Exploring meaningful experiences of black women with HIV: a qualitative study of relational care practices and spirituality

Cloy, Cherita Yvonne

http://hdl.handle.net/2144/19724

Boston University
EXPLORING MEANINGFUL EXPERIENCES OF BLACK WOMEN WITH HIV: 
A QUALITATIVE STUDY OF RELATIONAL CARE PRACTICES AND 
SPIRITUALITY 

by 

CHERITA YVONNE JOHNSON CLOY 

B.A., University of Central Florida, 2002 
M.T.S., Vanderbilt University Divinity School, 2004 

Submitted in partial fulfillment of the 
requirements for the degree of 

Doctor of Philosophy 
2016
Approved by

First Reader

Mary Elizabeth Moore, Ph.D.
Professor of Theology and Education

Second Reader

Steven Sandage, Ph.D.
Albert and Jessie Danielsen Professor of Psychology of Religion and Theology
To my grandmothers and great-grandmothers. Altamese Martin, Carrie Boyd, Mozell Johnson, and Emma Hanible.

To everyone living with HIV and the people who love you.
ACKNOWLEDGMENTS

I would like to acknowledge many people who offered consistent support and encouragement to make this project possible. I am grateful to The Albert and Jessie Danielsen Institute at Boston University – board of directors, private donors, senior clinicians, faculty, and staff – for their financial and caring support throughout my doctoral program. Appreciation is due to members of the African Methodist Episcopal Church (AMEC) not only for monetary gifts but for instilling in me values of speaking the truth in love, even when unpopular.

I owe a very special thank you to my readers, Drs. Mary Elizabeth Moore and Steven Sandage. They were extremely reassuring, diligent, and confident about this project’s success. Also, I am thankful for the members of my dissertation committee for their unique perspectives and encouragement, Drs. George Stavros, Robert A. Hill, and Theodore Hickman-Maynard.

I am grateful to colleagues throughout the Boston University (BU) community, who offered inspiration and friendship – the Counseling Psychology and Religion faculty, alumni of the Counseling Psychology and Religion Program, Marsh Chapel members, Residence Life staff, the Sexual Assault Response and Prevention (SARP) Center staff, and the leadership of the Graduate Division of Religious Studies. For unwavering support, advice, and mentorship, I thank Sharon Broder, Kenneth Douglass, Gail Doherty, Juan Cloy, and Charlene Greene; Drs. Chris Schlauch, Carole Bohn, George Stavros, Phillis Sheppard, Lynda Morris Parham, Asha Ragin, Anjulet Tucker, Pauline Jennett, Cristian Onofrei, and Yoo Yun Cho Chang.
I am honored to have a beautiful family of support. Beginning with my ancestors, I am humbled by their wisdom and comfort. I owe special thanks to my grandparents, many aunts, uncles, cousins, church family members, and many friends for contributing to my education and overall upbringing.

Most importantly, this dissertation would not have been possible without the prayers of my amazingly patient family, who not only support my academic ambitions but support my love for God and personal expressions of faith. They are my husband, Charles Cloy; my son, Charles Cloy II; my sister, Carrie Johnson; my parents, Reginald and Jeannette Johnson; my brother, sister-in-law, and nephew, Reginald, Jr., Alecia, and Reginald Johnson III, and my best friend, Odia Riche.
EXPLORING MEANINGFUL EXPERIENCES OF BLACK WOMEN WITH HIV:
A QUALITATIVE STUDY OF RELATIONAL CARE PRACTICES AND
SPIRITUALITY

CHERITA YVONNE JOHNSON CLOY

Boston University Graduate School of Arts and Sciences, 2016

Major Professor: Mary Elizabeth Moore, Professor of Theology and Education

ABSTRACT

Black women living with HIV share a common history of oppression and marginalization as people of African descent, as women, and as individuals living with HIV. The purpose of this study is to explore meaningful and health-giving relationships of Black women living with HIV in Massachusetts, a largely marginalized and invisible group of people, and to discover the relational experiences that they identify as contributing to their psychological and spiritual well-being. The method includes a literature review of therapeutic approaches drawn from medical science, psychology, and Black feminism. The medical literature in nursing and community health care reveals the value of holistic approaches to care for Black women with HIV, especially care that affirms the women’s strengths and internal resources, including spiritual life. The psychotherapeutic and Black feminist/womanist literature reveals the value of attending to Black women’s experience and trusted relationships. The research method of this dissertation also includes a qualitative study with seventeen self-identified Black women who are HIV-positive, with varied religious and spiritual beliefs, from the Boston area, using semi-structured interviews to elicit their experiences. Drawing on principles of
grounded theory and an ethogenic approach to analysis, the results reveal that participants value relationships that offer institutional support and intimate support. Such relationships that offer institutional support are: relationship with support groups facilitated by health clinic staff; relationship with trustworthy, accessible, skilled medical caregivers; and relationship with medication and medication providers. The relationships that offer intimate support are: relationship with comfortable spaces and special people, like homes and family members; relationship with self; and relationship with divinity, named in diverse ways. The study concludes with the recommendation that community leaders, medical professionals, and psychotherapists improve their expertise in relational care, especially the forms of care that Black women living with HIV name as meaningful to their psychological and spiritual well-being.
# TABLE OF CONTENTS

ABSTRACT ................................................................................................................... vii

TABLE OF CONTENTS ................................................................................................ ix

LIST OF ABBREVIATIONS .......................................................................................... xii

GLOSSARY ..................................................................................................................... xiii

CHAPTER 1  INTRODUCTION ...................................................................................... 1

  Background of the Problem ..................................................................................... 1
  Statement of the Problem ......................................................................................... 3
  Purpose of Exploratory Study .................................................................................. 6
  Research Questions .................................................................................................... 7
  Context and Significance .......................................................................................... 8
  Conclusion .................................................................................................................. 13

CHAPTER 2  METHODS: STUDY OF BLACK WOMEN LIVING WITH HIV 15

  Historical Perspective of AIDS in the U.S. ............................................................ 15
  Personal Narrative and Social Location of Researcher ........................................... 20
  Assumptions .............................................................................................................. 23
  Study Design ............................................................................................................ 28
  Conclusion .................................................................................................................. 36

CHAPTER 3  CARING FOR BLACK WOMEN WITH HIV ...................................... 37

  Current State of Care with People Living with HIV .............................................. 38
  Current State of Care from Community-based Organizations ............................. 42
  Stigma ....................................................................................................................... 50
Need for Holistic Health Care................................................................. 51
Integration of Holistic and Traditional Care........................................ 54
Care and Black Women Living with HIV............................................. 56
CHAPTER 4 WHAT IS RELATIONAL CARE?........................................... 58
  Relational Theories from a Psychosocial Perspective............................. 59
  Tell my Story: Black Feminism and Relational Psychotherapy............... 68
CHAPTER 5 RESULTS: RELATIONSHIPS REVEALED............................... 80
  Restatement of Research Goals .......................................................... 80
  Relationships that Offer Institutional Support .................................... 81
  Relationships that Offer Intimate Support ......................................... 89
CHAPTER 6 DISCUSSION AND CONCLUSION: THRIVING BLACK
  WOMEN LIVING WITH HIV ............................................................... 106
    Overview .......................................................................................... 106
    Relationships that Offer Institutional Support .................................... 107
    Relationships that Offer Intimate Support ......................................... 117
    Final Thoughts on Limitations and Recommendations ...................... 123
Appendix A ......................................................................................... 126
  Request to Recruit Email ................................................................... 126
APPENDIX B ..................................................................................... 127
  Informed Consent .............................................................................. 127
APPENDIX C ..................................................................................... 130
  Semi-structured Interview Questions ............................................... 130
Appendix D .......................................................................................................................... 133
Debriefing Protocol .......................................................................................................... 133
BIBLIOGRAPHY ................................................................................................................ 134
CURRICULUM VITAE ......................................................................................................... 165
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>ART/ARVs</td>
<td>Antiretroviral therapy/Antiretrovirals</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>ASO</td>
<td>AIDS service organization</td>
</tr>
<tr>
<td>BFT</td>
<td>Black Feminist Thought</td>
</tr>
<tr>
<td>BWH</td>
<td>Black women living with HIV</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organization</td>
</tr>
<tr>
<td>CDC</td>
<td>Center for Disease Control and Prevention</td>
</tr>
<tr>
<td>CHC</td>
<td>Community health center</td>
</tr>
<tr>
<td>PH</td>
<td>People living with HIV</td>
</tr>
</tbody>
</table>
GLOSSARY

AIDS. Auto immunodeficiency syndrome is an illness caused by the human immunodeficiency virus (HIV). AIDS is late or end stage HIV (HIV+ level three).

Black women. In this dissertation, the term refers to women of African descent.

Care. Care is the practice of offering compassionate help and a comforting presence.

HIV. Human immunodeficiency virus is the virus that leads to AIDS, attacking a person’s immune system, “specifically the CD4 cells, often called T cells” needed to fight infections (US Centers for Disease Control and Prevention [CDC], 2016, para. 1).

Communities infected and affected by HIV strongly encourage the use of person-centered terminology that is specific to the appropriate context and sensitive to the way individuals self-identify. Here are examples based on their recommendations: a person with AIDS diagnosis, people living with HIV, Black women with HIV, or Black women living with HIV (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2015; Wojciechowicz & Lynn, 2015).

Community health clinics (CHC). Community health clinics are institutions that provide comprehensive health services. In this dissertation, the term includes organizations identified as community health clinics, community health centers, and hospital departments.

Spirituality. An awareness of meaningful connections (with oneself, other individuals, the natural world, and/or the holy and sacred) that promotes growth and serenity. Spirituality is an experience of the mystical or the profound that has many meanings. These definitions are close to those of Mattis (2000) and Newlin, Knafl, and Melkus
(2002), researchers who examined common domains of spirituality articulated by African Americans. For example, spirituality can be the blend of peace, love, and hope; a journey of purposeful living; intimate connectedness to self, others, and divinity; attention to the existence of others; and the process of receiving kindness and enduring adversity. I will focus primarily on the descriptions of spirituality offered by the study participants, which are generally deeply personal, varied, and challenging for the interviewees to put into words.
CHAPTER 1
INTRODUCTION

When I walked in this door and got tested, I knew the results. I knew the results. I knew it. I had already known I was HIV positive. When he called me on back and my medical case manager to this day, when he called me and told me, “You are positive,” he’s never left my side. He’s stayed with me from the day he told me in 1992 to 2014. Him and I have grown together and I’ve never wavered. I’ve cried, I was in pain, I was angry. I was so angry. How at this age? What are you thinking? Are you sure? He said, “There’s no way around it, you’re HIV positive. But there is [sic] things you can do to live longer and to be here for your children.” (Erica1)

The day I met Erica, she seemed eager to talk and to share her story of how she lives with HIV. Her experience of thinking that her life was over, or at least limited, after receiving the diagnosis was a common theme among all of the Black women living with HIV (BWH) whom I interviewed. Like the others, Erica somehow found options for care, and she received the appropriate medical care and psychosocial support needed to maintain her health and to live with the illness for decades.

Background of the Problem

Significant scientific achievements have lessened the HIV/AIDS epidemic and its devastating affects over the past 30-plus years (Altman, 2011; Centers for Disease Control and Prevention, 2014; Forsyth & Valdiserri, 2012). In the U.S., HIV/AIDS-related deaths and the rate of new infections have decreased and stabilized, but a closer look at the statistics shows that certain populations are still more affected than others (Allgood, Hunt, & Rucker, 2016; An, Prejean, & Hall, 2012; Fischer, 2012; Krueger et

---

1 Names of each participant were changed.
al., 2015; Linley, Prejean, An, Chen, & Hall, 2012; Prejean et al., 2011). For example, Prejean et al., (2011) reported: “Each year [2006-2009] blacks/African American males had the highest rate of new infections, and among women, black/African American women also experienced the highest HIV incidence rates” (para. 17). The incidence rate referred to the new cases within a certain timeframe, such as 2006-2009, and in comparison to the number of new cases in the average population (Centers for Disease Control and Prevention, 2014). History showed that even before 2006, indeed from the very beginning of the epidemic, “Black Americans have been disproportionately affected by HIV/AIDS…, and that disparity has deepened over time… [even though] recent data indicate some encouraging trends, including declining new HIV infections among Black women” (The Henry J. Kaiser Family Foundation, 2014, para. 1). Such statistics about racial disparities reveal the vulnerability of Black women living with HIV, and suggest the importance of studying the experience of this vulnerable population and the interventions that they identify as life sustaining. In a CDC-produced HIV/AIDS surveillance sheet from 2008, the data listed for Black women were alarming and almost unbelievable: In 2004, “HIV infection was the leading cause of death for black women (including African American women) aged 25-34 years” (Centers for Disease Control and Prevention, 2008, p. 1). However, as of 2013, HIV/AIDS was the fourth highest cause of death among Black women aged 35-44, and the sixth highest cause of death for Black women aged 25-34 (Centers for Disease Control and Prevention, 2013).

Regarding the rate of HIV/AIDS in Massachusetts, the focus of this study: “Between 1981 and the end of 2013, a total of 32,345 people had been diagnosed with
HIV or AIDS in Massachusetts. Of these, 41% (13,180) had died and 59% (19,165) were living with HIV” (AIDS Action Committee, 2014, p. 8). Compared to early trends from the 1980s, these numbers were noticeable milestones as the AIDS Action Committee (AAC) report stated, showing that the prevalence of the disease and AIDS-related deaths have slowed. Further, “An estimated 25,000 to 26,000 people were living with HIV in Massachusetts at year’s end [2014]. This figure includes people who did not yet know their HIV status, who were first diagnosed in another state, or whose infection had not yet been reported” (AIDS Action Committee, 2014, p. 8). Newer data sets exclude data from individuals who were diagnosed outside of the state. Within Massachusetts, Black women made up 46% of the HIV/AIDS cases, only slightly behind white men at 51% (Massachusetts Department of Public Health, 2011).

**Statement of the Problem**

The purpose of this exploratory study is 1) to study the complexity of the experiences of Black women living with HIV; 2) to explore the various forms of care that hold the most meaning and hope for them; and 3) to draw conclusions to inform future studies and future directions of care, including care related to individuals’ medical, psychological, and spiritual needs.² The emphasis of this study is on the psychological and spiritual impact of that care, even if the care does not come from formally psychological and/or spiritual sources.

---
² Spiritual needs are included in the statement of the problem, alongside medical and psychological needs, because African American women’s strength, coping strategies, and quality of life are strongly associated with spirituality (Braxton, Lang, Sales, Wingood, & DiClemente, 2007; Cotton, Puchalski, et al., 2006; Cotton, Tsevat, et al., 2006; Utsey et al., 2007). Researchers such as these demonstrate the importance of spirituality for Black women.
This study responds to a complex problem: that as a result of the intersectionality of race, class, gender, and illness, HIV-positive Black women face particularly acute challenges in their lives, including their physical health, psychological well-being, social relationships, and spiritual lives (Braxton, Lang, Sales, Wingood, & DiClemente, 2007; Crane et al., 2000; DeMarco & Chan, 2013; El-Bassel, Caldeira, Ruglass, & Gilbert, 2009; Gazabon, Morokoff, Harlow, Ward, & Quina, 2007; Ironson, Kremer, & Lucette, 2016; National Coalition of 100 Black Women, Inc., Manhattan Chapter, 2013; Parsons, Cruise, Davenport, & Jones, 2006; Perry, 2012; Stennis, Purnell, Perkins, & Fischle, 2015; Tomlinson, Rohleder, Swartz, Drimie, & Kagee, 2010; Younge, Salem, & Bybee, 2010). Critical race and feminist theorists describe marginalized identities in terms of intersectionality, recognizing the interactive influences of diverse social structures, such as race, class, gender, and health status. Intersectionality is a particularly helpful concept when reflecting on Black women’s identities (Collins & Bilge, 2016; Collins, 2000; Crenshaw, 1991) and their triple burden or triple oppression (Jones, 1949; Quinn, 1993; L. Weber, 1998), or their simultaneous oppression (L. Weber, 1998). These three terms make certain that other parts of one’s identity are acknowledged and not ignored.

The diagnostic status of HIV positive Black American women compounds their experiences of social exclusion. HIV researchers and theorists describe these multiple sources of marginalization (S. Dalmida, Holstad, Dilorio, & Laderman, 2011; Frederick,

---

3 Critical race theory (CRT) is the study of “relationships among race, racism, and power” (Delgado & Stefancic, 2012, p. 3). CRT is both scholarly and action oriented; understanding society in terms of race and power is followed by efforts to change society for the better.
2003; Watkins-Hayes, 2009; Weekley, 2010; Wohl et al., 2010). Plainly stated, the many aspects of this population’s vulnerability suggest the need for multifaceted approaches to care, including care for physical, psychosocial, and spiritual well-being.

The city of Boston is well known for its breadth and depth of medical care, research, advocacy, and higher education training programs, and this contributes to Boston preparedness to help with a variety of illnesses, including HIV/AIDS. Even with these improvements, the overall response to people with HIV, in particular Black women with HIV, are inadequate. Female residents of Boston living with HIV corroborate this inadequacy. DeMarco & Johnsen (2003) explain:

Women clients from the inner city of Boston who were patients or consumers of medical, nursing, or community health support services, began to raise concerns to their providers that their needs were unique and complex compared to male clients. In many instances, the women had shared at their contact appointments (institutionally or home-based) that they were struggling with isolation, low self-esteem, family/child concerns, housing, violence, chemical addictions, different physical side effects from antiretroviral medications, and paralyzing uncertainty. (p. 52)

DeMarco & Johnsen highlight the importance of HIV-positive women’s self-advocacy in expressing their needs to their healthcare providers. This research shows the value and necessity of hearing from a wide range of individuals who are living with HIV. DeMarco & Johnsen briefly mention the little known fact that antiretroviral therapy (ART) having significant side effects. The existence of ART made it possible for persons living with HIV to live longer and active lives (Deeks, Lewin, & Havlir, 2013; Perrin et al., 1993; Watkins-Hayes, Pittman-Gay, & Beaman, 2012). People living with HIV for many years demonstrate that HIV has gone from an imminently fatal illness to a chronic illness easily
managed by medication. However, the label of chronicity being a favorable aspect of HIV can be misleading to the public and trivializing for people living with HIV.

Researchers are investigating Black women’s particular experiences of living with HIV with the hope of contributing more nuanced observations and therefore treatment approaches. For example, Brody and colleagues (2016), in a qualitative study of mostly Black women living with HIV in Chicago, discover a “relational matrix” that helped Black women managed HIV, a matrix that includes “mutuality and self-awareness” and “[a]ctive and shared participatory relationships” (p. 268). This study exemplifies the movement towards “intervention programs for women with HIV who face a unique set of intersecting life stressors based on gender/race and who have had to overcome traumas that are chronic, such as poverty, racial discrimination, substance abuse, and HIV stigma” (Brody et al., 2016, p. 270). This research exemplifies the increased focus on women’s narrative in which they describe for themselves what has helped them promote self-care and self-efficacy.

**Purpose of Exploratory Study**

The purpose of this exploratory study is to analyze previous work, investigate the present landscape of care for Black women living with HIV, and offer a nuanced description of Black women’s experience with HIV, particularly accounting for the role of relational and spiritual support. The exploratory aspect of this study is important, given the limited amount of empirical research on this topic. The analysis will yield theoretical constructs for future testing.
At the outset, I expect the study to reveal relational values and needs that HIV-positive women identify as being important to them. Then the findings will lead to more in-depth research by an increasing number of professionals willing to contribute empirical knowledge towards the health of African Americans: “African-American researchers, including behavioral scientists, anthropologists, psychologists and sociologists are being recruited to develop HIV prevention interventions tailored to the needs of the black community” (Laurencin, Christensen, & Taylor, 2008, p. 41). A study that focuses on Black women living with HIV not only contributes to understanding the experiences of these women, but can also offer guidance for better care and even contribute to the prevention of new cases.

**Research Questions**

The main research questions for this study are: What do HIV-positive Black American women describe as their psychological and spiritual needs? And, what forms of care, particularly relational care, do they identify as responding to those needs? These questions are amplified by others: How do HIV-positive Black American women spend time with each other, especially in programs of healing and in unplanned gatherings that they identify as important to them? How do they judge their interactions with others as influencing, improving, or detracting from their overall care and well-being? Given the historical richness of communal and spiritual life for Black women and the emphasis on the healing effects of relationality in HIV care literature, do the interviewees identify spiritual and relational aspects of their experiences? If so, how do they describe them, especially their experiences with other HIV-positive Black women?
The study may show that the majority of HIV-positive Black women find or initiate relationships with at least one other HIV-positive Black woman to enhance their care, to validate their unique experiences and needs, and to strengthen their spiritual journeys. This assertion will be tested by: reviewing empirical and theoretical work on Black American women’s relationships and on the interplay of their relationships with their illness, suffering, care, and healing; studying women’s self-reports through interviews; and analyzing the interview data from my study in relation to the existing literature (Frederick, 2003; Watkins-Hayes, 2009; Weekley, 2010; Wohl et al., 2010). Whether or not HIV-positive Black women actually seek, create, and receive support within peer relationships is empirically unknown because it remains untested. Also unknown is the range or forms of relational support that people experience as confirming their personhood, life experience, and journey with HIV.

**Context and Significance**

I propose a multilayered framework to understand the many aspects of Black American women’s illnesses and care. Such a framework includes a review of the historical and current context to foreground the broader issues affecting this cohort (see “relational framework” for African Americans in Mattis & Jagers, 2001). The intersection of marginalization and care receive careful consideration in this study.

**Marginalization by race.** Racial marginalization is an important starting place. I note at the outset that the distribution of power in most societies results in some groups of people being on the margins of power. Inequitable power distribution often results in the outsiders or marginalized creating their own spaces for mutual validation (Cohen,
Sociological theories of social stratification reveal that out-groups are usually granted reduced social privilege, based on discriminatory criteria, and institutionalized inequalities (Noel, 1968; M. Weber, 1964). Pastoral psychologists and theologians describe how such marginalization only intensifies the need for care that promotes survival, resistance, and justice (Sheppard, 2011; Watkins Ali, 1999).

Throughout U.S. history, and continuing into the present time, Black Americans have been marginalized and many have limited social privileges. Yet under oppressive conditions, such as slavery, they have often created their own spaces in which to validate their humanity. Slavery and oppression have had lasting effects, and many inequities and forms of mistreatment persist. Thus, African Americans often mistrust mainstream institutions, which they associate with mistreatment, and they have often developed alternative religious and educational institutions of support (Ashby, 1986; Geary, 2015). Church, in particular, has been and continues to be a “place of sanctuary” for Black Americans (Lincoln & Mamiya, 1990). Even within such uniquely African American spaces, however, social stratification exists. Such stratification is often based on gender, a topic to which we now turn (Dodson, 2002; Frederick, 2003; Gilkes, 2001; Higginbotham, 1993).

**Marginalization by gender.** African American women have often been pushed to the margins by gender as well as race. Faced with this dual oppression, they frequently bond with each other to find the strength persevere (Brody et al., 2014; Collins & Bilge, 2016; Hull, Bell-Scott, & Smith, 1982; Weekley, 2010). Historically, they have created
spaces to validate their self-worth, sometimes uniting through music, poetry, dance, visual arts, or support groups (Dodson, 2002; Hull et al., 1982; Waters & Conaway, 2007; Westfield, 2001). Such efforts in validating Black women’s self-worth and self-esteem are often implemented through religious communities, such as churches, and are interwoven with other aspects of religious and spiritual life, like prayer, bible study, teaching others, or learning about other people’s journeys (Chatters, Taylor, & Lincoln, 1999; Musgrave, Allen, & Allen, 2002).

In African American communities, including religious communities, tend to have gendered roles. Due to such gender distinctions within Black churches and to broader societal inequities for women, Black American women have often created their own formal and informal gatherings for survival and self-validation (Higginbotham, 1993; Keller, 1981; Zikmund, 1981). The process of creating and making use of female-exclusive space—occasionally concealed space—has validated their self-worth, sense of belonging, and inner resilience (Dodson, 2002; Waters & Conaway, 2007; Westfield, 2001). Though technically many Christian denominations have granted women equal access to leadership positions, the significant strides Black women have made in many churches does not negate the challenges they continue to face; power imbalances still persist (Baer, 1993; Grant, 2008; Zikmund, 1981). Even now that Black women can hold more leadership positions (e.g. as ordained clergy, teaching men and women simultaneously), they continue to gather in exclusive women’s groups (African Methodist Episcopal Church, 2009; Keller, 1981). In conclusion, Black American women represent
a marginalized group based on both race and gender, making them one of the most marginalized groups in American society (Zinn & Dill, 1994).

**Marginalization by illness.** HIV-positive Black American women are marginalized yet further by their stigmatized illness (Ion & Elston, 2015; Limage Pierre, 2016; Remien et al., 2015; Thomas & Quinn, 1993). African American women living with HIV are a marginalized group in society, meaning they are unwelcomed or insufficiently attended to in various situations of care. They have received little specialized attention by medical providers, mental health workers, personal caregivers, family members, friendship networks, non-governmental organizations (NGOs), and religious and/or spiritual institutions, even though they have distinctive needs.

Experts in the field of HIV/AIDS explain that power imbalances in gender relations and sexual encounters further affect women’s involvement with community support structures and treatment programs. This helps explain why some women are less likely than men to utilize primary medical and support services (Gupta, 2000; Quinn & Overbaugh, 2005; Sohler, Li, & Cunningham, 2009). Most researchers agree that significant gender imbalances, or the liabilities of womanhood, affect women’s use of services and overall care, even when they are available. Gupta (2000), for example, argues: “HIV positive women bear a double burden: they are infected and they are women” (p. 7). This “double burden” for women living with HIV often increases exponentially with the addition of other factors such as race and ethnicity.

Being marginalized as African American women living with HIV may also affect the care women receive from their medical providers, who represent the institution of
medicine (Bubeck, 1995; Büssing & Koenig, 2010; Kleinman, 1988). Evidence suggests that the dominant approaches to care offered by institutional medicine are inadequate in caring for those with chronic illnesses and for marginalized ethnic cultures (Bodwell, 2009; Büssing & Koenig, 2010; Herman et al., 2007; Kleinman, 1988; Szaflarski et al., 2006; Woodard & Sowell, 2001). Institutional medicine has faced historical challenges in treating chronic illnesses and in treating patients from marginalized demographics. Herman and colleagues (2007) reviewed studies on health care to determine how culturally sensitive practices are incorporated into health care, and how “psychosocial factors” affect patients’ health. They found that socioeconomic status and experiences of oppression are key factors that influence disease progression. Herman et al. offer a broad perspective on cultural sensitivity in health care and address the need for more knowledge about specific experiences of individuals in the health care system, such as people living with HIV.

Health care thus represents another collection of institutions that may be unwelcoming—albeit unintentionally—to HIV-positive African American women. Medical care providers and researchers have a responsibility to find opportunities to hear from people living with AIDS (PH) in their own words; and to counteract the situation described by Ayana Weekley (2010), that “[w]ithin HIV/AIDS discourses, black women and men have been ignored and relegated to the margins of the epidemic or vilified as a population that has not heeded the prevention messages” (p. 15).
Conclusion

In summary, this chapter has briefly introduced the complexities of Black women’s experiences and has illustrated the burden that Black women carry when they live with HIV. I reviewed the historical context in the U.S. to show reciprocity between social structures (power relations) and cultural perceptions (race, gender, societal status) (Collins, 2015). The factors associated with Black women living with HIV are systemic, the social systems carry the historical imprints of power, racism, violence, and subordinate roles (Geary, 2015).

Likewise, Black women living with HIV have other identity groups to which they belong that are just as valuable as their race, gender, class, and serostatus. However, this is also a limitation of the study, which, because of its limited scope, does not discuss many other aspects of identity such as: sexuality, gender, (dis)ability, class, education, housing, nationality, immigration, incarceration, other illness, trauma, and religious tradition. These are also significant identifiers.

The research question and context presented in this chapter trace some of the historical conditions that facilitate a caregiver’s attunement with a Black woman with HIV. In Chapter 2, I explain the steps used to gather such information through the review of literature and interviews with Black women living with HIV. Chapter Three presents literature about how medical science and care models currently help Black women living with HIV, or have the potential to help. In Chapter 4, I integrate relational theory from

---

4 Serostatus is another way to describe one’s HIV status. A person with HIV is seropositive and a person who has tested negative for HIV is seronegative.
psychology with Black feminist thought. In Chapters 5 and 6, I present and analyze data offered by participants in qualitative interviews, and close by making recommendations for individuals who care or have interest in caring for Black women living with HIV.
CHAPTER 2

METHODS: STUDY OF BLACK WOMEN LIVING WITH HIV

The sobering information about how the intersection of race, gender, and illness and its effects on Black women living with HIV (BWH) underscore the need to learn more about the life experiences and contexts of BWH. The purpose of the present study is to: (1) examine the complexity of relationships experienced by related to Black women living with HIV and the contributions of those relationships to their spirituality, psychological, and overall well-being; (2) explore the various forms of care that hold the most meaning and hope for them; and (3) draw conclusions to inform future studies and future directions of care, including medical, psychological, and spiritual needs. In the rest of this chapter, I strive to demonstrate my capacity as a researcher to be in the marginalized spaces of Black women living with HIV, all the while knowing that an actual joining-with is unattainable for someone who does not share all of the marginalizing factors the participants have; all acts of empathy are limited.

The remainder of this chapter is the landscape in which I have conducted this study. Divided into four main parts, I offer a brief historical context of HIV in the United States (U.S.), a brief introduction to my autobiography and social location; a summary of my theoretical assumptions; and the study’s design.

Historical Perspective of AIDS in the United States

I begin with a historical overview to illuminate the cultural setting in which HIV arises. The following sources inform the discussion: “A History of the People with AIDS Self-empowerment” (Callan & Turner, 1997), “AIDS: The Early Years and CDC’s
response” (Curran & Jaffe, 2011), After the Wrath of God: AIDS, Sexuality, and American Religion (Petro, 2015), and “World AIDS Day 2015: Year-by-year milestones in HIV/AIDS” (AIDS Action Committee, 2015). In 1981, AIDS was formally diagnosed in healthy gay men,⁵ which is why the illness was initially named gay-related immune disorder (GRID; Centers for Disease Control and Prevention [CDC], 2011; Curran & Jaffe, 2011). That name instilled the false assumption that if you were not a gay male, then you were safe from the disease, (Cohen, 1999; Geary, 2015; Salyer, 2001; Thomas & Quinn, 1993). The socio-cultural circumstances of that time influenced AIDS research and the overall public response, including relational factors and social stigma.

While medical researchers in the 1980s understandably focused their efforts on treating gay Americans, later epidemiological studies noted that other people with similar conditions had died prior to the young men in San Francisco being diagnosed with AIDS (Curran & Jaffe, 2011; Oppenheimer, 1992). With injection drug use increasing in the 1970s and ‘80s, Cohen (1999) noted that this population had multiple health issues and noticeably poor health care. Cohen said:

Other researchers, such as Cindy Patton (1990), have also discussed the prevalence of HIV and AIDS among injection drug users during the 1970s. Patton describes, in particular, an epidemic that some called “junkie pneumonia,” thought to be the precursor or manifestation of AIDS in injection-drug-using populations….The researchers found an additional twenty-five hundred [drug-related] deaths that seemed to be HIV- or AIDS-related but did not meet the federal (CDC) case-definition of AIDS at the time and therefore not recorded as AIDS-related deaths. (pp. 126-127)

⁵ “Healthy gay men” is a common phrase used when discussing initial phases of AIDS history. The phrase is complicated because it ignores the disenfranchise of gay men in general, and their known drug use and social issues (Cohen, 1999; Geary, 2015). The early researchers used “healthy” to refer to there being no previous signs of immunodeficiency in this population (Centers for Disease Control and Prevention, 1981).
One wonders whether the knowledge of other modes of disease transmission, such as infected needles, might have shaped the narrative and social support for larger groups of people beyond gay men.

Then around 1982, the CDC received reports of mostly heterosexual male Haitians diagnosed with AIDS. The federal government’s response was to designate Haitians living with HIV as “high risk” when they traveled to the U.S., a designation that meant mandatory HIV testing and/or being held in detention at Guantanamo Bay (Curran & Jaffe, 2011). This was a notable government over-reaction for a number of reasons, such as political leaders wanting to appear protective of US citizens by preventing Haitians living with HIV from entering the US. Curran and Jaffe reminds us of the CDC’s labeling of Haitians as a high-risk group for AIDS. In 1985, “Haitian” was removed from the CDC’s risk-group designation, leaving “homosexuals,” hemophiliacs, heroin users, and sex workers.

It does not appear that the CDC issued an apology or statement of regret for listing Haitian as a risk-group. Curran and Jaffe stand by the CDC’s public health decision, calling it necessary to have Haitians listed as a risk group, though they acknowledged that the labeling caused AIDS stigma for Haiti, Haitians, and Haitian Americans. Regarding the travel ban for HIV-positive immigrants and/or international visitors, President Obama’s administration lifted the entry ban against non-U.S. citizens living with HIV in 2009 and implemented this action in 2010. The policy action of lifting the ban was a part of extending the Ryan White Act, which is the federal funding program
The fields of medical research and patient care reinforced marginalization among people living with HIV because of the initial labeling; for example, homosexuals, heroin users, hemophiliacs, Haitians (the 4 H’s), and prostitutes. One way to understand the consequences of labeling people in this manner was that

the concept of risk contained and marginalized within kinds of people and their behaviors, so that the full burden for the technologies necessary to reduce risk (safe sex, latex barriers, clean needles) might be contained within those communities suffering the epidemic, as their “responsibility.” (Geary, 2015, pp. 16–17)

In other words, it may have seemed innocuous to identify populations most affected by AIDS, but the result seemed to place AIDS prevention solely on so-called high-risk populations. The labeling led to oversimplification rather than research into the societal problems that contribute to some populations getting less medical care than others. The problems for high-risk populations could have been related to poor medical care for marginalized people. If controlling the spread of AIDS was the responsibility of people living with AIDS, then the identities of vulnerable populations would be reduced to their behaviors as intravenous drug users, sex workers, people who have condom-less sex, or not seeking prenatal care to avoid mother to child transmission

The early years of AIDS teaches us to be cautious about oversimplifying the causes of health disparities. The efforts to reduce new cases and to better care for people living with HIV should take into account many issues, alongside personal
responsibilities. Geary states that individuals reduced to behaviors are othered and put into marginalized labels such as black and queer. Geary notes that,

Analyzing what people do (incidence and prevalence statistics organized by transmission category) was and continues to be a way of not talking about or investigating the conditions under which people live and are made vulnerable to disease…. As long as the concept of risk is contained within the discourse of queers, there need be no investigation into the structured relations of inequality and vulnerability, like racism, poverty, sexism, and state violence, that organize and distribute social risks, including the risk of HIV infection. (p. 18)

This is a call to action for us, the public, to scrutinize our own blind spots and unintentionally harm individuals already on the margins of society. Further, this is a call to action for health professionals to not reduce patients’ identities to their illness or behaviors, and to consider the cultural effects of how well-meaning public health messages contribute to systemic oppression.

In the mid-1990s, the breakthrough in HIV treatment came with the discovery of a combination of antiretroviral therapy (ART). With this therapy, people live longer with HIV and they generally take fewer pills than they did in the past, including Black women living with HIV (Black AIDS Institute, 2011; Deeks et al., 2013; Johnson & Gerber, 2000). Recognizing the significance of this ART, my focus is to increase understanding of the care experiences of Black women living with HIV. As a preparation for this study, I turn now to a narrative section that locates me as the researcher and acknowledges how the overall study is influenced by my own experiences. Next, I explain my ideological assumptions and study design.
Personal Narrative and Social Location of Researcher

I am a Black woman from the southern United States, raised in a working-class family who instilled in me the value of hard work, Protestant Christian beliefs within a Black church tradition, a collective sense of responsibility, and pride in our African and African American heritage. Growing up, I saw models of wise and strong Black women who supported each other and their communities. I saw many examples of how individuals of faith visited their neighbors and helped each other, among those examples my grandmother and great-grandmother go to the homes of others to help people who were sick or in need of help around the house. I watched my grandmother and great-grandmother enter spaces (e.g. living rooms, bedrooms, hospital rooms, rehabilitation centers) with ease, kindness, and sensitivity, attuned to the individual and the individual’s environment. They could be light-hearted and humorous, prayerful and contemplative; they could cook and clean, brush and braid hair, all while letting me watch or help. A key aspect of my identity was shaped by shadowing my grandmother and great-grandmother in such caregiving situations.

This research emerges from: a) watching family members looking out for their friends and neighbors, and b) growing up in the 1980s when HIV/AIDS had its first diagnosed person in the United States. I remember seeing images of AIDS patients on television who appeared very thin, with noticeable skin issues. Initially, like much of the population, I was fearful of what at that stage was considered to be an incurable disease, 6

---

6 AIDS organizations, such as Joint United Nations Programme on HIV/AIDS (UNAIDS), encourage no use of adjectives when describing AIDS because a term like “incurable” potentially increases fear and fuels discrimination (UNAIDS, 2015, p. 6).
a disease that puzzled even medical professionals. Famous athletes, such as Magic Johnson, a basketball legend and Arthur Ashe, a tennis legend disclosed their own HIV diagnosis yet seemed to be the picture of health. To my knowledge, HIV did not directly affect me, but I remember the way people quickly mobilized to help in some way. My family helped, with my mother leading the way. We joined other members of the African Methodist Episcopal Church (A.M.E.C) to donate supplies and money to our local community health centers and non-profit organizations, providing testing and treatment for people living with HIV. Participating in this larger faith family shaped my identity and taught me how much could be accomplished when people work together.

As an older youth, I observed how this same faith family needed reminders and education because we were complacent and uninformed. I saw women in leadership positions speak boldly about the ongoing need for us to do more for people living in African countries, as well as our neighbors at home. One of those women was Dr. Margaret Joan Cousin, the spouse of Bishop Phillip Robert Cousin, Sr. Dr. Cousin was bold and passionate. She was the most vocal of the African American women who spoke openly about caring for people living with HIV.

The literature is limited on the history of HIV and AIDS specific to how African Americans responded; thus, the evidence is limited to reveal how advanced Dr. Cousin’s advocacy and caregiving for people living with AIDS was, compared to that of other Black leaders and churches, specifically in the mid-1980s. Certainly, within the AME Church, Dr. Cousin is well known for her AIDS activism in Florida. “Under the supervision of Dr. Joan Cousin,” a Florida pastor states, “the Episcopal Supervisor in
Florida (1984-1992) [organized] some churches across Florida [and] began to serve persons” living with HIV (Reed, 2007). In 2002, AMEC bishops issued a position paper on the church’s response to HIV/AIDS and reported that the denomination’s initial AIDS response was to open eleven AIDS service centers in Florida, 1984-1992 (White, 2003). I imagine that my family and others were hopeful that AIDS would not be around for long.

In 1984, Secretary Margaret Heckler of the U.S. Department of Health and Human Services predicted an AIDS vaccine would be ready for testing within two years (“Thirty years of HIV/AIDS: Snapshots of an epidemic,” 2011).

I lived in south Florida in the late 1990s when areas around Miami, Fort Lauderdale, and Palm Beach had some of the highest rates of HIV infection in the US (Florida Department of Health, 2010; Marcelin & Page, 2007; Sanders, 2013). Those high rates have lingered in my thoughts, as have the disproportionate response from churches. Unfortunately, some of the most recent CDC data still identify three cities in Florida among the top ten US cities with the highest rates of infection, with Miami ranking first in the nation, Jacksonville third, and Orlando eighth (HIV surveillance report, 2011, 2013).

At the present, I provide psychotherapy to individuals and small groups in my role as a crisis intervention counselor on a large northeastern college campus. My role is to help students who are in the recovery process after surviving a trauma. I focus particularly on students who have survived gender-based violence, a type of violence that disproportionately affects people of color, feminine appearing bodies, gender nonconforming, and LGBTQ students.
My clinical home is thus with people who endure disruptions in trusted and safe places, such as being harmed physically or interpersonally by someone or something. My area of focus is the integration of spiritual and religious beliefs with relational and identity development (Benjamin, 2009; Chatters et al., 1999; Collins & Bilge, 2016; Dana Comstock et al., 2008; J. Jordan, 2010; Kohut, 1984; Mattis, 2004; Pargament, 1997; Sheppard, 2011; Springer, Hankivsky, & Bates, 2012; Vandecreek & Smith, 1991). I embody the teachings of my great-grandmother and grandmother, who taught me how to sit with others during suffering, emptiness, and dis-order; and how to intersperse hope-filled laughter with painful emotions. Their teachings have increased my lifelong awareness of social stigma (Crocker & Major, 1989; Tadese, Biadgilign, Deribe, & Escudero, 2013) and piqued my curiosity of about how caregivers’ respond to oppressed people, such as those in this study (Braye & Preston-Shoot, 1985; Griffith et al., 2007).

Assumptions

Just as one’s biography influences one’s research interest and questions, a researcher’s assumptions also have a shaping effect. For this reason, I identify my primary assumptions at the outset.

My first assumption is that the public needs to awaken to the continued urgent need for medical and social support for people living with HIV, specifically for Black women. The present study is meant to motivate the reader to become more invested in HIV informed care; and to learn more about the lives of women who are already marginalized for many reasons, but specifically because of race, gender, and living with HIV. Researchers from all relevant disciplines are members of the public, too, with skills
to contribute. As citizens with the expertise to conduct HIV/AIDS studies, “[s]cientists have a moral obligation first to be good citizens, second to be good scholars, and third to be good scientists” (Vucetich & Nelson, 2010, p. 49). I am aware that there is not a consensus that scientists have moral obligations to society. Some scientists argue about the importance of having a neutral stance when presenting data and not recommending specific responses to that data (Vucetich & Nelson, 2010). As I previously noted, when the first AIDS (initially GRID) diagnosis was reported, many scientists were not impartial nor value-free and their biases had lasting medical and social affects. I propose that the science community make amends for their missteps, by reducing morbidity, eliminating new HIV infections, and caring for people living with HIV, including BWH (Cohen, 1999; Geary, 2015; Smith & Whiteside, 2010). We all have a responsibility.

Secondly, Black women are “agents of knowledge” (Sheppard, 2011, p. 6). My own ideological assumption that Black women are “agents of knowledge” have to do with their experiences being equally valued and accepted, particularly within academic study, rather than an afterthought to so-called universal claims. Even as an afterthought, Black women’s ‘knowing’ is accessible in most academic environments; and now a marginalized individual can enter higher education and likely see themselves reflected somewhere in scholarly discourse.

Examples of Black women as “agents of knowledge” are offered by Black feminist and womanist scholars, who enter conversations with knowledge based on identity and cultural concerns (Collins, 2000; Love, 2016). These cultural concerns include, but are not limited to issues of race, ethnicity, class, gender-identity, sexuality,
abilities, embodiment, incarceration, spirituality, and religion. Womanist and Black feminist discourses are the locales for learning about Black women as knowers in the context of socio-cultural and identity development. The terms womanist and Black feminist are used interchangeably, which is what I intend to do. However, some differences are worth noting.

First, “womanist studies” are commonly associated with religious and theological studies, even though other disciplines sometimes draw upon womanist theories – disciplines such as literary criticism, anthropology, social work, nursing science, and others (Phillips, 2006). Womanist scholarship has been critiqued from individuals who identify as womanists and who do not, for the seeming lack of discourse on heterosexism in churches (for example, Douglas, 1997, 1999). However, my anecdotal observation (also shared by Coleman, 2006) is that the starting point for discussion of womanism is almost always in theology and religion. This has been the case since religious scholar Katie Canon (1988) published Black Womanist Ethics, which became a touchstone for womanist theology. Katie Canon and other womanists built upon the earlier description of a womanist as described In Search of Our Mother’s Gardens by Alice Walker (1983).

Many texts about Black women’s experiences, regardless of the ideology, use the terms womanist and black feminist interchangeably because their viewpoints overlap. Further many of these scholars view quibbles about labels for a field of study as privileged dialogue that takes time away from the normative experiences and pressing tasks of Black women (Collins, 1996). Throughout this study, I will use the preferred language of the authors I am presenting. The primary goal for me is to join the
conversation of other Black feminists across disciplines (e.g. Patricia Hill Collins, bell hooks, Audre Lorde, and others) to illustrate the credibility of Black women’s experiences in making meaningful claims.

Having said that, I align myself with Black feminist thought (BFT) as Patricia Hill Collins (2000) described it in *Black Feminist Thought: Knowledge, Consciousness and the Politics of Empowerment*, a classic text in sociology and Black feminist discourse across fields. In *Black Feminist Thought*, Collins (2000) taught that knowledge should be empowering, which stood in contrasts with some of her contemporaries who had not conflated knowledge (data) with the knower (principal researcher). Black feminist epistemology is “necessary for empowerment, particularly with respect to hegemonic power,” and where empowerment includes the capacity to define oneself (Christian, 1988; Dotson, 2015, p. 2325). For example, Collins validated and empowered other Black women to define themselves with their lived experiences: “Even after substantial mastery of dominant epistemologies, many Black women scholars invoke our own lived experiences and those of other African-American women in selecting topics for investigation and methodologies used” (p. 258). It is empowering to know that oneself is a welcomed, possibly necessary, when conducting theoretical or empirical studies.

In the research process, the knower is the one who gathers data, conceptualizes, and presents the knowledge articulated by empowered women defining themselves (Dotson, 2015). A conventional view in social science research is that “good research methods are supposed to be culture free, value free”; however it is improbable for researchers to do value free research (Harding & Norberg, 2005, p. 2010; Kourany,
2008). For example, in my study, although I worked to minimize my authority position, I found that asymmetry of power was unavoidable. A power differential inevitably exists between the researcher conducting the research and the participant. A researcher can moderate these differences can be modified by informed consent, the selection, and flow of questions, and encouragement for participants to understand their options, such as early withdrawal from research.

My third assumption is precisely that Black women have a “collective experience,” even while being uniquely affected by social realities of marginalization, oppression, and successes. According to Gilbert and Wright (2003), who study African American women and HIV/AIDS:

There is no single description of the “African American woman,” yet, we do not ignore that larger societal structures are designed in such a way as to impact the lives of diverse African American women collectively. It is from this collective impact that we speak of African American or Black women’s experiences…to express the collective experiences of societal discrimination and historical oppression of Blacks in the country [U.S.]. (p. xv)

The present study builds on this assumption that Black women have both collective and unique experiences and that both need to be studied. Thus, the study facilitated a small group of Black women living with HIV to share their collective and individual experiences of sufficient and insufficient types of care. The underlying hope was that the participants’ voices would begin to dominate narratives about Black women living with HIV, counteracting the despairing public health messages that remind Black women the public about our high incidence of HIV. The data about health disparities concerning Black women are one-sided and without refined explanations about why we are at-risk.
To learn the collective and individual experiences of Black women living with HIV requires a multi-faceted approach to listening. Foster (2007) agrees that future research about Black women living with HIV should include listening to their narratives and that "[f]eminism, and in particular black feminism” will help to challenge objectifying images and stereotypical behaviors attributed to Black women with HIV (p. 327). Foster continues to explain the value of Black feminism lens, stating that we should “understand the historical production of what it means to be an HIV positive black woman, thereby providing a way to deconstruct the ‘binary dichotomies’ that oppress and typify experience” (author’s single quotation marks, p. 327). I join Foster and others (e.g. Gilbert & Wright, 2003) who incorporate Black feminist thought to oppose stereotypical views of Black women, such as hypersexuality or deviance, and to focus on BWH’s experiences, ideas, observations, and meaningful interactions of other Black women living with HIV.

**Study Design**

In order to focus on their experiences, I studied the caring and meaningful relationships of Black women living with HIV using a qualitative method. Qualitative research is participant-centered. As the researcher, I tried to withhold hypotheses or preconceived ideas to allow the participants’ responses to rise to the top and aggregate around one or another viewpoint. The means of bracketing previously held beliefs in qualitative research happens in many ways – interviewing participants with open-ended questions before choosing a particular school of thought in which to position the developed conceptualizations and theories, and open coding instead of *a priori* grouping
when examining the data (Habermann-Little, 1991; Hill et al., 2005; Rennie, Phillips, & Quartaro, 1988).

**Grounded theory.** Grounded theory (GT) is one approach to qualitative research; the purpose is to explore new topics and construct emerging theories. The founders of grounded theory, Glaser and Strauss (1967), introduced this research approach with key identity markers to arrive at empirical results without being reductionists or too abstract. In my view, GT is a fluid approach among data, analysis, and participants, and GT is pragmatic in adjusting to new situations. For others, GT is the primer for theory evolution. GT was described as the “theory evolve[ed] during the research process itself and is a product of continuous interplay between data collection and analysis” (Goulding, 1999). While not a simple approach, GT is a practical way to learn about a new concept or theory. The researcher begins by choosing a topic of interest, where she has a fund of knowledge, but wants to know more. In its original form, GT was not supposed to include prior research and examination into the subject being studied.

Because I began studying literature on women’s experiences living with HIV, I formed some conceptual frameworks in advance of the qualitative interviews. Thus, my use of grounded theory did not meet the strictest intentions of grounded theory as taught by Strauss and (1967). More recently, Glaser (2014) distinguished between classic grounded theory (CGT), his intended version, and grounded theory (GT), where he acknowledged that researchers use GT more commonly as qualitative research, which is grounded in data and could be adapted to the needs of the researcher, such as
incorporating another method. Since Glaser’s and Strauss’ original presentation of GT, it has evolved as a commonly used method for conducting qualitative research.

The present study uses GT as a flexible term. Glaser (2014) would likely refer to my use of GT as qualitative research jargon. Nevertheless, Glaser also said that neither GT nor CGT were better or worse, simply a different choice that the researcher chose. I incorporate an ethogenic approach to help guide my data analysis, an example of a qualitative data analysis mixed with GT, clearly distinguishing the present study from CGT.

The present study was exploratory and explanatory in preparation for myself and others to study in the future, the care choices of Black women living with HIV. Thus, the following elements were included in the present study: literature review, individual interviewing, coding data, thematic analyses, and integration of the findings into theoretical constructs and proposals for practice. Each is described below.

**Literature review.** The study began with a literature review in order to gather the wisdom of this emergent area of study (Mertens, 2005). This first step helped to guide the process of naming and exploring healing factors for Black women living with HIV that have already been considered. Based on historical examples of the way African Americans coped with oppression by gathering outside of institutionally owned places, I too wondered if we would see similar behaviors and interactions among Black women living with HIV.

The literature selected for review was guided by information in library electronic databases such as JSTOR and Lexis Nexis, data about Black women living with HIV...
from the Centers for Disease Control and Prevention (CDC), and faculty and colleagues involved in counseling, case management, and HIV prevention. The subject areas with the most available and relevant sources were by medical professionals who focused on the needs of Black women living with HIV; these included nursing researchers and ethicists focused on the ethics of care, decent care, and companioning care.

In addition, I focused particular attention on psychotherapeutic theories that center on the unique relationship between the provider and patient. This relationship is based on socio-cultural factors that influence the provider-patient alliance and the patient’s interactions in society; its benefits of supportive bonding for overall health is already established. Further, Black feminist thought raised the importance of socio-cultural factors; thus, these factors should also be part of any discussion of BWH. In particular, I examined relational care in the context of W.R.D. Fairbairn, Heinz Kohut, and Jessica Benjamin, three psychoanalytic psychologists who articulate strong ties to relational care. Further, I have created a dialogue between these psychotherapeutic approaches and Black feminist perspectives, thus to shed light on the collected data from perspectives.

**Recruitment of participants and individual interviewing.** I recruited by word of mouth among colleagues, posted flyers at local AIDS service organizations, utilized a research participant registry, and encouraged people to share the opportunity with their friends. I placed flyers at local clinics in the Boston area that individuals living with HIV might frequent, and particularly Black women living with HIV. I placed flyers on bulletin boards inside clinics that assign a public space for community announcements.
and I confirmed that written permission was necessary per each organizations’ policies. For two organizations, the flyers required authorization before they could be placed in locations where BWH would be sure to see them. The authorization consisted of my emailing a copy of IRB approved forms and supporting documents, such as the consent form and flyer, to the leadership staff who were directly involved with BWH (see appendix for copies of the IRB-approved flyer).

In addition, a local research registry that maintains a database of individuals interested in participating in studies was instrumental in recruitment. The registry provided a list of women who met the study’s criteria. I called each woman to see whether she was interested and then met individually with her at an agreed upon location. The result of all of this recruitment was that I interviewed 17 Black women living with HIV. I offered a $15 gift card to each interviewee as an incentive and expression of gratitude; however, the women seemed highly motivated to discuss their experiences with the researchers.

**Procedure.** I interviewed each participant using prepared questions in a semi-structured format. The semi-structured format provided flexibility to ask follow-up questions.

**Coding data.** As previously stated, I set out to use the approach of Glaser and Strauss (1967), drawing upon the participants’ language and contexts in constructing theory (see also Ashworth, 1997; Corbin & Strauss, 2008; Denzin & Lincoln, 2000). I selected open coding so as not to pre-establish specific categories and themes (Mattis, 2000). Grounded theory is important for this study; as the researcher,
Adding to the nuanced approach of data analysis, I incorporated ethogenic practice, which is meant to “generate further research” (Moore, 2006, p. 416). Moore explains: “the ethogenic method includes listening to people explain their behavior, drawing upon the linguistic capacity of humans to explicate the origins and reasons for their actions” (Moore, 2006, p. 425). To be clear, this study cannot claim the full use of the ethogenic method in its purest form. Ethogenic research generally encompasses the study of a community through participation and observation; however, I did use the ethogenic approach to analysis as part of the coding process.

Qualitative research for a population of Black women living HIV is ideal because this is a population with many strengths, particularly in the realm of communication – verbal (oral, aural, written) and nonverbal (through intuition, discernment, facial expressions, etc.). A hallmark of Black feminism is the assumption that one has the “power to define oneself and one’s social context on one’s own terms, rather than have it defined for them by someone else” (Hancock, 2006, p. 266). A qualitative design is well suited to this population because it encourages participants to define themselves in their own way.

**Thematic analyses.** The primary steps of analysis are asking questions of the data—meaning of participants’ responses to the researcher’s questions. Moore’s (2006) ethogenic method serves as a model and means for looking at patterns in the data, and is consistent with grounded theory. That is to say, “This analysis asks five questions of the data: (1) frequent words and phrases; (2) symbols; (3) frequent actions and activities; (4) patterns of interaction; and (5) themes… [and researchers may move] back and forth as
they make new discoveries” (Moore, 2006, p. 425425). My process for analyzing data was first to identify symbols, frequent words, phrases, and actions; and then to identify patterns and themes that emerge. Also, I wrote memos of my internal experience of the process, which added to my formulation of themes. This process, along with consulting with colleagues and advisors, helped me to identify thematic categories: meaningful relationships systems of health and meaningful interpersonal relationships.

My choice to cluster the themes into institutionally-oriented relationships and intimacy-based relationships was based on the coding process. An IRB-approved third party transcribed most of the recorded seventeen interviews. I reviewed every transcription by listening to the audio and following line by line. The audio and transcribed interviews were loaded to NVivo 11, a qualitative data analysis software, which I used to organize, display, and query information. I read each interview using the ethogenic method described above, and used NVivo 11 to search for words and phrases that I coded as a way to verify the inclusion of data in the coding process.

Some may raise questions regarding the study of affect – if one can adequately study affect and, if so, how. An interviewer, in the course of relating with interviewees, can see, feel, and sense the interviewees’ affect. Affect outwardly reflects the emotions felt inwardly, and one can identify these processes with brain structures, which control the expression of emotions through the limbic system, parietal lobes, and frontal lobe (Othmer & Othmer, 2002). Even if a person seems more guarded and discloses less than the average respondent, a therapist/interviewer will likely notice subtle change in eye contact for particular topic(s) shifts in body positions, changes in word choice or
speaking style, changes the in the volume of a person’s voice, and other signals.

Counselors often analyze these signals to make a clinical judgment, a discernment that arises from years of strong supervised-training. I sought to be alert to such signals and to record them.

**Method for integrating findings and literature.** The research concluded with attention of self-reflexivity and to comparisons of the research findings with the literature.

In any research, the researcher must establish his or her study’s academic rigor, and it is no different with qualitative methods. Knowing that my experiences may influence the data, the skills of personal introspection and self-awareness were vital. I understand Glaser to be saying that grounded theories, especially novices, may not extend their analysis long enough to come up with a fully formulated theory. Glaser called them theory bits, saying that theory bits were not expendable; but were starting points that the researcher would continue to build upon. Thus Glaser recommended that researchers employing GT, regardless of experience level utilizing GT to end analysis with “Of course, these situations are very complex or multivariate, and without more data, I cannot tell what is really going’’(p. 12).

Different from the ethogenic method described by Moore (2006), my study did not include a research team, but my study made up for this through frequent memo writings about research experience and feelings/thoughts. This self-reflexivity permeated by stages of analysis, conversations with advisors, and introspection as the principal
investigator. Similarly, the research concluded with reflection on the literature in dialogue with my qualitative findings.

**Conclusion**

In this chapter, I described the methods used in the study, which included acknowledgment of my own social location, assumptions, and critical-clinical stance. In addition to identifying these theoretical and clinical assumptions, I have introduced my qualitative research and the interviews with 17 participants. I hope that readers can appreciate the generosity of participants in this study. The next chapter moves to the initial phase of the literature review of HIV care and other care models appropriate for relational care practices.
CHAPTER 3

CARING FOR BLACK WOMEN WITH HIV

There was this one caseworker who used to work with me… she's another one that taught me a lot about the virus. She [caseworker] was very educated about it [HIV]. When I first got my cat, she was telling me how careful I had to be with the cat …I never knew that. Ever since that, every time I go to clean my cat, I always think about her. But yeah, they were good. And my health-- my doctor they're good. So I have to say that I get the best health care. (Deidra)

In this chapter, the focus is on the health care of Black women living with HIV, and their interactions with treatment providers. The quotation above is an example of a participant talking about an experience she had with her medical provider. Deidra and I conversed about the place and people she selected for her health needs, and she recalled a caseworker that she found very helpful. The caseworker educated her on how she could maintain a healthy life with her companion pet. Throughout our exchange, it was apparent that Deidra appreciated that her caseworker attuned to many aspects of her life, and not only to her illness; although talking about pets was an important part of Deidra’s HIV care since pets can be problematic for people with immunodeficiency. Certainly, Deidra saw the caseworker as a knowledgeable professional; not only her words, but her affect while talking about receiving “the best health care” communicated her positive regard for those caring for her.

The purpose of this chapter is to examine how medical providers integrate traditional medical treatment with holistic care, specifically relation-oriented practices. “Holistic” connotes multi-faceted care, including case management, mental health services, basic living needs, and matters of faith. It is important to acknowledge that
many medical providers not only value holistic care, but also they find ways to incorporate this practice of attending to many facets of a patient’s life.

The first section of this chapter will attend to the nature of care and recent advances in HIV care, focusing on the health care of Black women living with HIV. I focused particularly on the field of nursing because it is a field that, more often than not, emphasizes and practices holistic care with clients (Clark, 2004; D. Vance, Struzick, & Raper, 2008). Nursing attends to multiple factors of care, such as medical and social needs, and the socio-cultural contexts of the people with whom they work. Thus, nursing, vital for community health settings, provide good lens for the present study. Next, I will offer three theories that align with holistic conceptions of care, each adding nuance to the holistic concepts. They are decent care, ethics of care, and companioning care. I have selected these because they represent significant movements in the literature regarding interpersonal relationships in the context of providing assistance, and they reflect my own clinical practices.

**Current State of Care with People Living with HIV**

Even with the alarming disparities of health and health care related to factors of race, socio-economic status, gender, and sexual orientation, many local community members and medical professionals work diligently to improve and sustain the lives of Black women living with HIV. Here I introduce meanings of care and some of the recent developments in the care of people living with HIV.

**Care.** Care is a process of attending to a person’s health, which may include the functioning of a health care system and the interpersonal interactions between a provider
and patient. While more specifically, care often refers to the work of experts or professionals who offer specialized support to persons, based on their special training. The term “care” refers to the act of being helpful and helping an individual’s health improve, quality care, competent care, relational care, companioning care, decent care and informal networks of care (Campbell, Roland, & Buetow, 2000; El-Bassel et al., 2009; Greenwood, Loewenthal, & Rose, 2001; Karpf, 2008; Richards, 2011). These descriptors of care imply that the term “care” on its own may be insufficient without an emphasis on the positive qualities of care. For example, a parent provides care for a child or a spouse provides care for a partner. Many acts of care are provided by individuals who have not been trained; yet, these acts are equally valuable, and are arguably necessary for the sustenance of health and well-being.

**Understanding the health of people living with HIV.** As we consider the current state of HIV care, it is perhaps surprising to learn how well people living with HIV (PH) are doing in general in terms of their overall care and the progress of their health. This is particularly the case if they discover the disease early and have good access to care (Airhihenbuwa, Webster, Okoror, Shine, & Bankhead-Smith, 2002; Allgood et al., 2016; Earnshaw, Bogart, Dovidio, & Williams, 2013; Feldman & Fulwood, 1999; Sohler et al., 2009; Stevens & Hildebrandt, 2009). Literature documenting that accessibility, quality, and availability may be more variable than initially concluded (Wingood, Funkhouser, DiClemente, & Fawal, 1998). Certainly, a sample size of less than 20 participants is not generalizable, and does not allow me to
make definitive claims that counter the overwhelming view that CHC provide insufficient medical care and support to BWH.

Further, research cited in the literature review shows that BWH continue to be disproportionately affected and infected by HIV compared to women of other races. The research implies that the quality of medicine – access and in-person service – is simply not the same for Black women living with HIV, and that this lesser medical care likely impacts the way BWH live with the illness.

Griffith, Maso, Yonas, Eng, Jeffries, Plihcik, & Parks (2007) talk about having four objectives, and two levels are important for this topic. They have to understand and assess racism. They explain that understanding and assessing one’s personal beliefs creates accountability not only for individuals but for institutions. Griffith and colleagues state that researchers tends to spend less time on health care interventions specifically from the perspective of institutional culture and practices. Instead, most interventions focus on making individual changes with health care providers, such as teaching cultural competency. I agree with Griffith’s approach that both organizations and individual providers need to adjust their practices as regards racism. For example, Griffith et al. suggests that medical facilities should use their internal data to assess their patterns of medical treatment across demographics. It is important that the institutions begin with the premise that racism exists (in and outside of health institutions) and that it reifies
health disparities. By starting from the position that racism currently exists, patients’ feedback becomes even more important.  

As Griffith et al. (2007) assert, data associates racial health disparities between people of color (POC) and White people as the primary reason that POC have lower prognoses with same illnesses. This very assertion informed my reasoning for wanting to ask my participants about their views of their medical care and why I anticipated that their experiences at CHC and other medically related places would be noticeable. Not that the participants necessarily would be noticing the institutional issues, but I did expect them to be able to speak to their experiences that did not feel quite right. However, this was not the case with my participants. Also my participants all had supportive families and/or friends, which potentially mitigated their anxieties, and made them less reliant on institutions for their support and care. One might explore further in research the degree to which patients notice racial bias and/or stigma and still maintain good health practices. Have these individuals developed some version of “healthy mistrust”? 

In general, we know that fewer AIDS related deaths occur when people living with HIV receive care. According to the Centers for Disease Control (CDC), “AIDS-related deaths occur when people who are infected do not receive the testing, treatment, and care they need. Treatment can help people with HIV live longer, healthier lives and also greatly reduces the chances of passing HIV on to others” (Centers for Disease Control and Prevention, 2015, p. 2). There are multiple benefits for a person to know

---

7 In this paper, racism is defined as an oppressive system that reinforces inequalities and rewards individuals in privileged positions (Geary, 2015; Jackson, Brown, Williams, & Torres, 1996).
their HIV status, whether negative or positive, and then to connect with physical and auxiliary services, and to receive healing, sustaining, or preventative care. Burgoyne and Saunders (2000) found that people living with HIV who request more support and educational opportunities do so because they do not have supportive spaces in their lives, such as family and close seronegative friends. This finding rings true for the women I interviewed, who found support in many places, including their own families, hospitals, and community health clinics. This finding dispelled my initial expectations that Black women living with HIV look primarily to each other for closeness and acceptance because traditional spaces fail them.

**Current State of Care from Community-based Organizations**

In this section, I focus on two particular areas of action and study that seem important when discussing the practice and duty of caring for Black women living with HIV (BWA) – practices and studies of nursing and of community health clinics. I will explicate areas in which nursing research and practice are succeeding well and less well, and those areas in which community health clinics are succeeding well and less well.

**Nursing practice and research.** The field of nursing leads the way among the medical sciences by learning about socio-cultural influences that affect their patients’ health, an observation shared by others (such as Grady, 2011; Yeager & Bauer-Wu, 2013). Grady (2011) espoused that nurses and nursing researchers lead the way in studying and translating into practice the research on aging populations, individuals managing multiple chronic illnesses, along with their cultural contexts. Likewise, Katherine Yeager and Susan Bauer-Wu (2013) discussed the leadership role of nurses, among clinical
researchers and practitioners, striving for “cultural humility” not just cultural competency. Nurses are fitting partners “to have interventions adapted to meet [patients’] contextualized needs and maintain fidelity of the intervention at the same time” (Stewart, 2014, p. 662). Their work shows that both interventions and general patient-clinician interactions can be “adapted to meet [patients’] contextualized needs” without compromising the quality of care (Stewart, 2014, p. 662). The field of nursing sets high standard for nurses and other clinicians to study the effects of socio-cultural issues of involved in the patient-clinician relationship. These are examples of personalized attention and intentionality when caring for patients.

Stevens and Hildebrandt (2009) are nurses who discuss the complexities of medication adherence for female patients. They explain that women living with HIV (WH) who are not medically compliant or adherent to medical advice, are not simply disobeying doctor’s orders because of laziness or apathy. The women have complex reasons for behaviors that influence their treatment response. This is true even if a Black woman living with HIV knows, for example, that taking medication properly will sustain their health.

Daily use of medication, for many Black women living with HIV, is imperative because HIV treatment leaves little leeway for missed doses or alterations in timing: “Beyond the threat to individual prognosis, intermittent adherence to HAART allows drug-resistant strains of HIV to emerge and so poses a problem for the entire population” (Stevens & Hildebrandt, 2009, p. 593). Stevens and Hildebrandt speak directly to their colleagues in medicine, specifically physicians, and admonish them to look deeper into
the lives of patients to understand fully what may or may not interfere with treatment. Without understanding, according to them, “we cannot come to know how adherence might be sustained and supported over time” (p. 595). Taking antiretrovirals (ARVs) is not as easy as seronegative people think. Many people, including medical professionals, think that taking pills is a straightforward act; however, this view is not held by all of their patients. In fact, some Black women living with HIV think that \textit{not} taking their medication is a positive step toward maintaining their health:

\begin{quote}
Using biomedical logic, it is indisputable: ARV nonadherence is a negative behavior. From the point of view of HIV-infected women who do not take ARVs as directed, nonadherence might not be bad at all; rather, it might be righteous, responsible, proactive, a sign of strength, and a matter of common sense. (Stevens \& Hildebrandt, 2009, p. 601)
\end{quote}

What Stevens and Hildebrandt found when interviewing Black women with HIV concerning their use of ARV treatment was surprising. They learned that some women made their decisions based on how unbearable the side effects were, so they were making the choice to live their lives freely without feeling all of the side effects that come with taking ARVs. These women were exercising their agency in understandable ways and choosing how they would spend the rest of their lives.

Nursing research indicates that what is not yet working well is the transition from understandings of holistic care as a niche in the field to understandings of holistic care as a rather than a normalized way of nursing. For example, there are abundant studies in nursing about the health benefits of engaging a patient’s meaningful contexts, like family, religion, and culture. This appears to be another niche area because nursing research that fully embraces socio-cultural contexts are most often found in hospice or end of life care.
These are health care systems that are fully staffed and not overrun with patients who only get the basic attention from nurses due to the facility’s ecosystem of not taking the time to relate more deeply to patients. One might suggest that some of these actions could be performed by chaplains and social worker, but is this being considered and practiced?

**Community programs and research.** The long-held tradition of people coming together in support of community members affected by something devastating in their community is often led by unsung heroes who work tirelessly and with little recognition from any beyond their own circles. Yet, when it comes to something as preventable and treatable as HIV, service providers need to be aware of what others are doing and to make opportunities to learn from these others. Likewise, in the academic community, scholarship about AIDS service providers (ASPs) is thin and not widely knows. Therefore, it is important for me to highlight some of the notable outreach programs and clinic settings.

The most notable community based organization (CBO) in the African American community is the Balm in Gilead organization (known colloquially as “the Balm”), which started in the early 1990s in New York. Harris (2010) examined from a public health perspective “how the Balm in Gilead, a nonprofit, community-based organization (CBO), has applied social marketing techniques to its AIDS awareness programs targeted at the Black Church, with the ultimate goal of reducing AIDS stigma and increasing AIDS education among Blacks in America” (pp. 71–72). The primary audience of the Balm is the Black Church, in part because of the widely held belief informed by “[m]any
researchers that the Black Church is large part responsible for the Black community’s negative perception of HIV/AIDS” (A. Harris, 2010, p. 74). The Balm was created by a community member and health professional who was concerned about the plight of Black people living with HIV, and concerned that even Black pastors, well-respected leaders in Black communities, were silent about the disease in their communities. Harris (2010) explains:

The Balm in Gilead and its CEO and founder, Pernessa Seele, are well known in the American AIDS education and preventive arena. Established in 1993, the [Balm] in Gilead is the first CBO that promotes AIDS education and awareness to Black churches in America and later provided similar services to religious institutions on an international level. (p. 75)

Seele saw the problem firsthand in local hospitals where she worked and saw AIDS patients in person. In her role as an “immunologist at Harlem Hospital at the time [she] was frustrated that Harlem religious leaders were, in her opinion, ignoring those with AIDS in not only the hospital, but in their congregations” (A. Harris, 2010, p. 75; “The Balm in Gilead, Inc.,” 2012). In response, initially Seele planned an initial call to prayer day and march, that subsequently took place on the streets of Harlem, NY.

Seele challenged local religious leaders, specifically church pastors in Harlem to stop ignoring the people in their congregations living with and dying from AIDS-related complications. Since this time, the Balm has expanded to be a social marketing hub that helps Black churches learn and teach about HIV as well as care for the people living with HIV among them. The Balm as become a one-stop shop of resources ideal for Black churches, working through the churches, because of the massive number of them.

Examples of the Balm’s tools are educational content and public health marketing using
language and images familiar and palatable to Black churchgoers. Harris (2010) explains:

Findings suggest that the Christian obligation and duty that Black churches emphasize in their teachings was key to the AIDS awareness marketing strategy that the Balm employed. More specifically, the findings suggest that the Balm utilized the Christian obligations of forgiveness, love, acceptance, and the responsibility to care for others to encourage churches to address AIDS. (p. 79)

By all accounts, the Balm staff believes what they are teaching, and sometimes wish they could encourage more preventative measures, such as condom use, which are not acceptable in some churches. The Balm tries its best to honor the tenets of its readership. Harris (2010) states it this way, “Although it is a community-based organization, workers at the Balm also feel as if the Balm is a religious organization that operates in accordance with Christian values” (p. 80).

Another strong aspect of the Balm is that it has a particular capacity to reach the many churches with smaller congregations (fifty members or fewer) in which people serve in multiple leadership roles and have insufficient resources to maintain a thriving health ministry with literature and paper resources. The health ministry that is usually in place at neighborhood churches consists of members visiting fellow members who are homebound and/or sick. Because it was so successful in such situations, and because it shared values and language with churches, the Balm became an ad hoc consortium for churches around the globe that supported the ideals of most Black churches, and offered its health care teaching with biblical references.

Since Harris (2010) examines the Balm from a public health perspective, it is unclear whether the Balm offers sufficient information about how best to care for Black
women living with HIV from multiple perspectives. As I see it, the Balm teaches fellow church members to care for each other, especially by debunking myths about HIV. But I wonder whether the Balm educates the medical team or those who offer treatment to members of Black communities about how best to interact and relate to this demographic by informing them of the firsthand knowledge that the Balm has acquired, and especially the strong teaching methods that are most accepted by Black church congregations.

Currently, one of the Balm’s most popular initiatives is the National Week of Prayer for the Healing of AIDS (NWPHA), which happens annually in March. The Balm provides planning guides, promotional materials, training webinars, educational guides, and suggested activities (“National Week of Prayer for the Healing of AIDS,” 2015).

Fortunately, the Balm is not alone in the work it does. Another ASO that has similarities to the Balm is Blacks Assisting Blacks against AIDS (BABAA) in St. Louis, MO. BABAA is a public health organization that offers resources for, but not exclusive to, Black Americans in a Midwestern city (“Williams and Associates, Inc. Addressing Minority Health Disparities,” 2014; Williams, 2003). While it does not offer HIV treatment per se or give medical advice, this non-profit conducts awareness events, HIV prevention initiatives, support for LGBTQ individuals, and support and educational group. As of 2002, BABAA has expanded its model to include support for people with all illnesses that result in significant health disparities among populations, all while maintaining its focus on resources for people living with HIV. This non-profit works to enhance the medical care that people living with HIV already receive. For example,
Williams (2003) documents the BABAA program, Steps to Living, which consists of five eight-week workshops. Each workshop is two hours long, the first hour is educational and second hour offers group support. BABAA provides transportation to all the workshops, including the Steps to Living, along with meals and childcare to make it easier for people to attend.

Weiss, Dwonch-Schoen, Howard-Barr, and Panella (2010) introduce participatory research for a community significantly affected by HIV. In the process of their research, “community leaders become concerned about a health problem… including HIV/AIDS” (Weiss et al., 2010, p. 19). Weiss and colleagues explain that social workers living within the communities were the key impetus for bringing other leaders together in this particular community of Saint Lucie county, Florida: “[This project] was initiated by community members, including social workers, community health educators, and county health department CHD) leaders” (Weiss et al., 2010, p. 19). Weiss and her research team conducted “community-based participatory research” in which the researcher involves herself in the community project that she’s studying, but does so alongside the individuals who are already teaching and caring for individuals, but also wanting to influence positive societal changes (Weiss et al., 2010, p. 19). Weiss et al. (2010), concluded that, “Because of their broad roles within communities, social workers are in ideal positions to lead communities to promote needed change” (p. 26). It is a model worth emulating.

---

8 The program Steps to Living does not currently appear on the Williams and Associates, Inc: Addressing Minority Health Disparities (minorityhealthstl.org) website.
Community-based participatory research is also understood as action research.

In comparison [to regular research] action research uses the collective wisdom and insight of the local community to formulate strategies that enhance the well-being of local community members (as cited in Stringer & Genat, 2004), but continues to use a systematic approach of naming the problem, [establishing a] goal for collecting information, and analyzing data. (Weiss et al., 2010, p. 19)

In other words, community members, including researchers, work together as co-collaborators. They draw upon their firsthand knowledge, and give feedback as the research is happening.

The Florida Department of Health presented statistics about St. Lucie County, the one being studied by Weiss et al: “This county had the highest HIV rate among black residents in Florida in 2005, with one out of 35 testing positive” (p. 24). This article does not specify the exact process of measuring, but it is likely based on CDC terminology referring to the prevalence rate described in the study of Weiss et al., study, which refers to understand the number of individuals with HIV during a specific time period (The Centers for Disease Control and Prevention, 2014).

**Stigma**

Medical professionals who treat STIs frequently and/or have a history of treating people living with HIV, often take for granted that all of their patients will see and understand their prognosis positively compared to decades ago when a diagnosis of HIV was a death sentence. While HIV treatments have come a long way, and while from a public health perspective, the spread of HIV has dramatically decreased, many people who live with HIV find a positive view of the disease as unhelpful, because the diagnosis changes so much in their lives. Many medical professionals likely assume that a
seropositive patient will have the support of family and friends, but unfortunately, this is far from always the case. Thus, “[i]t is important to note…however, that perception of social support may differ from the actual availability of social support” (McDowell & Serovich, 2007, p. 2).

I suggest that stigma is the primary reason why Black people who are living with HIV do not disclose their serostatus. They have good reason to believe that, if they do tell others of their serostatus, they will lose the life they know, and will consequently experience not only diminishment of their health but also diminishment of their social structure and support. Often this belief is based on firsthand knowledge because they hear conversations among their friends and family members who judge and speak ill of people living with HIV. It is human nature to protect oneself from harm. Unfortunately, being physically and emotionally harmed by those in one’s own household for being HIV-positive is commonplace. Researchers, Vance (1996) and Ware, Wyatt, and Tugenberg (2006), found that people with HIV are more prone to loneliness compared to the general public. The implication of this self-reported loneliness is that the people lack social connections, and their isolation negatively affects their treatment adherence to treatment (as cited in McDowell & Serovich, 2007).

**Need for Holistic Health Care**

The lack of holistic care for people living with AIDS, inclusive of physical, psychosocial, and spiritual care, is a special problem for African American women, for whom traditional institutions and practices may be inadequate because HIV disproportionately affects Black American women (Hicks, Allen, & Wright, 2005; Peltzer
& Leenerts, 2007; Williams, 2003). Because of this dilemma, these women may look to each other for aspects of care that are not found elsewhere, tacitly seeking to build their own holistic care.

Community programs do exist around the U.S. to address the care of Black Americans living with HIV. For example, Dana Williams (2003) highlights programs in the northeastern and west coast of the U.S.: Black Assisting Black against AIDS (BABAA); New Transitions; Steps to Living; and Coalition Empower Families Affected by AIDS (CEFAA). Williams offers these programs as examples of holistic care available for Black women living with HIV, and recommends that such organizations share their programs and research findings with others. Williams acknowledges, “We as community have embraced the stigma, denial, and discrimination” of HIV/AIDS (p. 221).

Based on the current state of care, what is needed now is a strong theoretical grounding to inform holistic care and to encompass the successful aspects of care options that presently exist. Three theoretical movements are particularly helpful: ethics of care, decent care, and companioning care.

**Ethics of care.** The ethics of care from feminist theories, is most notably attributed to Carol Gilligan who researched hundreds of young women from adolescent to young adulthood. Gilligan noted more emphasis on relationship among adolescent females, a crucial aspect of female interactions that Kohlberg neglects.

**Decent care.** Black women living with HIV clearly need care, but the care they presently receive in traditional sites is often limited (Dalmida, 2006; Walker, 2002). The need is for “decent care,” a term used in palliative care literature to describe holistic care
for people living with chronic illnesses. In that literature, holistic care includes attention to physical, financial, emotional, and spiritual well-being (Karpf, 2008). For example, HIV-positive African American women identify the importance of their spiritual needs, but they also have complicated spiritual lives, often preferring private to public religious practices. Researchers identify stigma as a possible reason why these women avoid mainstream religious settings (Dalmida et al., 2011). Likewise, Black women and Latinas living with HIV typically have health-related support from their families, but they also experience “stress” from those same family systems (Wohl et al., 2010). In short, relationships for this population can be complicated. Fortunately, anecdotal evidence suggests that people living with HIV (PH) are beginning to form groups among themselves to address some of their communal needs, which are largely unmet in traditional systems of care (Rastogi & Khanna, 2011). These many efforts might be viewed together as “decent care,” providing comprehensive care for the overall needs of the people.

**Companioning care.** Companioning care is a term from hospice that refers to maintaining a person’s dignity through the end of life, as in every other phase of life. I bring up companioning care not as a way of associating death with HIV/AIDS, but because companioning care calls upon fellow humans to dig deep into their wells of compassion to be present and ‘radically hospitable’ to carry out the wishes of a sick and/or dying person. We should see them as fully whole and worthy of the same adoration that family and strangers heap upon humans as they enter the world, regardless of the illness or causes leading to sickness and death. But perhaps I am in fact bringing
this up because of HIV being known as a death sentence, at least in the early days of the disease. As presented in Chapter Two, the initial responses to AIDS were outrage and fear in the United States. The larger public was responding to people who were dying of AIDS shortly after a diagnosis, and to patients dying alone, or only their partners and friends present. The public concern often intensified by the disclosures that accompanied the illness, especially when gay men contract the illness after years of being closeted while working in mainstream, high profile jobs. Secrecy was a high value because people diagnosed with the virus that caused AIDS often did not want others to know that they were connected to someone with HIV or were perhaps gay themselves.

In those days, when Black women living with HIV first learned their diagnosis, they tended to assume they would die rapidly. When doctors seemed to minimize that response of patients, they often came across as dismissive rather than realistic. In addition, it is no doubt difficult to talk about something both serious and highly stigmatizing; even if nowadays it is not a death sentence. HIV is still something no one wants to say they have, especially a Black woman, who will have a particularly hard uphill battle after leaving the doctor’s office. All diagnosticians, regardless of the discipline, are challenged to negotiate the delicate line between honest diagnoses and the tendency to pathologize. Some people are reassured when they receive a clear diagnosis, others feel scared, and still others go through a combination of stages.

**Integration of Holistic and Traditional Care**

From community care (via clinics, churches, and individuals), we learn that collaboration with other programs and individuals is what helps connect people living
with HIV so they can receive comprehensive care, overcome stigmatization, and receive the best of humane care from medical professionals, who learn in the process to offer the kind of treatment that they would want for themselves. Sometimes it seems as if people, including medical authorities, interact better with household pets than with people of a different background or in a different situation. Why is this? It is because they are more comfortable around household pets than they are around people of different background, based on SES (socioeconomic status). When someone is outside of their SES they are unsure how to be with them in their suffering. This kind of empathy may be where medical professionals of color have an upper hand because we are used to living as marginalized and underrepresented groups, as well as living among the individuals who are most like us on many levels.

I suggest that the burden is on all medical professionals to become competent professionals. If they are uncomfortable around any particular group for whatever the reason, they must educate themselves in experiential ways in order to become better professionals. Just as we expect people living with HIV to be compliant with their medication regimes and overall treatment, we expect that medical professionals will do what they should to become conversant in the latest treatments and to improve their competence and comfort at being with those in their care, especially those who are in some ways different from them. How to do this likely runs the gamut from formal medical training to putting oneself in informal settings, such as attending social, religious, political or sports gatherings with people who are different from oneself.
Black women are particularly attuned to inauthenticity and nonsense. Even if we are do not know the origin of the phoniness, we typically know that something is not right. Of course this sense of mistrust, which some call health mistrust, is not foolproof or without mistakes. However, our experiences as Blacks in the US and the history of our ancestors have taught us to be leery of people in authority, even in situations and locations and among people whom one might expect to be helpful. Yet such warranted mistrust may do us a disservice. While we are legitimately trying to protect ourselves, we may not realize that we need to trust the person and/or process, and these very people and processes can often be helpful to us. So while both parties in such a relationship bear responsibility for its success, I suggest the greater burden is on the individual with the greater power.

**Care and Black Women Living with HIV**

Nowadays, it seems that Black women living with HIV may be benefiting from the technological advances of HIV treatment, which brings benefit even to those who are last to receive it. Yet while some Black women living with HIV will indeed receive the care provided by outstanding nurses, a local community health clinic, an informed religious setting with a thriving health ministry, and the unconditional love of a family member, many Black women living with HIV are unable to access these resources. The way we disseminate care in our country is not equitable. The present study reveals some of these inequities: the incidence of HIV among Black women, a large number of Black women living with HIV who still live with inadequate care, and a disproportional percentage of Black women dying from AIDS complications.
All of these concerns point to the need for skilled training of caregivers who treat people suffering from a highly stigmatized disease. For some caregivers, their role is best accomplished by concretely meeting the needs of their patient. The interpersonal connection between caregiver and patient may be difficult to accomplish for many reasons. Building such a mutual relationship or alliance of care is often what makes the difference in a person’s health outcome.

While it is unclear what clinical approaches are vital to improve traditional systems of care, the present study focuses on the understudied relational approaches to care, or approaches that enhance and investigate one’s relationship with others. Relational approaches build on such theories as object relations and self-psychology, which describe human development as shaped by childhood caregivers and other significant relationships, and on theories about the “contextual-relational self” and “ethics of care” (Gilligan, 1982; Held, 2005; Larrabee, 1993; Noddings, 2000; Sheppard, 2011). It is to this relational care that I turn in the next chapter.
CHAPTER 4
WHAT IS RELATIONAL CARE?

When I got up there and I began to talk and I began to tell my story… I just unlocked a part of me that I didn't know I had a shackle on it. (Linda Scruggs cited in Landau, 2011, para. 42)

The purpose of this chapter is to provide a definition of relational care for Black women with HIV (BWH). The first step in answering the question about the relational care experiences of BWH was to identify a research design appropriate for surveying relevant literature and hearing directly from the individuals who are experts about their health, as noted in Chapter 2 about research design. The next step, as discussed in Chapter 3 on HIV and care, was to examine literature that highlighted current care practices, introduced theories of care inclusive of gender and spirituality. We turn now to psychological and Black feminist thinkers with careful focus on relationality.

Psychological theories and Black feminist thought (BFT) are both beneficial for understanding relationality. An integrative framework of these two perspectives is what makes this chapter crucial in the effort to define relational care for a portion of society’s invisible people, Black women with HIV. The framework provides insights for reflecting on the significant relationships that Black women living with HIV describe as necessary to their sustained health.

The chapter is organized as follows: discussion of three psychoanalysts and their contributions to current models of relational therapy, Black feminist/womanist contributions that illustrate the socio-cultural context of Black women living with HIV, and an integrative analysis of relational psychotherapy and Black feminist thought.
Others have put psychology/psychoanalysis in dialogue with each other, but less so in relation to the consideration of BWH.

**Relational Theories from a Psychosocial Perspective**

A comprehensive study on the theories of psychoanalysis and object relations is a worthwhile undertaking, and many scholars have written about them at great length - scholars such as Jay Greenberg and Stephen Mitchell (2000), Stephen Mitchell and Margaret Black (1995), and Ana-Maria Rizzuto (1979). Sigmund Freud is a standard-bearer for formulating theories of pathology based on human drives and individuation, especially from a maternal source. He focused especially on humans’ innate drives of sexuality and the psychodynamic interplay of internal forces in shaping human personalities, which he described as the id, ego, and superego. Yet, Freud has been critiqued for omitting social context and interpersonal relationships (beyond familial ones) when treating his patients. Even more serious are the critiques of Freud for distorted perspectives, especially on race, gender, sexuality, and religion (Gilligan, 1982; Sheppard, 2011).

A dominant theme throughout Freud’s work is that, over the course of human development, the individual unconsciously desires sexual connection with a parental figure, and that an individual’s ability to navigate such precarious emotions and memories is a sign of his or her maturity. For Freud, normal human development is marked by a child’s being dependent and fixated on the parental figure, then later negotiating unmet fantasies to facilitate appropriate separation, or individuation (Gay, 1989; Greenberg & Mitchell, 2000).
Other psychodynamic theorists see humans as inherently relational individuals. Harry Stack Sullivan and W. Ronald D. Fairbairn were leaders in developing relational theories of psychodynamics, or what Mitchell (1988) called “a social theory of mind” (p. 19). Mitchell elaborated on this shift to social theory: “Sullivan and Fairbairn, its purest representatives, felt that Freud had established the wrong unit for study of emotional life by focusing on the individual mind, the psychic apparatus, rather than on the interactional field” (p. 19). In sum, Freud laid the theoretical groundwork to understand how human beings relate to the conflicting forces within themselves, and others have extended Freud’s work to interpret emotional life as more complexly dependent on social engagement. Freud focused on an individual’s mind and dynamics created by internalized relationships and parent figures. He did not attend to the diversity of social and cultural contexts and the diversity of interpersonal relationships that influence human lives. In contrast, others began with the premise that “[s]ocial relations are regarded as themselves biologically rooted, genetically encoded, fundamental motivational processes” (Mitchell, 1988, p. 20). Such an emphasis on the complexity and primacy of relationships is a departure from Freud, while maintaining an accent on psychodynamic processes.

**Fairbairn and communal existence.** Fairbairn differed with analysts of his time, who focused primarily on theories of drive and pleasure, attending less to the quality of early childhood interactions with parents or caregivers relationships (Grotstein & Rinsley, 1994). Using the metaphor of magnetic force, Fairbairn suggested that, regardless of the quality of care, our need for relationships is fundamental, involuntary, and impulse-driven
(Mitchell, 1988). Perhaps Fairbairn’s language of interdependency and the necessity of relationships sound familiar. However, Fairbairn differed from other psychoanalysts in emphasizing the importance of learning about a patient’s child development and social context in order to understand the patient’s relationship history and relationship needs (Fairbairn & Fairbairn, 2013). Greenberg and Mitchell (2000) summarize the differences between Freud’s drive theory and Fairbairn’s relational theory like this:

In this view [Freud], human beings are simultaneously self-regulating and field regulating. [Fairbairn] concerned himself with both the creation and maintenance of a relatively stable, coherent sense of self out of the continual ebb and flow of perception and affect, and the creation and maintenance of dependable, sustaining connections with others, both in actuality and as internal presences. (p. 35)

Fairbairn does not see “maturity of relatedness” as a secondary process for human beings; rather it is a central part of our make-up to be intimate and mutual with the other (Greenberg & Mitchell, 2000, p. 157).

Fairbairn is helpful in understanding the experience of Black women living with HIV. His view suggests that relationship are essential for humans to survive and thrive. He described “[t]he essential striving of the child not for pleasure but for contact. He [sic] needs the other” (Greenberg & Mitchell, 2000, p. 172). Fairbairn is a significant figure in relational models, a relational purist, and his perspectives are compatible with what the literature and my interviews reveal about the needs of Black women living with HIV.

**Heinz Kohut.** In addition to Fairbairn, Heinz Kohut provides further foundation for relational models. There is vast scholarship on Kohut and I will focus on the aspects more important for this study. Some argue that the theories of Kohut and Fairbairn could
be combined or that one can posit a mixed model of drive theory with relational sensibilities. For example, someone like Otto Kernberg built relational configurations into drive theory. Others critique this approach, seeing the appeal and limits of such a theory “which is compelling on its own terms, but which violates many of the fundamental premises of the original framework” (Greenberg & Mitchell, 2000, p. 351). Greenberg and Mitchell do, however, highlight the resonances in the more relational perspectives on psychodynamics: “The vision of human experience which Kohut terms ‘psychology of the self’ operates on principles derived from the relational/structure model: it is strikingly similar to the approaches developed by Winnicott, Fairbairn, and the interpersonal school” (Greenberg & Mitchell, 2000, p. 352). This brief discussion demonstrates that theories of the mind/self can, and often do, give serious attention to the fabric of relationships. Such relational theories build on each other, borrow from each other, and enhance one another.

The self as a vehicle helps Kohut to explain various one-on-one interactions, with oneself and with others. Not only is the self functional, but for Kohut the self is what the other interact—with what he terms the selfobjects (Kohut, 1971). Selfobjects are other individuals who interact with the self from birth to death; “[f]or Kohut, the child is born into an empathic responsive human milieu; relatedness with others is as essential for his [sic] psychological survival as oxygen is for his [sic] psychological survive as oxygen is for his physical survival” (Greenberg & Mitchell, 2000, p. 353). Kohut equates empathy with life-giving oxygen. It is absolutely essential for living and thriving. Kohut describes this with regard to the child-caregiver relationship, but later the reader will see
that this same empathy, this same quality of relating, is central in any relationship. I would assert that the aspirational nature of empathy is especially true for individuals with traumatic psychological and sociological experiences. Kohut teaches that the self “requires participation of others to provide a sense of cohesion, constancy, and resilience” (Greenberg & Mitchell, 2000, p. 353).

This empathic environment has to be dependable, reliable, and sturdy enough to help a person withstand all of the traumatic and self-destroying forces that the person will encounter. What is the result of not providing empathy? Kohut’s supposition is that the incompetent nature, or absence of empathy, alters the internalization process of a selfobject to facilitate self-cohesion. One answer and further explanation for understanding relationships: The child innately needs these relationships. He [sic] is not object seeking in Fairbairn’s sense; the selfobject is a vehicle for homeostasis. Nevertheless, the establishment and maintenance of selfobject relations provides the basic motivational energy. (Greenberg & Mitchell, 2000, p. 356).

The differences between the way Kohut and Fairbairn understand the seminal child-parent relationship is subtle yet significant. Fairbairn has an ontological way of describing relationships, meaning relationships just exist like a law of physics or a magnetic process. Kohut suggests that relationships should include empathy and vicarious introspection in order for a person to maintain a kind of balanced existence, which can only be achieved through self-cohesion. Also, different from Fairbairn, is that Kohut provides more clinical material to understand how self-selfobject relating happens, and the role of relational goals. Kohut’s terminology of the self refers to the metaphoric
inner part of humans, and to self-objects as a differentiated person or entity. Therefore, when Kohut says that the self seeks out “relatedness, attachment, [and] connection to others,” he establishes a template of qualities necessary in early relationship and he foregrounds the corrective nature of such relationships (Kohut, 1971).

**Jessica Benjamin.** Another group of clinicians recently formulated a different relational model. One is Jessica Benjamin, who proposed a mixed-method approach that attempts to integrate drive theory and a relationally focused therapy. Thus, this mixed method gives rise to a discourse within modern psychoanalysis regarding relational models. Benjamin acknowledges the asymmetry of the typically dyadic relationship in psychotherapy, and she insists that a better model acknowledges and seeks mutuality, and is aware of intersubjectivity. Benjamin builds on object relations theories by bringing attention to the normative “space,” intra-psychically and directly, of a one-way field, meaning the therapist receives, seeks to understand, and explores the patient’s subjectivity during the clinical hour. In such clinical encounters, as well as in other relationships, Benjamin’s spatial shift, or space from a one person field to “two subjectivities,” adds complexity. Two or more individuals with their own interior relations (e.g., self in relation to self, self in relation to others, self in relation to roles, etc.) create a new set of relations, or subjectivities, between themselves (Benjamin, 1988, p. 3). Yet, although the two or more selves engage, they may or may not agree.

Benjamin reminds psychoanalysts that intersubjective engagement is what is happening when breakthroughs happen with patients, and that breakdowns reflect the inability for two selves to engage. Thus for relational therapy, it is vital for the dyadic
relationship to be authentic and genuine in spite of the asymmetry in power. The analyst has to connect or speak openly about how the analyst’s self-parts and patient is self-part. Benjamin reminds psychoanalysts that they are already aware of when breakthrough happen with clients and when the therapeutic process breaks down. Benjamin acknowledges that counter-transference expresses some of this dynamic but does not entail an acknowledgement by the analyst and sometimes confuses the patient, who is unable to articulate what is happening.

In sum, Benjamin’s work is important to me because she sees psychoanalysts not only as instruments of change, but as engaged in a mutual process that requires the psychoanalyst to have self-awareness, and the capacity to recognize her own and her patient’s self-states regardless of how cohesive or dissociative the patient may seem at a given time, empathy, and attunement. In Benjamin’s own words:

If in response to the patient’s hyper-arousal, the analyst retreats from the ‘music’ of mutual regulation (Knoblauch, 2000) into a dissociative use of observation in order to calm down, the patient can feel it. If, however, we are mindful of our failures, gradually we will learn together to recover from rupture, in attunement, and thus become sensitive to and use more effectively the inexplicable gaps created by the patient’s unintegrated or warring self-parts and the analysts failure to contain them. (Benjamin, 2009, p. 441)

There are instances where the therapist may be attempting to understand the patient’s hyperaroused state and instead of acknowledging right away the gaps or ruptures, considers these first internally and then shares a response to them with the patient in a way that reflects the tenor of their relationship, or the manner in which the dyad customarily recognizes each other mutually. Benjamin explains that, in her earlier works,
she defined “mutual recognition” in terms of “breakdown and restoration” (Benjamin, 2009, p. 441). This is an

…intersubjective [state] that emphasizes not just the fact of mutual influence (Stolorow and Atwood) but the consciousness that there is a bi-directional dance between patient and analyst that each person registers differently – a co-created dance governed by what we call the third (Ogden, 1994). (Benjamin, 2009, p. 441)

Benjamin highlights “the moral third,” a helpful metaphor to describe the spoken or unspoken guides for the interaction. The “third” is difficult to understand, and it varies with contexts; one might say that it is existential, indescribable, and you-know-it when it is happening. As Benjamin (2009) notes:

[The] moral third…refers to those values, rules, and principles of interaction that we rely upon in our efforts to create and restore the space for each partner in the dyad to engage in thinking, feeling, acting or responding rather than merely reacting.

The metaphor of a co-created dance is appropriate here because, like a dancing pair, the moral third emerges often with spontaneity and purpose. Yet Benjamin teaches that in therapeutic dyads, difficulties or misunderstandings are inevitable. Therefore, a relational therapist begins reparative work, by listening to and hearing client’s multiple states of self, or “multiple voices,” a practice that facilitates moral thirdness (p. 443):

In relational thinking, an important sign of re-opening thirdness is being restored to the capacity to hear multiple voices – I can hear both your voice and mine as can you without one cancelling the other out; I can hear more than one part of yourself, you can hear more than one part of yourself, you can hear more than one part of yourself – especially not only the part that is negating me, but also the complementary part that I have been carrying as you negate it. (Benjamin, 2009, p. 442)

Benjamin uses the self-state wisdom of Philip Bromberg, Lewis Aron, and Robert Stolorow to remind therapists of the unavoidable conflicts in therapeutic relationships,
the need for rupture and repair, and her own need and capacity to hear multiple voices of herself and her client. The client senses when they are not being heard, is not recognized, or is disconnected. “Self-correction,” Benjamin said, “is our [therapist’s, psychoanalyst’s] way of life” (p. 443). Reestablishing attunement not only helps to co-create a moral third, but also to minimize internal experiences of splitting – good/bad, right/wrong, etc.

Benjamin and others, recognize the necessity for self-reflexive therapists who acknowledge their own various self-parts, or self-states, not least because our self-states influence the moral third. This is hopeful and freeing for a clinician: she does not have to have to attend to and contain all parts of her client, but to recognize the aspects of an individual that are often less heard by the client. The beauty and strength of seeing and empathizing with patients can improve care in many disciplines. It is highly recommended for psychologists, religious leaders, nurses, doctors, and others. For those persons who treat patients who are already marginalized and stigmatized, as well as silent and invisible, Benjamin’s emphasis on of being recognized by their care staff is a vital part of the treatment process. Such attention to recognition would likely improve compliance rates and well-being.

Like Benjamin, I do not expect empathy and recognition to be a perfect practice, actually the opposite. As Benjamin (2009) states:

I emphasize that our “failure” to link is inevitable, to be unable to link feelings and parts is a natural part of our procedure, a liability intrinsic to our work, and not the failure it feels like. Self-correction is our way of life...When we acknowledge to the patient the felt experience of having recreated the original injury we are in effect inviting the abandoned, shamed and wounded part to
become more vocal. We thus avoid repeating the part where the original abuser or bystander adult denied the child’s reality. (pp. 434–444)

I do not expect non-psychotherapists to be experts at this kind of rupture-repair work, but those who treat or intend to help patients living with HIV should be prepared to learn, fail, and self-correct.

**Tell my Story:** 9 Black Feminism and Relational Psychotherapy

Fairbairn, Kohut, and Benjamin make good conversation partners with Black feminist thought because of the way they de-emphasize individuality and emphasize socio-cultural and interpersonal interactions that influence one’s personhood, or sense of self. 10 At the same time, Black feminist thought can enrich object relations and relational psychotherapy by considering relationships within marginalized groups and within the dynamics of the larger society.

**Relational Black feminist approach.** Drawing upon Black feminist thought (BFT) is appropriate because the discourse celebrates the commonalities among Black women: “BFT contends that knowledge exists in daily common knowledge shared by group members and is specialized and provided by expert group members that express the group’s standpoint” (McLane-Davison, 2015, p. 4). Where Collins and other Black feminists seem to assume that Black women will support each other regardless of the

---

9 “Tell my story” comes from the quotation that opens this chapter. Linda Scruggs is an HIV/AIDS activist and ordained minister from Atlanta, GA (Landau, 2011). She speaks around the globe about her own journey living with HIV as a Black woman. The key tenet in Black feminist thought is for a Black woman’s experience to be told by the Black women who have lived it.

10 Black feminism joins other critical and liberation theories, such as womanist theory, feminist theory, queer theory, etc.
struggle, many Black women living with HIV experience hurt and stigma from other Black women because of her socioeconomic status or other perceived missteps. For example, some Black women who worked as prostitutes or have addictions are shunned by other HIV-positive and HIV-negative persons who have led more traditional lives with jobs and family. BFT is less vocal about intra-group othering, such as Black women living with HIV being marginalized within a community of other Black women.

These issues of shunning and marginalization are important because research suggests that love and support facilitates a person’s healing process. Denise McLane-Davison (2015) states:

Many of the women [living with HIV] described experiencing suffering, including death, and how their love for friends, family, and sometimes their patients became the catalyst for actively engaging in community prevention education and intervention efforts. (p. 10)

This dynamic is evident among Black women living with HIV who experience their illness as suffering and want to share their experience within trusted relationships, then to work actively to help others. Strong relationships provide for many aspects of care that range from personal well-being to activism in the community:

For them, their power was centered in relationships, particularly, in mothering characteristics that extended past their biological roles. Mothering meant teaching prevention education, guiding and referring them toward appropriate health services, nurturing scarce resources, or/and advocacy on the part of their consumer base” (p. 10)

Scholars like McLane-Davison have compiled what we know about Black women’s leadership, particularly aspects that line up with BFT. “Their collective commitment to each other” as she says, “as community leaders was emphasized, as they talked about being side by side with other committed sisters, who provided a reciprocal peer
mentorship and a safe space for them to strategize, take risk, vent, and celebrate” (McLane-Davison, 2015, p. 11). So what is the end game regarding HIV, or why is it helpful to know about African American women’s leadership style when talking about HIV? From a historical perspective, it “can provide a blueprint for the development of future leaders in the HIV/AIDS fight and social service” (McLane-Davison, 2015, p. 11).

To explain further how Black feminist thought enriches relational psychotherapy and moves toward a model of relational care, I look to Phillis Sheppard (2011) as a model for integrating distinctive disciplines of knowing. Sheppard teaches that “[w]omanist theology, psychoanalytic theory, and culture woven together create a stronger framework for listening to and responding to the lived experience of African American women than either can provide individually” (p. 18). The multiple identities of Black women living with HIV are best understood by relational psychotherapy, Black feminist thought, and lived experiences that Black women living with HIV articulate (by telling their stories). Intermingling these three will help theorists to conceptualize a model for relational care.

In Chapter 2, I acknowledged subtle yet important difference between Black feminist and womanist perspectives. Both offer analyses from a variety of perspectives, including the theological, psychological, literary, biomedical, sociological, and many others. Both challenge cultural norms that disparage individuals who appear different from cultural expectations, such as people of color or Black women living with HIV. The two perspectives are dialogical, each pushing the other to consider issues slightly differently. Sheppard (2011) argues that womanist theologians can learn from Black feminist theorists because they historically make more use of psychoanalytic and object
relations viewpoints than womanists. She explains that womanists are leery of affiliating with the founding fathers [sic] of psychotherapy – psychoanalysts whose teachings are embedded with racist, sexist, and heteronormative perspectives. Sheppard suggests that, while womanist scholars tend to focus solely on empowering Black women, increased knowledge of psychoanalytical theories would help us all to understand and root out those inaccuracies found in human development theories that perpetuate internalized hatred.

I should note that Sheppard herself refers to a specific branch of Black feminism—Black feminist literary criticism—when she suggests that womanist theologians would benefit from expanding their understanding. Black feminist scholars in humanities, such as those studying historical fiction literatures, draw from psychoanalytic theories to explore layers of hidden meanings. Sheppard highlights that womanist theologians and Black feminist literary critics both examine literary texts to challenge harmful stereotypes. However, how a Black feminist examines those texts compared to how a womanist does so is what distinguishes the two. Sheppard cites womanist Stacey Floyd-Thomas that the “difference that separates them [womanists and Black feminists] is that literary criticism is not the end point for womanists” (p. 10). In other words, womanist scholars explicate texts beyond the relationship between one’s interior and culture, and here Sheppard is specifically pointing us to how womanists consider and listen-in to Black women’s spirituality and belief in divinity.

Womanist theologians unapologetically embrace the fullness of Black women and our varied experiences, identities, and beliefs in sacred ideas, and particularly the
supernatural, transcendent, benevolent divinity. It is not that BFT does not consider spirituality to be important in theory or practice, but that process is more in the background than the foreground. Collins (2000) states, “[s]tories, narratives, and Bible principles are selected for their applicability to the lived experiences of African Americans and becomes symbolic representations of a whole wealth of experiences (p. 258). Connecting sacred teachings and practices to Black women’s experiences, as Collins describes it, is similar to how womanist theologians (such as Jacquelyn Grant, Emilie Townes, Katie Cannon, Delores Williams) make those connections; however, womanist scholars added credibility by describing their own spiritual and religious experiences.

Black feminist thought and womanist theory clearly inform each other. So why do I choose BFT to be a conversation partner with relational psychotherapy and the voices of seventeen BWH? I am intentional about my choice of BFT because the term itself seems to cast a wider net for inclusion and mutual learning. That is, the term womanist may be a slight barrier to people who perceive the term as an exclusive pivot toward Black women without reference to other women, such as is implied by the term “feminist.” Further, womanists are historically associated with Black Nationalism, parts of whose rhetoric elevates them above other racial groups, such as White people in the US. I want to widen the conversation and engage intentionally and across identities. These would include identities shaped by: race (including biracial and multi-ethnic); sexuality (including lesbian, bisexual, asexual, pansexual, and queer); gender and gender expression (including non-binary conforming, trans*, genderqueer, feminine, masculine,
and androgynous); ethnicity and nationality (including African American, Caribbean, African, Cuban, and Indian American); problems of gender-based violence (including rape, domestic violence, and sex trafficking); and international health problems affecting mothers and children (including poverty, malaria, and HIV). As a psychotherapist, working from a Black feminist relational care perspective, I consult individuals from a range of identities and backgrounds. My blackness and womanhood are front and center, but my relational stance teaches me to hear another person’s experience of devastation and strength (Frederick, 2003). In the study of this dissertation, I particularly seek to hear the experiences of Black women living with HIV as they contend with difficult interactions, limits, and perceptions their identity, often with limited support.

**Black feminist psychotherapy.** Feminists in the field of psychology also contribute to the clinical practice of relationality. Notably, the Stone Center at Wellesley College was created to focus on the experiences of women, children, and families through research and educational outreach. This group of feminist scholars formed a theoretical model called the Stone Center Model and eventually the RCT or Relational-Cultural Theory. Beginning in the 1970s, the Stone Center was initially a small group of feminist psychologists working together to examine and provide better therapeutic practices for female clients.

In the past 20 years, the Stone Center has made efforts to include the voices of other women often not included within the research and theoretical teachings. Beverly Tatum received an invitation from the “The Stone Center Theory Group” whose goals was to gain a “better understanding of the specifics of women’s experiences based on
class, race, age, ethnicity, and gender” (Tatum, 1993, p. 1). Tatum looked closely at the racial identity development of a small group of middle-aged Black college-educated women, and framed that identity development in relational terms to help others, like the Stone Center group, understand issues of race and marginalized groups (p. 1). Tatum inquired about how relational theory fits with this group of Black women:

If, as Stone Center theorists suggest, connectedness is the goal of development, and those connections which are growth-enhancing are mutually empathic and mutually empowering, how do Black women in White communities develop these growth-enhancing connections as they move outside the boundaries of their families? (p. 2)

Embedded in Tatum’s question is the acknowledgement of how racism negatively affects interpersonal relationships regardless of the setting, but especially among groups with a history of mistrust and systemic oppression. Tatum’s question tests or challenges the meanings of relational theory. She goes on to ask:

If mutual empathy requires the interest and motivation to know the other, then everyday racism often, if not always, represents the failure of mutual empathy. As Judith Jordan writes, ‘in order to empathize one must have a well-differentiated sense of self in addition to an appreciation of and sensitivity to the differentness as well as the sameness of another person.’ (Jordan, Surrey, & Kaplan, 1991, p. 29, italics Tatum)

Here, Tatum equates everyday racism with lack of mutual empathy, and racism negates the necessary factors for relationality to exist. It seems that Tatum’s use of “racism” is between one or more individuals, and that racism impairs interpersonal relationships. If a differentiated self contributes to one’s capacity for mutual empathy, what might Jordan and Tatum recommend when racism is embedded in cultural systems, such as employment, housing, and education? How do institutions learn to appreciate differences among the people they serve? Further, how does an organization (i.e. individuals who
make up the organization) mutually empathize with its own employees and the people it serves, especially with a power differential, such as a patient and clinic/clinic staff? One of many challenges regarding racism and relationality, as concepts and knowable experiences, is to learn how they influence each other in multiple areas.

**Black feminism and HIV.** In terms of HIV/AIDS research by Black feminist scholars, the focus tends to be on prevention and intervention through education, empowerment, use of kinship, and or commitment to community (Stewart, 2014). As McLane-Davison (2015) states, many Black women are leading the way in the fight against the spread of HIV, including women living with HIV. Nevertheless, there is little scholarship and literature that shows the work of countless Black women living with HIV who work daily with others and their peers. McLane-Davison, who identifies as a Black feminist scholar, says, “While black women have been engaged as leaders in localized community efforts to address the HIV/AIDS epidemic for the past 30 years, their efforts have been largely unrecognized by mainstream society” (McLane-Davison, 2015, p. 1). In McLane-Davison’s research, she focuses on the Black feminist leadership styles evident in communities responding to HIV crisis. Her research on the leadership styles of Black women in the HIV struggle will be helpful in the discussion of how Black feminism can contribute to HIV care.

Based on historical evidence that Black women often do whatever it takes to help people who are suffering, McLane-Davison refers to the qualities that enable Black women to respond so effectively, such as being maternal and CEO-like. Because Black women have been there for everyone else when help was needed, one might assume that
Black women, regardless of their serostatus, would also provide this assistance for others. “Black women,” says McLane-Davison (2015) “have a history of being intrinsically involved in the welfare of their communities as leaders, organizers, and activists” (p. 1). Yet, their involvement has gone largely unnoticed by the broader population and scholarship. “Researchers have concluded that Black women developed a unique leadership style, in response to being marginalized and devalued as leaders, as well as in consideration of the intersection of race, gender, and class” (McLane-Davison, 2015, p. 2). In short, women’s first response is often empathy towards suffering others. The evidence supports this idea that Black women who offer and receive empathy often do so because they know what it is like to be overlooked. According to McLane-Davison (2015), “Black women who engaged in the early efforts of HIV community work built upon and adapted models of leadership similar to their foremothers of the BWCM and Civil Rights Era, but also in responses to being ‘left out’ of initial community efforts and health campaigns that focused primarily on gay white men.”

The descriptions offered in this literature resonated with my study as well. Participants told of feeling mistreated and unwelcomed in care centers, and of feeling uncomfortable around gay white men and having to seek help outside of their neighborhoods as a result. The tradition of Black women is to do whatever it takes to strengthen their community even if that requires them to go outside of existing structures to help themselves and each other. According to McLane-Davison, this has long been a kind of leadership common among Black women, “Black women’s self-deflated leadership (Abdullah, 2007) centers Black women’s leadership development in African
traditions and as a response to political unrest in the community. Moreover, Black women’s leadership [often is in] response to political unrest in the community. Moreover, Black women’s leadership emphasizes a communal model developed from grassroots efforts” (McLane-Davison, 2015, p. 3).

Based on this analysis, care for and among Black women living with HIV is relational, and it integrates the psychosocial and Black feminist perspectives. Problems persist, however. Ruth Zambrana (2001) says that, when it comes to ideas about how to care holistically for BWH, there are “many solid and innovative suggestions,” but fewer resources are available to implement and “increase access and improve quality of care for women of color in the United States” (p. 357). This is a stark reminder of the complexities associated with care for women of color living with HIV; care cannot be separated from institutionalized oppression. Lynn Weber (1998) says:

Looking at the relational nature of these systems of inequality rather than the differences in ranking of resources that accompany these systems forces us to focus on privilege as well as oppression. Because the one cannot exist without the other, any analysis of race, class gender, and sexuality must incorporate an understanding of the ways in which the privilege of dominant groups is tied to the oppression of subordinate groups. (p. 21)

Early in the AIDS crisis, prominent advocates fought against mainstream views about the disease and HIV stigma; they gave less attention to other systems of disempowerment. Even with these limitations, the cultural resources within marginalized groups “…may develop such tangible resources if they are surrounded by loving family members” (L. Weber, 1998, p. 23). I would add that the community also needs to develop resources that respond to the importance of spirituality to Black women living with HIV.
**Spirituality and Black women living with HIV.** Based on earlier research, we know that spiritual matters are significant for Black women (Mattis, 2000; Younge, Salem, & Bybee, 2010); further, for individuals with HIV/AIDS, regardless of the race or gender, spirituality has profound relevance (Cotton, Puchalski, et al., 2006; Cotton, Tsevat, et al., 2006). But what are the spiritual dimensions of care that matter to Black women living with HIV, or the ways that they themselves experience and define spirituality? Some individuals living with HIV, particularly African American women, manage their illness and quality of life with spiritual practices (Cotton, Tsevat, et al., 2006; Ironson et al., 2002; Lorenz et al., 2005; Woodard & Sowell, 2001). Sian Cotton and colleagues define spirituality as “that which gives meaning and purpose to life,” and they further define spirituality/religion as a “construct that can incorporate both the internal, personal, and emotional expression of the sacred … and the formal institutional and outward expression of the sacred” (p. S5).

Within the field of health and faith, many studies examine the relationship between chronic illnesses, such as HIV, and spirituality (Bower & Collins, 2000; Cotton, Tsevat, et al., 2006; Fitzpatrick et al., 2007; Frenk & Chaves, 2010; Holt, Houg, & Romano, 1999; Ironson & Kremer, 2009). Based on this literature, one may infer that my research participants would define their experiences with each other—their interpersonal closeness—as therapeutic and spiritual. Indeed, pan-African and African American research in pastoral theology and psychology has emphasized the spiritual dimensions of healing (Ali, 1999; Berinyuu, 1989; Masamba & Kalu, 1985; Mitchem, 2007; Nyengele, 2004; Raboteau, 1978; Townes, 1995; Wimberly & Wimberly, 1986; Wimberly, 1991).
These studies suggest the value of spiritually-oriented approaches to care for African American HIV positive women.

In this chapter, I have shown the importance of relational care, especially needed for individuals who have been made to feel marginalized based on their identities. The focus of this chapter has been on discourses regarding relational theories and research in psychology and women’s studies (especially womanist and Black feminist studies). The research reveals the necessity of relational care, and the need for understanding relationality from a psycho-sociological perspective. In the next chapter, the participants explain their medical choices and decisions about where to receive support. In addition, the results help to define relational care as a process in which individuals recognize the full humanity and dignity of each other, often experienced as safety, security, and authenticity. These values do not always connote healthiness; yet these are the values that the women in my study deem to be particularly important to them.
CHAPTER 5

RESULTS: RELATIONSHIPS REVEALED

I say describing myself depends on where I am. In church, I describe myself differently. In social group, I describe myself differently. In politics, I describe myself differently. With my doctor, I describe myself differently. So it depends on which of those areas. I am a black woman who wants to help other people. (Dawn)

The previous chapters highlight the significance of holistic and relational care, and this chapter offers a more nuanced look into the lives of the seventeen interviewees, for whom such holistic and relational care is vital. In this chapter, the reader will be presented with the study’s results and the correspondence of the interview data with the initial research questions and stated goals. Dawn’s statement above subtlety signals emerging themes to be presented. Dawn describes herself in terms of context – church, socio-political culture, and medical settings.

Restatement of Research Goals

The goals of the research were to examine the supportive and meaningful relationships of Black women living with HIV as an aspect of their spiritual, psychological, and overall well-being; to explore forms of care that hold the most meaning and hope for the participants; and to make recommendations for future research and relational care practices. The results suggest that participants have complex ways of receiving support and choosing meaningful interactions, influenced by their own contexts and interpersonal relationships.

Analysis of the interviews reveals several relational themes in the participants’ lives. These can be grouped into two clusters: themes that relate to health care systems
and themes that relate to personal and interpersonal relationships. In the first cluster, three themes emerged that reveal interviewees’ relationships with health care systems: relationship with support groups facilitated by health clinic staff; relationship with trustworthy, accessible, skilled medical caregivers; and relationship with medication and medication providers. In sum, these themes are associated with traditional health systems and institutions required for living with any illnesses, and necessary for living with HIV/AIDS.

The second cluster of themes focus on personal and interpersonal relationships identified by the interviewees as vital for sustaining their health. The themes are: relationship with comfortable spaces and special people, like homes and family members; relationship with self; and relationship with divinity, named in diverse ways.

Themes from relationships that offer intimate support are: relationship with comfortable spaces and special people, like homes and family members; relationship with self; and relationship with divinity, named in diverse ways. These themes emphasize on participants relating to a (physical and interpersonal) space that facilitates safety and comfort, relating to selfhood, and relating to a transcendent being and/or beliefs. These six themes illustrate a multidimensional way of relating to the other.

**Relationships that Offer Institutional Support**

This first cluster of themes reveals how much the interviewees valued relationships with institutional care providers. The interviewees spend time in groups, specifically groups run by community health centers and hospitals in the Boston area. They also describe at some length their relationships with medical caregivers, expressing
gratitude especially when they see these providers as trustworthy, accessible, and excellent in their care. Finally, they speak extensively about their relationships with medication and medication providers, often crediting them with their survival and quality of life.

**Relationship with support groups facilitated by health clinic staff.** One prominent theme is the importance to the Black women living with HIV of support groups facilitated by health clinic staff. The prominence of responses regarding group support is not surprising since many interview questions were designed to understand more about how Black women living with HIV spend time with each other. The surprise, however, was to learn that the women I interviewed gather with other Black women living with HIV largely through formal staff-led helping groups, rather than informal gatherings. The interviewees did not gather on their own with other Black women living with HIV, meaning outside of the groups held in medical centers.

Participants described how formal groups take place in various clinics and other locations in the community, compromised of people with HIV regardless of race or gender or compromised only of other Black women living with HIV. All of the participants were in support groups at various points in their diagnosis, and at the time of the interview. Some of the participants also continue to attend formal gatherings on a consistent basis.

One participant, Nadia, talks about experiences in groups with other people living with HIV and how she preferred groups for Black women living with HIV because they felt like her “sisters.” Compared with other participants, Nadia tended to downplay the
importance of groups at clinic health centers (CHC) as compared with other participants.

However, Nadia attends multiple groups regularly, and the experiences she describe sound helpful. When I asked why she attended groups as often as she did, Nadia said:

The women. The women, I just don't want to be alone I get very emotional. When I go, you don't need to cry. I think that's just me, because I don't be with a lot of them. I be with my kids, I be with my grandkids. I have to be around some womens [sic] -- not a lot, but a couple. (Nadia)

Nadia went on to describe about another group that was exclusively for women living with HIV, but she described her participation in that group as motivated by mild obligation because it was not her favorite group location, the physical meeting room was auditorium style that held more women. Nadia preferred smaller groups. Nadia said,

I love [the group leader] but-- she's known to speak the truth all day. I love the group, I'm in for the gift card, I'm going to be honest with you…. They don't give me much support like [the smaller group] do. I can sit there and just burst my feelings out. You can't do that at [the clinic] because it's a lot of-- it's about 200 women. (Nadia)

A third group that Nadia attends was a small group but co-ed. She said:

The [male group leader] got a small group, I can press that out. I can say that I can really express my feelings, and they sit there and listen to me - but that's a coed group, but this is a women's group and I rather go to a women's group, because I know these ladies in here and they can give me a lot of feedback. (Nadia)

In all three locations, Nadia receives help from groups structured specifically for people living with HIV. The locations provided structure and the presence of professionals. They allowed Nadia to see other Black women living with HIV, receive financial gifts, and get “feedback” from fellow attendees.

The sentiments of Nadia about regularly attending groups at clinical centers, is consistent with those of other participants, such as Aisha. She highlights that groups
have played a large role in managing her health, especially when she was younger, and now she has found a group with other people over the age of 50 living with HIV. Aisha said:

It's at the [clinic] there. We meet like once a month. We have a workshop once a month… most of the group of people there are 50 and over, and I could totally identify with them. Because age matters in how you live with this [HIV/AIDS] as well. So, I didn't think so before, but it does…I've cut out a lot of the groups I was-- I was connected with everything... Every HIV agency. (Aisha)

Aisha shows how the various health institutions have offered groups throughout her life of living with HIV, particularly at the beginning of her diagnosis.

**Relationship with trustworthy, accessible, skilled medical caregivers.** The theme of medical care being adequate and significant to the participant emerges from interviews, which is not surprising given the criterion that women in the study have to be receiving care for HIV currently. The participants had no reservations about describing how much they appreciated their doctors, nurses, case managers, and other medical staff. Referring to the quality of the care, she receives for managing HIV, Erica reported, “To be honest with you, my healthcare is wonderful. It truly is. I am not going to sit here and sugarcoat no lie. My healthcare is wonderful. Right on point.” Erica’s repetition of how wonderful healthcare is shows how satisfied she is. The participants seem to receive care they appreciate and seek in terms of living well with HIV.

Within this same sub-theme of their health care being good, some participants had remained in Boston for the good medical care. To some, that decision seemed to be something of a sacrifice; they wished or would have preferred to be in other places, to be with extended family or for other reasons. One example that reflects the sentiments of
other participants is Tyra’s response. She talks about how much she misses her family and close friends in another northeastern state that is close but not close enough for her to visit as often as she wants. Tyra states:

There are very few people in my life who still hold on to that [being loyal], and unfortunately, none of them are here in Boston. … That was my friend there. They call me from Philly. They want me to come to Philly, and all that stuff, but, the medical care in Boston for the HIV, there's no way in hell I'm leaving. I really don't like it here. I'm unhappy here. I feel like an apple in a bowl of bananas.

(Tyra)

Despite the fact that she feels out of place and uncomfortable in Boston, Tyra so values her health and the quality she receives in Boston that she sacrifices having the loyal support of friends and family. In talking to Tyra, I sensed the longing she had to be in familiar surroundings and among familiar people. I sensed the strength that it was taking for her to remain in Boston for the quality of care that she receives that enables her to stay healthy. It seemed as if Tyra also recognized that being among those friends and family, who used drugs, would thwart her medical well-being. Tyra stated:

One thing about me when I came here, and they [family] had tried to get me here for years. For freaking years, I was strung out. A total of ten years, I was in the streets. My husband kept telling me, "You got to go to Boston. You're HIV positive. They have medical service.” Like 2002, it [Boston] was like paradise. Now, a lot of the stuff is cut. I came at a good time, because a year or two later, stuff started going.

Tyra refers to the time before she moved to Boston and was already aware of her positive serostatus. Tyra’s husband told her plainly that Boston was the place to be for the best medical care. Once Tyra came to Boston, she experienced Boston as a mecca, a “paradise” of assistance for people living with HIV thanks to the available healthcare and other resources. She did not spell out the specifics of what exactly the paradise included
for her, but she identifies that there has been a shift in what was originally offered when she came to Boston and what is available now for people living with HIV. Yet clearly coming to Boston with its healthcare resources gave Tyra hope that she could actually live a long life with HIV. Tyra said:

I never forget going to the [clinic], like the first three months I was here [Boston], and people staying [sic] up saying, "I had it for 17 years." I damn near fell off my feet, and I just stood there crying. And I didn't know you could live with it, and then when I was at that dinner that changed things for me. Oh, I'm going to get clean.

Tyra went to a clinic in Boston for supporting people living with HIV, and was given the hope that she had a chance to live as the individuals met there. The experience seemed to prompt her to seek out help and recovery, and subsequently she had many more experiences of receiving good quality health care through particular professionals and centers. When I prompted Tyra’s to talk about the significantly helpful care that she receives, she immediately named her doctor:

I love him [doctor]...he's seen me come so far. When I first started seeing him, I was just really severely trying to deal with the drug thing. I was so strung out. And I remember him, I would go in and see him and I would tell the stuff and he would jump up, and whatever I needed, he would go talk. It was for a therapist, I told him, "I'd been calling, I can't get in." He'd jump up, "I'll be right back. You go over there right now." He'd make it happen... So he's over there, [the clinic] ...Yeah, and like [if] anything new or innovative happens, he knows. He's very well respected because he's a beautiful person. He's got a good heart. So I would never leave him.

Here, Tyra offers another example of what keeps her in Boston rather than returning to the city in which she feels more comfortable in because of family and friends.

Professionals in Boston definitely cares for Tyra’s health in a significant way. Tyra
appreciates that she has access to a doctor with connections and power to make things happen quickly for her.

Several other research participants also mentioned the clinic’s reputation for good care. For example, although Vera’s doctor was unaffiliated with the clinic, she had heard from people living with HIV that the clinic has “a good team.” The clinic’s additional staff impressed Vera:

They have people there in the office to talk to people once they get diagnosed. At [the clinic], they don't have that. They don't have that. They have the caseworker, yes, they have doctors, yes, that's it. They don't have somebody where if I-- if someone got diagnosed today, they can bring somebody in that's sick, [and ask a professional,] "Can you talk to this person?" They don't have that. (Vera)

Vera’s observations about the clinic, highlights the persona of Boston as a mecca for health care. While she is admittedly disappointed by not having access at the clinic herself, one wonders how comforting it must feel to her knowing that she’s in the area of the US where that kind of care is possible.

Similar to Tyra, Aisha came to Boston from another northeastern US city to Boston to receive medical treatment for HIV. Aisha described a “rough” time in her life when her partner died from AIDS complications and she had to raise their child alone. Aisha said, “When I first moved to Boston, I didn’t really have anyone. I was in this transitional place. As I said, I came here [Boston] for treatment. And then I was in a transitional place, which was for HIV mothers and their kids.” Aisha, too, came to Boston knowing her seropositive status to receive the best possible care for herself, her daughter, and services available to her. Further, Aisha explained some of her thought
processes for choosing to stay in Boston even after being in good health and managing HIV well. She said:

I tell you, Boston has more than anywhere. I used to travel all over the country, with just the medical care, period…And that’s why I’m still here. I did my research going down south to Atlanta. I was going to move to Atlanta. Forget it. What we have here, I mean, we take for granted. (Aisha)

**Relationship with medication and medication providers.** The importance of taking medication cannot be overstated when it comes to a person living with HIV. Medication was readily available to the participants. Everyone in this study reported being at a point in the progress of the disease where their health depended on taking their medication daily. In the examples that follow, participants talking about their own habits regarding taking medication.

I take my medication. I have not yet once missed taking my meds, not once. (Erin)

Yeah, I take my medication between 7:00 and 9:00 at night. My fiancé's also undetectable, so we're good about taking our medication at the same time. (Deidra)

…

She [friend] said she never thought about the virus until we used have to go downstairs and she used to have to watch her [child] take the meds. That's when it would hit her. And so we all would have to go downstairs and take our meds and that's when it would also hit me. (Deidra)

…

I got the best health care…I get my medicines once a month delivered to me. (Deidra)

…

My doctor, my medications. That's the most important. (Deidra)

I’m on one pill a day. I take my pill every day and never miss a day. I used to. But for the past 5 months, I take my pill every day. Me and my husband we take our pill every day. (Aida)

…

I know if I take my medicine, I will live a long life. …
Plus I deal with a pharmacy that brings my medicine to me. They already be in a pack. I just found that place. It comes in a pack and it comes on time. (Aida)

Actually I've realized this like eight months ago, that if I actually took this medication that I am admitting to myself and recognizing to myself that yes, I am positive. So I think-- I know, not I think. (Neffie)

It's fear in the morning, because I need to take my medication. If I don't take my medication, I feel sick (Rhea)

I have to take it, because I use[d] to play with my medications—take medication holidays, skip medication. (Rhea)

I found that out, because I got very sick. Now, I take my medication every day, twice a day—all my HIV medications. (Rhea)

When she [nurse] came out with the two new ones [pills], I was like, "Okay. Now I definitely have to be adherent to his one because it's once a day." And I was overjoyed because I'm like, "Once a day? And only two pills?" Like, "What? After all these years I've had to take five pills twice a day?" And I was just overjoyed like, "Okay, I have to make this work at this point." But it was a struggle for the past—I don't know how many years it has been. It has been 18 years, it's been a struggle. (Vera)

These responses help to answer the research question about the level of access and quality of interactions participants have with medical personnel, health necessities, and key aspects of where participants choose to live based on their health.

**Relationships that Offer Intimate Support**

This second category of questions looks into the themes about care happening in relationally secure places where the participants explain that intimacy or things that are very personal in nature. How the participants are intentional about choosing these places to be comfortable and they identify these relationally secure places is vital to their care and overall well-being.
**Relationship with comfortable spaces and special people.** Words of home, housing, and lodging emerge as the places in which participants feel most comfortable, most authentic, and most safe talking about their diagnosis. The word “comfort” was a part of the prompt to help each participant identify place(s) where she is most comfortable and most true self. Therefore, it is not surprising that the theme of having a place of comfort arises. Nor is it surprising that some participants would name being at home as a comfort-seeking-providing space. Here are some examples that represent the participants’ sentiments.

I definitely feel at peace at home. Home is my serenity, but also [the clinic]. My house is very well right now. (Neffie)

At home. At home, yeah. At home. I’m kind of shy. I’m more comfortable at home. And then around family. (Deidra)

I like being with my family. They don’t know that, because I tend to isolate myself a lot. But when I am around my family, like I'll go to my parents' house and I'll just lay on the couch and that’s my [comfortable place]. (Vera)

Yes, I feel safe in here – at the clinic. Most of the time, If I'm not here at the [clinic], I'm at home. So I have two places, at home and in the [clinic] settings. (Rhea)

When I’m at home. Yeah, when I’m at home. At my niece’s house of course. (Erin)

Home. Because there’s nobody there but me and my youngest daughter and she’s my calm after the story. (Erica)

I like being in my house. I don’t have people bothering me, I don’t have people knocking on my door all the time. I feel very comfortable at home. (Mattie)

We see a good example of how the themes of relating to a healing space and relating to another individual come together in comments from Hannah. Hannah explains to me how support groups have helped her maintain health and overall well-being. She says the
groups helped her so much. When asked about her experience around other women
living with HIV, Hannah says that she tries

To empower them. I try to give them something that was not given to me when I
was diagnosed. Because when I was diagnosed, I was a mess. I was mean. I was
evil. I was sad. I was emotional. In addition, that is because I did not understand
it. Now that I know, I am going to give – if you have it and you do not understand
it, let me be in your world.

In other words, Hannah says she wants to be the helpful individual safe enough for others
living with HIV. Later Hannah says, “I’m not judgmental. Let’s live together and deal
with it. Let’s just do this together.”

Before doing the interviews, I anticipated that participants would talk explicitly
about their preference for being in the presence of other Black women living with HIV.
However, this was not the case. Even though the participants’ were in groups with other
BWH, it was not because they sought out those groups. Their preference not to be in a
co-ed group was more important to them than the racial/ethnic make-up of the group.
Again, Hannah’s response is representative of other participants. She said, “I, myself,
need to be around a variety of people.” Hannah continues:

It might take us a little longer as black females…But as black females, it might
take us a bit to just grasp it. But then, there are some whites, Cambodian,
Vietnamese, Asians, that won’t even let you know they have it. So I try to say
things that keep them in a comfortable place with me. (Hannah)

I think Hannah was saying that non-Blacks in her experience were hesitant to accept their
diagnosis or be comfortable talking to others about it, and that she tried to go out of her
way to make such people feel comfortable around her. She, however, clearly enjoyed
diversity in her groups:
In a lot of the groups that I’m in, for HIV, they consist of Puerto Rican, Blacks, that’s about it, Latinas. I feel comfortable with them to express myself because nobody’s judgmental. Do you know what I’m saying?"

In one group in particular, Hannah illustrates the way she opened up in the group over time:

It took me five years to come to terms with it. Because I could sit in the group and cry, cry, cry, cry when they say one word…After a while, I was like, ‘You know what? You can’t look at me and says, “she’s got HIV.” So I’m not gonna judge that person. I’m going to help them. If you feel you need to cry and you don’t want to come out with yourself, that’s fine. I’m right here with my shoulder for you. That’s how I look at it….But it took me years to get this point…Just, over time being in the groups, I learned to respect that of them as a woman. And I respect your spirituality or your God…You know, if you need to cry about it, like in groups, one of them might be saying something that really hit home for me and I’ll start crying. And they’re crying, so I know there’s some kind of connection…You know, if you need a hug, I’m here…Because at least with us, spiritually, mentally, emotionally we’re not, “Oh, I don’t want to touch you.” Come on, we all got it [meaning HIV][laughter] Group hug! Group hug! [silence] That really hit home for me, and I would start crying. And they’re crying, so I know there’s some kind of connection.

Many participants identified at least one person as their confidant, and one relationship in which they feel particularly comfortable, real, and authentic. Therefore, it is not surprising that the theme of significant relationships emerges. For example, Deidra shares that her important relationship is with her partner and it is clear by the strength of her words that their relationship is a key part of her staying healthy. Deidra and Erica say, respectively:

I really truly believe that if it wasn't for my fiancé I probably wouldn't have been as far as I am right now. I don't think that I would have dealt with it the way that I am. Because me and him are HIV positive we talk about a lot, you know? That's my friend and my buddy and we share a lot …and he brings them [medicine] to me. Without him, I don't think that I would be, truth be told, I don't think I would be as comfortable or be living like I'm living. For some reason, maybe-- I don't know. Because he's helped me a lot. (Deirdra)
Like I said, I love it just me and my daughter. I do. (Erica)

Deidra’s fiancé and Erica’s daughter represent healthiness, comfort, life, and love to them. These relationships are so representative of how every participant described their most significant relationship. Deidra’s description of the meaningful relationship with her fiancé illustrates how relationship contributes to her health a clear choice to be with and around the individual who gives her relational security. See how other participants state this:

Outside, I have maybe one or two people I could talk to, but it’s just mostly my family. Family is the most important. I had friends that turned their back and talk about me and that’s one thing about the stigma with the virus – you can get easily hurt if you’re not strong. People will still try to bring you down. (Deidra)

Most comfortable? I like being with my family…They don’t know that, because I tend to isolate myself a lot. But when I am around my family…that’s my comfort. (Erica)

I just didn't have any support from the church at all. I felt alone, even though I kept going and kept praying and kept [saying], "God, I need You," but I never had anybody to really be there besides my mother. (Vera)

Erin speaks lovingly about her father who was the person she felt most comfortable around before he died. Erin said, “I miss him [father] so much because he just passed away about a year or year and a half ago.” Erin reflected on an experience that reminded her of his care:

At first, I thought he was going to reject me, and then one day I was over at his house making some…cooking dinner—and I cut myself. He jumped up, ran in the kitchen, grabbed my hand just like I was just a little girl. He said, "Just run it under the cold water… No hesitation, didn't put no gloves on, no nothing, and wrapped it up and what not because I cut it pretty bad. He put the gauze around it and taped it up and everything. He said, "You all right now?" He says, “…here are some gloves you can put on it.” I said, "Okay, it's cool, dad [chuckles].” I was like, "You go dad.” (Erin)
**Relationship with self.** How the participants experience themselves varies, but it is mostly as overcomers and as people who have accomplished staying healthy. Overall, they convey self-pride, while occasionally showing signs of internal conflict, consistent with how most people communicate.

I use the descriptor “overcomer” for how participants’ facial expressions, word choices, affect, and voice conveyed their emotions when I asked them at the beginning and end of their interviews to describe themselves. Their responses throughout the interviews illuminate their happiness about their personal progress, and their sense of pride at overcoming difficult times. For instance, one participant, Hannah, spoke with pride about positive changes in her life since receiving her HIV diagnosis and how much she had grown emotionally. She also stated that she is a woman of color:

> I’m proud of who I am. I’m proud to be me. I’m comfortable within my skin. I look at myself every morning, “Girl I love you,” and I look a mess in the morning [laughter]. Cap and all with drool, I love you, [Hannah]…and I do that all the time, every morning. (Hannah)

Hannah’s assertion reflects how she feels about her identity as a person of color. Hannah’s use of the word “girl” was not used in the sense that she saw herself as girlish but rather as a common term of endearment that one might hear among women. Also, she declares self-love and her comfort level of having brown skin. To be clear, Hannah expresses her pride as an embodied female regardless of how she looks physically looks at a given time of the day.

Erica likewise implied that she was proud of her own strength since her diagnosis, and proud of making better healthy decisions concerning her substance use. Erica reported:
I’m stronger. I’m more understanding of my status. I know what I can and cannot do. Before, I’d have just did it [laughter]. Today, I can’t. I’ve got to think before I act. I can’t use. I can’t drink alcohol. I have a slight cirrhosis of the liver. I don’t mind you having a taste, but I prefer you not to if you can help it. And it’s okay, but make it that and nothing else. No problem. I can do that today. I can do that today. (Erica)

I vividly remember sitting across from Erica during the interview when she said the words about strength. Erica spoke many declarative statement – “I’m stronger,” “I can’t use,” and “I can.” The tenses she used are notable, and seem to emphasize that Erica knows quite clearly what she can and cannot do. Also, Erica’s use of “Before” indicates she understands the significance of life choices, such as that abusing substances is bad for her health, and that her current choices by contrast positively affect her health. I noticed from her posture and confident speaking voice that she was proud of the changes she had made to become healthy.

This pleasure of being able to say proudly that one has changed for the better was something I noticed in all of the participants, even if some participants’ word choices were less emphatic than others’ were. Their vocal inflections and phraseology made their words seem almost like a testimony—something I address at more length in the discussion section.

An example of my impressions while listening to participants describe their self-pride is evident from Leeza’s interview. In contrast to Erica, who talked openly about her previous drug abuse throughout the interview, Mattie conveyed her pride of internal growth since her diagnosis, growth quite unrelated to substance abuse. The excerpt below is Mattie’s response to my question about where she feels most comfortable and authentic, a place where she can be herself.
It’s so interesting you said that. I’ve just bought this big plaque. Maybe I’d say [hold hands up as if estimating size] that’s probably six inches. It’s just two letters – B E, and it’s written in writing “yourself.” Probably, within the last three years, I’ve been thinking more of myself becoming a little – I don’t want to say selfish – but have a self-ness feeling I need to take care of me. So I feel a little more comfortable in my skin, even being at – believe it or not – at the shelter. Because it’s just me and I’m with myself, I have become more, I don’t have to prove anything to anybody. I can just be more of me and work on the things I want to work on. (Leeza)

Leeza marks the passage of time when she speaks of the “last three years,” identifying some form of change in herself over time. To validate her point, Leeza recognizes that she is not “selfish” but learning to care for herself. I recall the careful way in which she seemed to choose wording as if she wanted to respond accurately to a question or she wanted to make sure she accurately got her point across. Her care was also evident in her delivery; she would look upward as if she were thinking of something or being reflective.

Mattie’s measured form of speaking was not halting; it seemed authentic and flowed smoothly in conversation over the course of our time together. For these reasons, Mattie seemed to me to be proud of her growth or transformation towards being herself.

Some participants shared more of their internal conflicts about living with HIV. For example, Vera described being in a denial and refusing to take her medication early on after she received. It clearly did not help her motivation that she experienced side effects of the medication that made her not want to take it. Vera said:

Me not taking it seriously because over the years I am like, "If you don't come in here you'll become resistant.” I didn't take it seriously because I felt like they're coming up with all these medications. You hear them in the news, "They're coming up with all these medications.” But all these medications are not for me because of this one is a class for that and I am already resistant to that… [side effects were] terrible. I struggled so hard, and they [physician and nurse] were like, "You have to take it. You have to take it.” I wouldn't take it until I got sick and I was in the [clinic], and I remember feeling calm like, "Oh, think about your
[child], you need to live for your [child].” I called my [relative], and said, "...I can't do this.” She was like, “God is going to give you what you need.” When I was in the [clinic], they gave me the capsule. I wouldn't take it, so the nurse called the doctor [chuckles] and my doctor... he came in and...So I'm like, "Oh my god, God really answered my prayer.” So that made it easier for me because the side effects [weren’t] as bad. I started taking that. I was like, “Okay. Now I definitely have to be adherent to this one because it’s once a day.” And I was overjoyed.

Vera takes us through her challenge of not taking medication and reaching her last chance, and finally being able to take it consistently, for several reasons: the mode of medicine (capsule vs. tablet) was easier for her to swallow; there was the possibly motivating factor of being sick in the [clinic]; she had time to reflect on her role and responsibilities as a mother and realized she wanted more than anything to be present for her child; and she realized that she did not want to let the opportunity to live pass her by.

Vera explains:

Well for me I feel like I don’t tell everybody everything that I’m going through and I tend to...Maybe it’s because of my pride that gets in the way of how I really feel. Like I can tell my boyfriend today, “I’m good, whatever.” But deep down inside, I’m like, “I really need him to hold me. I really need him to listen to what I’m saying.”

And for me, personally, I feel like even though I've learned to take the medication, I still have to get comfortable with being HIV positive because I've dealt with rejection from it. I've dealt with rejection from family, I've dealt with rejection from friends, so trust is a big issue with everybody. With our community, it's like, who can you trust? Who can I cry to when I'm feeling this way? And like I said before, depression is the biggest issue. And people are not going to say that they're depressed. It took me to get to this point, to say that I'm depressed, like, "I'm not depressed.” Even though I used to talk to therapists, but that was because my doctors said, "You need to talk to somebody.” “Okay, I’ll talk to somebody.” But now I see it, like, it's really bad. And nobody is addressing it. Nobody is saying, "How can I help you? What do you need from me?” And sometimes we don't even need much. It's just a resource. “Okay, where can I go to just cry out?”
I notice that Vera used the word “pride” differently from how I use it. Vera used to describe her stubbornness or arrogance in not saying how she really feels. Vera portrays sentiments common among participants, such as both stubbornness towards and vulnerability with health providers, and resistance to taking medication. Vera denied part of HIV identity to the point of being sick and admitted to [the clinic]. Her role as mother does not appear to waver; in her words, the “caregiver” role is present for Black women. Vera clearly associates taking medication with some level of acceptance of her illness. She explains that stigma and rejection have influenced her identity and her relationship to herself affected her identity and relationship to herself and her serostatus. It is not that she is in denial about being sick; she simply has not yet reached a place of living in complete comfort because she knows what rejection feels like. Later on Vera told me that her parents came around and became two of her biggest supports and relationships. The rejection Vera fears from others is likely the rejection she enacts internally where she denies her self-state of illness as if she herself does not deserve acceptance. That Vera HIV+ is worthy of acceptance, not just because she is a caregiver, but also because HIV+ Vera is just as good as the worker, student, etc. is something she has to learn to believe. Until that point, it is difficult for her to see herself as worthy of the best available care. The absence of self-cohesion likely contributes to Vera’s depression because when one aspect of oneself is denigrated, self-states will want to withdraw and avoid doing what needs to be done, whether that is caring for others, or revealing to one’s partner that one is depressed, or that one needs particular things in order to regain good health. In short, such internal conflicts perpetuate relational complexities and hinder healing.
**Relationship with divinity.** Many participants described experiences with other Black women living with HIV as helpful and implicitly spiritual, and even if they did not use the word “spiritual,” the sense of belonging and being cared for that they describe echoes the role we understand spirituality to play in people’s lives. Others described a relationship with God or church, or mentioned their religious beliefs.

Most of the time, though, they spoke about being cared for, and mentioned factors such as the helpfulness of others were identified in formal settings, like local community health clinics and church. Several Boston area health organizations are doing great work to help people living with HIV. The participants affirm how well these organizations help them and how they include elements that resonate with the participants. Nadia recalled a group led by staff at a local community health clinic that met at a church, meaning once for the group at the clinic, the staff person would accompany group members to a church close by to meet. Nadia said:

I'll speak about [the clinic]. [The group leader's] spiritual, she's into church. She talks about the church to us, when we talk. She even gave us the paper with the… what do you call it? "Where to go in the Bible" it’s where we’re connecting. Again, we’re sitting in a church, in a group.

Nadia’s response is an example of how she understands spirituality in the context of other individuals living with HIV. Based on parallelism in her word selection and word order when talking about her group leader, (“she’s spiritual, she’s into church”), she seems to understand being spiritual as having a relationship to church. I recall Nadia as appearing jovial and pleased when talking about her experience of this particular group and its connection to church and spirituality. It was as if she appreciated being a part of a group
for people living with HIV that met in a church, that provided her inspirational readings, and that was led by someone open about her own spirituality.

The benefits of church emerged from the data. Nadia talked about how much attending church adds to her life currently, and about how the church could improve. Nadia stated:

I go to [a predominantly African-American church] with [my friend]. Yes, sometimes I go there-- I go to Bible class. I really need to be with any church, I have to. Every Sunday I go to church.

Nadia appeared adamant about her “need” to be at church, specifically a class setting to learn about the bible, possibly indicating her preference for a teaching setting in which there is teaching and smaller group of individuals than one would customarily find at Sunday worship services. This “need” takes on the feel of other needs of remaining healthy such as, the need to take medication, the need to attend small groups with other people living with HIV, the need for a support system and so on. The benefits of being at church also seems to include connecting with the divine or something sacred or transcendent, and for Nadia these contribute to her spirituality. Nadia goes on to say,

…I love my church, don't get me wrong I love my pastor, but I'm not ready to open up to him. I mean I don't have no problem, don't get me-- I don't have no problem, but I'm not ready. And in a church I go to, I got word that if you say you're HIV, everybody's going to be [voice trails off]. I don't care, I'm not here for the gossip. I'm here to hear the word, and if the pastor accept[s] me, I feel good.

Nadia speaks about acceptance and belonging when it comes to attending church, but she does not depend on churchgoers to encourage her in the area of her health and serostatus. Clearly, she enjoys attending church and feels good enough in the space to return each week. However, she is clearly aware of the negative ramifications if she were to disclose
her serostatus to her pastor or any members. She anticipates that such a disclosure would result not only in gossip, but many other stigmatizing actions that would make her feel uncomfortable with coming to a place that she likes to.

Tyra’s experience of God is representative of other participants who distinguish their understanding of God in pre- and post-diagnosis. They either directly state or imply that the diagnosis changed their lives, specifically that is stopped behaviors that may have increased their risk level of being infected. Tyra explains her past and current relationship with God:

My God is a God of love now. Back then-- it's so funny most of my life, because I grew up in Catholic school, most of my life whenever I thought about God I thought about this picture of Jesus with brown hair and a white robe. I always had that visual in my head and God was a punisher and I didn't know-- I felt that I was being punished to some extent and I didn't understand, so there was a lot of anger and a lot of confusion [after diagnosis]… Back then, when I got tested…because I didn't know God then. In fact I just-- what I feel [is that] I have a relationship with God now that started two years ago with my divorce, this last marriage. That's when I got to know God. (Tyra)

In the exchange between Tyra and myself, Tyra tells me that she used to ask God, “Why do I have it [HIV]?” When I asked if and how God responded to her question, Tyra’s immediate response was “no,” but she later pivoted back to the question and stated that years later she’s accepted that “It wasn’t [her] fault” because she’s a product of her environment and that her troubles stem from her “upbringing.” The question to God about why something like HIV has happened is a fundamentally human question in many circumstances. The question of why is in most of the participants’ responses. Similar to Tyra’s interrogatory lament to God, Dawn recalls a time when:
I said...God, why should this type of thing happen to me? You know? You ask yourself so many questions that you cannot answer and you say why, why, why, why, why, why. That’s it. (Tyra)

Dawn addresses God and herself about her fate of living with HIV. Ultimately, she said, she decided that “Things happen for a reason. So God if it's that I committed sin and this is how I was punished, do forgive me, and make me to live my life like a normal person.”

I recall Dawn saying these words with a smile on her face, as if she had some level of peace about having been forgiven.

Tyra asserts that because of her life experiences, she is a “great friend” and “very good person, very spiritual person, very loving person,” and that she uses her life experiences to help others in similar situations, especially people with addictions and survivors of sexual abuse. She goes on to explain:

My perspective right now – the Lord didn’t have me go through all that to be selfish about it. To me that’s what Christianity and Islam is about. It’s not about a scarf... What Islam, what Christianity, what Christ and Mohammed and Abraham and Moses and all these prophets are about is how you treat other people. Okay, anybody can be soft and be a Christian. I’m not impressed by that. What I’m impressed by is when you walk out of that church and you see somebody out there who’s strung out or whatever. They get scared, they look at you like you got a freaking leprosy. They don’t want to touch it that could be your ass. What separates anybody from being a one step? Everybody one step away from being what they afraid of and what they judge.

In Tyra’s specific situation, she acknowledges the importance of morality in her upbringing, something not only emphasized but also enforced by a Punisher, which is how she understood God. For Tyra, her diagnosis was a turning point and put existential thoughts of life and death, finite and eternity, loneliness and solitude front and center in her mind.
Tyra’s words indicate that in the absence of her spouse and harmful substances she “got to know God.” She accepts the reality of living with HIV from an individual perspective, and feels she has to leave the support she is accustomed to and seek relationship with divinity, who supersedes all things known and unknown.

Tyra’s conviction about how religious people should respond to hurting people is powerful to witness. Her sermonic cadence flowed from her as if she had been waiting for an audience and the opportunity to be heard. Later, she apologized to me for raising the volume of her voice and said, “I need to get this out because for 12 years, nobody has known.” I responded with gratitude for her passion and honesty.

I also noticed that participants talk about God and helpful people in the same breath. When participants speak of individuals, being helpful, many participants attribute their (un)planned contact of running into helpful persons to God and they name God as the change agent and Changer who allowed the interaction to happen. I asked a participant, Dawn, to talk more about her experiences in church, since she named the church as a place in which she feels comfortable. Dawn answers by talking about her understanding of God, saying:

those doctors are good. But to me, I feel like God, God is the Almighty. God always say go this way, you'll see somebody who will help you. And it's God because, if not for God. I was first to go back [home], a friend of mine said to me, let's go to the [clinic]. She said let's go. I said, "no, no.” And we did it [HIV testing] and it came out positive. I know it's God who was pushing me. (Dawn)

Dawn attributed God as urging her, or “pushing her,” to go to the clinic to be tested for HIV. Moreover, part of how God pushed Dawn was by sending her friend. One might ask why Dawn did not simply go by herself, sort of in the company of God. But to
Dawn, it was God who sent her friend to carry out God’s plan. In any case, it is evident that Dawn is in a place of comfort and peace.

When Leeza talked about her spiritual experiences, she typically included descriptions of her own beliefs and practices that encompassed contexts in which there were other individuals, such as church or local clinics and agencies. For example, she said: “Pretty much I would say that I’ve been fortunate enough to just be around very positive people trying to be positive in that. I guess in a sense I definitely believe in God, in that sense [I’m] a spiritual person.” Leeza makes a direct and seamless connection between positive people, belief in divinity, and being spiritual. They are seamlessly related.

Hannah’s description was a bit different. She spoke of her experience in the context of a support group held at a community health center (CHC) with other women of color living with HIV. Hannah watched a group member cry and thought, “Mentally, I’m like, ‘okay I’ve been there.’ So it kind of eases me because I’m not by myself.” Hannah seems to make an internal, spiritual connection with another person, psychologically empathizes with another’s situation, and acknowledges her own state of comfort or well-being. Hannah’s brief thought showed me the simultaneous importance of building space and staff resources as well as relational responses within a group setting. In seeing another group member cry, Hannah seemed to communicate to me a mutuality between them.

Insufficient support. While the primary finding of this research was that the participants did not informally gather with other Black women living with HIV, the lack
of support also emerged. Participants expected to receive help in particular locations and were surprised when that help was not given. Tyra’s comments here are representative of other participants who felt neglected, specifically by members of a church. In what follows, Tyra was responding to a prompt about how her health may be affected by her experiences with a religious group. She said:

It upsets you. Anything that's upsetting-- yes, I've been struggling in my house by myself. I don't have any bathroom tissue. This woman from [church name]- for the past two years, I was a member of church and had just become a missionary and everything. They all know I'm ill. I haven't gotten one phone call. I'm sitting here everyday day thinking, "What did I do to them?" I was in there two or three times a week. Pastor held me after every service, held me, told me how much he loved me. I haven't heard from that Negro since. Even if you haven't seen one of your members in a month, do you not wonder? But I left messages for the assistant pastor. It's very hurtful. (Tyra)

Regarding her health, Tyra identifies stressors that would negatively affect most people’s health such as lack of basic needs like toilet tissue, and being rejected from a place intended to help people who are in need. Other participants likewise felt unwelcomed at churches for various reasons, whether because they were drug users or not, straight or gay.

These results help to answer some parts of the research questions and respond to stated goals, particularly about how the participants judge their interactions with others as influencing, improving, or detracting from their overall care and learning more about the complexities of their relationships that hold meaning and hope. For example, the themes indicate that the participants have positive interactions with health institutions and the care that they provide. I also learned about how participants experience relating to their peers, family members, and those in religious centers and their own homes.
CHAPTER 6

DISCUSSION AND CONCLUSION: THRIVING BLACK WOMEN LIVING WITH HIV

The purpose of this final chapter is to draw insights from the literature and interviews to inform future research and practices of care with Black women living with HIV. The chapter parallels the results in Chapter Five, building on the themes identified there, but focused especially on the contributions and limitations of research to date. The analysis will add nuance to the discussion in the previous chapter, but also shape recommendations for future research and practice.

Overview

The two thematic clusters – relationships that offer 1) institutional support and 2) personal and interpersonal support – illustrate how Black women living with HIV cope, make meaning, and arrange for their relational care (RC). The participants described many meaningful relationships in which they felt comfortable, at ease, authentic, and real. I integrated grounded theory techniques, ethogenic practices, and Black feminist psychology, in order to explain the interpretations that follow in this chapter.

In qualitative data analysis, the researcher tends to use theoretical perspectives to guide the interpretation of emergent themes, as I did with using ethogenic and Black feminist perspectives. However, grounded theory (GT; based on Glaser & Strauss, 1967), which is not a qualitative research method because GT takes into account all data, does not rely on philosophies or theories to guide interpretation. Grounded theory approach leads to constructing a theory, and any modifications to the constructed theory come from
the analytic movement between data and the conceptualized theory (Draucker et al., 2014; Glaser, 2009). Glaser (2014, 2009) critiqued the misuses of GT and noticed how many researchers claiming to use GT, would use philosophical perspectives along with GT jargon sprinkled-in to justify interpretations.

For many qualitative researchers, it is important to name theories and perspectives that help when determining interpretations. Since classic grounded theory is atheoretical, the researcher is concerned with all available data to form patterns, and researcher is not concerned with introducing other perspectives, especially not to comparisons. Glaser (2014) said, “The perpetual debate over which different perspectives are best in various methods is a waste of time not solvable” (p. 11). Glaser (2014, 2009) uses the term “rhetorical wrestle” when he notices a GT researcher incorporating other perspectives in her write up.

Since I did not use classic GT, I am comfortable with introducing other perspectives, such as ethogenic and Black feminist perspectives, to balance out the participants’ voices, and my unintentional biased throughout this study. Black feminist thought is grounded in Black women’s agency, our role as knowers, and the knowledge based on our experiences. Thus, the two clusters, or categories, and the themes within those categories emerged during coding and analyses, based on aspects of grounded theory, ethogenic method, and Black feminist thought.

**Relationships that Offer Institutional Support**

Relationships that offered institutional support took many forms. The results showed that participants spent time in groups, such as support and educational groups,
run by community health clinics (CHC), and they sought a trustworthy location to receive medical care, meaning the City of Boston and, more specifically, their individual HIV care specialist. In addition, the results showed that participants chose key aspects of their care, such as finding a trustworthy location to receive medical care, meaning the City of Boston and their individual HIV care specialist. Also, the participants chose how and from whom they would receive their medications, such as medication mailed to their homes or picked up during a clinic visit from at an in-house pharmacy.

As I referenced in Chapter Four, Black women are disproportionately affected and infected by HIV and generally have poor health outcomes associated with access to medical care (Airhihenbuwa et al., 2002; Allgood et al., 2016; Earnshaw et al., 2013; Feldman & Fulwood, 1999; Sohler et al., 2009). My study seems to reveal something different, which is worthy of further analysis.

**Relationship with support groups facilitated by health clinic staff.** In terms of relating to CHC settings, my study showed that CHC provide good care. Research participants communicated satisfaction with the availability and accessibility of care, in terms of location and ease of transportation. Further, participants observed and appreciated that, when there were gaps in the services of the CHC, clinic staff referred them to other CHC that serve people living with HIV. The results of my study thus revealed positive relationships between Black women living with HIV and the CHCs, which the women experienced as nurturing, knowledgeable about medical guidance, and helpful with suggestions about adhering to medication.
Black women living with HIV from other studies reported finding comfort and a sense of belonging at their support group (Houston, Osborn, Lyons, Masvawure, & Raja, 2015; Thompson & McRae, 2001). The comfort and sense of belonging seemed to prompt consistent group gatherings of participants, and their sentiments were reflected in literature that described such peer interactions as a “major source of support,” for Black women, including those with HIV (Galvan, Davis, Banks, & Bing, 2008; Hall et al., 2012; Houston et al., 2015). Although this theme emerged from my study’s data and literature review, the findings were unpredictable. I imagined that Black women living with HIV might feel uncomfortable disclosing personal aspects of their lives in a formal setting, especially if the clinic used by most people in their community had a reputation for poor service.

Prior to the study, I assumed that Black women with HIV would be less comfortable in medical facilities for many reasons, and possibly due to my background of growing up in smaller towns and spending time in rural areas. Walker (2002) and Miles, Isler, Banks, Sengupta, Corbie-Smith (2011) studied how well rural communities support Black women living with HIV by surveying Black women living with HIV. In general, their results showed that many Black women living with HIV were isolated or did not want to be seen at the only place that accepts people living with HIV. The care of Black women living with HIV seems to vary by geographical location, as discussed in the next section. A recommendation for future studies would be to compare the quality of care in various cities in the U.S., especially those communities with large population of Black Americans. Once we know which cities are resource rich for Black women living with
HIV, the chances increase that BWH will meet in support groups and develop meaningful relationships.

One explanation of why the participants in my study were satisfied with formal support groups may be associated with self-selection bias. In other words, the women who volunteered for the study may have learned about the study at a clinic with support groups for BWH, and therefore the participants would be primed to share their group experiences.

While support groups are credited with positive health outcomes, groups are imperfect (D Comstock, Duffey, & St. George, 2002; Quashie, 2004). Groups will find ways to marginalize someone, or someone will feel othered, or the developmental stages of groups oscillate between connection and disconnection and either thwart or promote building stronger bonds. A closer look at the published research shows that Black women build friendships in the context of less hostility and more approachability, for example in religious settings in which an authority figure (such as a case manager or teacher) introduces Black women to each other to spark a friendship.

Recommendations. An important area for further research is to study what patients find helpful and less helpful from health care providers and facilities. This study has focused on relationships and semi-structured interview questions geared towards relationships between patients and medical staff. I asked very few questions about participants’ experiences with medical institutions overall. Because I did not ask specific questions about the facilities, it is notable that the themes that emerged had to do with women’s relationships with their CHC, locale of care, and medication. The CHCs were
conduits for BWH’s relationships with other BWH, with their medical providers, and with resources that could sustained their health (medication). Future studies could usefully examine characteristics of the support groups to determine what features of these groups are most valued by the women and what features are least valued. Similar studies could be conducted to identify the most and least helpful medical services offered by the medical and community health institutions.

Any discussion of medical institutions and African Americans, or all people of color, cannot understate the historical mistreatment of enslaved Black people (Brandt, 1978; Randall, 2010; Townes, 1998). Medical professionals and institutions misused their power throughout history. Black Americans hold these abuses of power in their communal memory, or Black consciousness. They include sickle cell screenings (1970s), involuntary sterilization (1970-80s), experimentation on enslaved people, Tuskegee Syphilis experiment (1932-1972), experimentation on prison inmates (1962-1971, 1990), and medical justification that Black people were inferior to White people (Randall, 2010). Racism continues to influence systems and institutions, and the destructive power of this racism needs to be identified and eradicated. Ideally, the focus will be on institutional racism so that traditionally privileged individuals will not be frozen in guilt, but will work to fix the unequal systems that remain. In the case of this study, the specific inequalities have do with HIV treatment and prevention.

My study makes recommendations mostly to health care providers. Thus, a limitation of my study is that it does not focus on the broader settings involved in health disparities. My study does suggest the necessity of always including the voices of those
persons whom institutions seek to help. For example, assessments of institutions should always ask for feedback from the patients who are actually using their services.

While the goal of making systemic changes seems broader in scope than changing practices at the micro-level, clinician by clinician, the likelihood that systemic change will actually happen in time to benefit current Black women living with HIV is slim, based on the slow movement of systemic change in the US. More immediate changes can and should happen with individual therapists in order for each patient to receive the best possible care. The broader messages of systematic change cannot drown the need for basic relational care. This matter surpasses the basic level of cultural competency, and beyond having the right assessment tool to ask the right questions. Relational care requires the provider’s interiority, her compassion and authenticity, to be engaged with patients. Regardless of their own race or ethnicity, the individual providers working at medical facilities must engage equally and fully with Black women living with HIV. This largely positive results of this study in regard to CHCs contrasts with other studies about Black women’s association with CHC or AIDS service organizations (ASO). While this study found that Black women living with HIV have mostly positive appreciation for CHCs and committed staff working in them, a larger study of the CHCs is needed if the results are to be generalizable. One next step would be to conduct a meta-analysis of literature on BWH of the last 30 years to see how these CHCs are valued in scholarly literature across a range of disciplines. Another important step would be to increase professional activism, especially to increase opportunities for Black women
living with HIV to engage in policy planning at the local, state and federal levels (DeMarco & Johnsen, 2003).

**Relationship with trustworthy, accessible, skilled medical caregivers.** Similar to the first theme, participants have strong connections to where they receive medical care in the Boston area. The participants frequently cited the importance of their physicians being knowledgeable and comfortable with being around BWH, which is consistent with reported literature. Decade-old research showed that the bonds and connections between patients and physicians, and patients and medical institution are vital for Black women living with HIV to maintain treatment adherence and regular doctor’s visits (Roberts, 2004; Sullivan, Stein, Savetsky, & Samet, 2000).

The location of health care options are key aspects for Black women living with HIV. This surprised me because I anticipated that a person’s family, job, or place of familiarity would most influence where they decided to get medical care. However, what emerged from the study was that participants chose to remain in Boston in order to continue receiving quality health-care, although in many cases participants would like to be closer to family. This choice is presumably because Boston is a leader in medical research, hospitals, medical professionals, quality health care, and health insurance. Also, the City of Boston benefits from the early advocacy of white gay males and the broadening of programs from NYC, such as beginning a Boston chapter of ACT UP-Boston in 1987 with the goals of increasing HIV awareness, improving access to health insurance, and starting the first national online registry for AIDS clinical trials (AIDS Action Committee, 2015). Even though participants overwhelmingly highlighted their
choice to remain in Boston for good medical care, some mentioned the difficulty with other quality of life issues, such as poor housing options, inability to work, and work and unemployment issues, such as HIV interfering with work attendance and productivity.

Robert Burgoyne and Douglas Saunders (2000) offer another reason why some people living with HIV may seek help from clinics. Burgoyne and Saunders found that seeking help is likely influenced by a patient looking for emotional-informational (E-I) support. E-I is one of four supports identified in a social support instrument administered to people living with HIV recently registered at an outpatient clinic, and E-I refers to what gets expressed and offered, where understanding and encouragement get expressed and guidance and information get offered (Burgoyne & Saunders, 2000). Even though this study’s inclusion of women was on the low side at 13% of the sample, it can help providers listen-in closely to the supports that their patients describe. For example, Burgoyne and Saunders found that participants who said they had tangible help, usually are referring to an intimate partner who helps with activities of daily living, and participants who did not have tangible help were less likely to seek help at an outpatient clinic. Therefore providers who notice that a patient doesn’t have assistance at home should be mindful about a patient’s self-care needs and lack of assistance, especially if the patient’s health declines (Burgoyne & Saunders, 2000).

For my study, emerging themes of trustworthiness of CHC and medical care in Boston may indicate that participants seek help at these health care systems because they do receive emotional-informational support from providers and their educational-support
via support group. Also these medical care providers like to make particular effort understand their situations and offer encouragement.

**Recommendations and limitations.** A limitation to this study is the sample size add the specific criteria I used. The results from a larger sample would likely give a more accurate reading of the degree to which individuals choose to stay in Boston for HIV treatment. Also, the participants in this study had to be receiving care currently for HIV by self-report. Future studies would not only increase population size, but also broaden the criteria for participants, collaborating with CHC and medical practices to shape a working definition of “receiving care” other than by self-report.

**Relationship with medication and medication providers.** The participants’ descriptions of how they relate to medication is complex. Many participants share how their relationship to medication changed over the course of their illness. The importance of adhering to medication for people living with HIV is not understated in literature about how to reduce new cases and how to live well longer with HIV (Kremer, Ironson, & Kaplan, 2009; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006). Again, given the alarming statistics of BWH and dying from the illness, one would assume that access to medication was/is an issue – “HIV/AIDS has been one of the leading causes of death since 2000 for African-American women ages 10 to 54. In 2011, AIDS complications were the number one cause of death among Black women ages 35 to 44” (“Addressing HIV Among African-Americans,” 2012).

People commonly say in casual conversations that Magic Johnson is healthy is because he has the money for medication. In the case of Magic Johnson, his financial
resources obviously do assist him in ways that the average people living with HIV does not have. However, participants in this study deny having many problems with acquiring their medications safely, securely, and with discretion because the medications can be mailed to their homes. Further, the social assumption that HIV is not that bad of an illness because of the new medication options is a false way to understand the other things involved in taking medication. The participants explained that medication adherence is not as easy as it might seem. Seronegative people rarely consider in advance the psycho-social-spiritual issues involved in taking medication daily for the rest of their lives, but the interviews show that they do come to realize those issues over time.

**Recommendations & limitations.** I recommend that health professionals promote further collaboration between physicians and other mental health providers at the point of diagnosis, so that medical professionals can work together to support Black women living with HIV and to guide them in taking their daily medicine, which will often make them feel nauseated or experience other side effects (Rintamaki et al., 2006). Individual and group interventions must be available at every stage of a person’s illness. In addition, a study to determine which populations are being missed in medical care and medications would be useful (Stevens & Hildebrandt, 2009). The involvement of family, friends, and peers outside of medical settings also seems to be vital for newly diagnosed individuals if they are to develop regular patterns for medications. Research should be conducted to determine whether or not, or to what degree, a medication buddy might be a helpful support to a Black women living with HIV; this could be a trusted support person, regardless of HIV status. The possibility of being rejected, or having to face other
challenges associated with stigma, are noticeable throughout this study. Perhaps having a support buddy would mitigate those challenges.

In sum, previous research and the literature review demonstrate more variability than what I subsequently documented in the field. Research studies attributed the high incidence of Black women living with HIV to quality and access of medical care. Therefore, I anticipated that participants’ responses would point to poor quality of care and disenfranchisement from health care services. Instead, the women reported satisfaction – and even great satisfaction – with the health institutions from which they receive care.

**Relationships that Offer Intimate Support**

The discussion turns now to the second cluster of themes that center on personal and interpersonal relationships and the intimate support that emanates from them.

**Relationship with comfortable spaces and special people.** The importance of comfortable spaces and special people often appeared together in my interviews. For example, the participants often described areas of comfort as their homes and with their families. They also revealed some degree of agency in selecting spaces of comfort and security. The literature supports the finding that Black women living with HIV have high regard for closeness with family members and their kin, and that, during moments of crisis, family support tends to deepen that connection (Hudson & Morris, 1994).

Most of the participants in my qualitative study stated that their families were currently supportive and helpful to them in maintaining good health; however, they reported immense guilt after receiving their diagnosis and were unsure of whether or
when they would tell family members. For the participants who disclosed diagnosis to their children first, they talked about their immediate concerns and their openness to receiving help from their children. The participants who told their parents about the diagnosis reported that their parents typically were not immediately receptive. Their parents tended to express concerns about extended family members finding out or they made disapproving statements about their daughters’ behaviors that led to them to contracting HIV. However, these same participants who did not having immediately supportive parents, currently have better relationships with them, and they attribute their overall well-being to their parents’ help, especially the participants’ mothers, who often learned more about the illness by reading or attending educational groups.

**Recommendations and limitations.** Many health conditions that necessitate safer places for getting their support, such as alcoholics anonymous (AA), narcotics anonymous (NA), and gamblers anonymous (GA). Would organized spaces like those serve the same efficacious way for Black Women living with HIV? How might family involvement and support be encouraged? One might assume that, if a family member suffers from cancer, the other family members will offer much support; however, when the same Black woman suffers from HIV, the assumption is less obvious.

This study did not ask about women’s mode of infection, although many alluded to how they contracted HIV. Because of the many ways a person might contract HIV, the process of restorative justice may also require CHC or AIDS service organizations (ASOs) to provide opportunities for difficult conversations about hurt, betrayal, and next
steps, between sexual partners, or between family members or friends who want to make amends with Black women living with HIV.

Further, rather than placing the entire burden on the victim, patient, or individual in need of help to address the health care issues and needs, others can also act in helpful ways. Fellow citizens and fellow Black women could sound the clarion call to make HIV a public health priority, not unlike mothers against drunk drivers (MADD) advocating for wearing seat belts in the car and helmets while riding bikes. Fix things for them. However, fellow citizens and fellow Black women could sound the clarion call to make this a public health priority, not unlike Mothers Against Drunk Drivers (MADD) advocating for wearing seat belts in the car and helmets while riding bikes. Such outcries lead to changes in laws and public attitudes, as well as services.

**Relationship with self.** Relating to oneself is an important aspect of living with HIV. Not surprisingly, participants’ have diverse ways of seeing themselves from psychosocial perspectives. Unprompted, participants described themselves before and after they became adherent to treatment, noting especially the release of shame, guilt, and uncertainty after beginning regular treatment. Participants also described their increased comfort level with sharing parts of themselves; however, their language choices, voice inflections, and clarifying questions were clues about ongoing intrapsychic struggles.

Phillis Sheppard and Jessica Benjamin both expand psychological understandings of relationships to include interiority, or our intra-psychic relationships. Other descriptions in the literature emphasize how mutuality and social connections are important to people, particularly people who have experienced trauma, such as Black
women living HIV. Bad news, such as an HIV diagnosis, threatens the homeostasis of the relationships on which most people depend.

**Recommendations and limitations.** One research recommendation is to study typologies of Black women living with HIV or stages of living with HIV, similar to developmental models. For this theme (and undoubtedly others), my personal bias as a counseling psychologist in training informed the judgments I made about participants’ responses in terms of relating to themselves. While not having another entity to respond to my biases and judgments, such as a co-rater to verify my formulation, I was assisted by committee readers in drawing out implicit messages. Further, there may be the limitation of optimism bias or socially acceptable bias in participants’ responses. Were participants trying to say what they thought I wanted to hear? Whatever the case, the participants’ showed interest in this study and were pleased to have been selected.

**Relationship with divinity.** The participants in this study helped to affirm and build on what we know about Black women’s spirituality as defined in previously cited literature. The theme of participants valuing spirituality, in terms of spiritual practices and gathering in traditional places, such as church, is consistent with the majority of the literature that observes that spirituality is a protective factor for people in general, and for Black women specifically (Mattis & Jagers, 2001; Sarvela, Sagrestano, Mizan, Kittleson, & Rowald, 2001). As a reminder, Mattis (2000) says the “lived experience of spirituality” is a “complex interweaving” of experiences that tend to be positive in nature, such as “peace, calm, wisdom, happiness, love, and hope” (p. 112). Participants in this study contribute to definitions of spirituality by highlighting, in their thoughts and
practices, their relationship to divinity. Many of them attend religious services; yet they typically do not share aspects of their health identity with those at services, nor do they seem conflicted about interacting in a religious community, such as church, without sharing a significant aspect of their lives. On the surface, participants’ involvement without sharing with others key aspects of their life could appear to be contradictory because they worship regularly in church, designated sacred spaces, and avoid negative attention by not disclosing their status the way a fellow congregant might share having hypertension or cancer. As noted in the previous chapter, Nadia’s sentiments were about her enjoyment of church services and how good she felt about attending church service each week. Ironically, Nadia’s enjoyment of weekly church services and sense of belonging at church, do not include Nadia sharing that she lives with HIV, either to the pastor or parishioners. Nadia takes an appropriately protective stance of not disclosing her serostatus to churchgoers. Doing so would risk her ability to enjoy service as she has always done, because others would likely gossip, and the stigma of HIV could affect her ability to maintain leadership roles in her church. Nadia’s choice to attend a church regularly, knowing that others attending with her would probably not accept her or treat her well, could be challenging for others in a similar position. Why doesn’t Nadia attend another church that is more accepting of people living with HIV? Why does she choose to enter a sacred space that is commonly recognized to be a welcoming place, but that in praxis does not welcome her as a Black women living with HIV? This complexity and paradox was not something I discussed with Nadia, but I surmise that Nadia would be just fine living with this complexity. As a marginalized person, she is likely familiar with
not sharing with others particularly aspects of her identity, and has likely developed a sophisticated way of being both accepted and unintentionally rejected without signs of internal conflict.

Yet African American women living with HIV who do self-disclose, appropriately, are more likely to see decreased depression and improved quality of life (Vyavaharkar et al., 2011). A similar study about self-disclosure happened in the Democratic Republic of Congo, an area known for having strong faith and Christian beliefs. Maman, Cathcart, Burkhardt, Omba, and Behets (2009) learned that after diagnosis the Congolese women living with HIV turned to their church leaders for prayer and for guidance with how to disclose their HIV status to others.

While participants in my study shared different understandings of divinity, they all spoke of the importance of being in relationship with the divine. Some specifically related to the Judeo-Christian God, some described a higher-power, many uttered the word “God” with frequency as a conversational expression, such as “oh my God,” and others implied an other-worldliness presence in the world.

Some further acknowledged such a spiritual connection with others and having a sense of spiritual belonging. A key theme that emerged was that their changed life, specifically their getting clean and sober because of HIV, was a gift from God. Consequently I suggest that the spiritual practices such as prayer, attending religious services, and communication with a divinity, should continue to be studied in light of Black women living with HIV.
**Recommendations and limitations.** Future research could explore some of the question identified above. Researchers could also explore the possible relationship between spirituality and behavioral patterns, such as adherence to medication or stepping away from drug abuse.

**Insufficient Support**

The seventh theme in intertwined with the other six, but naming the real experiences of insufficient support is critical if we are to understand the experience of Black women living with HIV. Insufficient support can be a problem in the health care systems and in personal and interpersonal relationships. The experience of being unsupported can be especially start in relation to institutions and communities that are typically associated with safe and secure relationships, such as medical care providers, families, and religious communities.

The participants in this study revealed some of the issues that exist presently: the segregation of CHCs and ASOs by neighborhoods and other demographics, and the consequent inequity in resource distribution; inadequate training of health professionals to empathize with the holistic human needs of their patients, and the stigmatization that continues in families, religious, and the larger public. Further resources are needed for Black women living with HIV to receive help beyond the diagnosis, beyond the therapy session, and beyond the doctor’s visit. More adequate training is needed for medical personnel, and more concentrated effort to educate the public, including family of Black women living with HIV and the religious communities to which they often turn.
**Recommendations and limitations.** CHCs and ASOs should continue to increase staff and training, especially peer support, and more opportunities for Black women living with HIV to be paid members of medical staff. CHCs and ASOs should collaborate even more with each other to create programs for Black women with HIV, as should religious communities and other service organizations. What is needed also is further research, including case studies on CHCs and ASOs in order to analyze the communal dynamics more fully.

**Final Thoughts on Limitations and Recommendations**

This study was conceptualized to be an exploratory study, which means it has inherent limitations due to its broad scope, and small sample size of 17 women. The sample is too small for generalizability, but the results were sufficiently informative to suggest the value of replicating this study with a larger number of women in a broader range of geographical locations. Other helpful strategies would be to conduct follow-up interviews with the participants, individually or in focus groups, and to gather demographic information (age, mode of transmission, marital status, substance use history, etc.) in order to study corrections with a range of variables.

Another research recommendation is to increase the scope of the literature review, perhaps by grouping the literature about Black women living with HIV into a central interdisciplinary portal available to all through the Internet. New research about HIV continues to grow, and the more aware we are of other researchers working in similar areas the more our knowledge base – presumably appropriate treatment – will be.
Another area for future research is to study the HIV preventions efforts and the potential role of Black women living with HIV in the work of prevention through their personal witness, their advocacy, and their wisdom about the disease. The present study did not attend to prevention, but prevention and treatment may be interwoven in ways that have not yet been fully studied.

The goal of new HIV research, technology, health care, and prevention is to be sensitive, nuanced, targeted, timely, and efficient. This study focus on 17 Black women living with HIV in the Boston area. I put their experiences in dialogue with compatible scholarship – care practices, psychological theories and practices, and Black feminist perspectives. The findings of this study could enhance all of these areas of thought and practice in the future. In particular, the study of Black women with HIV suggests the importance of care practices in which they are collaborators and part of their own treatment team. It underscores the significance of relational theories in psychological and relational counseling practices. Finally, it reveals the power of Black feminist thought to uncover the vulnerabilities, strengths, and wisdom of Black women.
Appendix A

Request to Recruit Email

Dear [community health clinic] staff,

Hi, my name is Cherita Cloy, and I am a doctoral student in Counseling Psychology and Religion at Boston University studying relationships of black women living with HIV/AIDS. I am currently conducting a study to understand the support that black women living with HIV/AIDS have with each other and how these relationships relate to their overall spiritual and psychological well-being. I would like the opportunity to recruit among the women at your site who will receive a $15 gift card for their participation. The consent form, which is attached, provides further information about the study, along with my contact information. Thank you for your time!

Sincerely,

Cherita Cloy
Doctoral Candidate
Counseling Psychology and Religion, Boston University
Email address
Office phone number
Mobile phone number
APPENDIX B

Informed Consent

<table>
<thead>
<tr>
<th>Protocol Title: Exploring Healing Experiences of HIV-Positive Black American Women: ¹¹ A Qualitative Study of Relational Care Practices and Spirituality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal Investigator: Cherita Y. J. Cloy</td>
</tr>
<tr>
<td>Description of Population: HIV-positive black women</td>
</tr>
<tr>
<td>Version Date: 2/10/2014</td>
</tr>
</tbody>
</table>

Introduction
Please read this form carefully. The purpose of this form is to provide you with important information about taking part in a research study. If you have any questions or need assistance completing this form, including clarification about words that you do not understand, please ask the interviewer.

Taking part in this research study is up to you. If you decide to take part in this research study we will ask you to sign this form and give you a copy of the signed form. The persons in charge of this study are Cherita Cloy and Mary Elizabeth Moore (faculty advisor). Cherita Cloy can be reached at [office phone] or [email]. Mary Elizabeth Moore can be reached at [office phone].

Why is this study being done?
The purpose of this study is to learn how black women living with HIV/AIDS interact with each other inside and outside of traditional settings, such as healthcare sites. I am interested in learning how people experience these interactions and what words they use to describe them.

We are asking you to take part in this study because you are a black woman living with HIV/AIDS over the age of 18 who speaks English as your first or second language. Fifteen to twenty women will take part in this research study.

What will happen if I take part in this research study?
The research will take approximately one hour of your time at a mutually convenient location. Research questions will include questions related to HIV/AIDS. Interviews will be digitally recorded for transcription and further analysis. The interviews will be available to the person in charge of this study, Cherita Cloy, and her faculty advisor.

If you agree to take part in this study, we will ask you to sign the consent form before we do any study procedures.

¹¹ The study’s original title included the word “healing.”
Audio recording
We would like to audio record you during this study. If you are audio recorded it will not be possible to identify you in the audio. We will store these files on USB drives in a locked cabinet and only approved study staff will have access the audio files. We will label these audio files with a code instead of your initials. Only the key to the code connects your initials to your audio file. The researcher will keep the key to the code in a password-protected computer file to be stored for 3 years.

Do you agree to let us audio record you during this study?

______YES  ______NO  ______INITIALS

Storing Study Information for Future Use
We would like to store your study information for future research related to the topic of HIV-positive black women. We will label all your study information with a code instead of your initials. The key to the code connects your initials to your study information. The researcher will keep the code in a password-protected computer file.

Do you agree to let us store your study information for future research related to HIV-positive black women?

______YES  ______NO  ______INITIALS

How Will You Keep My Study Records Confidential?
We will keep the records of this study confidential by keeping study information in password-protected computer files and a locked cabinet. We will make every effort to keep your records confidential.

The results of this research study may be published or used for teaching. We will not put identifiable information on data that are used for these purposes.

Study Participation and Early Withdrawal
Taking part in this study is your choice. You are free not to take part or to withdraw at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential.

What are the risks of taking part in this research study?
You may feel emotional or upset when answering some of the questions. Tell the interviewer at any time if you want to take a break or stop the interview.

You may be uncomfortable with some of the questions and topics in the interview. You do not have to answer any question that makes you feel uncomfortable.
Loss of Confidentiality
The main risk of allowing us to use and store your information for research is a potential loss of privacy. We will protect your privacy by labeling your information with a code and keeping the key to the code in a password-protected computer. Only I, as the researcher, and my faculty advisor will have access to the code.

Are there any benefits from being in this research study?
You may or may not benefit from taking part in this study. Possible benefits include (1) the opportunity to talk about aspects of your life possibly hidden from others in a confidential setting and (2) learning about more resources.

Others may benefit in the future from the information that is learned in this study. This study will be informative for medical professionals and spiritual/religious leaders who care for people living with HIV/AIDS.

Will I get paid for taking part in this research study?
You will receive a fifteen dollar ($15) gift card after the interview, even if you decide to withdraw from the interview early.

What will it cost me to take part in this research study?
There are no direct costs to you for taking part in this research study. You will cover the costs for transportation to and from the mutually agreed upon location of the interview.

If I have any questions or concerns about this research study, who can I talk to?
You can contact us with any concerns or questions. Our telephone numbers are listed below:
Researcher – Cherita Cloy, [office phone, email]
Faculty Advisor – Mary Elizabeth Moore, [office phone]

If you have questions about your rights as a research subject or want to speak with someone independent of the research team, you may contact the Boston University IRB directly at [IRB office phone].

Do you agree to participate in this study?

______YES  _______NO  _______INITIALS

Thank you for taking the time to participate in this study!
## APPENDIX C

### Semi-structured Interview Questions

<p>| 1. | What words would you use to describe yourself? |
| 2. | How would you describe the status of your health? |
| Prompt: | What is an average day like for you? |
| Prompt: | What about your HIV? |
| 3. | Where do you feel most comfortable and at home? |
| Prompt: | Describe the relationships or locations where you feel most like your real self. |
| Prompt: | What about your spiritual or religious community (such as church)? |
| Prompt: | Do you feel comfortable and authentic in your spiritual or religious community? |
| 4. | Describe your experience when you’re around other women with HIV/AIDS. Other black women with HIV/AIDS. |
| Prompt: | Could you describe how your experience when you’re around other women with HIV/AIDS or other black women with HIV/AIDS is different from being with others who do not have HIV/AIDS? |
| Prompt: | How have you experienced other black women living with HIV/AIDS? |
| 5. | How do these experiences make a difference in your well-being? How do these experiences with other black women living with HIV/AIDS contribute to your overall health? |
| Prompt: | Would you describe your experiences in these relationships as spiritual or religious? If yes, how so? |
| Prompt: | Would you describe your experience in these relationships as supportive? If yes, how so? |
| 6. | There are many groups, sites, organizations, institutions that have provided care that may have been important to you. Among those |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>How has your experience with HIV/AIDS influenced your thoughts about spirituality or religion?</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prompt: Do you experience HIV/AIDS as something that you need to understand religiously or spiritually? If so, how has it shaped your thinking?</td>
</tr>
<tr>
<td>8.</td>
<td>What is most important to you about your religious community?</td>
</tr>
<tr>
<td></td>
<td>Prompt: How have you experienced your religious community succeeding well in addressing your experience and needs?</td>
</tr>
<tr>
<td>9.</td>
<td>What is inadequate in your religious community?</td>
</tr>
<tr>
<td></td>
<td>Prompt: How have you experienced your religious community not succeeding well in addressing your experiences and needs?</td>
</tr>
<tr>
<td></td>
<td>Prompt: Have you ever felt stigmatized by your religious community?</td>
</tr>
<tr>
<td>10.</td>
<td>Is there anything that has surprised you the most throughout your experience of your religious community?</td>
</tr>
<tr>
<td></td>
<td>Prompt: Have your experiences with your religious community changed since your diagnosis?</td>
</tr>
<tr>
<td></td>
<td>Prompt: How does that make you feel?</td>
</tr>
<tr>
<td>11.</td>
<td>What is most important to you about your healthcare treatment (such as your PCP, health advocate, etc.)?</td>
</tr>
<tr>
<td></td>
<td>Prompt: How have you experienced your healthcare treatment as successful in addressing your experience and needs?</td>
</tr>
<tr>
<td>12.</td>
<td>What is inadequate in your healthcare treatment?</td>
</tr>
<tr>
<td></td>
<td>Prompt: How have you experience your healthcare team not succeeding sufficiently well in addressing your experience and needs?</td>
</tr>
<tr>
<td>13.</td>
<td>Is there anything that has surprised you the most throughout your experience of your healthcare treatment?</td>
</tr>
<tr>
<td></td>
<td>Prompt: Have your experiences changed since your diagnosis?</td>
</tr>
<tr>
<td></td>
<td>Prompt: How does that make you feel?</td>
</tr>
<tr>
<td>14.</td>
<td>Have you found a community – alternative or complementary to your community – that addresses well who you are, what you’re experiencing, and what you need?</td>
</tr>
<tr>
<td>-----</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Prompt:</strong></td>
<td>What is it about this community that works for you?</td>
</tr>
<tr>
<td><strong>Prompt:</strong></td>
<td>How, in particular, does your participation in this community manage to address your spiritual and religious needs?</td>
</tr>
<tr>
<td>15.</td>
<td>At the beginning, I asked you what words describe you best. How have these descriptions of you changed since your diagnosis?</td>
</tr>
<tr>
<td><strong>Prompt:</strong></td>
<td>Has anything changed regarding the way you think about yourself, in particular as a black woman?</td>
</tr>
</tbody>
</table>
Appendix D

Debriefing Protocol

Protocol Title: Exploring Healing Experiences of HIV-Positive Black American Women: A Qualitative Study of Relational Care Practices and Spirituality
Principal Investigator: Cherita Y. J. Cloy
Description of Subject Population: HIV-positive African American women
Version Date: 2/10/2014

1. After thanking the participant, the interviewer will explain the purpose of the study, the logic, and predictions

   The purpose of this study is to learn how black women living with HIV/AIDS connect with each other inside and outside of traditional settings, such as a healthcare site. I’m interested in learning about your experiences and interactions with each other and how those relationships are important to you from a religious and/or spiritual perspective.

2. Assess possibility of stress or discomfort experienced by participant, by asking participant how she's feeling.

2a. If stress is related to emotions and feelings being activated, such as depression and/or anxiety…

   Sometimes people find that talking about personal topics raise other questions and concerns. How are you feeling? Have you noticed any changes in how you were feeling before you started the interview? If answering any of these questions led you to feel distressed and you want to talk about your thoughts, I encourage you to speak with your individual counselor, case manager, nurse, or physician that you feel most comfortable.

2b. If stress is related to the content of their responses...

   I want to remind you that your responses are confidential and that all results are published anonymously. The audio from our meeting will be removed from this device and uploaded to a password-protected computer that only I have access to and my advisor, as necessary. The notes I’ve been taking will be stored in a locked filing cabinet that only I have access to.

BIBLIOGRAPHY


Centers for Disease Control and Prevention. (2014, March 6). HIV among women
[Division of HIV/AIDS Prevention]. Retrieved from

(Report: Diagnoses of HIV infection in the United States and dependent areas, 2014 No.
vol. 26) (p. 123). Atlanta, GA: Division of HIV/AIDS Prevention, National Center
for HIV/AIDS, Vira Hepatitis, STD, and TB Prevention, Centers for Disease
Control and Prevention (CDC), U.S. Department of Health and Human Services.
Retrieved from http://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-
surveillance-report-us.pdf

participation: A multi-sample comparison. Blackwell Publishing on Behalf of

http://doi.org/10.2307/3177999


Cohen, C. J. (1999). The boundaries of blackness: AIDS and the breakdown of black

Black Scholar, 26(1), 9–17.


http://doi.org/http://dx.doi.org/10.1016/S0140-6736(13)61809-7


http://doi.org/http://dx.doi.org/10.4278/ajhp.120227-QUAN-115


http://doi.org/10.1080/01419870.2015.1058496


http://doi.org/10.1016/j.outlook.2011.05.017


Hull, G., Bell-Scott, P., & Smith, B. (1982). *All the women are white, all the blacks are men, but some of us are brave: Black women’s studies*. Old Westbury, NY: Feminist Press.
http://doi.org/http://dx.doi.org/10.1016/j.whi.2015.03.012


http://doi.org/10.1037/h0079765


http://doi.org/10.1089/108729102753429398


CURRICULUM VITAE

Cherita Y. J. Cloy
cloycyj@bu.edu

Education

Boston University, Boston, MA
Ph.D. Candidate, Counseling Psychology and Religion, 2016
Dissertation Title: Exploring Meaningful Experiences of HIV-positive Black Women
Advised by Mary Elizabeth Moore, Professor of Theology and Education

Vanderbilt Divinity School, Nashville, TN
Master of Theological Studies, 2004
Areas of concentration: Psychology of religion and Women’s sexuality
Immersion trip abroad: Windhoek, Namibia

University of Central Florida, Orlando, FL
Bachelor of Arts, English Literature, 2002
Areas of concentration: Southern U.S. literature and African American literature
Research Experience

**Boston University, Boston, MA**
Doctoral Dissertation Research, 2016
Conducted exploratory research on the relational experiences of Black Women Living with HIV. Conducted semi-structured interview. Analyzed data using grounded theory and ethogenic approaches with the assistance of NVivo.

**Boston University, Boston, MA**
Graduate Research Assistant at The Danielsen Institute, 2009-2010
Advisor: Lynda Morris Parham, Ph.D.
Conducted research on perceptions and activities of black ministers in Boston, MA, regarding mental illness, persons who are mentally ill, and their families.

**Boston University, Boston, MA**
Graduate Research Assistant, Counseling Psychology and Religion program, 2005
Advisor: Professor Marsha L. Cutting
Conducted research study on religiosity scales with the goal to determine reliability and validity among various populations.
Clinical Experience

**Boston University, Boston, MA**
Crisis Intervention Counselor, Sexual Assault Response and Prevention Center, 2013 – present
Provide initial assessment to BU students who experience traumatic events, including but not limited to, sexual and physical assault, traumatic loss, and interpersonal violence. Provide short- and long-term treatment through individual and group therapy based on psychodynamic, relational, and cognitive behavioral therapy. Advocate for BU students by providing accurate information about reporting options and navigating large systems, including higher educational institutions and the legal system.

**Boston University, Boston, MA**
Psychology Intern
The Danielsen Institute, APA-accredited 2012 – 2013
Provided psychotherapy for Boston community adults, specifically individual, couples, and group psychotherapy, under the supervision of licensed psychologists. Areas of focus: women’s development, spirituality therapeutic support group, couples in crisis, pastoral counseling, and life transitions.

**Boston University, Boston, MA**
Counseling Psychology and Religion Practicum Fellow
The Danielsen Institute, 2006 – 2010
Provided psychotherapy for young adults, couples/families, and interpersonal groups. Administered neuropsychological, personality, and ordination testing batteries. Offered weekly, individual and group, spiritual care at comprehensive elder care health centers.
Boston University, Boston, MA
Graduate Practicum Fellow
Psychological Services Center, 2008 – 2009
Provided individual cognitive behavioral treatment to college students with social phobia and depression, under the supervision of a licensed psychologist. Assessed intake clients using semi-structured interview.
Relevant Work Experience

**Boston University, Boston, MA**
Residence Hall Director, The Towers, 2010 – 2012
Successfully managed residence hall with approximately five hundreds domestic and international undergraduate students. Supervised sixteen Resident Assistants, administrative staff, and five student office assistants. Advised student-led Residence Hall Association. Performed conduct hearings for students who violated University policies. Served in senior staff level on-call rotation for Upper Bay State Road residential campus. Presented Residence Life department in University’s 2011 New Student Orientation program. Awarded Hall Director of the Year for 2011-2012.

**Boston University, Boston, MA**
Senior Resident Assistant, Student Residence of 10 Buick St., 2007 – 2010
As part time live-in position, assisted residence hall director in supervising fifteen resident assistants, including supervising, training, and evaluating. Facilitated memorable event planning. Supported resident assistants in conducting roommate mediations.

**The Renewal House (residential treatment program), Nashville, TN**
Spiritual Care Coordinator Intern, 2003 – 2004
Conducted semi-structured spiritual assessments during intake process. Provided individual spiritual counseling. Facilitated weekly spirituality group of 8-10 outpatient and inpatient clients, culminating in successful one-day spiritual retreat. Transported inpatient clients to weekly local worship services.
Professional Involvement

Trainings


Conference presentations


References available upon request