that a secure attachment to God (versus insecure attachment) and changes in religious belief could change how well individuals cope with a serious illness (Carney, Park, and Gutierrez 2019; Cassibba et al. 2014). Not all prior research has agreed as to whether strong religious beliefs were positive influences on health, negative or mixed, there was agreement that providers ought to inquire about changes in beliefs of their patients. Specifically, this suggests that providers should ask about the context and relational aspects of a change in belief, which may illuminate religious/spiritual resources that need tending, or critical barriers to accessing religion/spirituality or social support that have health consequences, especially when coping with a chronic illness.

The interpretation of data included in my dissertation revealed how religious/spiritual practices, relationships or beliefs evolved as the participants experienced anxiety or depression, family relationship problems and losses, as well as health emergencies and hospitalizations. My dissertation research revealed how acute medical events, such as hospitalization or surgery, influenced religious/spiritual practices, and that religion/spirituality shaped how Women of Color patients dealt with acute medical events. It has been established that religious/spiritual coping can support the well-being of patients following hospitalization or an acute event in their cardiovascular disease. The protective effects of R/S identity on patient survival have been widely discussed and debated in medical research (Koenig, 2008). However, despite this attention to levels of religiosity and patient outcomes, *how* religious/spiritual beliefs and practices work in the context of underserved patients has not been fully addressed. Health care

providers should consider the increasing religious/spiritual diversity of the US population alongside the growth of communities of Color and immigrant communities for whom religious/spiritual beliefs and practices are embedded and linked to health practices.

As an example of the implications for care approaches for Women of Color with heart disease, integrative medicine's vision of mind-body-spirit in integrative health care ought to fully address the "spirit" component of their approaches especially in relation to their uptake among Women of Color. Embedded and organic religious/spiritual practices are important to Women of Color with chronic conditions, so religious/spiritual practices can play a role in how patients who are Women of Color perceive the goals of integrative medicine. The development of integrative clinical specialties, such as integrative cardiac care, presents an opportunity to learn how religious/spiritual lives and concerns of patients are engaged within the context of conventional and integrative care. Integrative medicine is a fitting arena in which to improve access to resources that cultivate resilience among Women of Color who are dealing with chronic illness.

In this study, religious/spiritual experiences overlapped and connected with the use of integrative medicine and the effectiveness of mind-body-spirit approaches for the women in this sample. Two-thirds of participants in this research described the use of one or more integrative approaches, such as meditation, biofeedback, or yoga, as one of the spiritual activities that helped them to care for themselves and cope with heart disease. Participants described how their coping practices changed over time, especially when treatments or other resources were not accessible to them or did not resolve their distress or pain. They also explained how their religious/spiritual beliefs or important spiritual relationships supported them in changing their health behaviors or seeking out providers and treatments for their symptoms. These findings

show how religious/spiritual experiences activate mind-body practices or support active coping with one's disease. Another implication of my research findings is that because religion/spirituality is often embedded in the lives of Women of Color and plays a role in how they access health care, "organic" religious/spiritual practices likely influence how they experience the spiritual dimensions of integrative approaches or transport their religion/spirituality to their care.

Health Equity

Whole-person health for underserved populations with chronic health conditions, includes religion/spirituality. My interpretive account uncovered ways of being in which religion/spirituality mitigated the intensity of distress or pain of a chronic illness during challenging life circumstances (e.g., the COVID-19 pandemic, job loss or "starting to use oxygen all the time") for Women of Color with heart disease. To challenge health disparities and achieve health equity, it is widely accepted that researchers must address unequal social conditions and systemic forms of exclusion and discrimination in health care (Gee et al. 2012; Sheifer et al. 2000; Williams, Priest, and Anderson 2016). As an antiracist researcher, I was also committed to investigating the cultural resources, R/S experiences, and social conditions that *promote resistance* to the effects of systemic oppression on health. For instance, Women of Color who volunteered for service in a R/S organization explained how these experiences provided them a sense of community and helped them to gain self-advocacy skills. Also, women who had periods of serious illness in which financial stress and family relationship problems also took place, were unable to access adequate support. For two women in this sample, this resulted in losing custody of their child. Health equity is a principle requiring intentional practices and partnerships; investigating the milieu of resources embedded in the

lives of Women of Color with chronic conditions is a vital path toward reducing the science-to-practice gap for integrative medical research seeking equity.

IMPLICATIONS FOR RELIGION

My findings also have messages important for religion and spirituality as institutions and fields of study. Women in my sample described their religious/spiritual practices that activate ways of coping with their illness, which link to their overall worldview or religious/spiritual beliefs. Interpretive phenomenology oriented my investigation into how Women of Color deal with their heart disease using religion/spirituality in order to listen to lived experience on its own terms, with the goal of getting as close to religious/spiritual practices as they are practiced, which are contained in full and complex lives. When I talk to someone about their religion/spirituality solely on the basis of one factor or one point in time, I do not receive the fullness of how religious/spiritual practices, beliefs and community take shape in their lives; more importantly, we don't gather a sense of how those practices, beliefs and community shaped *them.* I believe what I've shared in my discussion is how religion/spirituality as a practice acted upon the embodied experience of illness, and is acted upon by it. Often, the women with whom I spoke were provoked toward religion/spirituality by experiences they had as a person with heart disease. What would it mean for a religious/spiritual professional to ask "how does your religion/spirituality help you cope?" without knowing how an experience disrupted their core understanding of what it means to be human, or morphed their way of life in ways they never expected. Religion/spirituality as a category is not internally consistent, as other social factors or social determinants may be. It is both fragile and sturdy. For instance, sometimes God is a rock. Sometimes, God is absent. The backstory was not always matching the rest of an experience. For the former, it did not always mean that religion/spirituality was

wholly useful and supportive in their lives; for instance, there were narratives in this research sharing how God was a rock, because *no other people were as reliable* as God. For the latter, it may mean that they have relationships that are more like God to them than they have ever known before, regardless of their belief status. Given the impressionable aspects to the relationship between religion/spirituality and health over time, religious/spiritual leaders and professional chaplains have tremendous power as influencers of how Women of Color view themselves in relation to their religion/spirituality and experiences with heart disease. Words, and phrases, such as miracle and God's plan, have lasting effects.

The women in my sample showed that there was a diversity of practice and belief among Women of Color who are religious/spiritual. Women of Color who rely on religion/spirituality when other resources may be exhausted, deserve to be asked better questions about how they use religious/spiritual practices and beliefs. This dissertation is one exploration into creating a space for "really *seeing* practices" as they are, in order for clinicians, chaplains and researchers to know religious/spiritual experience in the fullness of individual women's lives, and for religion/spirituality to be less confounding as a variable and social factor. Notably, participants rarely mentioned the role of a clergyperson or chaplain in their experiences of religious/spiritual coping with heart disease. In fact, there were four examples with only one having a significant active role in the relationship between religion/spirituality and health for the participant. These include: (1) Joel Osteen who I discussed extensively; (2) A'huva's priest who did not follow through on an anointing of the sick nor follow up with pastoral care; (3) assistant pastors in Violet's congregation who participated in the online groups important to her; and (4) Mary's pai-de-santo or babalorixá, who provided rituals for her healing, divination rituals to guide her decision-making and was an actively supportive presence

in her healing journey. Mary's religious and cultural context includes traditions, which historically hold healing from illness and religious experience as interstructured. Healing from illness is not simply a matter of individual concern, but it has broader significance and impact upon the universe, including the spirit world (Olupano). Historically, these traditions and their adherents have faced stigma, xenophobia and exclusion in the United States. Scholars of religion and health have a responsibility to take a culturally humble approach in engaging people from syncretic traditions hailing from Latin America and Africa. Resisting white Christian supremacy has important implications for religion/spirituality and health in this country.

SIGNIFICANCE OF A COVID ANALYSIS

These findings show how Women of Color with heart disease use religious/spiritual resources to cope with the pandemic's effects on their lives as well as how they adapted these resources during a pandemic may help shine a light on tools to mitigate the intensity of social effects (e.g., loneliness or anxiety) in a global public health crisis. More research is needed to understand the social effects of adapting religious/spiritual coping during a pandemic. For instance, in this sample, Women of Color who adapted their religious/spiritual practices to meet their needs and reached out to form new religious/spiritual relationships had not sustained their new practices for a long period of time. It is also possible that frequently, the adaptation of religious/spiritual practices is an ongoing process.

Religion/spirituality became embedded in people's lives through connections to family and loved ones, participation in groups or communities, and making commitments inspired by morals or role models. In a relational framework, religious/spiritual beliefs, practices, and forms of support change as relationships change and critical events in one's life take place. During the

COVID-19 pandemic, religion/spirituality has exhibited a complex relationship with other social factors. For instance, some religious groups have promoted community precautions, testing and vaccinations, and other religious groups did not adjust their programs to prevent the spread of the virus or openly spread misinformation (Boddie and Park, 2021). Participants in this study found themselves at times in sync with their religious community's regulations, at times underserved by the resulting programming, and at times, disconnected from their community because of the precautions they needed to take for their health.

Changing pandemic restrictions changed interpersonal contact in important relationships, interrupted everyday forms of psychosocial support and caused people to delay accessing emergency or routine care for their symptoms (Guzik et al., 2020). US COVID-19 prevention guidelines have changed how people access religion/spiritual practices, support, and communities (Weinberger-Litman et al., 2020). Some religious/spiritual organizations shut down all activities; other groups moved in-person activities to online formats. Congregations that have remained open without instituting any COVID-related precautions or social distancing guidelines in their religious/spiritual communities have received some media and research attention (Boddie & Park, 2021).

Modell and Kardia (2020) explored how religion/spirituality may be a "health promoter" during the COVID-19 pandemic as religious organizations may provide hope as well as services to broader communities. The body of literature on the social and religious/experiences of historically marginalized groups, such as Women of Color, during the pandemic is relatively small and early in its development. Interpretive phenomenology, the relational framework of religion/spirituality and qualitative research, in general, are poised to contribute observations of

the religious/spiritual experiences of Women of Color "holding it together" during the pandemic (Mattis and Jagers 2001; Vera).

At the end of her book, *Paging God: Religion in the Halls of Medicine*, sociologist Wendy Cadge told a story from the end of her ethnographic fieldwork, in which a physician called her up out of the blue after googling for help and finding her contact information. He told her that his child was in a coma and his physician colleagues had exhausted most biomedical options to help the child. His question for Dr. Cadge was if she had thoughts about prayer chains, messages of prayer for the restoration of a person's health spread across broad networks. He wondered if she thought that something like that might help save his child. Holding Cadge's story among accounts from my own ministry and personal experience, led me to wonder: how might interpretations of the interplay of lived religious/spiritual and illness experiences unsettle the categories in which medicine, sociology and religion have thus far attempted to work? If we honor the embeddedness of religion/spirituality within cultures and families, and the multiplicity of religious/spiritual experiences over the life course, the strict demarcation of the sacred from the secular blurs. There's a moral responsibility for scholars, providers, and religious/spiritual leaders to learn the life worlds and patterns of being of people who use religion/spirituality to deal with their chronic condition.

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APPENDIX A. INTERVIEW GUIDE

I am interested in learning from you about your experiences with religion and spirituality. When I say religion and spirituality, I mean all the beliefs, practices or activities that you might call religious or spiritual. I'm also interested in learning about your experience with your heart condition, as well as your health in general and your views of yourself. I'll be asking you some questions about your daily life, and I'll also ask you about meaningful moments in your life, positive or challenging.

Some of the questions I ask you may not feel relevant for your life, and that is perfectly fine. In order to get a fuller understanding of your experiences, I think of it as a curious person turning over many stones in order to see what's there. Some of the stones may uncover a memory or experience for you, and others may not bare anything relevant for you. If it is alright with you, I'd like to start out by asking you about how religion or spirituality fit into your life right now.

1. I realize that some people think of religion or spirituality as part of something organized or connected to a community. But there are many ways to be religious or spiritual, and I am most interested in learning about your personal religious or spiritual experiences as you've lived them. Can you talk to me about how religion or spirituality fits into your life right now?
2. I'd like to start with the past week. In the past week, have you been aware of, or involved in, your religion or spirituality?

[Regarding a specific example]

2.1 Can you tell me a little more about that experience? What happened? And next?

2.2 Had something like this happened before or was it a unique experience? (Or, how often are you aware of/involved in _____?)

[If it was unique]

What else was going on that day? What led you be aware of or involved in _____? How did you feel after the experience? Or, looking back on it today, what do you make of it? Would you do/participate in/believe _____ again? Has it come up in any other ways?

[if a regular occurrence]

How long has _____ been a part of your life? Can you tell me how it first started? Has this experience changed at all over time? Was there a turning point in which _____ changed or you felt a shift? What was going on at that time in your life? Would you say it is different than it was a year ago? Is there an example of a situation in which _____ is different now?

3. Are there religious or spiritual **beliefs** that are important to you?

3.1 (if yes) Can you explain to me what that belief means to you? (repeat with any other beliefs mentioned)

3.2 Can you share with me a recent experience when you've felt _____ strongly?

3.3 Can you tell me about a time in the last year when _____ has been helpful to you? What was going on for you at that time? What happened? And next?

3.4 Has _____ always been important to you? How did you start believing ____?

3.5 Have you every stopped ____? Can you tell me how that happened?

3.6 Can you share with me a time when you felt disconnected from ____? What happened?

3.7 Was there a turning point in which _____ changed or you felt a shift in your belief? What was going on at that time in your life? Can you tell me how that happened?

Are there religious or spiritual **practices** that are important to you?

4.1 (if yes) Can you describe for me how that practice works? What do you do?

4.2 Can you share with me a recent experience when you've practiced _____ more frequently or intensely?

4.3 Can you tell me about a time in the last year when _____ has been helpful to you? What was going on for you at that time? What happened? And next?

4.4 Has _____ always been important to you? How did you start practicing ____?

4.5 Have you every stopped ____? Can you tell me how that happened?

4.6 Can you share with me a time when you felt disconnected from ____? What happened?

4.7 Was there a turning point in which _____ changed or you felt a shift in your practice? What was going on at that time in your life? Can you tell me how that happened?

Are there religious or spiritual **communities** that are important to you?

5.1 (if yes) What does your involvement look like? What do you do or how do you participate in that community?

5.2 Can you share with me a recent experience when you've felt a strong connection to _____? What happened?

5.3 Can you tell me about a time in the last year when _____ has been helpful to you? What was going on for you at that time? What happened? And next?

5.4 Has _____ always been important to you? How did you start to become involved?

5.5. Have you every stopped being involved in ____? Can you tell me how that happened?

5.6 Can you share with me a time when you felt disconnected from ____? What happened?

5.7 Was there a turning point in which _____ changed or you felt a shift in _____? What was going on at that time in your life? Can you tell me how that happened?

My next set of questions shifts topics slightly. I'd like to ask you some general questions about your heart condition and your health. How are you doing with your heart condition right now?

Can you tell me a little bit about how your heart condition started or when you became aware of it?

Can you tell me an example of one of the ways in which your daily life has changed while you've had heart disease? Since you were first diagnosed?

(if applicable) What about since the last major incident with your heart?

How would you describe your mood or how you've been feeling emotionally in the past month? In the past year?

How's the rest of your health today, generally speaking?

[if follow-up interview] Have there been any major changes in your health since we last talked?

Looking at your daily life overall, would you say there is an experience you've had dealing with your heart condition that stands out the most to you?

7.1 What happened?

7.2 Who (or what) was most helpful to you in getting through the experience? Who or what was unhelpful? Or, was there anyone that you expected help from who didn't provide support to you at that time?

7.3 Were there any turning points in this experience where you felt a shift in how you were feeling or thinking about your heart disease?

7.4 Is that experience at all different now from when you were first diagnosed with your condition? How about in the last year?

7.5 Did you use your religious or spiritual [belief/practice/community] during that experience? Can you explain how that worked?

I'm interested in the ways your religion or spirituality supports you in dealing with your heart condition, as well as the ways your religion or spirituality has changed while you've been dealing with this condition. Have you had any recent experiences in which you felt support in dealing with your condition from your religion or spirituality?

8.1 [if no]

8.1.1 Have any of the things we talked about before [cite examples] offered you support for your health condition? (if yes, move on to "if yes" below; if still no, ask questions in next bullets)

8.1.2 Has religion or spirituality had another kind of role in relation to your heart condition? Or how would you describe the connection?

8.1.3 Is there an example of something else or someone in your daily life who supports you in dealing with your heart condition?

8.2 [if yes]

8.2.1 Can you share an example with me?

8.2.2 What about that experience helped you regarding your heart condition?

8.2.3 Did you notice a change in your health or heart condition from taking part in _____?

I'd now like to follow-up with you about some of the other experiences we talked about earlier (or last time). Is there a recent time when [name of spiritual/religious experience from earlier] helped you cope with heart disease?

Please tell me the story of what happened.

9.1 How would you describe your health at that time?

9.2 What was going on for you that day or at that time? What happened? And after that?

9.3 Were there any turning points in this experience where you felt a shift in how you were feeling or thinking about your heart disease?

9.4 Who (or what) was most helpful to you in getting through the experience? Who or what was unhelpful? Or, was there anyone that you expected help from who didn't provide support to you at that time?

9.5 Were there any turning points in this experience where you felt a shift in how you were feeling or thinking about the [religious or spiritual practice/belief/community] itself?

9.6 Looking back on that experience now, is there anything you would do differently?

9.7 Is there anything in particular that you learned by going through that experience?

9.8 Has your experience with [religious or spiritual belief/practice/community] changed since that experience? Please share an example.

9.9 Is that experience at all different now from when you were first diagnosed with your condition? How about in the last year? Is there another example that comes to mind you could share with me?

9.10 Are there other religious or spiritual beliefs/practices/community that are helping you cope? [repeat bulleted questions above with new example]

I have a few questions about religion and spirituality during difficult times in your life (maybe the ones we talked about or new ones that come to mind).

10.1 Can you tell me about a difficult experience in which your religious or spiritual belief was especially important to you?

10.1.1 (If yes) What happened? How did you rely on your belief in _____? Or, how did it help you get through that experience?

10.1.2 (if no) Is there a time in your life when you relied upon your belief to get you through something difficult?

10.1.3 (if previous example from Q.3 is not mentioned) in the story) What about ____ that we talked about before, was that belief present or important to you during this difficult experience?

10.2 Can you tell me about a difficult experience in which your religious or spiritual practices were especially important to you?

10.2.1 (If yes) What happened? How did you rely on your practice of _____? Or, how did it help you get through that experience?

10.2.2 (if no) Is there a time in your life when you relied upon your practice to get you through something difficult?

10.2.3 (if previous example from Q.4 is not mentioned) What about ____ that we talked about before? Was that practice present or important to you during this difficult experience?

10.3 Can you tell me about a difficult experience in which your religious or spiritual community was especially important to you?

10.3.1 (If yes) What happened? How did you rely on your community? Or, how did it/they help you get through that experience?

10.3.2 (if no) Is there a time in your life when you relied upon your community to get you through something difficult?

10.3.3 (if previous example from Q.5 is not mentioned) in the story) What about ____ that we talked about before, was that community present or important to you during this difficult experience?

10.4 Are there other relationships or communities that get you through challenging or difficult times?

The next few questions are turning over a couple more stones to try to get a sense of all the ways religion/spirituality is a part of your life. Has there been a there a time that you felt disconnected from your religious or spiritual community because of your condition? Is there an experience that exemplifies that for you? Can you tell me more about it? At the time, how did you feel about this? What about now - how do you feel about that experience now?

How about a time you felt disconnected from your belief _____?

11.2 Or, how about a time you felt disconnected from your practice of _____?

Has there been a time that you felt a stronger connection to your religious or spiritual community because of your heart condition? Is there an experience that exemplifies that for you? Can you tell me more about it? At the time, how did you feel about this? What about now - how do you feel about that experience now?

[follow up question of community with examples of beliefs or practices] How about a time you felt your belief _____ more strongly?

Or, how about a time your practice of _____ became more passionate or important in your daily life?

I'm also very interested in how dealing with heart disease may have shaped or changed your religion and spirituality. Would you say having heart disease changed the way you practice _____? (believe _____, participate in _____).

13.1 Has there been an experience with your heart disease that exemplifies that shift? What happened? Had you had any other experiences with _____ quite like that?

13.2 Was there a turning point in this experience where you felt a shift in how you were feeling or thinking about your religion or spirituality?

13.3 Would you say this change made a difference in your health? Is it a pleasing change? Or, more unsatisfying? Please share an example.

13.4 Did the shift in _____ make a difference in how you felt or thought about your disease? Has that change lasted? How would you describe how you feel about ____ now as opposed to _____?

13.5 What about a difference in your religion or spirituality overall? Has the change in _____ made a difference overall in your daily life as a spiritual or religious person? Is it a pleasing change? Or, more unsatisfying? Please share an example.

13.6 As you think back on this experience now, is there anything you would do differently? Are there religious or spiritual things you did before you had heart disease that you no longer do? How did it stop?

14.1 Looking back at the last time you did ____: What was going on that day? Was the change in _____ sudden or gradual? Please tell me all you can about what that was like.

14.2 Would you say that stopping (or losing) _____ made a difference in your health? Is it a pleasing change? Or, more unsatisfying? Please share an example.

14.3 Did stopping (or losing) _____ make a difference in how you felt or thought about your disease? Has that quality lasted or do you feel the same way now? How would you describe how you feel about ____ now as opposed to _____?

14.4 What about a difference in your religion or spirituality overall? Has stopping (or losing) _____ made a difference overall in your daily life as a spiritual or religious person? Is it a pleasing change? Or, more unsatisfying? Please share an example.

14.5 As you think back on the time you did ____, is there anything you would do differently? Is there anything that would have made it possible for you to continue _____?

Has there been a time when you felt that the support from your religion/spirituality was lacking? Or, just not quite right for what you needed? Can you tell me more about that?

15.1 Did the lack of feeling supported from _____ come on suddenly or gradual? Has that quality lasted, or in other words, do you feel the same way now? Please tell me all you can about what that was like.

15.2 Would you say that this lack of support from _____ made a difference in your health? How about with your heart condition? Please share an example.

15.3 Did the lack of support from _____ make a difference in how you felt or thought about your disease? Has that quality lasted, or in other words, do you feel the same way now? How would you describe how you feel about ____ now as opposed to when you received the right kind of support?

15.4 What about a difference in how you felt about religion or spirituality overall? Has that lack of support from _____ made a difference overall in your daily religious or spiritual life? Please share an example.

15.5 As you think back on your relationship to _____, is there anything you would do differently? Is there something you'd ask for or you wish for? Is there anything that would have made it possible for you to get support from _____?

16. Has your religious or spiritual community (or practice or belief) changed in any other ways due to your heart condition? How about in terms of other health issues? Please share an example.

17. Has your religion or spirituality affected your health or how you've dealt with your heart disease in any other ways? Please share an example.
18. Is there anything you wish other people in your life would understand about how you use _____ to cope with your heart disease?
19. Is there anything you wish people in your religious/spiritual community would understand about your heart disease?
20. We've gone through all the questions I brought with me, but I wonder if there is. Is there anything important that we didn't cover or you feel we missed that you would like to discuss?

APPENDIX B. SAMPLE CHARACTERISTICS

Table 1. Selected Results from Demographic and Health Questionnaire					
Name	**Age**	**Race/ Ethnicity**	**Level of Religiosity**	**Self-Identified Health Status**	**Years Since Diagnosis**
Kay	25	Latina, Salvadoran	Somewhat	Very Good	26 years ago
Violet	59	—	Very religious	Good	4 years ago
Ayo	30	Black	Somewhat religious	Good	27 years ago
Sloane	37	Asian	Somewhat religious	Good	5 years ago
B.	31	Hispanic	Only a little religious	Fair	7 years ago
Diya	54	—	Extremely religious	Very Good	47 years ago
Carmen	57	African America	Very religious	Poor	4 years ago
A'huva	55	Person of Color	Somewhat religious	Very Good	7 years ago
Vera	38	Filipino American	Somewhat non-religious	Excellent	13 years ago
Diane	50	Hispanic	Somewhat non-religious	Very Good	21 years ago
Mary	43	White, Latina	Very religious	Poor	2 years ago
Denise	54	Black	Only a little religious	Poor	2 years ago
Cherie	57	Black American	Extremely religious	Good	7 years ago

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