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Aging Women with Human Immunodeficiency Virus: A Narrative Analysis of Stigma

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Aging Women with Human Immunodeficiency Virus: A Narrative Analysis of Stigma

Seja Jackson, Ph.D.

University of Connecticut, 2020

Over 50 % of people living with HIV are over age 50 (CDC, 2019a). Older women face unique challenges due to Human Immunodeficiency Virus (HIV) stigma, which leads to complications including late diagnosis and poorer outcomes. Despite the transition of HIV to a chronic disease, HIV stigma remains.

In alignment with feminist principles, this author used Catherine Riessman's (1993; 2008) method of thematic narrative analysis to illuminate the stories of aging women living with HIV. I interviewed 12 women over 50, aging with HIV. Their stories were individually analyzed and a meta-story of all stories was completed. Individual stories remained whole within the meta-story. This revealed five overarching themes: Persistent HIV Diagnosis Related Trauma: *I Keep It All Bottled Up Inside,* Self-silencing Disclosure: *I Would Take It To My Grave,* HIV Stigma: *It Ain't Goin' Nowhere,* Education: *We Can End the Stigma,* and Resilience Despite Challenges: *I Kick Rocks To The HIV.*

This study helped close the knowledge gap and provided valuable insight for nursing about this population. Nurses can prevent HIV stigmatization and offer safe spaces for such women. They can be aware of ongoing depression. Nurses can support programs, funding, and legislation to end HIV stigma and include HIV care in their curricula. Nurse researchers can explore issues of importance for women aging with HIV. This study provided strong evidence for the ongoing HIV stigma status for women over 50 aging with HIV. The study demonstrated how nurses are critical in the struggle to end HIV stigma.

Seja Jackson – University of Connecticut, 2020

Keywords: *HIV, HIV stigma, stigma, older women, thematic narrative analysis*

Aging Women with Human Immunodeficiency Virus: A Narrative Analysis of Stigma

by

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Aging Women with Human Immunodeficiency Virus: A Narrative Analysis of Stigma

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Dedication

I dedicate this dissertation to my amazing, patient, supportive, smart, and beautiful wife, Setoria. Thank you for entering this journey with me and for supporting me throughout 7 long years. “I’m good all by myself, but you, you make me better,” and I appreciate everything about you. I could not have done this without you. I love you now and forever.

I also wish to dedicate this dissertation to one of my longtime patients, Joanne M., who did not live to see its completion, but who was a champion for all those aging women living with human immunodeficiency virus (HIV). She desperately wanted to tell her story, and I hope that I have represented her in describing what she experienced through the stories of other women. Thank you for teaching me so much and sharing your life with me.

Acknowledgement

To the many wonderful friends, family, colleagues, fellow students, and professors who assisted and tolerated me throughout the past 7 years, I can only try to express how much you meant to me. You kept me sane, gave me good advice, held me when I cried, praised me when I did well, supported me when I was sinking, and most of all never gave up on me. The best advice I received was from Dr. Chela Belcher who reminded me to PERSIST. Each one of you told me you believed that I had something important to contribute. I am so grateful.

I would like to acknowledge and thank the many wonderful people, living with HIV, whom I have cared for over the past years, especially the women who participated in this dissertation, sharing their most intimate experiences with me. You can finally actually call me "Dr. Seja" and be accurate. It has been my pleasure and my blessing to care for you.

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Chapter 1: Introduction

Older women face unique challenges when addressing human immunodeficiency virus (HIV) risk or living with HIV. Myths, misconceptions, and stigma affect rates of testing, adherence to care, and provision of educational material (Beaulaurier et al., 2014; Stewart & Graham, 2013). According to the Centers for Disease Control and Prevention (CDC, 2019a), 47% of people living with HIV are over age 50, which is expected to rise to almost 70% in the near future. Women make up 23% of that population, and of these women, 42% are African American (CDC, 2019b). Older women get tested later, enter care at a more advanced stage of the disease, have lower T helper cells (T cells) — also called cluster of differentiation 4 cells (CD4) — and are more immunocompromised. This process leads to poorer outcomes, including more opportunistic infections, increased hospitalizations, and even earlier death (CDC, 2019b; Ulett et al., 2009; Wigfall et al., 2011). Stigma remains as a barrier to obtaining HIV testing and care for aging women, leading to delayed HIV testing and initial engagement in care (CDC, 2019a; Magnus et al., 2013; Messer et al., 2013; McDoom et al., 2015; Warren-Jeanpiere et al., 2014).

This chapter introduces the research study, *Stories of Women with HIV* (CITE), with the dissertation title, *Aging Women with Human Immunodeficiency Virus: A Narrative Analysis of Stigma*. Background information about HIV and older women, stigma, thematic narrative analysis, and feminist emancipatory social justice theory are presented. The significance, study aims, and purpose of the study are discussed.

Background

In the 1980s, early in the HIV epidemic, most people living with HIV were young men who had sex with men (MSM), African American males, and people using intravenous drugs. In the 1990s, there was a transition to young African American women becoming infected in record numbers (Higgins et al., 2010). The demographics of the epidemic are rapidly changing again. In 2016, approximately 24% of new HIV diagnoses for people over 50 were female (CDC, 2019b).

There are several reasons for this change, including easier to take medications, earlier use of medications, and earlier recognition of opportunistic infections. An aging population, more emphasis on HIV testing, medications for prevention or prophylaxis of HIV (PrEP), and the change in considering HIV as a chronic disease versus a death sentence (Deeks et al., 2013) have contributed to the shifting demographics of the current HIV epidemic in the United States. However, myths, misconceptions, and stigma about aging women with HIV persist. Studies have shown that these fallacies affect the rates of HIV testing, the provision of HIV treatment, and adherence to care for the population of women over 50. The provision of HIV-related educational material is also affected (Beaulaurier et al., 2014; Hillman, 2008; Stewart & Graham, 2013).

Older women who were diagnosed at an early age still feel the effects of stigma. For some women, it may mean inadequate medical care because they do not disclose their diagnosis to all their health providers. For other women, it may mean living in isolation, avoiding interacting with sexual partners, listening in silence when people around them talk negatively about HIV, and experiencing other manifestations of secrecy about their HIV diagnoses.

Stigma

Sociologist Erving Goffman first explored stigma in 1963, examining cases of those rejected and considered abnormal by society. Goffman described stigma in the early Greek and Christian times as physical marks that indicated moral judgment or flawed and damaged persons. Even the marks on the hands of Christ were considered stigmata, a physical representation of His difference from the norm. In the preface to his 1963 writings, Goffman defined stigma as “the situation of the individual who is disqualified from full social acceptance” (p. preface). Goffman (1963) explained the modern concept of stigma as someone being a “stigmatized person” or being a “normal person” with the major concern for social context situated within acceptance. He discussed the use of information control (passing, silencing, concealing, and covering) to avoid the negative effects of people’s stigmatizing conditions (Goffman, 1963).

Presently, society considers physical differences, such as a missing limb or a facial birthmark to be stigmatizing; however, social context issues are inferentially more evident and pervasive, such as claiming a lesbian, gay, or transgender identity (Herek, 2004); being without a home (Belcher & DeForge, 2012); being a prisoner (E. T. Tyler & Brockmann, 2017); or even having an illness (e.g., hepatitis C; Butt, 2008). Most medical conditions can be identified as having an associated stigma, including diabetes (Kato et al., 2016), psoriasis (Parkhouse, 2019), and others. In these situations, stigma is perceived as something *in* the person, as opposed to *on* the person.

In research, stigma has been defined in a multitude of ways, including having no precise definition, Goffman’s original definition, and definitions specific to a particular social context. Jones et al. (1984) and, more recently, Link and Phalen (2001) added to the concept of Goffman (1963) that resultant discrimination is a facet of stigma. New researchers of stigma have addressed stigma as a form of power and control over groups of people with limited power (S. Tyler & Slater, 2018). This issue involves a deeper and broader understanding of the societal norms of power, injustice, social inequalities, and their relation to individuals and groups.

The CDC (2019c) defined HIV stigma as “negative attitudes and beliefs about people living with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable” (p. 1). Presently, HIV is considered a chronic disease; however, HIV stigma stays intact. Researchers have well-documented the experience of HIV stigma in African American women (Fletcher et al., 2016; Jacobs & Kane, 2010; James-Borga & Frederickson, 2018; Sangaramoorthy et al., 2017). Researchers have documented HIV stigma behaviors throughout the health care system (Davtyan et al., 2017; Fletcher et al., 2016; Gagnon, 2015).

For this study, Link and Phelan (2001) defined stigma as “elements of labeling, stereotyping, separation, status loss, and discrimination … in a power situation that allows the components of stigma to unfold” (p. 367). The components include distinguishing and labeling human differences, linking people to undesirable characteristics or negative stereotypes, separation of “us” from “them,” the labeled person’s experience of loss of status, and the experience of discrimination which leads to unjust outcomes (Link & Phalen, 2001). In addition, the CDC (2019c) definition of HIV stigma is used in applying the stigma phenomenon to HIV.

People living with HIV have faced stigmatization since the first days of the epidemic. Society has considered people with HIV outcasts, deviants, and even criminals. They embody all the components of stigma defined by Goffman (1963) and by Link and Phalen (2001). In examining older persons, Goffman (1963) discussed that when people acquired a new stigma later in life, it might be easier to relate to new people rather than previous acquaintances or family. He suggested a “turning point … when the individual was able to sort out his situation and arrive at a new understanding of what is important and worth seeking in life” (Goffman, 1963, p. 40). This finding was consistent with older women’s experiences dealing with the diagnoses of HIV as related in their stories (Buseh & Stevens, 2014).

HIV does not exist in a vacuum. People living with HIV experience multiple structural and intersectional stigmas, including those due to age, race, ethnicity, gender, sexuality, and poverty (Poteat & Wesp, 2019). Stigma has been delineated into various types, such as structural stigma, public stigma, self-stigma, institutional stigma, racial stigma, and several other manifestations. Often, it is difficult to delineate whether an individual stigma or the interaction of one stigma on the other causes a person to be stigmatized or to feel the effects of these stigmas. For example, Sandelowski et al. (2009) conducted a meta-analysis of studies of stigma with HIV positive women and found that neither gender, sexual orientation, nor social class was addressed in most studies. Race was the only category that received attention regarding stigma, and that was primarily addressed by the inclusion of minority women. The study of stigma, especially multilayered stigma, is complex and often confounded by the many factors involved, such as different approaches, different disciplines, and different diseases or conditions being studied. Different disciplines have focused on various aspects of stigma, such as the sociological focus on social effects of stigma in conditions, such as HIV, and the psychological focus on the individual effects of stigma, including mental health. In this context, psychology often conceives of the stigmatized individual as a victim. However, nursing is primarily concerned with a disease-specific focus, such as the stigma of hepatitis C (Butt, 2008); moreover, this disease or medical focus may be due to most nursing being subject to functioning with a medical model. Researchers of HIV stigma have concentrated on attitudes of the non-HIV infected population toward people living with HIV (R. Parker & Aggleton, 2003), although this has recently begun to include some studies of people living with HIV. The study of prejudice and discrimination and concepts related to stigma have focused on certain characteristics, such as gender, race, and sexuality.

Pescosolido and Martin (2015) argued that because of the intricacies of stigma, a systems approach to stigma research, such as the framework integrating normative influence on stigma (FINIS) model, could clarify the complexities. However, even this system method is found embedded in a social context and does not provide an actual conceptual definition of stigma.

Major manifestations of stigma often associated with HIV are *felt stigma, enacted stigma*, and *courtesy stigma*. Felt stigma relates to the fear of being stigmatized. Enacted stigma delineates an actual occurrence of stigma to the person (Lekas et al., 2006). Courtesy stigma refers to stigma by association, such as children of people living with HIV experiencing negative behaviors toward them because their parents had an HIV diagnosis (Scambler, 1998). Currently, there is controversy about the use of the word stigma in research, with some researchers feeling that the use of the word *stigma* is stigmatizing. In 2016, results from a study comparing the use of stigma to the use of the words “prejudice” and “reaction” indicated no difference between the use of stigma and prejudice, while the reaction was found significantly less disrespectful (Sheehan et al., 2016). Based on the evidence of the negative connotation of the word stigma, researchers of the study, *Stories of Aging Women with HIV*, made no mention of the word stigma. Instead, the researchers asked women about difficult situations related to their experiences of living with their chronic disease of HIV. Based on the findings of that study, the dissertation title was named *Aging Women With Human Immunodeficiency Virus: A Narrative Analysis of Stigma.*

Significance

The significance of this study is considered by addressing the issues of HIV and stigma in a population of aging women living with HIV within the theoretical feminist emancipatory social justice context. Despite the increasing number of women over 50 living with HIV, there is little research with this population. The research that does exist suggests more studies are needed, including replication studies (James-Borga & Frederickson, 2018; Psaros et al., 2015; Stoudmire, 2008). The change from considering HIV a terminal illness or a death sentence to HIV as a chronic medical disease has not decreased the stigma in the lay community and even in the medical community (Poteat & Wesp, 2019). This finding is noticeable for older women. A Canadian qualitative study of people living with HIV, most of whom were older, found that stigmatizing behavior in the health care system was often “episodic” and “institutionalized.” The participants felt fearful confronting stigma behaviors and were apprehensive they might not receive appropriate care if they did. They felt vulnerable and powerless in many situations. Participants discussed being labeled as substance users or promiscuous when their HIV diagnoses were revealed during health care experiences (Gagnon, 2015).

The U.S. health care system often overlooks and undertreats women about HIV, and particularly aging women. The U.S. medical education system does not address aging women and HIV. Medical residents are often not taught the CDC or the U.S. Preventative Task Force (USPSTF, 2019) guidelines to screen all people, ages 13 to 65, for HIV, at least once in their lifetimes. Medical residents, primarily young and often male, are embarrassed to discuss sexual issues with older women. Emlet et al. (2002) discussed this behavior when exploring feminist-based clinical practices for older women living with HIV; essentially, the practice has not changed since then. In a study of 703 women taken from the 2010 National Social Life, Health, & Aging Project, only 23.8% of women over 50 stated they discussed sex with their health providers (Bergeron et al., 2017).

Theoretical Foundation

Many older women are diagnosed with HIV when they are hospitalized for another condition, usually respiratory, and found to have pneumocystis jerovocci pneumonia (PJP), formerly known as pneumocystis carinii pneumonia (PCP). This may take multiple hospitalization admissions to determine as HIV is not included in initial differential diagnostic possibilities. Researchers have yet to acknowledge or document these types of experiences of older women and HIV, particularly in a feminist, emancipatory social justice context (Jackson, 2015; Stoudmire, 2008). Women often remain silent; therefore, feminist emancipatory social justice theory is especially valuable in listening to women's own words to uncover/discover their experiences (Belenky et al., 1986; B. Parker & McFarlane, 1991).

Feminist theorists have endorsed multiple ideologies (Harding, 1987; Tong, 1989); however, specific, consistent principles are incorporated within all. Gynocentric research is unique (Tuana, 1989) because it includes three primary elements: (a) the recognition of female empowerment, (b) a focus on women or issues of importance to women, and (c) the nonhierarchical status of researcher and participant. Kagan et al. (2014) provided a framework for utilizing feminist research to inform praxis in work settings and communities. The researchers described feminist emancipatory social justice research as that which interrogates what is believed true, self-reflecting on one's own experiences, encouraging participation by the communities served, respecting the experiences of patients or clients, and advocating for social change (Kagan et al., 2014).

Methodological Foundation

Feminist emancipatory social justice theory, as a foundation in nursing research, particularly lends itself to qualitative methods. Accordingly, nurse researchers have often used

Riessman’s (2008, 1993) thematic narrative analysis method by undertaking qualitative research of phenomena because it permits the story to show the experience of the participant. There are genuineness and emotional depth generated with narrative research, which is limited in other methods. The use of narrative research methods is addressed in detail in Chapter 3 of this dissertation.

Riessman (1993) did caution that even narrative research might be limited in representing women’s experiences. She suggested that sometimes, the available language was insufficient for describing women’s experiences or feelings. Riessman also noted that in much research, the researcher was not of the same race, class, or educational background as the subjects and, therefore, may not allow for a full understanding of the narrative. Remedies of this issue are discussed in Chapter 3.

Study Aims

Researchers have previously documented that the stigma experiences of women living and aging with HIV are not well understood (Jackson, 2015; Stoudmire, 2008); therefore, I conducted a narrative analysis to explore these experiences in more depth through the stories and voices of women aging with HIV. A more personal exploration of such women’s stories provided insight into identifying and challenging the stigmas of aging and HIV in this population. This understanding should enhance the provision of sensitive health care to women living with HIV. Researchers and health leaders could use the findings to provide a better foundation for developing essential HIV education for health providers and for the community to decrease stigma toward this population. Most importantly, health leaders and researchers can use the findings to develop improved health outcomes, such as more effective HIV prevention strategies, earlier HIV testing and diagnosis, fewer hospitalizations, improved mental health, and a longer, healthier lifespan for at-risk and HIV positive women. I provided the unique opportunity for women to uncover/discover their experiences in new ways through their stories and to be heard in alignment with feminist emancipatory social justice theory principles. The findings might inspire personal change, as well as speak to societal change to decrease stigma.

Purpose

As the population of aging people living with HIV becomes larger and more commonplace, understanding this experience for aging women becomes even more important. Aging women living with HIV are often marginalized and dismissed; their experiences, thoughts, and feelings go unheard. The purpose of this study was to bring to light the stories of the experiences of aging women living with HIV and their feelings about these encounters, particularly when stigma was involved. Identifying and reflecting upon those experiences, within a feminist emancipatory social justice framework enables nurses to incorporate this knowledge to change nursing practice.

Conclusion

Understanding the experiences of aging women living with HIV, particularly using the thematic narrative analysis method while maintaining a feminist emancipatory social justice standpoint, allows for nurses and other health providers to empathize in a way that doesn’t happen when there is only silence. Researchers have demonstrated that stigma from health providers occurs for all populations living with HIV (Davtyan et al., 2017), and studies have indicated that stigma remains an integral issue for people aging and living with HIV (CDC, 2019a; Poteat & Wesp, 2019).

I conducted a further study of this phenomenon in this population to provide knowledge to address specific needs to decrease stigma in older women living with HIV. The findings might be used to encourage improvement in medical and nursing education programs, development of new attitude scales for health providers, creation of ongoing community education, and development of social media programs to combat stigma.

Chapter 1 introduced the research of *Stories of Women With HIV.* The background section of this study presented statistics and previous studies to document the need for this study. I explored stigma as a concept and in relation to HIV, aging, and gender. The significance section included the importance of the study, and the theoretical foundation section introduced the framework of a feminist, emancipatory, and social justice standpoint. The methodology of thematic narrative analysis was introduced in the methodological foundation section, as further discussed in Chapter 3. Study aims were elucidated, and the purpose of the study was then presented.

Chapter 2 presents a review of the literature. Chapter 3 describes the method, the research design, narrative analysis in general, and specifically Riessman’s (2008, 1993) thematic narrative analysis. Chapter 3 presents the procedure, including the sample, the research questions, the protection of confidentiality and participant rights, the data collection and analysis, and measurements of rigor. Chapter 4 discloses the results. Individual narratives and themes are presented. The overarching story, including themes and subthemes, is presented. Chapter 5 contains an examination of the significance of the findings, comparing it to previous research findings. The strengths and weaknesses of the study are identified. The applicability to clinical practice, future research, nursing education, and advocacy are then explored.

Chapter 2: Review of Literature

Chapter 2 contains an exploration of the literature from the 1990s to the present, ascertaining what is known and identifying gaps in the knowledge base for HIV stigma and women aging with HIV. Due to changes in the epidemiology of this epidemic, as described in Chapter 1, I found it important to explore the literature regarding HIV stigma and older women living with HIV, from as far back as the early 1990s.

One of the challenges of this literature review was locating studies specifically about aging women living with HIV and their experiences of stigma. More recent studies exploring the experiences of women living with HIV that include aging women are primarily qualitative (James- Borga & Frederickson, 2018; Stoudmire, 2008). Researchers have studied younger women living with HIV regarding concerns about fertility, pregnancy, and childcare, but few have addressed the needs of aging women. Those studies specific to aging women focused on menopause or comorbid conditions of aging, such as diabetes or hypertension (Fantry et al., 2005; Kanapathipillai et al., 2013; Santoro et al., 2007). In the 1990s and the early 2000s, some researchers explored the experiences of living with HIV by including aging women, along with aging men (Emlet, 2007; Foster & Gaskins, 2007).

Procedure

This literature search incorporated online databases, including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Scopus, Women's Studies International, PsychInfo, and Sociological Abstracts. Keywords used for the search included: *HIV/AIDS OR human immunodeficiency virus AND aging women OR older women OR elderly women AND stigma OR HIV stigma OR social stigma.* Modifiers included: English only, North America only, female, middle-aged. A manual search of reference lists and current HIV related journals were also included. Inclusion criteria included the following: focused on aging women living with HIV, addressed HIV stigma, study occurred in the United States. The search was not limited by date; rather the results were stratified to inform three periods in the HIV epidemic; the early years of the epidemic (1990 -1999), the years after medication became available (2000 - 2009), and the years after HIV was considered a chronic disease (2010–present).

Search Results

A total of 29,537 studies were originally located, and 28,897 were disqualified after limiters and duplicates were removed. Eighteen studies were identified from a manual search of current journals. Six-hundred-forty records were screened by title and/or abstract and 555 excluded as not relevant because those either did not meet the inclusion criteria, did not have a significant number of women participants, were not about women, were related to countries not in North America, or were about a different topic (e.g., hearing aids or health aides). This search left 85 full-text records to review. After review for the inclusion criteria, 17 records were deemed relevant and appropriate to this study (see Appendix A). Of the total 17 relevant studies located, 14 were qualitative studies, none were quantitative studies, 1 was a mixed-methods study, and 2 were qualitative dissertations (see Appendix B).

Studies were then sorted into those studies published between 1990 to 1999, 2000 to 2009, and 2010 to the present. Information about HIV, including status, medications, and care guidelines, experienced significant changes each decade. Studies were sorted to acknowledge these changes, and in particular, the status change of HIV infection as a terminal illness to a chronic illness in 2010 (Deeks et al., 2013). No studies meeting the inclusion criteria were published prior to 2000. Between 2000 and 2009, four studies were published; three were qualitative, and one was a dissertation based on a qualitative study. Thirteen studies were published post-2010; 11 were qualitative, 0 were quantitative, 1 was a mixed-methods study, and 1 was a dissertation presenting a qualitative study (see Appendix B).

Published 1990 to 1999

In the years that followed the beginning of the epidemic, the research initiative remained on men who have sex with men (MSM). Older women were still not seen as at risk for contracting HIV, nor did the younger women who were diagnosed with HIV live to an older age. Therefore, the small population of older women living or aging with HIV was rarely included in studies.

An assumption was that many health studies of HIV stigma occurred early in the literature; however, this assumption was not the case for older women. Many articles addressed the stigma of MSM, especially those living with HIV. Many of the studies identified in the 1990s, addressing the issue of HIV stigma, focused on legal and policy issues such as whether HIV was covered by disability, or whether someone could be fired for having HIV infection, and name reporting of HIV test results (Gostin & Hodge, 1998). Several articles included the issue of health care professionals living with HIV or whether health care professionals were legally or ethically required to give care to those living with HIV (Bellani et al., 1996; Elford, 1990; Scheerhorn, 1995).

An exploration of stigma for women associated with HIV was published in 1996 (Bunting, 1996); however, despite the intersectional exploration of gender, poverty, race, and sexuality, there was no mention of age or aging women. Bunting (1996) discussed the concept of women as vectors or carriers of HIV. Bunting wrote that early in the epidemic, women with symptoms of HIV were not identified as having HIV because it was considered a disease "of gay men." Bunting considered that poor women and Black women faced their own particular injustices that prevented early identification of illness and allowed for subsequent stigmas layered on stigmas. Early in the epidemic, nurses and nurse practitioners, who were primarily female, were advocates for people living with HIV. They suggested ways based on their clinical experiences, that earlier identification of women who had contracted HIV could improve outcomes and allow women to have longer and healthier lives. Many of these nurses were ignored or rejected as they were not physicians but “just nurses” (Bunting, 1996, p. 20). The author explored the role of nurses in the HIV epidemic, the societal view of women infected with HIV, and stigma associated with being female, but at this time, aging with HIV was not even being conceptualized (Bunting, 1996).

Researchers focused on women caregivers of people living with HIV (Caliandro & Hughes, 1998) and women who were pregnant or mothering a child with HIV (Holman, 1992; Sacks, 1996). Caliandro and Hughes used van Manen’s method, in a phenomenological study to investigate how grandmothers cared for their grandchildren living with HIV. Many of these women had children who were unable to care for their own children due to substance use, serious illness, or who were deceased due to the progression of HIV. The grandmothers accepted the exhausting work with love and devotion but were constantly aware of the stigma, particularly in the form of bullying that their grandchildren faced if their HIV status became known. Although these older women were not living with HIV, they remained aware of HIV stigma and protective of their families by using proxy stigma management techniques (Caliandro & Hughes, 1998).

Holman (1992) discussed only counseling and testing for women of reproductive age with the focus on risks for pregnancy—a time when there was about a 33% chance that a woman living with HIV would have a baby born HIV infected. Articles written in this timeframe were fairly consistent in identifying women living with HIV as young and having contracted the infection from prostitution or drug use (Sacks, 1996). Sachs (1996) presented a different perspective in her article. Sachs examined how women living with HIV are portrayed in the media. She discussed the characterization of women living with HIV as either virgins or whores, innocents, or despicable deviants. In all cases, the women were seen as “vectors of disease” (Sacks, 1996, p. 20). In no cases are the women depicted as older; the assumption at the time was that they would not survive.

Fear of intimate partner violence on HIV positive status disclosure was also discussed as a major concern. “Fear of mistreatment figured prominently in decisions about disclosing a positive HIV status” (Gielen et al., 1997, p. 29). Gielen et al. (1997) had no participants over the age of 45; therefore, no conclusions were drawn about HIV stigma experiences for women aging with HIV.

Sandelowski et al. (2004) conducted a meta-synthesis of 93 qualitative studies between 1991 and 2002; of these, 61were published, 32 were unpublished reports, and approximately 40% had overlapping samples. The researchers found that both perceived and enacted stigma were ubiquitous in the lives of women living with HIV. Almost 80% of the reports indicated stigma as a finding, and HIV stigma management was the most common reference to stigma in the studies. Only 16 studies with HIV stigma findings specifically investigated HIV stigma while the rest explored the broad experience of living with HIV. All the studies included in the review were of women of “reproductive age,” and aging was not mentioned (Sandelowski et al., 2004). The authors described the key finding of this meta-synthesis in this way: “Stigma is virtually synonymous with the experience of HIV infection in women (Sandelowski et al., 2004, p. 124). Sandelowski et al. (2004) found that the female gender experienced an increased risk for stigmatization, primarily as women are seen as vectors for infection and who can bear and infect children. Sandelowski et al. described that these women had conflicts identifying with MSM who were living with HIV, as they had something in common (HIV status), but they had nothing in common (lifestyle). These younger women had to protect their children from courtesy stigma or stigma by the association of having a mother living with HIV.

No studies of older women facing the stigma of living with HIV were located. This timeframe was still considered early in the epidemic. Medications were just becoming available, and not all people had access to them. Many people were still rapidly progressing from asymptomatic HIV to acquired immune deficiency syndrome (AIDS) and then to death. If we consider this, and, as Sachs (1996) presents, the fact that women were primarily viewed as "vectors of disease" it is not surprising that there are no specific studies exploring the experiences of aging women living with HIV.

Published 2000 to 2009

The epidemiology of the HIV epidemic was slowly shifting. New, more effective medications (protease inhibitors) were now commonly used, enabling people living with the HIV virus to live longer lives. The population of older women living with HIV continues to grow slowly at this time; but, it is still not recognized as important. In this time range, the literature begins to include studies of older adults living with HIV. Although the epidemic was changing, only four studies focusing on aging women were published in this timeframe.

Emlet et al. (2002) conducted a qualitative focus group study of seven women over age 45 to explore women's experiences living with HIV. The women identified the following themes: included a sense of isolation from not knowing other older women living with HIV, not knowing how aging medically effected HIV or HIV affected aging and their acceptance of their diseases over time. However, they did not talk about stigma or discrimination based on their HIV statuses (Emlet et al., 2002).

Another qualitative study explored how older women managed growing older with HIV. In this study, women discussed attending not only to physical health but also to “heart, mind, and soul” (Plach et al., 2005, p. 20) as critical to their well-being. They did not mention HIV stigma as an issue (Plach et al., 2005).

In one of the first studies on the intersection of aging and HIV stigma (Emlet, 2006b), aging was assessed with overlapping HIV stigma in a Venn diagram delineating rejection, stereotyping, and feeling alone or separated (Emlet, 2006b p. 785). Although most participants in the study were men (70%), the women in the study also experienced the same feelings.

Buseh and Stevens (2007) published results from a study of African American women with a mean age of 40, and a high age of 54, which at the time, were considered older for women living with HIV. The study was a longitudinal qualitative study conducted over two years. Women described their experiences of HIV stigma and how they learned to cope with this over time. These resilient women related to resisting stigma, using stigma management strategies, and not allowing either the HIV disease or the HIV stigma define who they were.

Stigma, self-silencing, and other issues for older adults began to be explored as medication use became more extensive, and people living with HIV lived longer. In 2008, a qualitative dissertation study explored older women living with HIV, and their experience of stigma (Stoudmire, 2008). Stoudmire used Black feminist theory to encourage the participants to reveal their true feelings and experiences. The author described several themes, including the existence of stigma, stigma management, depression, and resilience.

Although studies regarding HIV, stigma, and older adults were increasingly published in the early 2000s, these did not focus on older women, unless they were in a comparative study with younger women or men (Emlet, 2006a; Foster & Gaskins, 2009). Emlet (2006a) wrote, “Our knowledge concerning age and disclosure of HIV status is virtually undeveloped” (p. 352). Emlet (2006a) found no evidence to support older adults with HIV would experience more stigma than younger persons. There was no difference noted by gender; however, it was difficult to tease out how many females were in the study (Emlet, 2006a).

In a different study of older adults and HIV stigma, Emlet (2007) found, “HIV stigma is a multidimensional concept” (p. 749). Emlet (2007) highly associated the stigma with depressive symptoms, negative self-image, and limited disclosure. The study was a mixed-methods study; 68% of subjects were male, and 60% of the subjects were White. The author stated that gender was not found to be a significant factor in experiencing stigma, although race was a factor with African American subjects experiencing more stigmatizing behaviors (Emlet, 2007). He did not discuss racial stigma as a structural or institutional stigma layered upon other stigmas. He did mention that it was known that “older gay men” (Emlet, 2007, p. 749) experience ageism anecdotally within their own community.

In 2009, Foster and Gaskins published a mixed-methods study, utilizing focus groups and surveys to explore how older African Americans, living with HIV, manage HIV stigma. Unfortunately, the study sample was 70.8% male, all identifying sexual transmission as the route HIV was contracted, though no mention was made of sexual identity. The results did suggest that this sample employed non-disclosure or selective disclosure as stigma management techniques. The participants in this group also strongly suggested that public education about HIV was needed to decrease HIV stigma.

Multiple studies addressed refinement or development of new stigma measurement instruments (Emlet, 2005, 2006a; Kalichman et al., 2009). Kalichman et al. (2009) evaluated the Internalized AIDS-Related Stigma Scale (IA-RSS) for “internal consistency, time stability, associations with depression and social support, and the scale’s ability to differentiate individuals who have experienced AIDS-related social discrimination (Kalichman et al., 2009, p. 88). They tested this scale in South Africa, Swaziland, and Atlanta, Georgia. Interestingly, in South Africa and Swaziland, women made up 61% and 67% of the subjects, respectively, while in Georgia, this percent was only 23. Age was not a consideration in this study. The study did report stigma findings; however, they did not have the same focus as this study.

There was also a shift in focus to globally relevant articles as opposed to primarily North American articles (Genberg et al., 2009; Kalichman et al., 2009; Wingood et al., 2008). Wingood et al. (2008) examined the HIV stigma and mental health of women living with HIV in South Africa. They did not examine age as a factor, as inclusion criteria limited age to 18-45. They utilized several screening surveys for stigma, depressive symptoms, suicidal ideation, and other indicators of mental health and determined that “HIV stigma is associated with adverse mental health sequelae among black Xhosa women living with HIV” (Wingood et al., 2009, p. 237).

Genberg et al. (2009) studied negative attitudes and perceived discrimination acts in four countries (Tanzania, Zimbabwe, South Africa, and Thailand). They evaluated how these constructs related to HIV testing and the availability of medications across different sites. Negative attitudes and discrimination were highest in places with the lowest testing, the least availability of medications, and with the lowest prevalence of people living with HIV. The authors conclude that this was most likely due to the lack of education about HIV, promulgating misinformation, and fear.

In a meta-analysis of 32 articles addressing the intersectionality of race/ethnicity, gender, and social class as they related to HIV stigma, Sandelowski et al. (2009) provided an in-depth assessment of the state of research on women and HIV stigma through 2009. Sandelowski et al. found that a full one-third of the articles focused on mothers disclosing their diagnosis to their children (gendering), and none were focused on aging women. The researchers identified the concern that simply including African American or minority women research subjects should not be considered sufficient to address the interactions and intersectionality of various factors (e.g., race, gender, sexuality, socioeconomic status, etc.). Additionally, the majority of the articles they reviewed focused on HIV status disclosure and not on the actual experience of HIV stigma or the intersectionality of HIV stigma (Sandelowski et al., 2009). During this timeframe, women continued as an increasing part of the HIV epidemic, and HIV stigma began being addressed by all people living with HIV; however, little research was conducted on the population of aging women living with HIV.

Published 2010 to 2019

Considering HIV as a chronic disease and not a terminal illness begins taking hold in 2010 (Deeks et al., 2013), and is maintained to the present time. New medications with minimal side effects that are taken as one tablet once a day allows many people living with HIV to lead full lives. Research continues to explore all aspects of living with HIV disease, including studies focusing on identifying a cure. Qualitative research is now considered an effective and accepted way to study issues such as HIV stigma or aging with HIV and is performed and published more often. During the years 2010 to 2019, eleven qualitative studies of older women are published in addition to a qualitative study of a dissertation, and a mixed methods study.

Though still limited, recent literature shows an increase in studies including significant numbers of middle-aged or older women as subjects or participants (James-Borga, 2013; Psaros et al., 2015; Teti et al., 2010; Warren-Jeanpiere et al., 2014). These studies were primarily qualitative; however, they used a wide variety of methodologies to investigate the experiences of older women living with HIV, including stigma experiences. Teti et al. (2010) used intervention groups that were similar to focus groups on exploring the experiences of women living with HIV, whose average age was 43. This study was part of prevention for HIV positive people program, which compared prevention messages from three sources for effectiveness. The investigator's analyzed the data using "two strategies derived from grounded theory: coding and analytical memo writing" (Teti et al., 2010, p. 208). During the intervention discussions, participants described types of social discrimination. The authors concluded that poverty, gender discrimination, and AIDS stigma were felt as social discrimination and led to significant depression. The authors suggest that more investigation of the intersection of these conditions needs to be done to better understand the interactions and the role of each condition (Teti et al., 2010).

James-Borga (2013) used the approach of van Manen to describe the experiences of 10 African American older women living with HIV in a phenomenological dissertation study. The researcher related their experiences of stigma and their use of stigma management techniques. She identified an overarching theme of self-transcendence supported by seven essential or subthemes:

1. knowledge as empowerment, concealing while revealing, dealing with HIV stigma,
2. responding to one's emotional life, maintaining rationality, caring while being cared for, and

3. self-transcending adversity and becoming. (James-Borga, 2013, p. 29)

Warren-Jeanpiere et al. (2014) used focus groups to assess how women aged 50 to 78 managed their HIV condition and found that these women were not focused on stigma or discrimination. Twenty-three women attended one of 5 focus groups that consisted of 3 to 7 participants. These women expressed that they were happy to still be alive, taking advanced regimens of one pill a day, and feeling good. Many related that this exceeded all their expectations of having HIV infection. These women suggested that caring for their other medical conditions such as diabetes, cardiac disease, or cancer was far more complex and difficult; then it was to care for their HIV disease. Their stresses came from multiple responsibilities such as work or caring for grandchildren, and poverty or lack of health insurance. Loneliness played a prominent role for single women as they felt that living with HIV made it more difficult for them to meet new partners. Four central themes emerged from this study including: “taking it one day at a time, age ain’t nothing but a number, forget the single life, and daily life struggles” (Warren-Jeanpiere et al., 2014, p. 20).

Psaros et al. (2015) used semi-structured interviews, analyzed with a grounded theory approach, to explore the experiences of 19 women aging with HIV. They discussed their uncertainty about how the course of HIV would affect their lives as elderly women. Some women shared how, over time, they had come to accept their diagnosis and shared their strategies for living healthy lives while aging with HIV infection. They were not directly asked about stigma, but several women shared their thoughts about their experiences of HIV stigma and how to overcome HIV stigma for a better future (Psaros et al., 2015). This follows the pattern that Sandelowski et al. (2009) identified in their meta-synthesis.

Conducting more studies of older women living with HIV is useful in assessing if there is consistency between study findings and if the experience has changed over time. The studies of James-Borga (2013), Psaros (2015), and Warren-Jeanpiere et al. (2014) showed consistency and coherence in the findings. The findings showed the persistence of HIV stigma, aging women's creativity in stigma management, and their abilities to rise above the situation to live happily with fulfilled lives.

International studies focusing on women and HIV were more prominent (Medema-Wijnveen et al., 2012; Renesto et al., 2014), though most continued to focus on younger women. Medema-Wijnveen et al. (2012) discovered that one of the major influences for young pregnant women in Kenya, living with HIV and choosing to deliver their babies at home, was the fear of stigma from the health care institutions and the fear of lack of confidentiality. Renesto et al. (2014) explored the situation for younger women living with HIV in Brazil and found that stigma was ongoing in that society, leading to limited diagnosis disclosure. The participants in this study also discussed the institutional stigma found in the health care system, which led them to resist obtaining appropriate medical care (Renesto et al., 2014).

Underlying Concepts Discussed in the Literature

Examining the literature revealed several concepts that were underlying the research on HIV stigma and women aging with HIV. Stigma management, intersectional stigma, and resilience were prominently discussed in the literature. The next sections will examine these concepts, as presented in the literature.

Stigma Management

Stigma management describes the actions that people take to avoid being stigmatized. It involves a complicated thinking process to decide to whom and when a person living with HIV will disclose their diagnosis. Stigma management has been seen as a tool of information control (Goffman, 1963; Sandelowski et al., 2004). Goffman makes the separation between discredited (visible condition) and discreditable (invisible condition) and how stigma is managed differently for each. He suggests various methods of information control such as passing, covering, presenting limited or even untrue information, and denying certain information (Goffman, 1963). Joachim and Acorn (2000) present a framework for decision-making about disclosure of diagnosis based on the visibility or invisibility of a medical condition. They discuss the different thought processes that are involved in this decision. They suggest that understanding the process of stigma management is important to nurses, as patients will often want to discuss how to control their stigma revealing disclosures with nursing staff (Joachim & Acorn, 2000). As the treatment of HIV has changed, people may no longer have easily identifiable, visible manifestations, such as wasting syndrome, Kaposi's sarcoma lesions, "Crixivan belly," and facial lipoatrophy. People currently living with HIV may only take one small pill a day, which can be done without attracting any attention. Therefore, people living with HIV may be able to "pass" as negative if they do not purposefully disclose their diagnosis. Stigma management weighs the risks and benefits of revealing their diagnosis to any particular person or group of people.

"Stigma management," primarily achieved by non-disclosure and disclosure decisions, was a prevalent theme in a qualitative focus group study of older adults living with HIV (Poindexter & Shippy, 2010). The study included two groups of older women (*n* = 14); one was all African American women. A grounded theory framework was used to analyze the transcripts of the focus groups. Although the intention of the focus groups was to discuss social network development, much of the conversation was centered around HIV disclosure, HIV stigma, HIV stigma management, and what they termed HIV stigma resistance. Some women in this study used activism and knowledge to combat stigma in what they believed was a positive manner. Making choices to eliminate negative elements in their lives, being open about their diagnosis, and teaching others about living with HIV, were all seen as resisting HIV stigma (Poindexter & Shippy, 2010).

A 2013 phenomenological study also found that women managed stigma exposure by limiting and careful screening of revealing their diagnoses (James-Borga, 2013). Grodensky et al. (2015) used semi-structured interviews for a qualitative study of 15 Southern women, over age 50, to assess information on "the psychosocial aspects of their lives," as it related to the diagnosis and management of HIV (p. 13). These women reported limiting their social interactions to prevent having to disclose their HIV diagnosis, which caused them shame. They took strength in their spirituality; however, many did not reveal their diagnosis to other church members or even to pastors or ministers (Grodensky et al., 2015).

McDoom et al. (2015) conducted a qualitative study of 20 African American women over age 50, exploring HIV stigma in relation to social support and medical care participation. They discussed how women might or might not engage in care based on what perceived stigma experiences they previously had or anticipate they might have when engaging in care. Women managed some social situations by determining if disclosing their HIV diagnoses might net them more support, such as from family, or less support, such as from medical providers (McDoom et al., 2015).

Some older women managed stigma by volunteering as HIV support group leaders, working in prisons to educate inmates about HIV prevention, or just helping those with fewer resources. This gave them a sense of being a valuable person and allowed them to disclose their diagnosis at their own choosing, thus, minimizing the stigma (James-Borga & Fredrickson, 2018).

Another way that many women managed their stigma experiences was to concentrate on staying physically and mentally healthy. Despite the uncertainty of how their lives might be affected by aging with HIV, focusing on good health seemed to provide support to deal with their fear of and experiences of stigma (Psaros et al., 2015). Some women aging with HIV, describe a feeling of "empowerment and fulfillment" when deciding to manage their HIV stigma by disclosing their diagnosis (Shen et al., 2019).

Intersectional Stigma

Intersectional stigma occurs when multiple factors such as age, gender, race, sexuality, socioeconomic status, religion, and many other factors that interact and impact upon each other to create unique stigma experiences. Bunting (1996) discussed the impact of gender, sexuality, poverty, and race as these stigmas interacted with HIV stigma. She described how gender carried its own social norms that led people to view any woman with HIV as either promiscuous or using intravenous drugs. Race then becomes layered on this stigma. Black women living with HIV are seen as hypersexual, and Latina women living with HIV are seen as unworthy and illiterate immigrants. Each stigma becomes layered on top of the other, increasing the effects of the individual stigmas (Bunting, 1996). Shen et al. (2019) examined intersectional stigma in older adults and concluded that different stigma origins allowed for differing levels of discrimination and differing strategies for stigma management as a result.

Researchers have struggled to show the contributions of the various factors that influence stigma, and, many times, the impact is compounded by the multifactorial structure. Older women living with HIV often experience this type of stigma, particularly if they are also Black and living in poverty (McDoom et al., 2015; Sangaramoorthy et al., 2017; Subramaniam et al., 2017). However, Shen et al. (2019) found that “women seem to experience the deleterious effects of HIV stigma the least among all group(s) studied” (p. 146). The reasons for this are not explored in this study but could potentially include better utilization of resources or social supports, less self-disclosure, or more resilience. More research is needed to clarify this finding.

Lekas et al. (2006) examined the stigma experienced by women in the pre-HAART era (1994 to 1996) and the post-HAART era (2000 to 2003) and identified issues of race, ethnicity, and gender as persisting in the experience of stigma particularly felt stigma. Stereotypes from both within and outside their own communities contributed to the HIV stigmatization these women either experienced or feared. Stigmatization remained high even in the post-HAART era, although medical provider stigma was perceived to have decreased (Lekas et al., 2006).

Poverty, race, and fear of HIV stigma all interacted with a group of older Black women in accessing care and in their connection to social support systems. Fear of institutional HIV stigmas such as labeling a clinic chart with “person with AIDS” (PWA) or the name of the clinic such as Infectious Disease Clinic, was identified as preventing women from obtaining medical care (McDoom et al., 2015).

Several recent researchers have examined intersectional stigmas, such as HIV, race, gender, economic status, institutional, and structural stigmas, as well as HIV status (Sangaramoorthy et al., 2017; Shen et al., 2019). The experience of stigma for older African American women living with HIV has been described as persistent and intersectional (Sangaramoorthy et al., 2017). Stigma remains high in the community, the workplace, and institutional structures such as health care facilities. However, as women aged, they developed increased coping mechanisms to prevent these stigmas from deleteriously affecting their lives and demonstrated great resilience. Some of the women in the study discuss the disrespected status of HIV in the community when compared to illnesses such as breast cancer. The need for education to change stigma related to HIV was also expressed (Sangaramoorthy et al., 2017). This contrasts with a study by Shen et al. (2019), who conducted four focus groups with population-specific participants (MSM, heterosexual men, female gender, and Spanish language speaking only). The group leaders asked eight predetermined questions to stimulate dialogue, but they did not use the word stigma in any of the questions. The authors found that women did not experience aging as an added stigma to their HIV stigma experiences. In comparison, aging men in the same study did feel that aging imposed a negative and additional stigma to their HIV stigma (Shen et al., 2019). The stigma of aging was particularly felt by aging MSM compared to all other groups.

The belief of many medical providers that women over age 50 do not have sex or only have sex with a married partner and therefore are not at risk for STDs persists. This leads to older women being less likely to obtain STD or HIV screening (Frazier et al., 2018). This is one example of how the intersectional effect of age and gender as it relates to HIV prevention affects care given to aging women.

Resilience

Researchers have described resilience in a variety of ways, such as relating to a person’s ability to “function adaptively following a traumatic experience” (Dale et al., 2015, p. 3). Many factors likely interact to determine resilient functioning, such as personality characteristics, genetics, social situation, coping strategies, and other unidentified factors (Dale et al., 2015). Often it is seen in a positive manner as someone overcoming challenges and difficulties. As in the study conducted by James-Borga (2013), resilience may be called by other names, such as self-transcendence. Resilience is a phenomenon that has been identified in the literature as one of the strengths of women aging with HIV (James-Borga & Frederickson, 2018; Rice et al., 2019; Subramaniam et al., 2017; Warren-Jeanpiere et al., 2017). Women use resilience to recover from receiving their diagnosis of HIV to coping with their diagnosis of HIV and living a rich life with positive feelings and gratitude for each day.

As early as 2005, older women began to describe the ways in which they coped with their diagnosis of HIV as addressing all their needs, including emotional, mental health, and spiritual (Plach et al., 2005). These descriptions showed the resilience that aging women living with HIV continue to articulate in more recent studies. They spoke about the importance of taking their medications, adhering to medical regimens for all their health needs, eating healthy and nutritious foods, getting enough rest, and exercising. They described a reliance on faith and spiritual health. A common description was that of putting oneself first. Many women revealed that they believed if they looked young and healthy and were active and happy, then no one would suspect that they were living with HIV (Plach et al., 2005). Many older women in the current studies stated that they were happy to be alive and took joy in every day and everyday events such as playing with their grandchildren or going for a walk in the sunshine.

Hypervigilant awareness of HIV stigma, using knowledge to combat HIV stigma, and transcending HIV stigma with resilience were significant findings in a 2013 dissertation study (James-Borga, 2013), and a subsequent article describing the phenomenological investigation of the lives of 10 African American women over age 50 (James-Borga & Frederickson, 2018). Subramaniam et al. (2017) described findings of optimism, self-acceptance, and overall resilience of eight African American aging women interviewed in their grounded theory study.

They found that aging seemed to have a positive effect on how the women coped with their HIV diagnosis and their life challenges (Subramaniam et al., 2017).

Consistent with these studies, older African American women attending focus groups suggested that they were learning how to put their own needs first, to enjoy life, and to cope with the stigma that exists when living with HIV (Warren-Jeanpiere et al., 2017). Warren-Jeanpiere et al. (2017) suggested that "the findings of participants' optimism within HIV chronicity stands in stark contrast to research that purports that, over time, chronically ill people may begin to question their own self-worth and view their limitations as losses" (p. 399). Moreover, Frazier et al. (2018) compared younger and older women in a quantitative study assessing HIV viral load, screening for STDs, adherence, and depression. Although not directly examining stigma, the findings add to the understanding of some of the differences between young and old women. Older women were actually less likely to be depressed and more likely to have undetectable HIV viral load results (Frazier et al., 2018). These findings were consistent with many of the findings that older women have developed strong resilience over time.

Some relevant studies did not limit the age range to women over 50 but provided a structure for understanding HIV stigma in these women's lives. In a mixed-methods study investigating treatment adherence issues, approximately 60% of the participants were HIV positive women over age 50 (Rice et al., 2019). Rice et al. (2019) had participants who identified multiple stigmas as influencing their lives, including HIV stigma and HIV stigma in health care settings; however, these participants still described resilience and strength in dealing with their diagnoses.

Conclusion

Despite the limited number of studies focused on HIV and aging women, epistemologically, I identified that HIV stigma remained a major concern in the literature. When compared with literature from as early as the 1990s to 2010, the identification of HIV stigma has not declined in the current literature. Prior to 2000, there was minimal literature about the experiences of women living and aging with HIV, particularly about HIV stigma. Researchers focused on MSM and young heterosexual female adults. The literature from 2000 to 2010 was generally consistent with the current literature in describing aspects of HIV stigma experienced by older adults and especially older women. The change of medical status to chronic illness does not seem to have changed women's perceptions, fear of HIV stigma, or their handling of HIV stigma. Limiting disclosure to "a need to know" basis continues to be the most common method of HIV stigma management. In this way, women are aware of HIV stigma in the community, but they keep it at arms-length by not self-disclosing their HIV status or becoming involved in any community events related to HIV. They do not focus on the prevalence of HIV stigma but spend their energy being positive and optimistic.

Recognizing the many factors that interact to create HIV stigma and using personally appropriate HIV stigma management methods appears to allow women living and aging with HIV to stay adherent to medication, maintain a positive attitude, and focus on the blessings in their lives. Chapter 2 reviewed the literature as it related to HIV stigma, women, and aging with HIV. HIV stigma management, intersectional stigma, and resilience were discussed. Chapter 3 addresses the method utilized for this study, including a discussion of concepts related to narrative analysis. This is followed by a discussion of narrative analysis methodology with an emphasis on Riessman's (2008) thematic narrative analysis method as used in this study.

Chapter 3: Method

Chapter 3 presents information on the research method used for this study. Narrative analysis, as described by Catherine Riessman (1993, 2008), was chosen for this research because it is a method that captures stories as they are told. This chapter discusses the research method in detail. The following sections address the research questions, the research design, the sample, the procedure, the protection of confidentiality and participants from harm, the data analysis, and the methods to ensure research rigor.

Research Design

Narrative Analysis: Concepts

Narrative analysis is a qualitative research methodology that utilizes personal stories to reveal meaningful findings. Understanding meaning and human experience are concepts that are intrinsically connected to philosophy and psychology. Paul Ricœur (1975/1990), a French philosopher, focused on the process of self-reflection that leads to self-knowledge by an indirect pathway. He described a hermeneutic arc that occurs in interpreting text—an interactive movement between explanation and understanding, naivete and in-depth conceptualization, and the parts and the whole when interpreting a text. He suggested that there is a distancing between the oral speaking of words to the written presentation of text that changes the material. The written discourse may no longer be interpreted as the oral speaker intended. It may be read differently by readers who are other than the initial listener. He warned that reducing the interpretation of the text to language structure may diminish the search for the inner world of the other, which is contained within the text. He discussed how he came to expand his belief that hermeneutics as the interpretation of symbolic language was intrinsically complicated with text interpretation and the relationship of metaphor to reality and truth (Ricoeur, 1975/1990). This belief arose from the reading of a discussion in the book, The Phaedrus, between Plato, known as the father of modern philosophy, and Socrates, his teacher, and father of moral philosophy. Socrates objected to written language because the written text could be interpreted differently than intended in verbal communication (Plato, ca.370 BCE).

Ricœur (1975/1990) discussed the idea of interpretation starting as a naïve process and progressing to grasping a deeper understanding of the whole and the relationship of the parts to the whole, progressing in stages as in the hermeneutic circle (Ghasemi et al., 2011). In Ricoeur's (1975/1990) masterwork, *Time, and Narrative,* he discussed the concept of time in its various forms, such as phenomenological time, lived time, universal time. mythic time, calendar time, mortal time, and cosmic time. He expanded upon his ideas of historical narrative and fictional narrative, and particularly historical knowledge or narrative. Ricoeur (1975/1990) examined the concept of past reality as "standing in for [*vertreten*]" (pp. 143–158) or an actual but not currently real experience that becomes the mediator of past and present time. "In as much as the problem of reconfiguration of time by narrative comes together in the narrative, it does not find its outcome there" (Ricoeur, 1975/1990, vol. 3, p. 179). Therefore, I realized that when utilizing narrative analysis as a research method, I could not assume that the told story is accurate to the event but rather accurate to the memory of the event. Ricoeur (1975/1990) described it as a reenactment of the past in the present.

A more contemporary perspective on narrative was put forth by Donald E. Polkinghorne (1988), a psychotherapist who described narrative as a way that humans could take events and experiences that occurred with a certain temporality and make sense of those events as a whole. He suggested that the human ability to have language allows humans to experience the culture and to take such events and experiences and create meaning from them. He then stated that the study of meaning is essential to the understanding of human experience. Exploring narratives is a way of understanding human experience through temporal descriptions of experiences that have meaning to a person. Polkinghorne (1988) described the human experience as "a construction fashioned out of the interaction between a person's organizing cognitive schemes and the impact of the environment on his or her sense apparatus" (p. 16). He described narrative stories as organized by plot lines that are temporally ordered. Descriptions of events are woven together to construct plots that reveal the meaning to the person. Polkinghorne (1988) defined language as the process that takes these experiences and "molds them into meaningfulness that is greater than the meaningfulness they originally hold" (p. 31).

Language, both verbal and written, explores experience, describes perception, and may reveal hidden meanings during the process of narrative research. However, researchers must be mindful to remember that words may not be accurate to the actual event, but to the memory of the event. Ricoeur (1975/1990) suggested that in utilizing the hermeneutic circle (i.e., the hermeneutic arc when interpreting text), moving back and forth from the parts to the whole, researchers could formulate a deeper understanding of the essence of the experience in question.

Narrative Analysis: Variety of Methods

The research methodology of the narrative analysis incorporates several different processes that may be used to explore a research question. Riessman (2008) describes these as a "family of methods" (Riessman, 2008, p. 11). Methods have different ways of interpreting the texts of stories. They may focus on structure, sequence, the *how* or the *why* of a story, and may even be an analysis of a photograph or a painting. The constant requirement for all forms is that they are case-based or case-centered, examining language and intention, and "grounded in the study of the particular" (Riessman, 2008, p. 11). Case-centered research is able to develop “conceptual inferences about a social process” (Riessman, 2008, p. 13); however, the focus is not upon generalizations to the whole population as it is in quantitative research.

William Labov (1972, 1997) and James Paul Gee (1991) are two well-known narrative researchers who developed individual methods for performing narrative analysis. Labov defined narrative as “a method of recapitulating past experience by matching a verbal sequence of clauses to the sequence of events … (Labov, 1972, p.360). In later writing, he refined this to include that the sequence of events or experiences being recalled “must-have ‘entered into the biography’ of the speaker,” or they are simply a “recounting of observations” (Labov, 1997, p. 399).

His method utilizes a structural analysis method of narrative interpretation focused on the function of the clause in a spoken narrative. These narratives are usually brief, time focused, and topic-centered. He compared the placement of clauses within a story and examined for common or recurrent usage across stories. Labov (1972) described the importance of the vernacular or the natural speech of a particular group. He incorporated five principles of speech: style-shifting, attention, the vernacular, formality, and the observer’s paradox. With these principles, he outlined his understanding of how people use speech.

Labov (1972, 1997) asserted that people have a main style of speech but use multiple styles of speech, which vary with the situation. The style may be ordered “along a single dimension,” depending on how much attention one pays to speech. Vernacular speech is an automatic speech to which little attention is paid to the structure creating a natural flow for the speaker. Formal speech occurs when the speaker is aware of a listener, and the speaker then pays attention to how they speak. The use of a recording device will shift speech more towards formal structure just by its presence. Labov stated that the “Observer’s Paradox” for utilizing speech in linguistic (or narrative) research involved knowing how the speaker usually speaks to overcome formality speech and obtain the true meanings of what is being said. The interview situation is not a natural setting and it may take some time and adjusting before the interviewee is comfortable enough to slip into the vernacular which then can be analyzed for its true meaning (Labov, 1972, p. 112-114). Labov (1972) described what happens when a person in a face to face interview becomes so deeply involved in the relaying of personal information that it becomes a "partial reliving of that experience, and he is no longer free to monitor his own speech" (p. 354).

Though I utilized Riessman's (1993) thematic narrative analysis approach to narrative research, I was aware of the initial effects the recording device had on constraining women's speech. I identified that as the interview progressed and the interviewees became more comfortable, they slipped into vernacular speech. Many of the interviewees were emotionally entwined, even partially reliving the events they were recalling, and thus spoke from the heart of their own biographies.

Gee's (1991) approach to narrative analysis was directed to *how* a verse was spoken. He examined extended passages such as lines, stanzas, strophes, or parts and idea units to explore how the structure relates to the interpretation. Lines become stanzas (a group of lines on a single topic), or strophes when there are related pairs of stanzas. These, in turn, become larger parts that eventually form the whole of the narrative. Differing emphasis or pitch changes can alter the way a story is interpreted. Gee used five levels of structure to contribute to the meaning and interpretation of a text or story: line and stanza structure, syntax, and cohesion, main or non-main line, psychological subjects, and focusing system. Gee associated these levels with textual structure and then with a role in interpretation. By focusing on the complex structure of a story he was able to deconstruct and reconstruct the meaning of the story, including underlying and hidden meaning (Gee, 1991). Although I did not use Gee's narrative analysis method in my research, I did consider indicators such as changes in pitch, tone, hesitations, and word choices to assist in identifying emotions, meanings, patterns, and themes.

Riessman (2008, 1993) used many approaches to narrative analysis but focused on thematic narrative analysis, using stories to find meaningful themes in events. Grounded in Labov (1972) and Gee (1991), her method of thematic analysis is particularly useful in analyzing the narratives of interview participants, including older women living with HIV.

Research Design: Thematic Narrative Analysis

Riessman's (1993, 2008) use of thematic narrative analysis differs from Labov or Gee in that she focuses on the content of the story rather than the structure to find meaning. She views stories as having structure within non-structure, sequence, and temporality among what may seem to be nonsequence and nontemporality (Riessman, 2008). Each narrative can reveal the plot of what happened and how the individual telling the story interprets that story considered as an individual narrative (Riessman, 2008, 1993). As opposed to other research methods, Riessman (2008) cited the importance that thematic narrative analysis is grounded in a "case-centered approach" (p. 74). This approach is then colored by the researcher, choosing what is significant within the story. The researcher may choose to retain or omit non-related incidents, as well as "silences, false starts, emphases, non-lexicals like 'Uhm,' discourse markers like 'y'know' or 'so'" (Riessman, 1993, p. 12). When considered together, multiple narratives can reveal common themes or patterns between individual narratives, allowing discovery of an overarching meta-story. Narratives are interpretive and interpreted. Thus, the truths they reveal are also interpretive and individually interpreted. Diverse researchers may realize different themes within the same story. However, when commonalities and patterns are discovered, they give strength and validity to the narrative truths (Riessman, 1993, 2008). Riessman's (1993, 2008) methodology for thematic narrative analysis includes five steps for analysis that she describes as *representations*: attending, telling, transcribing, analyzing, and reading.

The attending to experience. The attending to experience signifies how attention is paid to the surroundings; the environment within which the story is told. It signifies an awareness of the surroundings of the teller and the hearer of the story. The level of awareness and comfort one has with their surroundings can alter either the telling of the story or the hearing of the story (Riessman, 1993, p. 9).

In this study, the medical clinic these women attended is in a low-income neighborhood in a large city of a Northeast state in the US. Over a third of the population live below the poverty level. Seventy percent have graduated high school, but only 15% have graduated from college. In this city, 10.7% of new HIV diagnoses in 2017 for both males and females were in people over age 50. In 2017, women age 50 to 59 made up 37% of all people living with HIV, and 23% were over age 60 (CT.gov, 2018).

The medical clinic was familiar to all the women in the study; however, many had never been in the office in which the interview took place. The office contained bookshelves with many books, a desk, phone, and computer. There were pictures on the wall with inspirational sayings and a few personal pictures of myself and my family. Many of the participants commented that they had not seen those personal pictures before and were happy to see them. The room was quiet, with few distractions other than a phone ringing on occasion. The women were able to focus and concentrate in this environment, yet it was not a sterile or clinical setting. The researcher was comfortable in this setting but distracted momentarily when the phone rang.

The telling of the experience. The telling of the experience relates to how the researcher relays the stories given to her by the participants. The telling allows for others to provide suggestions, ask questions, and make comments about the narratives. The stories were told by the interviewer to the research team, and their feedback was considered in the analysis. However, when people hear a story and then tell the story to others, they alter the story in some way, usually by focusing on what they found significant or important (Riessman, 1993, pp. 9–10).

In this study, I sought to represent the descriptions of the experience of living and aging with HIV by a group of women over age 50. These women provided the stories of their experiences, and I re-interpreted this telling's to my comprehension of them. I cannot say that I have lived the experience, but I understand the richness of the experiences and translate that into new meanings. As a White woman, I may have different understandings of the experiences than many of the African American, West Indian, and Hispanic participants; however, sharing the narratives with the participants also allows for their cultural influences to participate in authenticating the meaning of their stories.

Transcribing the experience. Transcribing the stories includes listening to tapes and converting the oral presentation to a written construction. Transcribing is a particularly difficult step in the narrative research process (Riessman, 1993, pp. 11–13). This is not because of the physical process but is due of how it is easy to lose the essence of a spoken interview in the transcription of words into writing. Riessman discusses how easy it is to misinterpret the story itself by deciding to leave out all the "non-lexicals," not capturing the rhythm of the speaker, or the hesitations and false starts. One transcriber may group together different lines than another transcriber and thereby associate a different meaning. Riessman emphasizes that different transcription methods or styles can allow for different interpretations of the same story

(Riessman, 1993, pp. 12–13). Riessman (2008) discussed that researchers were not just writing down what was said in a neutral, objective way but are "implicated every step along the way in constituting the narratives we then analyze" (p. 28). This issue can lead to various interpreting decisions leading to differing emphasis and outcomes of the same story.

All interviews in this study were audiotaped and transcribed by a HIPPA certified, IRB approved company (iSource). I found when reading the transcripts, that much could be lost without the sound of voice: the intonations, the hesitancies, the angry sounds, and the tearful sounds. These are an integral part of the intensity of the emotions revealed by the participants; therefore, I listened multiple times to the raw interviews as well as conducting multiple readings of the written transcriptions. I tried to capture the intensity of the telling that might be lost in the physical transcription of the experience. In the thematic narrative analysis, the emphasis is on the content of the story or "the told" not the actual language (Riessman, 2008); however, I tried to achieve a balance of inclusion of "non-lexicals," such as "y'know" or colloquial and slang language, consistent with the essence of the story itself. Additionally, many stories are nonsequentially told episodes of the overall experience, and I attempted to attend to structure and plot, as well as the spoken episodes.

Analyzing the experience. The next step in the narrative process is analyzing each participant's story for their own meaning, patterns, and themes and then analyzing them together, seeking to find any overarching themes. This becomes a very personalized process with the researcher choosing what is significant and determining what the participant is voicing. Then the researcher reviews the narratives, deconstructing, and reconstructing to describe the soul of the experience. At the same time that a researcher must not betray the essence of the stories the participants are telling, a researcher must also remain aware of their own biases and assumptions.

In Riessman's (1993) methodology, bracketing is not necessary, but maintaining awareness is critical to capturing the individual's experience. Participants reviewing the researcher's findings (member checks), assists in determining their validity. At this point, the story becomes a collaboration between the researcher and the participant (Riessman, 1993, pp. 13–14).

Once each individual participant's story is analyzed, the researcher may explore all the stories for common patterns or themes, while at the same time maintaining the case-centered focus of the research. Many experiences have common patterns, but it would not be unusual to find different interpretations by the various participants of any particular experience.

Reading the experience. Once the previous steps are completed, the researcher proceeds to the final step: the presentation of the final findings to others. This process is usually in written form, though it may also be through oral presentation. Throughout the process, the goal is to adequately represent the stories that are told and to interpret them with the richness and intensity in which they were presented. The truths of the analysis must be considered as the participants' truth of the experience though not necessarily an absolute truth for all who experience similar situations (Riessman, 1993, pp. 14–15).

The presentation of this study to others begins with the dissertation defense, where the presentation of these women's stories brings life to the condition of HIV stigma for women over 50 living with HIV. As the women in the study suggested, the value of the study is in its presentation; to bring light to the experience of HIV stigma for women aging with HIV and to educate the public. Therefore, it will be important to present the results in as many formats as possible, including poster presentations, journal articles, community events, medical and nursing education programs, and varied media presentations. This study will be presented as a poster and has already been presented orally at a 2020 World AIDS Day event. At that event, one of the study participants also spoke and told her truth out loud, supported by the results of the study. I hope that I captured the truths of these 12 participants in a way that would honor their experiences, their storytelling, and their lives.

Research Questions

The research questions addressed in this study included the following:

1. How do the stories of being an aging woman, living with HIV, inform the experience?
2. Is there an overarching narrative or a variety of patterns of this experience?
3. What misconceptions and experiences of stigma are described by the participants?

Sample

A purposive sample of 12 women, over 50, living with HIV, who attend an inner-city, infectious disease care clinic of a nonprofit health care delivery system, was recruited and enrolled by clinic staff research assistants. Over 50% of the women living with HIV receiving care in the clinic are over the age of 50. Approximately 80% of the women living with HIV attending this clinic are African American or Caribbean American, 15% are Hispanic American, and about 5% are Caucasian. The study participants reflect this racial and ethnic composition. As African American or Caribbean American women constituted the primary participants in the study, I recognized and utilized their narrative, cultural practices, including storytelling. Interviews with these women over 50, living with HIV, were focused on stories of their HIV-related experiences. Three women, who were approached, opted not to participate due to work commitments or being out of the state during the interview schedule times.

The following were the inclusion criteria: (a) HIV positive by patient report, (b) age 50 or older, (c) English speaking, (d) female, (e) attend the designated clinic, and (f) willing to participate. The exclusion criteria included (a) not HIV positive, (b) over age 99, (c) unable to speak or read English, (d) not female, (e) did not attend the designated clinic, and (f) were not willing to participate. I considered the female gender as a self-identified status. Transgender female persons were not excluded; however, when completing the demographic survey, none of the participants self-identified as transgender females.

Protection of Research Participants

I obtained Institutional Review Board (IRB) approval from the hospital and medical center’s IRB and the University of Connecticut’s IRB through a letter of agreement. All participants received and signed written consent forms. I reviewed those forms with them using research assistants before enrolling in the study.

I made all attempts to preserve participant confidentiality. Demographic data were identified with a study code and kept in a locked cabinet in my locked office. The demographic data were kept separately from the interview data, which were also identified only with a study code. The study code was derived from a number that reflected how many people had enrolled in this study (e.g., sequential digit code, such as 009). A code key list that linked names and codes was destroyed once the study completed. Names were changed in the study report to increase confidentiality further. All names and identifying information in the transcripts were redacted.

Mental health resources were available for those participants who experienced emotional distress by recalling their stories; however, this process was not needed by any of the participants. Participants were free to discontinue study participation at any time for any reason; however, this occurrence did not happen. There were no direct benefits from this research to participants, but I hoped that their participation would help to improve care for women aging with HIV infection. Participants received a $25 Walmart gift card per interview (maximum two) for their time.

Data Collection

Potential participants were identified by the study research assistants who contacted them to determine their interest and arrange an interview time. The research assistant then completed the registration form and consent form with the participant. A convenient time for an interview was arranged for the participant to meet with the researcher.

Interviews took place in a confidential setting of the participant’s choosing. A private room at the clinic was available and offered to all participants. All participants availed themselves of this opportunity. Interviews were audiotaped, and field notes were taken. Participants were asked to respond to the question:

> Please tell me in your own words, the story of your experience of being a woman living and aging with HIV. Tell me any thoughts and feelings about aging with HIV. Take your time and tell me anything you think is important to know about your experience.

Follow-up questions that clarified points in the conversation were asked. Additionally, participants were asked what advice they would give to other women living and aging with HIV as another way to get further information for understanding their experiences. Interviews were transcribed by a HIPPA certified, and IRB approved translation service (iSource).

Follow-up member-check interviews were conducted with five participants. All participant names were written on paper, placed in a bowl, and five were picked without seeing the names. The women whose names were picked were invited to a second short interview to review their stories, themes, and overarching themes. They all accepted the invitation.

Data Analysis

Riessman's (1993, 2008) five methodological representations were utilized to analyze the interview data. These representations are discussed in the following subsections.

First Representation: The Attentiveness

I considered the environment and how it affected the participants and myself as a researcher, as part of the first representation: the attentiveness. I was careful to ensure privacy, convenience, and comfort for the participants. I explained the audio-recording equipment to the participants so that they would be relaxed during the taping. I noted that the participants became more relaxed and less aware of their surroundings as the interviews progressed.

Second Representation: The Telling

I shared the unidentified content of the interviews with the research team to obtain feedback as part of the telling representation. This included a physician, a pharmacist, and a social worker. All members of the research team were IRB approved.

Third Representation: The Transcribing

All oral interviews were converted into text by an IRB approved, HIPPA certified transcription service. Transcribing as it is used in these representations is more than just conversion to text. I listened multiple times to the taped interviews, paying attention to changes in vocalization such as pitch, pauses, and speed to better comprehend the meaning of the words. I connected field notes to these, including tearfulness, crying, laughing, and hand movements. I also noted my own impressions.

The Fourth Representation: The Analyzing

As part of the fourth representation, data analysis, I again read and reread the transcripts. I analyzed each individual interview as a whole and then assessed for significant statements or findings, indicating patterns, or contributing to themes. I used this iterative process to expand and contract findings until themes were reached for each participant. I then compared all the interviews with each other, assessing patterns to identify overarching themes and a metastory.

The Fifth Representation: The Reading

This dissertation is the main construct for the fifth and final representation of Riessman's (1993, 2008) thematic narrative analysis process. Additionally, data were presented at a community World AIDS Day presentation and will be submitted for poster or podium presentations at various professional conferences. A manuscript is planned for publication.

Research Rigor

Qualitative research is not assessed for reliability and validity in the same manner as quantitative research. Qualitative researchers are not concerned with the ability to generalize results to large populations. They are, however, concerned with increasing understanding and grasping the essence of the experience they are investigating. "The aim of narrative inquiry is not certainty but believability, not control but insight and understanding" (Pellico & Chinn, 2007, p. 63). This process necessitates a different set of criteria for evaluating the worthiness of the data. Credibility, coherence, correspondence, and pragmatic use are among the tools used to assess rigor in narrative research.

Credibility

This measure of rigor relates to the trustworthiness of the findings. Findings must seem believable and accurate to the question, especially by the participants. This measure is highly related to coherence. In this study, I examined credibility by bringing five participants back to review the interviews and conclusions. The goal was to provide feedback.

Coherence

Researchers can use coherence to examine research rigor from the stance of consistency and sense-making. I showed coherence by returning to the participants to determine if the stories and the conclusions were consistent with what they had attempted to convey in their narratives. I conducted second interviews with five participants and reviewed the findings of the research with them. I showed coherence by reviewing previous studies and comparing findings. Two dissertations that employed different theories and methodologies in exploring a similar question had findings consistent with this study (see James-Borga, 2013; Stoudmire, 2008). An additional qualitative study also showed consistent results (see Jacobs & Kane, 2010). One caution in utilizing coherence to assess rigor is that coherence can be interrupted by critical life events, such as war, natural disaster, or even a diagnosis of HIV infection. Traumatic events can affect memory and interpretation of situations.

Persuasiveness

The use of persuasiveness to convey authenticity is one form of research method rigor; however, as Riessman (2008) suggested, it could be fraught with pitfalls. Using quotes out of context can provide a false sense of truthfulness. Factors, such as subject memory distortion, the time elapsed, and personal point of view can affect the results of the research. However, persuasiveness can be powerful when accounts are supported by multiple similar narratives, and dissimilar accounts are addressed. Riessman (2008) suggested that researchers should use a recorded interview method and keep a journal or log as an audit trail to provide increased persuasiveness and believability to their findings. This study was audiotaped, and field notes were taken.

Correspondence

Correspondence is a method of validating the historical facts of the story. This is not a fool-proof method; however, it can be useful in certain situations. One might utilize historical records, medical records, newspaper stories, or other written or visual texts to confirm a narrative. The facts might be hard to verify, and at times the narrative supersedes the importance of verifying the facts. I showed the use of correspondence by examining the history of the epidemic and HIV stigma and determining consistency with the contents of narratives.

Pragmatic Use

Pragmatic use is evaluated by how the results of the study can be utilized in the future to make a difference. This sentiment was strongly expressed by the participants in the study. Pragmatic use relates to the ability of the study to identify future areas for research, as well as to be utilized to develop mechanisms to address significant findings.

One aspect of this study, specifically the possible identification of post-HIV diagnosis-related disorder similar to posttraumatic stress disorder (PTSD), might be the basis for several studies, including the use of specific criteria to assess diagnoses or a study of treatments, such as eye movement desensitization and reprocessing (EMDR), for treatment of women diagnosed with HIV. This treatment method has been successful in treating other forms of PTSD. A study examining women who received immediate psychological counseling versus those who received no counseling and the effect on disclosure could be another pragmatic use of the findings from this study.

An example of pragmatic use for this study would be to develop educational programs for health care providers addressing the issues, particularly HIV stigma in the health care setting, identified by the aging women living with HIV in this study. This research could support instituting community education programs. The participants had extensive ideas, such as contacting Oprah or Dr. Oz, for worldwide exposure of this information.

Political and Ethical Use

Riessman (2008) discussed the complicated topic of the ethical utilization of research, especially for political purposes. This is particularly important when research is viewed through an emancipatory social justice feminist lens. Narrative research with women is an important method to allow women's voices to be heard on a wide range of topics and experiences that might ordinarily not be vocalized. I ensured the findings remained consistent with the participants' concepts and meanings. I returned to participants for a confirmatory review and interview of the transcript and interpretation of their original interviews to verify the results.

The use of narrative research findings for political purposes is possible but must be approached cautiously. Participants might not agree with this use of the research. Results might not be generalizable to the whole population. Time might pass between the research activity and the publication of results, during which political and social structures might have changed. Similar situations might be viewed differently at different times.

Conclusion

Chapter 3 contained a discussion about narrative analysis, specifically Riessman's (1993, 2008) research method of thematic narrative analysis—the research design for this study. The procedure, sample, research questions, and issues of confidentiality protection were addressed. The data analysis process was described. Issues of rigor, including credibility, coherence, correspondence, and pragmatic use, were addressed. Several ideas for the pragmatic use of future research and community education were suggested.

Chapter 4 presents the results of the study. Each participant's interview is presented as a narrative story with attention to plot, timeline, and significant occurrences. Patterns, subthemes, and themes for each individual participant are identified and discussed. All stories are then considered for overarching patterns, subthemes, and themes. The research questions are answered based on the individual stories, the composite analysis for overarching themes, and the meta-story.

Chapter 4: Results

This chapter begins with the interpretation of the 12 individual narratives. Each interview was developed into a narrative, attending to plot, temporality, and relevant content. After examining the individual narratives for patterns, subthemes, and themes, an overall analysis of the narratives, identifying the similarities and differences, and any common subthemes and themes composing the mega-narrative was completed. The results of the research questions are then provided.

All participants expressed feelings of nervousness because they were speaking aloud about their experiences of living and aging with HIV. Some of the interviews included tangential or non-related stories, but most were focused on the lives of the participants from the moment of their HIV diagnosis, moving forward to the present time. Even those who professed to have nothing to say or "no story" to tell were able to tell their story of living and aging with HIV. All names are fictious to protect the participants. Analysis of individual narratives, as interpreted by the researcher, follows below.

Individual Interviews

Interview 1

Participant 1, Claudia, was a college-educated, White woman in her 50s. Claudia began her story not at the very beginning, which she later described, but at the moment, that was *her* beginning: when she became ill, went for medical care, and received her diagnosis of HIV. She stated, "I remember when they told me that I was positive I felt like I'd been hit by a train. I was kind of in shock, and anything they said after that, it's kind of like, I didn't hear it." Her story continued, focused on her partner, who had advanced AIDS and diabetes at that time. She then reverted to the actual beginning of her story, talking about being a drug addict and her fear of not having her partner around to help her when she did not have enough money for drugs or to bond her out when she got arrested. She revealed that, at first, being diagnosed with HIV pushed her further into her drug use, primarily with crack cocaine. She believed she had no coping mechanisms to deal with her new diagnosis, and drugs were what she knew.

At that point, Claudia began stuttering and eventually cried during the interview. She moved forward to the time after her diagnosis when her partner was dying:

> How am I ever going to have a sexual partner again, how am I ever going to fall in love again and tell somebody that I'm HIV positive … After he died, I just thought "fuck it," I want to die too. I don't want to live. And in the back of my mind thinking that I'm HIV-positive, I'm an addict, and I don't know how to get out of this.

She recalled isolating herself because she didn't want family and friends involved in her life. She spoke about telling her elderly mother that she had HIV, and her mother responded, "Am I going to catch it through wearing your necklace?" She remembered her feelings at that moment, "And that really, really hurt because I thought okay, it's her ignorance and her age, and I said, 'No, mom, that's not the way you catch it.'" She first stated that her parents were going to disown her but then, upon clarification, stated,

> No. I was the one choosing not to be around them because I didn't want them to get involved with my lifestyle or see me like that … I was scared to tell them that I was HIV-positive because I didn't want them to worry more about me.

Toward the end of the interview, Claudia remembered that she told her sister that she was HIV-positive, and her sister then emailed her brother with this news:

> That made me really, really, angry because I wanted to tell him myself, and I thought it was just really callous to send it through an email. And this is my own sister, and my

> sister, I thought, I think pretty highly of her, she is my elder sister, and she is smart. I was so angry. I called her, and I yelled, I screamed, I cried.

Claudia revealed that she entered a 30-day treatment facility, told the facility staff her diagnosis, completed the program, and has been drug-free ever since. She stated that she had been in therapy for 11 years. She has a Narcotics Anonymous (NA) sponsor and attends meetings regularly. She talked about the importance of changing her lifestyle, taking her medications, and keeping her appointments. She stated that she did not think of it as “horrible” any longer. Claudia talked about how “going through menopause is worse than getting HIV-positive, you know, just getting older or just dealing with the energy levels.” Claudia also revealed her diagnosis to her closest friends and has what she considered a supportive network of people who care about her.

She dedicated herself to fighting the stigma of HIV. She spoke before a class of new medical students and shared her experience of living with HIV. She stated, “So, it made me feel good because I know that I’m speaking for all of us, and a lot of people who can’t speak about it, and who are afraid to.” She believed that she wanted to get across the information that contracting HIV could happen to anyone and that she was a good person to talk to them because “I’m a White female and older; they wouldn’t think that I was HIV-positive.” Moreover, she stated that when she would visit a new doctor, she had “been a little afraid sometimes to tell them I am, but I know that’s the right thing to do.” She could not recall being treated any differently by any health providers.

Claudia related that she had been with a new partner for 8 years. He was HIV negative and extremely accepting of her past lifestyle and her HIV diagnosis: “I told him about my past as an addict and recovery. And he said it made him love me more, because of everything that I’ve been through, which totally floored me." They would use condoms, and she maintained an undetectable HIV viral load. Her partner had chosen not to utilize PrEP.

When asked what advice she would give to other women aging with HIV, she stated the following:

> Keep thinking positive. Take care of yourself. I do a lot of yoga, meditation. I believe in spirituality, in a God, and I pray, and I believe that the higher power here is protecting me. And I think that it's a really important thing to keep your mind and body and spirit healthy throughout growing older with HIV.

The end of Claudia's story was positive and forward-looking. She has found a way to get through her initially devastating diagnosis to a place of acceptance and good health through changing her lifestyle, adopting new habits, and new spiritual beliefs. Choosing to be open, to seek therapy, and to reveal her diagnosis to family, close friends, and others such as medical providers have allowed her to move on with her life.

The following central themes were found in Claudia's story:

1. Mental Health: "Depression is Ongoing, but With Therapy, you can Move Forward."
2. Substance Use: "Recovery is of Prime Importance, One Day at a Time."
3. Stigma: "I'll Do Whatever I Can Help Eliminate the Stigma of HIV."
4. Education: "Learn All You Can. It Can Happen to Anybody."
5. Aging: "Keep Your Mind, Body, and Spirit Healthy."
6. Resilience: "My Higher Power is Protecting Me."

Interview 2

Participant 2, Celine, was an African American female in her 50s who formerly used drugs. She first stated that she had no story, but she continued to talk. She began her story, talking about being diagnosed with HIV in the late 2000s. She received her diagnosis in late December and considered it "my Christmas present." She believed that "this can't be me; this is not happening to me." Celine contracted HIV from her husband, who knew he had HIV but did not tell Celine. He later died. She revealed how she felt: "It bothered me because, like, how can you not tell a person, your sexual partner, that you're HIV positive." She was in denial for a long time, feeling, "this is not for me, this is not happening to me … this is all a nightmare, you know, when am I going to wake up from this shit."

Celine identified a nurse who shared with her that she (*the nurse*) also had HIV, as a critical person in her journey. This nurse made it possible for Celine to think differently and feel differently about what was happening to her to see it as a "steppingstone" in her life. Despite Celine's conversation with the nurse, Celine remained in denial for quite some time and did not want to take medication. She thought the nurses and doctors were against her because they would not give her the Percocet she wanted; they just wanted her to take HIV medications and seemed to ignore the pain she was experiencing. She emphatically stated she did not like continuing to get new doctors when they rotated through the clinic she attended for care, as they repeatedly asked her the same questions, which she found invasive, "And it angered me so much that, sometimes, I'll be cussing the doctors out. I have a quick temper; I'm quick to get angry."

Celine stated that even though she resisted taking medications, once she started taking them, she was adherent: "I'm non-detectable, and I take my meds every day … I think out of 10 years; I might have missed maybe three (*pills*)." She developed a positive attitude about living with HIV: "I think about it, but don't dwell on it." At another point, she stated, "I feel good inside and out."

Despite this acceptance, she primarily kept her diagnosis to herself. She informed her doctors, her therapist, and her psychiatrist but believed, otherwise, that “My disease is on a need to know basis.” She believed that others would automatically think she contracted HIV from drug use, and telling them the truth was not really going to change their thinking. She believed she would not only be judged but also pitied, and she did not want that to happen: “I chose not to tell anybody, not because I was scared, but the judgment. And I don’t have time for nobody’s [*sic*] judgement. I don’t have time for nobody’s [*sic*] self-pity. I’m not pitying myself; I don’t want you pitying me.” She strongly stated that “when I accepted the fact that I had to live with this disease for the rest of my life, I accepted the fact that I would tell nobody. I would take this to my grave.”

She talked about the ongoing stigma in the community:

> [When] you tell someone that you have the virus, their whole persona changes. They look at you in a different manner … trying to figure out how you caught it …don’t get too close to her, don’t drink after her, don’t smoke after her.

She had not experienced discrimination because she had not told anyone her diagnosis because of “discrimination I’ve seen people go through. It’s not a pretty sight … it’s like they’re shunned.” She noted that some people still believed, “We have to bleach the forks, the silverware, the plates, and all that, we have to do this and do that as if sitting on a toilet stool will make you catch it.”

The lack of accurate knowledge, such as distinguishing between HIV and AIDS, is upsetting to her. She repeatedly stated, “Educate yourself.” Celine also advocated practicing safe sex, though she did not mention telling sexual partners. Her advice to other women aging with HIV was the following:

> Put on your big girl panties and just accept it … Just do what you feel is best for yourself; you know what I mean, and fuck others. Sorry, but screw others, you know what I mean, because don't nobody have to live with it but you; and do what makes you happy.

The following were the themes found from Celine's story:

1. Education: "Educate Yourself Before You Speak on It."
2. Stigma: "Like They Have Some Kind of Leprosy."
3. Self-Silencing Disclosure: "My Disease is on a Need To Know Basis."
4. Resilience: "Live with It, Deal with It, It's a Part of Who I Am."

Interview 3

Participant 3, Tanisha, was a West Indian-American female in her early 60s; she began her story with her HIV diagnosis experience. She recalled having a painful case of shingles, so she went to the local clinic where she was not only treated for shingles but also tested for HIV. It took 2 to 3 weeks to obtain the results of the HIV test, but she remembered that "he told me then that I was diagnosed and that there was really no treatment, and basically, I had up to 3 years to live." She stated that she accepted the diagnosis, but

> I'm a very private person, so I really didn't tell anyone, no one, my mother, no one. At the time, I had just left my husband, and I got it from him being a cheater, and I didn't tell anyone, my sisters, my brothers, anyone.

She told another story of a time about 6 years later when she became ill with pneumonia:

> I got this terrible cough, and the cough got worse and worse and worse. I just couldn't stop coughing. And then one day I woke up and I couldn't breathe … and when I tried to get up, I went to the bathroom and almost fell.

She then called her mother, who called the ambulance. Tanisha discussed the ambulance ride: “It was a bad experience.” She was questioned by one of the ambulance staff. She remembered it this way: “Well, how did you get it, what did you do, did you have sex with multiple men, would you don’t just … come on, tell me, let me see your arms, I know you was doing drugs.” Tanisha recalled this experience vividly. She was admitted to the hospital and diagnosed with AIDS.

In a later story, she related, “I don’t do drugs. I don’t smoke. I don’t drink. I’m a very private person.” This experience led her to feel she had to let some people know her diagnosis:

> I had to tell my kids, I had to tell my mother, and I had to tell everybody. I didn’t tell my sister because she had multiple sclerosis. I didn’t tell my brother, because he is on drugs and I know it will get out. So, I told my mother, told my kids, oh, I told my cousin because my mother was older.

Tanisha asked this cousin if she would take care of her children if something happened to her, and the cousin agreed. Then, her cousin went and told other family members: “She went to a lot of my family members, my cousin, so it got out very quick [*sic*]. It got out, and I didn’t want it to get out.”

Tanisha brought disclosure issues to the present as she talked about how her brother just found out that she was HIV positive:

> Just recently, I don’t know why, my son told (*her brother’s name*), I think he was mad because I sold the house. My son told my brother. My brother’s been in jail all his life, and we don’t get along. And my son told my brother, and my brother got out of jail, when he told him, and he wants to spread my business all over the street, so now like a lot of people was like, “Oh, she positive, or she has AIDS.” And I don’t know who all he told.

She then went on to tell a story about how when she was out in the community, and she saw people with whom she grew up:

> They are pointing me out. Twice I got a phone call, one was a friend from my childhood … and she said, "Well, this certain person, she's saying that you're HIV, so I'm just going to ask you … she said she saw you at the dentist."

As an example of these unwanted disclosures, she related a story about her niece asking her if she had AIDS. Her niece said, "I am just asking you because I asked my mother, and my mother said she heard it's true." Another situation where she felt "outed" about her HIV status was when she came to the clinic for care. She explained:

> And when you see people, and they see you here, you don't have to be here for that. But they are going to assume that you're here for that reason. And then they'll point you out, "You, know, I see her at, you know, at the clinic," and then you know a lot of them do drugs.

Tanisha believed no one could tell if she had HIV because she took good care of her health, ate right, and looked good. She also had no guilt or remorse about lying to people who she believed did not need to know her status, and she did tell them she was not HIV positive.

Tanisha became a great-grandmother, but she remained fearful that if her granddaughter found out her diagnosis, she would not be allowed to see her great-granddaughter. She also secretly feared for her granddaughter's health and sexual safety from HIV infection:

> I don't want her to look at me and say, "Well, my grandmother has HIV, I can do this, and it won't affect me." I want her to still be protected, you know live a safe life, don't trust anyone because trusting someone, the closest one to you will be the one to do it to you, you know, so I still want her to guard up and like I tell her, okay, you got this baby,

> that don’t [*sic*] mean it’s safe to go out there and lay around. Don’t even trust him, make him strap it up, because you don’t know what he’s doing, okay.

Her 11-year-old granddaughter told her stories of children using HIV as a bullying threat in school:

> They tease all the kids, and he was—saying to her, “And that’s why you have AIDS, or that’s why you’re gay.” And I don’t want them to feel some kind of way, “Oh, her grandmother have AIDS” … so, I keep it a secret from them.

Tanisha talked about the stigma she found in her church situation. She felt that if people in the church found out, they would “gossip.” She stated the following:

> Gossip, church people are the worse, they are, especially, Baptist churches, I can say that they will laugh and grin at your face, but they are the worse, okay. They’ll smile and act like they—because I’ve heard them talk to me about other people, so I know that they will get out and they will put it on the street, you know, so yeah.

In talking about HIV stigma and the church, she told a story about another church member who had AIDS and who had died. Tanisha angrily recalled:

> And the Church wasn’t very supportive, like, you know, they—it was a fake love that they will give to her, and I will never forget when she passed, the way people talked and everything came out, and I was like, like, I got told my sis, she bleeds [*sic*] just like everybody else, she eat just like, she’s no different to anybody else, you know, but people will look at you like you’re contaminated, you know. You don’t touch that doorknob, or I’m going to—don’t touch that light switch.

She had other experiences where she felt health care providers had not treated her respectfully or appropriately. She recalled a clinic doctor who treated her in a stigmatizing manner. She believed the doctor was the following:

> Very, very, rude. She made me feel like she didn't want to touch me. She was just very nasty, the way she talked to me like she didn't believe, like, like she was looking for tracks on my body or something.

Tanisha ultimately changed doctors.

She spoke about having two friends who are nurses who talk about patients for whom they have cared. This made her worry about inadvertent disclosure of her own status. She stated the following:

> I wonder if they could see my medical information, it makes me think, you know, like can they go into the records of the hospital, I don't, they don't work for here (*the clinic*) but can they go into the hospital and like you know in a record … pull up my name, and find out my information, I don't know.

She worried because once she left her HIV medication out in view on a shelf in her bedroom, she had company, and one of the nurses with whom she was a friend, went into the room to change her baby's diaper. Tanisha never found out if she saw the pill bottle, but she remained anxious about it to this day.

When she talked about getting older, Tanisha said the following:

> My life really to me hasn't changed besides being a grandmother, enjoying my kids, or whatever. I've always been a private person. What I found, though, as I got older, I got more private because of the people I was around, sitting back and listening, how they

> reacted to other people or how they talked. I became alone, yeah, and I like it that way, yeah, I like it that way.

The following themes were found in the interview:

1. Mental Health: “I Lived My Life as Normal.”
2. Isolation: “I'm a Very Private Person.”
3. Self-Silencing Disclosure: “It's None of Their Business.”
4. Stigma: “There’s a Lot of Pointin’.”
5. Aging: “I’m A Great-Grandma with HIV.”
6. Resilience: “Eat Right, Take Your Meds and Do What Makes you Happy.”

Interview 4

The fourth participant interviewed, Alana, was in her late 50s. She was an African American female who found out she was HIV positive in the 1990s. She, too, began her story when she was diagnosed, which she identified as “at the beginning.” She was diagnosed during the height of the epidemic when many people became extremely ill or died, “so I was terrified.” At the time, she used drugs and exchanged sex for drugs or money. She recalled the following:

> I know I could have gotten it many different ways because I was in a community shooting drugs, and smoking crack, and robbing, and still sleeping with any Tom, Dick, and Harry to get paid so I can get more drugs.

She pivoted from her diagnosis story to talk about other things, returning later to describe the experience in more depth. Her diagnosis story weaves in and out through her experiences living with HIV: “I was in a treatment facility, but when you first find out you’re positive they put you in a room, and that room they put you in is, like, all gray walls. Just give you your result.” Alana then recalled how she felt receiving her result:

> So, I don't want that feeling for nobody else. I don't want that because it's a—you feel alone. It's a glass bubble. Don't touch me. I'm going to give you something. The nurse don't want to touch you, the doctor just giving you the paperwork, and 'now go do something with yourself.'

Later in her story, she alluded to the circumstance of her diagnosis by saying, "When you're first finding out, and then all you see is gray, gray, gray, gray and then red from the anger."

Alana told some people she had HIV, most often in the context of her work as an HIV prevention counselor. She believed there were particular times and some people to whom she could tell her HIV diagnosis:

> Because you can't speak about living with the virus just like that. You got to be in a room with people that understand it because there's [*sic*] some people, "She got the what? Why she's out there? Dah, dah, dah," you know what I mean, but they don't understand.

She also has told medical providers her diagnosis as she believes they need to know this to provide appropriate health care. However, she felt the response she gets is not always what she expects. She gave an example of going to the dentist:

> Worst experience ever is going to the dentist. They found out you have the virus, and they put the gloves on all the way up here (*indicates elbows*) … and they put this mask on, and they, what the hell. And, they treat you all rough and stuff. Like this is a waste of time. Waste of my time trying to take care of this person.

She continued on, saying, "Once they ask you the question and you tell them you're HIV positive, it's like a red light went off. Ooh." She stated that they isolated her, and "They made it known that they don't do HIV positive people."

Alana also related an experience describing how many medical providers consider anyone with a diagnosis of HIV to be an active drug user, sex worker, or promiscuous person. She had one medical provider who "put everybody under one umbrella." This attitude influenced how she felt her care was provided. She described her feeling that the provider did not care about her because she was HIV positive:

> Sometime when you're holding a conversation with a person or your patient, your back don't [*sic*] need to be turned. That means you're not really hearing me. You are over here. You're hearing me, but you're not really giving me your undivided attention.

She added that this applied even to infectious disease specialists:

> So, not everybody that's in the field for the specialty that you are can deal with patients like us. They would rather you either drunk, high on something, then they can just put you under that, "Ugh, make sure you take your meds, and here's a prescription, and then go."

Alana does not disclose her HIV status to many friends, family, or other people:

> And then, if you tell someone that you feel is close to you, that's not going to spread it, you're taking your whole life, and you're being discussed behind your back, and you really be thinking "No, I trusted this individual." This individual told Tom. Tom told Mary, June, Mary Poppins. And then, now you want to know why people are looking at you differently.

This experience happened to Alana when she told one person at work. She described this scene:

> I told one person, and I really thought we were close. And I started getting funny feelings of, looking at—and that is not my feeling. I mean, I'm saying that people used to eat out of my chips. They stopped doing that. Little things, though. I open up a soda. "I'mma

> pour you some soda. You want some?" "Did you drink out of it?" You know little things that you will catch it because you just catch it. And then, "Oh shit. Oh, no, she didn't. Oh, yes, she did."

Alana described living with HIV in jail as difficult and sad. She believed that people were discriminated against by employees and other inmates and that confidentiality was not respected.

> I do remember that you get locked down and you positive, they're not supposed to tell nobody, but they do. Your information get out." And, "That bitch is sick. She got the bird … Nobody wants to fight you because they're afraid that they're going to catch it."

Alana was focused on being a positive person and a role model for other women. She was adherent to her medication, always practiced safer sex, and tried to do other positive activities to keep herself healthy. She had not used drugs for many years. She considered herself a fighter and a survivor, saying,

> It's up to you to make up your mind if you want to survive. I'm a survivor because I want to. I want to, and me sharing that want and desire to others, I'm grateful, because I have no problem talking about it, but I always pick my time and place.

She described her relationship with the HIV virus in this way, "Me and that virus got a fight going on, and he's still leaving a little bit behind, but I'm still fighting him." Moreover, she believed the most important message was that both medication and education were essential to surviving living with HIV. She emphatically gave this advice:

> Your health is your wealth. Grow up, please. You can have a million dollars but if your T-cells is number two, and that because you done messed up, and you gone did that, your health is still your wealth. It's up to you to fight because your health is your wealth. I mean that how I feel because I'm rich … That's what I tell myself, 'I'm rich.' Get up,

take my meds. Do my little Cocoa Mocha. Maybe have me a biscuit. Go to work, but I feel rich.

The following were themes derived from Alana’s story:

1. Traumatic HIV Diagnosis: “I Was Terrified.”
2. My Health is My Wealth: “An Extremist in My Addiction, An Extremist in My Health.”
3. Education: “Knowledge is the Best Weapon to this Virus.”
4. Self-Silencing Disclosure: “I Trusted this Individual.”
5. Stigma: “People are looking at you differently.”
6. Resilience: “Me and that Virus Got a Fight Going On.”

Interview 5

Sophia, the fifth participant, is an African American female, in her early 60’s, who began her story by briefly revealing how she felt when she was first diagnosed as HIV positive, in the 1990s, “It scared me at first. I thought I was going to die. I had a fit.” She quickly jumped to the present and to discuss how other people should stay safe: “Safe sex is the best sex.” On prodding, she revealed her actual experience: “Two doctors came to my house. And that’s when I found out, oh that just took me, it made me like, turned my life around, it really did.”

She told me how she went to the sexually transmitted disease (STD) clinic because she had a rash. She had some blood work done: “They came to my house unexpectedly, and that’s when I found out. That’s how I found out … I couldn’t believe it. I said, I mean, I just cried. What can I do?” Sophia denied being HIV positive has affected her healthcare experiences. She stated that her diabetes is a bigger problem for her to manage than her HIV. She did not feel that she had experienced any stigma from health care providers, except for when she stated, “I’m the one being a hot-headed one." She blamed herself for any stigmatizing behavior that she experienced.

Concerning disclosing to other people, Sophia stated, "Nobody know but my family, because I always don't let, I won't let people know my business. People out here like to talk too much." She did say that if she was extremely close to someone, she might tell them, but she was afraid they would not relate with her after. She did not tell anyone in church because of the following: "Ladies like to talk. Especially in the church, oh my goodness, they like to talk, that's all. I don't say nothing to nobody." However, she explained that her pastor preached that they should not judge anyone for who they are or "what they got." She felt comfortable with him, but she would not reveal if she had told him her HIV positive status.

Sophia believed her family was "behind me 100%. I told my mother, my brother, who is (*now*) dead. My brothers knew, but one is alive. My cousin was the first one to know. Just me and my immediate family." She stated that she did not let her grandchildren "drink behind me," which was her decision, not her family's request.

Her positive attitude, excellent medication adherence, and, most importantly, her spiritual faith had helped her to cope with her HIV positive status. She was emphatic about the importance of taking her medications and remaining undetected. Additionally, she said she doesn't think much about HIV. "It's buried. You got to dig its own grave. I can't say no more that it's buried." She talked about using HIV as an "up-lifter." She advised other women to do the following:

> Don't let nothing take your joy away. I don't care if it's HIV, diabetes, cancer … you can beat it; if you really want to beat it, you can beat it. So, this, use it as an up-lifter, and you'll be alright.

The central themes of Sophia's story were the following:

1. Traumatic HIV diagnosis: "It's Buried. You Got to Dig Its Own Grave."
2. Self-silencing Disclosure: "I Won't Let People Know My Business."
3. Aging: "My Diabetes is the Main Game."
4. Resilience: "I Use HIV as an Up-lifter."

Interview 6

The sixth participant, Maria Elena, is a married, Hispanic female, in her late 50s, who was diagnosed with HIV in the late 1980s while incarcerated. When asked about her story, she stated the following:

> I will start at the beginning, even before I was diagnosed with HIV, my sister, my brothers, were drug addicts, and they were … they used to shoot up heroin; they used to share needles … my sister … gave birth to a child, but she did not know she had HIV, and the child was born with HIV. So, as my mother's helper, I went through a lot with this baby. I grew scared of HIV, but I grew more scared of the stigma that people put around it … so from there, I started being scared of HIV.

Maria Elena revealed that she became addicted to crack cocaine, and "the best way to support my habit was prostitution." She was arrested for prostitution and went to jail. It was there she was diagnosed with HIV. She stated shakily:

> I was told, but I don't know how I responded to it. I, I mean, I had no response to it … it didn't faze me one way or the other … I kept prostituting myself … I found out you could get charged with manslaughter for doing this while you are HIV positive, and you don't let that other person know. So that really put a stop to my prostitution.

When she received her diagnosis, in jail, she stated that no one really explained anything to her. They gave her a pamphlet to read that told her it was contagious, and she could die from the disease. She stated she never really thought about it because of her state of mind: “I never gave HIV a second thought.”

Maria Elena was aware that people talk about others that have HIV: “They say stuff like, she’s contagious … and people think this is, this is such a bad thing I just want to scream out.” She had told her immediate family and her husband. She had, on occasion, told an immediate supervisor, but only if she cut herself on the job. She had not told friends. She related a story of being involved in an outreach program and speaking to a group about living with HIV: “That was the one time I openly said that I am HIV positive. I didn’t know who was listening.” She believed it was a relief. She thought it would be a relief to tell her friends, but “because I know how they feel, how they react because I’ve heard them speak about other people that have it.” She refused to tell anyone, though: “I wish I could, but they wouldn’t understand it.” She could not recall being stigmatized by the medical system, although, earlier in the epidemic, she felt her niece had been treated differently than someone without HIV.

Maria Elena believed she was healthy because she was not skinny: “I was big. I was thick.” She refused to take medication until she stopped using drugs. She believed no one could tell she was infected with HIV because she looked good. Additionally, she repeatedly talked about her fear of other people finding out: “They’re not open to this, they’re not. I don’t think people will ever be. It’s just like a plague, and that’s it.” She believed a person must tell a “serious” sexual partner, but “if you don’t have to tell nobody, you don’t have to tell nobody, because people are ignorant.”

Maria Elena’s husband had been incarcerated for over 10 years; during that time, she had not had sex with anyone until one recent experience. She used protection but did not tell him her status, which created extreme fear and anxiety for Maria Elena. She described how she feared this sexual partner would get tested, find out he was HIV positive, and come back to her in an accusatory manner, blaming Maria Elena for infecting him with HIV. She believed it could be a dangerous situation. Remorsefully, she stated the following:

> It could be very dangerous in many ways, that if he finds out that I’m HIV, he’s going to come at me in a bad way because I didn’t tell him … I put his whole family at risk, and that’s wrong of me.

She continued to hold on to her feelings of guilt over not telling this person she was HIV positive, despite being on medication, having an undetectable HIV viral load, and being at minimal risk to transmit the virus, and used protection. Maria Elena believed that educating people would be “way bigger than what science has done with HIV… so that we can come out openly, like everything else, and say, ‘Hey I live with HIV.’”

The central themes of Maria Elena’s story were the following:

1. Self-silencing Disclosure: “You Don’t Have to Tell Nobody.”
2. Fear of Disclosure: “A Greater Fear to me Then Living with HIV.”
3. Stigma: “It’s Just Like a Plague.”
4. Education: “People Don’t Know How Far Science Has Come.”
5. Resilience: “I Have Grown to Live With It.”

Interview 7

Renee, Participant 7 was an African American, widowed female, in her late 50s. Renee was diagnosed with HIV over 30 years ago. She revealed that at her diagnosis, she experienced "shock, disbelief … frustration at myself. Wow. With it came frustration, fear." Her initial experience was intense and included being stigmatized and feeling suicidal. She described it in this way:

> There were a lot of emotions going on in me at the time. People wouldn't talk to me. I couldn't get anybody to. When they first found out that I had it, they wouldn't touch me. I felt like an outcast, as usual. I felt like killing myself many a time, but I just couldn't bring myself to do it. Tried overdosing … mentally, I was numb.

She refused treatment for many years because she believed the medication "had a little bit of rat poison in it," and that scared her. She also believed that nothing would happen to her in terms of disease progression, so she did not need medication: "Why take it when I don't feel bad?" and "I look so good, and I look so healthy" that no one would know. She refrained from sex, so she would not pass the virus to anyone else.

Renee, who was young at the time she was diagnosed with HIV, told her immediate family of her diagnosis, and "they sighed and looked at me funny." She believed they accepted her diagnosis. She also went to substance use rehabilitation programs, where she believed other patients had no information or knowledge about HIV. They asked the question, "What do [*sic*] HIV look like?" and "I'm sitting here among them with them not knowing I'm the victim, you know. Here you are sitting, and you don't know it, but once they found out, it became so strange." She believed this reaction came from other participants and professional providers. She recalled that she isolated herself: "Most of the time, I sat in my room … I didn't talk to nobody, and that made me feel some type of way." She left the program early due to these feelings.

In another story, she told how the other people in the rehabilitation program "shunned" her when they found out her diagnosis. The disclosure was difficult for Renee; however, she stated she told her doctors and whoever she "laid down with." She also thought she would not find a partner or a lover again; however, this aspect turned out not to be the case, so

> whoever approached me with the sexual … on the sexual tip, I let them know. I told one guy, he still came back and I was like, he's still coming back, and I'm like, wow … I do protect myself, Trojans.

She stated that she told her two husbands and her boyfriend about her diagnosis before they had sex; with all of them, she insisted on using condoms: "The ones that don't want to deal with a Trojan, don't get to deal with me."

Renee did tell the pastor and the members of her church about her diagnosis and felt she was accepted. She put restrictions on herself in terms of activities in which she would or would not participate. She explained her feelings in this way:

> I felt they should know that they are living among me, and I'm living among them … I will not participate in no food activity because the first thing they cry is if you get cut, 'oh, the blood,' you know … so I do other things … so when I first joined that church, that was the first thing I did; I got together with my pastor, the deacon… the pastor's wife and the secretaries to let them know … Put precaution on them … I wanted to be in the background. I didn't want to be in the front, forefront.

As far as disclosing to her family, Renee stated that she felt "better and more clear [*sic*] to open up about it to certain people. I don't open up to everybody." She decided who to tell based on how she had seen various family members respond to people on the street, who were "thin and skinny, and their teeth are all messed up." She used "the expression on their face" to decide on whether to reveal her diagnosis: "So, I'll know, if I tell you that I have it, I'll get the same reaction. So, I refuse to tell you."

She chose to tell people her diagnosis “on a need to know basis.” She gave an example of telling her stepdaughter, who did not treat her any differently. She emphasized that people, in general, were a different story: “But the streets, they treat you as if the world just ended. So, I don’t—I keep my mouth closed.”

Renee stated that HIV being a chronic illness had not changed her experience. She felt good, but she now takes her medicine because her T-cells dropped, and “I said that either I live, or I die. It’s my choice, and I choose to live.” She believed that aging had not changed anything, and she was proud to be her age of 55 years: “It makes me feel better that I can get this old, you know, and live with this mess, you know. I’m proud of where I am right now.”

The central themes of Renee’s story were the following:

1. Traumatic Diagnosis: “Shock and Disbelief.”
2. Self-Silencing Disclosure: “It’s on a Need to Know Basis.”
3. Stigma: “They Treat you as if the World Just Ended.”
4. Resilience: “It’s My Choice, and I Choose to Live.”

Interview 8

The eighth participant, Carol, was a Black female in her late 50s. She had separated from her husband. She was diagnosed with HIV over 25 years ago. She, too, began her story with her diagnosis from past-to-present and back to the past. She was in the hospital for pneumonia and was treated and released but continued to become sicker until she had to return to the hospital. She spoke to a nurse there and was tested for HIV. At that time, it took 1 to 2 weeks to get test results. Carol got a phone call to come to the hospital because the nurse did not want to talk on the phone, except to tell her that “there is something that is going to really affect your life.” When Carol went to the hospital again, she had a long conversation with the nurse who explained HIV and AIDS to her and advised her she needed more tests to determine the stage of the virus. She and her nurse discussed her risk factors and determined that drug use was the probable way she contracted HIV, and she was advised to tell all those with whom she had been sharing needles, which she succeeded in doing. Her “associates” did not believe the diagnosis. They attributed her illness and her symptoms to the drugs they used and the alcohol they used to clean their needles.

Carol related that they all knew little, but they had heard of a famous actor who had it (she called him Robert Redford, though it might have been someone else). Their feeling was that because he lived in California and was rich, he would not bother with them. She stated the following:

> Ain’t coming around nobody, so ain’t that a bunch of crap, because that man don’t [*sic*] know who we is, he ain’t never seen us, he don’t know, you know, we all get high, whatever, don’t believe that crap, tell that lady she selling a bunch of garbage.

She did stop sharing needles with her “associates.” However, it was not until several years later, when they could utilize syringe exchange truck services, that her drug-using companions were tested.

Carol’s mother had custody of her children; therefore, Carol believed she had to tell her mother. Carol was genuinely concerned for one of the children because she was pregnant with her at the time she was diagnosed. She later added that it still took her 2 years to get the courage to tell her mother. She stated that her mother knew nothing of the disease but understood the children needed to be tested. Her stepfather did not want to because he was embarrassed that his stepdaughter used drugs and was infected with HIV. Eventually, Carol went with her mother to have her children tested, and she described it as a significant event for her in changing her behaviors. She learned that her mother had faith in her for telling her and said, “I love you, and I didn’t expect you to go as far as you did, that goes to show that you can stop just right now, and you can get your life together.” To Carol, this message meant that “God has a plan; he must want you to stay. He don’t want you to die and give your soul, give up like that.” Therefore, she started coming to the clinic; with much encouragement and persistence from her nurse practitioner, she started taking medication. Carol talked about her mental status at the time: “It really affected me mentally because I felt like I was the plague. I was a plague, and I could never have sex again, normal sex again, with anybody.” She recalled being a “wreck,” weighing only about 91 or 100 pounds, having “a really nasty attitude because I didn’t want to come in here, and thinking that she was going to die anyway, so why stop using drugs.” She credited the nurse practitioner, who convinced her to take medication and get help to stop using drugs.

She recalled that she was afraid that other people would find out she was HIV positive, and she would be looked at differently and badly:

> I was really scared … I was like, “Please don’t tell anybody this” … don’t, just don’t. The whole clinic’s going to know. I don’t want to come back here no more; people are going to start looking at me … like I’m different and stuff, and I’m running around here with a disease … and when I told my mother … oh my God, my mother’s going to tell my sister …then my (other) sister’s going to find out … she’s going to look at me different … And I mean, they did, they did … so I felt like I was, I mean I felt really bad because they looked at me really dirt, like dirty.

She went to family gatherings, such as cook-outs, and family would act differently as if they were afraid that they would catch her disease. They asked if she had her own cup from which to drink. She stated that this experience had changed over time as people received more education and understanding of HIV. She stressed the level of difference between HIV and AIDS as a crucial factor in changing people’s reactions to her diagnosis. When she realized she had HIV, not AIDS, and started getting better on medication, which meant she was not going to die, Carol felt more motivated to stop using drugs and eventually did so.

Carol eventually met someone who wanted to marry her. She did not tell him her diagnosis for over 2 years. He did see her taking medication, but she told him it was for her asthma or her liver disease. She insisted on using condoms, which she believed was a reasonable alternative to telling him because “we wasn’t having free sex.” Carol also believed she was afraid to tell him because “it will put me back in the state of mind to where, when, I first found out,” and she “didn’t want no flashback.” She went on with her story repeating what happened when she first found out and began coming to care. She utilized the assistance of her nurse practitioner provider to disclose to her husband so that she could correctly explain the status of her disease and things, such as undetectable equals untransmittable (U = U) and pre-exposure prophylactic medication (PrEP). Carol talked a considerable amount about the story of her marriage, obviously of concern to her, though not related to the status of her HIV.

Despite being undetectable and having high T-cells for many years, Carol still believed, “I’m not normal like somebody my age, somebody else that doesn’t have it. Like I still have, in the back of my brain, that I still feel like I’m not physically healthy.” She continued to have the fear that her medication would stop working, and she would get ill. She believed that she had made progress in changing her life, including taking HIV medication and not using drugs; however, some people who knew her diagnosis still looked at her differently and waited for her to die because they wanted her belongings and such.

> I can feel it in the back of my head that they are talking about me; his family, okay. And my sisters and brothers are talking about me. My mother is gone and my children, because they know my status, …they just want what I got, what am I going to leave behind … they want to come in here and take all my furniture and go, whatever they can get. And nobody is going to show up at a funeral because everybody don't do that.

She ended her story with the hope that they will find a cure while she is still alive, and she would "be here for it, and I'm going to laugh (at) it all."

The central themes of Carol's story included the following:

1. Traumatic HIV diagnosis: "It Really Affected Me Mentally."
2. Substance Use: "I Didn't Know How To Do It Sober."
3. Significant Relationships: "She Flipped Over Backward To Save Me."
4. Self-Silencing Disclosure: "It Took Me Almost Two Years to Tell Her."
5. Stigma: "People Are Going to Start Looking At Me."
6. Resilience: "God Has A Plan."

Interview 9

Participant 9, Carmen, was a Hispanic woman in her mid-50s. She was a single college graduate who was diagnosed with HIV approximately 20 years ago. Carmen has three children and four grandchildren. She began her story, talking about her wonderful children and being married for 15 years. She became divorced and then met a man whom she later married. He never told her he had HIV. When she found out, her two boys were away in college, and her young daughter was living with her. Though she did not begin her story with her diagnosis, she focused on that time for a significant part of her story.

She recalled being extremely sick. Her hair was falling out, she was losing weight, and she had the sweats. She was hospitalized and credited a "beautiful doctor" with saving her life and keeping her as his patient after she was discharged from the hospital. Later in the interview, she talked more about how she received her diagnosis; she was in the hospital, and a doctor she did not know came in and said, "Oh, you have HIV, and that's why you're sick, you have this." Carmen stated that he just walked away after: "Yeah, he told me and walked away, and I was shocked."

Then, Carmen faced the dilemma of disclosing her HIV diagnosis. She remembered the following:

> I had to hide the stories and not let them know that I was HIV. It was very hard to keep it a secret. Living with that was always a shadow. [I] went to doctor's appointments, doctor's appointments … hiding the HIV … hiding my medicine, living in the back of this shadow, that what I had, trying to live normal … So, that's when I had to start living my lie. I was very careful and made sure I didn't get caught.

She decided to stay with her second husband because he gave her the virus, "and I was his reminder." He left her 14 years later. At that time, she found out that he had tried unsuccessfully to molest her 11-year-old daughter, so she was glad he left. She continued to keep this secret, as well as her secret of being HIV positive. She was afraid that if people found out, it would also affect her children's lives and "change(d) them from college kids to prison kids." She thought they would also get angry and do something to her ex-husband to hurt him for what he had done: "Again, I started living a secret, living with my kids. My secret was … I am an average, and beautiful lady that you have no idea is living with this …"

After 14 more years, she met another man. This person told her his status, but she stated the following:

> And I kept mines quiet … made sure I was protected, protected him, but I knew what he had because I noticed his medication … And then I approached him, and then he told me, but then I know why I kept mines quiet because it didn't make a difference.

When she thought about receiving her diagnosis and keeping her secret, she stated the following:

> I couldn't tell nobody about it, just my husband or my little brother but he was there. When adults, people, know about it and having lived with this in my, to myself for over 15 years … And there might be a lot of some people, women out there still living with secrets over 50, because they don't want their family to know, it's sad.

She recognized the reason she spent all the years, not telling anyone. She stated, "As a single grandmother, you have to worry about how other people will react with this." She also talked about dating when women were older and living with HIV:

> I feel like leprosy when it comes to people dating … I always prayed to God to get me a partner that will understand, because I'm a good woman, and I found one, and we talked about it, he understands, and we are living now as a couple; both HIV and beautiful numbers.

Carmen did not disclose her HIV status to anyone else, but she had several instances where people found out without her involvement or permission. She told the story of how her daughter-in-law learned she was HIV positive. Her daughter-in-law worked in food service at a hospital where Carmen was admitted for a back problem. Someone saw Carmen's record and told her daughter-in-law her HIV diagnosis. According to Carmen, she blurted this out when Carmen’s daughter was in the room. Carmen went on to say the following:

> Anyway, I don’t drink; I don’t do drugs, I just keep it to myself with HIV. You keep your story to yourself, as I’m a grandmother, a great mother, a great-grandmother, and a great friend. I go to church, and I focus myself, but you always had to keep this secret away from everybody.

Carmen kept her secret at church because she believed people still have misconceptions and did not understand HIV. She was afraid that her siblings would know neighbors and people in the church. She said, “The pastor knows, the bishop knows, but other people don’t, and I would love to stand up and tell my story. But it would never happen because people wouldn’t understand what it is.”

Carmen had not experienced any discrimination from medical professionals; however, she stated she did not really talk about her HIV diagnosis and believed she looked so healthy that they might not even realize she lived with HIV. She wondered what would happen if she was a substance user and not looking so good. She did have an experience with a pharmacy where the staff provided a list of medications in an envelope but did not seal it. Her daughter picked it up for her, and the list had the names of the medications and what diagnoses they were treating. Her daughter pieced this together with what Carmen’s daughter-in-law had said and realized her mother’s HIV diagnosis. Carmen’s oldest son found out through a girlfriend, and then he increased his drinking. Carmen blamed herself and her HIV diagnosis for this situation. She believed, “A lot of people should understand, good ladies get sick, grandmothers get sick, and your neighbors get sick, and if you ever got to meet me, you will never think (it) until you look at my records.” She believed that there should be more information about HIV, as there was about other medical conditions, such as Alzheimer’s disease, cardiac disease, hair loss, diabetes, and more medical conditions, on TV and the Internet.

She believed she had mental depression and other mental issues, but she had no one in whom to confide, particularly as an older woman. She believed that older women, who had lived with HIV for some time, were forgotten, more so than people with other diseases, such as diabetes: “HIV gets put aside as I started like lepers do, and we are not people with a leper, we are people with HIV.” Carmen had the creative idea of having a TV talk show do segments on where HIV was now, allowing people to be introduced to people over 50 living with HIV: “Grandmothers, there’s a lot of us; grandmothers that are good people and surviving. Let the people, the public, know it’s ok.” Despite her depression, she described herself as a fighter: “There’s a lot of us that … and look in the mirror and say, ‘I’m here,’ and ‘I’m not going nowhere.’

Her advice to older women was to get to know someone first before they had sex. She believed that at an older age, sex was not the most important thing for her and sharing with a partner was about sharing oneself not just sex: “As you get older sex is not important, this is more important, sharing time and having somebody there that you could talk to and understand.”

Carmen advocated for more services for people, particularly women, who lived with HIV, including more support groups and education groups, to decrease the isolation. She had an idea for a website that could both “teach us how to live with it.” She believed the following:

> If we have a secret, have support, so they could keep our secrets to ourselves and have somebody to talk to. Like AA (*Alcoholics Anonymous*) have somebody they could mentor that don’t know them … I could be a support to somebody.

Carmen ended her story talking about all the unanswered questions about HIV and on a personal level, spoke about women over 50:

> Ladies over 50, we have a question mark, and I know about it because of a lot of questions. We know about different things, and but we don't know enough about HIV or AIDS. So, if I can leave you anything, it is a big question mark.

The central themes of Carmen's story were the following:

1. HIV Diagnosis Trauma: "Cancer is Easier to Know Then HIV."
2. Self-Silencing Disclosure: "Living in the Back of This Shadow."
3. Stigma: "We are not People With [Leprosy]."
4. Aging: "There's a Lot of us Grandmothers … Surviving."
5. Education: "We Need Talk Shows on What HIV is now."
6. Resilience: "I'm Not Going Nowhere."

Interview 10

The tenth participant, Sandra, was in her 50s. She was a West Indian, Black, female. She completed high school, was employed fulltime, and was married. Her story began with "the saddest day of my life." The memory remained as vivid for her today as it was only 7 years ago. Sandra had a pre-operative physical for a minor procedure, and blood work was obtained. The doctor called her to come to the office. When she arrived at the office, she said this happened:

> He took me to a room with a nurse, of course, and he was telling me that we had run some tests, and it showed that you are HIV positive. I go into a state of shock, where I start getting these sweats. I start sweating, my whole body starts to get wet, and there was a paper towel, a roll of paper towel on the desk, and I wanted to reach over to take a piece to wipe the sweat from my body, but my hand just couldn't move, and the tears just keep

> trickling down, and all I could say to him, can we discuss this another time after my surgery?

After her surgery, the doctor approached her again and offered to refer her to counseling, which Sandra accepted; however, “that didn’t help.” Sandra explained, “I was still feeling depressed and sad, not knowing what to do, how to approach it because of the stigma, and that I didn’t want to say anything to anyone.” She did not tell her husband because she was angry that “I knew I didn’t get it before I met him.”

Separately, Sandra and her husband were asked to come to the doctor. The doctor tested her husband, and he was HIV positive. They began to discuss the situation and concluded that he contracted HIV from a previous partner who also was not aware of her diagnosis. She had died, either not knowing her diagnosis or not revealing it to Sandra’s husband. Sandra and her husband now had a difficult decision to make:

> And then we make a promise not to tell our kids because of this stigma number one, and we don’t want them to go into the same depression that we were in. So, we didn’t tell them. But my sister, who is in the medical field, I told her, and she seek advice … And until this day, it’s only me, my husband, and my sister and her husband know anything about this.

When asked if she ever told her children, Sandra stated,

> Never. My daughter … I didn’t tell her either … so it’s like living in a secret world and the stigma that comes with it. That’s why you don’t want to tell people like that what is happening with you, because of the stigma. You don’t want to say anything to your close friends or relatives. Not even my husband’s mother, we don’t tell, nor his father.

When her husband first found out his HIV diagnosis, he was suicidal, wanting to hang himself. However, Sandra became his support and strength. She did this act in addition to dealing with her own feelings of hurt and fear. With the support of her sister, she concluded the following:

> This disease will not take me out of this world … I'm going to take the best care of myself. I'm going to try not to go into depression, no matter what. I try to stay happy so that this won't affect my life.

Sandra discussed how she identified HIV stigma at work and, therefore, continued not to share her diagnosis with anyone. She recalled the following:

> I remember one day I was at work a nurse said to me, making sign to me to double up my gloves to go into our room to pick some trash, and she was using her lips to tell me, and she was using her hand doing sign language, and I pick up on what she said … even if the patient in the room didn't want anyone to know their status, she told me, which I think is not good. So, the stigma is still out there.

Sandra remembered another nurse, a friend of hers, who did not know that Sandra was HIV positive, who was upset that the doctors did not tell her that a patient was HIV positive. This nurse was afraid she would contract HIV by caring for the patient. Sandra confronted these nurses' misconceptions, telling her that she would not get HIV by touching the patient. Additionally, she related another time when HIV stigma affected her directly. She was at the U.S. embassy, accompanied by her teenage son, who did not know her status. She tried to get a visa, and the counselor used the microphone, so everyone that was there that day heard what he said. He said, "You are HIV positive; we cannot let you into the United States of America." Sandra was embarrassed and afraid after that happened: "I feel like I could go into the ground," and her young son was present. She and her son had never talked about this experience or her HIV diagnosis.

When Sandra was in (*island name*), she refused to go to the free clinic, choosing to work more hours to pay cash for her visits and her medications, due to fear that someone from her community would recognize her face. Everyone at the free clinic could identify a person by the specific nurse that called a person into the clinic, even if the person did not go in through the infectious disease side of the clinic. Her husband went to the free clinic and would tell Sandra about the people he saw there, especially if they had the same nurse or doctor that Sandra had seen: “So sometimes the stigma don’t [*sic*] allow people to get treated, so people will suffer and die because the stigma is too much. It is too much. In my opinion, it is too much because I’ve experienced it I have.”

Sandra talked about the way the nurses treated her when she was in the hospital for surgery. She stated they made her feel dirty and worthless:

> There were nurses there that treat me as if I was nobody. I ask for linen; they bring me dirty linen. I ask for a pillow because I couldn’t breathe properly. I asked for a pillow to elevate my head; they didn’t bring it. I asked if I could put on oxygen, they said no … so it was really traumatic being in the hospital with those nurses.

She remembered a time after the surgery when she had a urinary catheter in place. She was waiting in the clinic waiting room when she started having a large amount of frank bleeding through the catheter. She could not get the nurse to attend to her, even when an unrelated person got upset at seeing this issue and tried to help her get attention from the nurse. When she did receive care, it was not from her doctor but from a “junior doctor” whom she did not trust. She decided then not to go back to that clinic. She still had a surgical wound, which she and her daughter dressed by themselves, rather than go back to the clinic for care where she would be treated poorly because of the stigma of HIV: “So, it was a hard time for me, very, hard, very, hard. Sometimes I would lay in my bed at night, where do I go from here? What is going to happen?” She recounted how constricted she felt because of the restrictions from certain countries, from not being able to get a work permit, not being allowed certain jobs, and not being able to get medications. She recalled she had often traveled between (*an island name*) and the (*another island name*), where she had family, but how difficult travel was now that she was HIV positive.

Sandra had not told anyone at her church, either in the United States or in (*island name*) of her HIV diagnosis. She emphatically stated the following:

> Not even my Bishop that was in (*island name*). I have never told him … I don’t tell anyone at this church that I’m going right now; I don’t. As I said, I keep it to myself and in the back of my head is four of us into this [herself, her husband, sister, and brother-in-law].

She stated that people feel “that if they touch you if you drink from the same cup if you just walk with them, they catch it.” She also talked about not trusting condoms because her daughter had gotten pregnant when a condom broke. Her advice to everyone included not having affairs. Moreover, Sandra strongly believed that education was a key to conquering stigma, including from people in health care and the public: “So, people need to be more educated about the HIV, so that stigma can go away because it’s really a stigma that it seems like it’s not going nowhere, not right now.”

She ended by saying the following:

> So, you know, the stigma is high. Just the stigma gives me a problem, yeah, and oh dear, you don't want to see who you are and what you are and all of that because of the stigma I try to keep away from, you know, disclosing what my status is to people. Keep away from the stigma.

The central themes of Sandra's story included the following:

1. HIV Diagnosis Trauma: "The Saddest Day of My Life."
2. Self-silencing Disclosure: "It's Like Living in a Secret World."
3. Stigma: "The Stigma is High, Keep Away From the Stigma."
4. Education: "People Need to be More Educated so That Stigma Can Go Away."
5. Resilience: "This Disease Will Not Take Me Out of This World."

Interview Eleven

Participant 11, Daniella, was an African American female, in her 50s, diagnosed with HIV almost 15 years ago. She began her story with a narrative of being quite ill, becoming dizzy, falling down the stairs, and being rushed to the hospital. During her hospitalization, she had many blood tests as the doctors did not know what caused her symptoms. She related that her mother and father were with her in the hospital when she received her diagnosis. She started her story with this recollection:

> And the doctors came in, there was, like, six doctors. He said, "We got bad news, and we got good news." So, my father, he walked out the room, and he *(the doctor*) said, "You want the good news first or the bad news?" I said, "You can give me the bad news." He said, "Well, you're HIV positive, but we don't know how long you had it." … And after that, all I could do was see my life gone … I was stressed, I was depressed, and it's to a point that I just wanted to take my life.

She discussed the difficulties of taking medication. Then, she told me how she was rehospitalized for an infection on her brain and her spine, and she had to have intravenous antibiotics. At the time, she was quite angry and upset, and she called the police to report her son's father because he never told her his diagnosis. Daniella believed this issue was a death threat. She stated that he was arrested and jailed.

She tearfully recalled that she was pregnant, and when her child was born, she breastfed him because she did not realize she could pass the virus to her baby in this manner. She stopped as soon as she learned this fact. Fortunately, her son repeatedly tested HIV negative until they stopped testing him at age 5. Daniella had an incident that led her to disclose her diagnosis to the rest of her family. Her son had a nosebleed, and she would not touch it because she was afraid that she would pass HIV to her young son if their blood mixed together. Thus, she told her other son, her daughter, and her sister, who were all there, the reason she would not take care of the youngest son's nosebleed was that she was HIV positive, and "their mouth just dropped."

Another day, she purposefully disclosed her status to her youngest son. Daniella was tearful as she recalled this incident. Her son had accompanied her to a doctor's appointment, and he asked her, "Why they got to check your kidneys?" She told him, "Because your father infected me with HIV." She went on to say:

> And his mouth, you know, he dropped, he didn't want me to see him crying, because he went in the room, he slammed the door, and he cried … I said, "I was pregnant with you. I didn't know I had until after I had you …and you was nursing, and I didn't know that it was coming through my breast milk, you know."

At this point, her son asked if he had HIV, and she told him, "No, the tests were negative."

Daniella often spoke of her father, who was significant support in her life. Prior to his death, her father told her she would meet someone who would take care of her and love her, even if she was HIV positive. He said, “I’m going to send him to you before I pass on.” Her father passed away on her youngest son’s birthday. Daniella met someone who did what her father said he would, and they have been together for 14 years. She revealed what happened when they met:

> And before we fell in love and got involved with each other, I told him straight out. I said, “I have something to tell you.” He said, “I know you’re HIV positive, I’m not going nowhere. God sent me to you … You’ve been through a lot.”

To this day, Daniella did not know how her partner knew that she was HIV positive. She did speak of still being fearful of the stigma that HIV created in the public arena. She said the following:

> I don’t want anybody else to know because they may look at me, like, you know, “Don’t get next to her,” or “We’re going to jump off for her” … People will stare at you, you know. Then, they will sit there, and they will judge you.

Daniella told a story about unintentional disclosure of her HIV positive status by a physician during a clinic visit. She waited for her discharge instructions, sitting in a seat with no door or curtain or privacy, when the doctor, who was changing her HIV medication, came up to her and loudly said, “You’re HIV, you know, you’re undetected.” There was another patient sitting in the next seat who looked at her and moved further away. Daniella had enough self-esteem to take the doctor aside and tell him what happened was wrong and to respect people’s privacy. She also spoke to him about the stigma of HIV. Daniella stated that she was terribly upset by the experience. She cried as she told me the following:

> I thought like, "I can't believe he did that." You know, I went to the bathroom, and I cried, you know, because I was hurt, you know. And then you said my name, even though it was just my last name, you know, that's not the point. The point was you could've pulled me to the side or go in a room and close the door, and then you can tell me. You had no business telling my personal business out there … that's why I don't like telling nobody. I keep it all bottled up; you know. That's why I get depressed because I don't have nobody to talk to about this …it's just hard, you know. I can't do it every day.

She responded to a question about disclosing her HIV diagnosis to other people, such as friends, church, and community, by saying that she visited her mother and would go right home. She had little to do with anyone else.

Daniella expressed how important it was for her to take her medication and how she felt physically terrible and emotionally frightened if she missed even one day. Now, she sets the alarm on her phone and takes medicine every day. She advised other aging women to "be honest," though she stated there was a large risk in doing that: "If you tell your friends, you could tell them, but it's the way that they're going to react towards you once you tell them, if they're going to be my friend or if they're not." As far as partners, she believed the following:

> If you have a boyfriend or whatever, tell them, you know, on the get-go, because some will stick by you and some won't, you know. You got some good ones, and you got some bad ones … Just be honest.

When she talked about aging, Daniella stated the following:

> I am happy that I'm on this earth today …I'm getting younger. My kids are getting older … I thought I'll never see my kids having kids, and I thought I'll never be a grandma, but, you know, but thank God, got me here to see them.

The central themes of Interviewee 11, Daniella, included the following:

1. Traumatic HIV Diagnosis: “All I Could Do Was See My Life Gone.”
2. Depression: “I'm Still Going Through it, I Keep it All Bottled Up.”
3. Self-silencing Disclosure: “I Don’t Want Anyone Else to Know.”
4. Stigma: “People Will Judge You.”
5. Isolation: “It’s Like I Live in a Box and the Box Ain’t No Good.”
6. Resilience: “I Am Happy That I’m On This Earth Today.”

Interview 12

The last participant, Tereza, was a single, Hispanic female, in her late 50s, who had been living with HIV for over 30 years. She also started her story from her diagnosis date: “When I found out I was HIV, that like turned my whole world.” She was pregnant at the time, was fearful, and almost certain that her son would be HIV positive as well. She believed, “Spiritually, it was killing me.” She apparently did not discuss this diagnosis with her doctor until her son was 4 or 5 months old. When the doctor told her that her son had tested negative, she cried tears of joy, “I said, ‘God, thank you, Lord.’ You know, because I didn’t have to go through that guilt.” She did not realize she was HIV positive when she got pregnant. She had used drugs and not “timing my period.” She believed she contracted HIV through her boyfriend at the time. She remembered thinking, “I was thinking of leaving my kids, I was hurt … I didn’t go out there to get this … I used to ask the Lord to take this, all so heavy.” She asked for “some kind of sign, some kind of relaxation, because I was crying, and I couldn’t believe it.”

Later in her story, Tereza described how she had been depressed since her diagnosis. She “used to lock myself up within myself and just cry for many years.” She described how her fears stopped her from doing even the littlest things: “The fear stopped me from reaching out, the fear stopped me from going to meetings, and the fear stopped me from even going outside." She was afraid that people would know her diagnosis by looking at her face. She thought she would develop distinguishing marks, such as Kaposi's sarcoma lesions, and everyone would know she was HIV positive and "that kept me scared all the time." She remembered going to a mental health facility: "because I found myself in a bottle with and then I put the bottle and the cap on it. There was no way out; I was thinking there was no way out." She described, "I felt suffocated … it's like I locked myself in there, and then I put the cap on it."

She related that she had been poorly treated by health care professionals and gave an example of going to the emergency room for a chronic obstructive pulmonary disease exacerbation and telling a doctor, "you don't have to treat me like this." She stated they mistreated her because of her drug use and her HIV diagnosis. She felt judged by the physicians who cared for her and stated sadly:

> Yeah, I got mistreated many times by the emergency room doctors, and it is a sad situation. Sometimes I'm really scared to go to the hospital, and I let them know, please don't judge me … Please don't judge me.

Tereza talked of another time in the hospital when she was mistreated. She recalled the following:

> I had the nurses, the head nurse from the floor, come talk to me because of the … room or the expression that the doctor made to me that day. And I was just crying, crying, and I was really hurt. Things like that will stop me from talk [*sic*] to people about my situation.

She has disclosed her diagnosis to her first boyfriend, whom she believed gave her HIV, but not until she had been positive for 30 years. When she did hint to him, he said, "So, you're HIV," and when she said, "Yes," her boyfriend said, "Yeah, I'm HIV too." Other than her children and medical doctors, she stated she only told her boyfriend, though she later remembered that she also told her sister.

Tereza refrained from telling anyone because of how people discussed HIV when she happened to be there: “It puts me in a bad situation because I’m not going to admit to them because I already know how they are talking.” She just told them that they were misinformed and needed to become educated: “It puts me in a situation where that I’m scared almost to talk to it, about my HIV, to people because of their ignorance.”

She told a story about talking with a friend’s friend who started telling her that you can’t even kiss anyone because you could get HIV. Tereza became very “defensive or offensive” and told her she was misinformed, but “I didn’t want to tell her my experience.”

She described another experience as the following:

> “They should have living buildings, people that are HIV themselves.” There are many buildings like that, but I guess they she didn’t know that. “Yeah,” I say, “Why?” and she says, “Oh, because they don’t need to be out here in the public living with other people.” I’m like, “Wow.” I just walked away.

At this point, Tereza began to cry and said the following:

> “They don’t deserve”—I’m like, we don’t deserve what? But then I said no, I’m not going to put the—I’m going to put myself there because, you know, why this is, that’s a tough one I need to swallow, we shouldn’t be around? Why? We’re not criminals, but no, this was just something that happened. Oh, my goodness, I’m sorry. [Crying]. I’m sorry … so yeah, it’s crazy the crazy things I’ve been hearing and that right there cause me not to talk too much about my HIV status.

She emphasized how important education about HIV was for everyone. She believed that learning about how to stay healthy—and she was not doomed to die—had made a huge difference in her attitude toward life. Tereza described her recovery from her depression in this way:

> Now, I’ve got a little knowledge where I could understand that I don’t have to lock myself up no more and no bottle with no cap on it and suffocate like that now more because life is beautiful and how can I say it, “I kick rocks to the HIV” and just keep on living to the fullest.

She closed her story by saying:

> That’s my honest story … it’s not easy. There was a time that I couldn’t talk. There was a time that I couldn’t talk about the situation because I’ll get choked. I started choking; I’ll start crying, and then you know, in the end, I shed a tear or two. But I deep breathe, and I swore not to let it happen, and here I am now.

The central themes of Tereza’s story included the following:

1. Traumatic HIV Diagnosis: “That Turned My Whole World.”
2. Depression: “There Was No Way Out.”
3. Isolation: “I Put Myself in a Bottle With the Cap On It.”
4. Fear: “The Fear Stopped Me From Even Going Outside.”
5. Stigma: “Please Don’t Judge Me.”
6. Education: “You Don’t Have to be Scared No More. There’s a Lot of Knowledge.”
7. Resilience: “I Kick Rocks to the HIV.”

Composite Analysis of Interviews

My first impression when reading the interviews was how difficult the oral interview is to convey in writing. Every woman spoke with an intensity of emotion that brought the past to the present. For these women, being diagnosed with HIV was life-altering and life-threatening in more than a physical way. All but one woman was tearful or cried at some point in her story. The feeling of anxiety and stress was palpable in the air. This study was qualitative in nature and understanding how the participants perceived their experiences was essential to the results.

Miriam-Webster (n.d.) defined *ontology* as “the branch of metaphysics concerned with the nature and relation of being” (Def. 1). This goal of this study was to bring forth and develop a deeper understanding of how aging women living with the diagnosis of HIV perceived their experiences—what the experience was and how it affected them *being in the world*. The ontological aspects of this study were reflected in the interviews. The information the women disclosed was from their own experiences and related to their core beings; they described how it affected them being in the world. I fought the urge to provide therapeutic comments or questions to the disclosures that they made. After the conclusion of each interview, I felt an overwhelming sense of depression and realized I held back tears when listening to many of the stories.

Some forms of narrative analysis utilize coding processes, but, in coherence with Riessman’s (1993, 2008) methods for thematic narrative analysis, I chose not to use coding but to identify larger structural patterns that developed into themes. Each individual story maintained its own themes, but when patterns were discovered between stories, those were identified as overarching themes.

There were minor variations in patterns of the experiences for these women. Some contracted HIV due to substance use, some were exchanging sex for drugs or money, one had a known HIV positive partner, and several had unprotected sex with partners who had not told them they were HIV positive. The use of substances did change some perceptions, and, at times, the women believed it was more difficult to address substance use than living with HIV. All expressed initial overwhelming depression or despair, except one person who used drugs to cope. All had feelings of anger, fear, shame, humiliation, hopelessness, and anxiety that persisted in some form for many years. The two participants who had attended therapy had more positive views and less current depression.

All participants reported experiencing HIV stigma when their diagnoses were revealed. Participants who self-silenced and limited disclosure reported observing stigma behaviors against others with HIV that they did not want to experience. All participants agreed that HIV stigma remained prevalent in the community setting. According to the participants, stigma by medical and nursing caregivers still happened but less so than many years ago. This stigmatizing often takes subtle forms, such as double gloving, signing to other caregivers that a patient is HIV positive, or presuming someone is a drug addict or a promiscuous person. Several women spoke of having a provider who subtly demonstrated stigmatizing behaviors, such as appearing not to want to touch an HIV positive patient, not listening to the participant, or implying that the participant had done something immoral to contract HIV; however, this occurrence was infrequent.

Most participants expressed that the education they received helped them to a greater understanding of how to stay healthy and survive. Additionally, they strongly believed that education that was updated and accurate would be a critical factor in fighting HIV stigma. Many believed that receiving current education helped them to conquer their depression and to have hope for the future.

The feeling that they were “survivors” and “fighters” was prevalent among all the participants, which occurred even while self-silencing and not disclosing their diagnoses. Some stated that they did not feel like they had an illness at all. All talked about medication adherence and education as significantly important to their maintaining healthy lives. After examining the interviews individually, listening and reading multiple times, and then looking for patterns between the interviews, I initially identified three themes: (a) Persistent HIV Diagnosis Related Trauma: “I Keep It All Bottled Up Inside,” (b) Self-Silencing Disclosure: “I Would Take It To My Grave,” and (c) HIV Stigma: “It’s Not Going Nowhere.”

Theme 1: Persistent HIV Diagnosis Related Trauma

Ten of the 12 women began their stories at the time of HIV diagnoses—the day life as they now remember it began. The day, time, place, and surroundings were indelibly etched into their psyche. Women remembered details, such as “that room they put you in is, like, all gray walls” (Participant 4) or the following:

> I start sweating, my whole body starts to get wet, and there was a paper towel, a roll of paper towel on the desk, and I wanted to reach over to take a piece to wipe the sweat from my body, but my hand just couldn’t move. (Participant 10)

Eleven of the 12 participants described aspects of severe depression at diagnosis with HIV that had lasted in some form to the present time. They revealed feelings, such as “I felt like killing myself many a time” (Participant 7), and “I was depressed, it’s to a point that just wanted to take my life” (Participant 10). The outlying woman who did not report depression at her diagnosis stated that, at the time, she used illicit drugs at a level that blocked all feelings. Two women proceeded to get long-term therapy and could move on and transform their depression into positive actions. Women described themselves as “isolated,” “in a bottle with the cap on,” “in a box,” “leper,” or “like the plague,” and other indicators of depression, decreased self-esteem, or guilt.

The first theme, Persistent HIV Diagnosis Related Trauma: “I Keep It All Bottled Up Inside,” was manifested by anger, sadness, fear, isolation, and burying feelings. Participants identified these feelings as impeding their lives, occurring during health care visits, and impacting relationships. The women’s stories reveal how the initial depression, sometimes transformed, and sometimes buried, persisted, and still continued to underly many of their lives. Participants identified feelings of persistent depressive symptoms lasting from diagnosis with HIV infection to the present day, in the form of an unrecognized and undocumented post-HIV PTSD. Participant 12 described her life as different after her diagnosis because she “used to lock myself up within myself and just cry for many years.” She spoke about how she stopped going out anywhere, even to medical care or substance use care. One woman stated that she did not disclose her diagnosis because she did not want “flashbacks” of the time she was diagnosed as this was too painful. Others denied these symptoms but talked about “burying” their feelings or that there was “nothing wrong with me” as if they did not have an illness.

Theme 2: Self-Silencing Disclosure: “I Would Take It to My Grave”

The second theme, Self-Silencing Disclosure: “I Would Take It to My Grave,” was voiced by almost all the participants in varying degrees. Two participants stated they had changed this choice to allow some to know their diagnoses on a need to know basis due to receiving counseling and their occupations as a substance abuse counselor and an HIV prevention counselor. Theme 2 represented one way that women have established to protect themselves from constantly having to deal with HIV stigma. Those who reported that they did not experience HIV stigma had also not told anyone the diagnoses beyond a partner or immediate and close family members. Several reported they had observed others receiving the brunt of HIV stigma and yet not done anything for fear of being identified as HIV positive. Some had heard acquaintances say things about HIV that they knew were inaccurate and from ignorance or lack of education. A few women corrected these inaccuracies; but doing so made them extremely anxious. One woman reported lying about her HIV statuses so that others in the community would not discover the status. In the member check, Participant 4, who had described being upset when someone else revealed her HIV diagnosis after she revealed it in confidence, stated that she now did not care who discovered the status. She would use her HIV diagnosis to teach people about risky behaviors and the consequences. She was employed in an HIV prevention counseling field.

Often, participants found themselves in conversations where someone was inaccurately talking about HIV, and the participant was afraid to educate or correct the speaker for fear they would be found out as HIV positive. Avoiding HIV stigma was addressed by self-silencing and isolating oneself from the community to minimize the possibility of diagnosis discovery. This theme was common throughout the interviews.

Theme 3: HIV Stigma: "It's Not Going Nowhere"

The third theme, HIV Stigma: "It's Not Going Nowhere," was common for all 12 participants. The third theme, HIV Stigma: "It's Not Going Nowhere," showed the ongoing and enduring issue of stigmatizing those who had been diagnosed with HIV. As these women stated in many ways, this issue was due to ignorance and lack of education about the progress in preventing and treating HIV. Born out of fear of a deadly disease established almost 40 years ago, this stigmatizing behavior persists despite the transition of HIV to chronic, treatable disease.

The medical community has considered HIV a chronic medical illness since 2010 (Deeks et al., 2013). Spurred by significant research, new and improved medications, and a changing course of HIV disease, it is no longer a “death threat” or a terminal illness. However, HIV stigma remains prominent in the lay community, “in the streets,” or “in the hood.” Stigma can even be found to persist among health providers. The third theme was common to all participants.

Fear of HIV stigma led 10 of 12 women to report limited disclosure of their HIV diagnosis. Several described themselves as being “a very private person,” revealing their HIV statuses only “on a need to know basis.” This revelation usually only included partners, medical personal, and sometimes close family. The fear that confidants would leak their diagnosis was often borne out by experience. All feared the HIV stigma of the community or the “streets.” Many described how others would look at them differently, shun them, or move away from them. Even in their own families, when their HIV diagnoses were revealed, some women experienced these and other behaviors, such as not being invited to events or being disallowed to play with or hold children in the family. All the women feared they would be negatively judged and were self-protective about revealing their HIV diagnosis for this reason. Even women who believed they were not at fault for contracting HIV, such as contracting it from a husband who did not reveal or know their own HIV statuses, believed others would assume they had used drugs or having promiscuous sex. These behaviors were painful to the women, and they quickly learned not to tell anyone their HIV diagnoses.

Participant 2 described this experience. Participant 2 said, “When you tell someone that you have the virus, their whole persona changes. They look at you in a different manner.” Not only did she not want to be judged, but she stated she did not want to be pitied. These fears were especially prevalent when women thought about dating or finding a partner. Participant 9 stated, "I feel like leprosy when it comes to people dating." Participant 8 said, "I was a plague, and I could never have sex again, normal sex again, with anybody."

When they were younger, women did not obtain needed health care for fear of being identified as living with HIV and being subjected to the existing HIV stigma. As they aged, they realized the importance of health care and became more adherent, though some remained fearful of the experience. Several described humiliating, stigmatizing, inaccurate labeling, or inconsiderate actions by health personnel. These included the assumption that they were promiscuous or a drug user. Medical personnel exhibited fear of contact with a person with HIV despite the statistics for routine contact leading to the exposure being extremely rare. Participant 3 recalled "a clinic doctor who was "very, very, rude. She made me feel like she didn't want to touch me. She was just very nasty, the way she talked to me like she didn't believe, like, like she was looking for tracks on my body or something." Participant 6 stated, "Once they ask you the question and you tell them you're HIV positive, it's like a red light went off. Ooh." She stated that they isolated her, and "they made it known that they don't do HIV positive people."

Medical providers are often unaware of their surroundings and the need for a higher level of confidentiality for certain situations, such as addressing issues of HIV. Participant 11 related a story about this situation, when the doctor, who was changing her HIV medication, came up to her and loudly said, "You're HIV, you know, you're undetected." There was another patient sitting in the next seat who looked at her and moved further away. The participant was angry and upset about this situation, "and I went to the bathroom, and I cried, you know because I was hurt." She told the doctor, "You could've pulled me to the side or go in a room and close the door, and then you can tell me." This action was a strong, confident action, yet it left her depressed and drained, fearful her HIV diagnosis would now be known in the general community.

Participants described friends and acquaintances who feared they would contract HIV from drinking from the same glass as someone living with HIV or by using the same utensils. They talked of the family who bleached the bathroom after the participant had used it. Not eating food that someone with HIV had prepared was another way that misconceptions were demonstrated.

Iterative Approach

I used an iterative approach with much reflection, and two additional themes emerged. As I reviewed and reread the interviews, the women identified not only the depression, the need for silence, and the stigma of living with HIV but also the creative ways that health care providers and others could work to end the stigma. They talked about correcting misconceptions through education on all levels. They strongly believed that they could live full, satisfying, and healthy lives despite living with HIV. Therefore, I added the next two themes to the findings: We Can End the Stigma" and Resilience: "I Kick Rocks to the HIV."

Theme 4: Education: "We Can End the Stigma"

The fourth theme, Education: "We Can End the Stigma," referenced the importance of education for the public and for those living with HIV. The participants repeatedly suggested that stigmatizing remarks were made due to ignorance and lack of education. Most believed that if people were not afraid of contracting HIV from someone living with HIV, because now medications could prevent that, they might be less fearful. They related that people still had many misconceptions about living with the virus that led to stigmatizing beliefs. They believed accurate and updated information would make significant inroads into the current level of HIV stigma. They also believed that the study was important, and it needed to be used to educate others and make a difference.

Theme 5: Resilience: "I Kick Rocks to the HIV"

The fifth theme, Resilience Despite Challenges: "I Kick Rocks to the HIV," was demonstrated by inner strength in the face of a daunting challenge. The stories provided insights into the resilience, strength, and coping mechanisms of the participants. All the women found ways to cope with their HIV diagnoses, which were positive and future-oriented. They changed their health behaviors to include medication adherence, healthy eating, abstinence from drugs and alcohol, exercising, yoga, and such. They described joy in caring for grandchildren and great-grandchildren. Many used their experiences to allow them to be more compassionate to others. They demonstrated a belief in themselves and their own inner strength. They used spirituality, faith, love of family, belief in their own ability to survive, and hope for the future to live fulfilled lives.

Women expressed sentiments about being fighters and survivors. Participant 2 stated, "put on your big girl panties and just accept it." Participant 4 stated, "Me and that virus got a fight going on, and he's still leaving a little bit behind, but I'm still fighting him." Another woman stated that she felt healthy, and HIV was not an issue for her any longer: "It's buried. You got to dig its own grave" (Participant 005). A few women stated that other issues, such as menopause or diabetes, were currently more difficult for them to treat than HIV.

Several women said that they would love to talk to others with HIV in a group setting but were afraid to do so. The few who had done this felt it was terrifying but also rewarding. One woman stated she felt better after the interview for this study as she had let out some of the "bottled up" feelings and speaking aloud had taken a weight off her shoulders. Another revealed she had not talked about her feelings of being HIV positive to anyone in more than 20 years, and she felt a sense of relief after the interview.

Member Checks

Member checks are an important part of ensuring the trustworthiness of qualitative research. At times, investigators do not understand or correctly interpret what a participant is trying to communicate. This issue may be because of transcription issues, cultural misunderstandings, or even a change in view or memory of the participant.

I chose 5 participants who were chosen, as described in Chapter 3, to review their interviews for accuracy and authenticity. They then reviewed the themes determined for their individual interview for consistency with what they said and believed. Finally, they reviewed and discussed the composite themes based on all the participant interviews for authenticity with their knowledge and feelings.

All five participants agreed with the findings as being genuine to their words and experiences. Two participants cried when reviewing their stories. Participant 4 believed she had more to say on the topic and advised me to add, “Trust your doctor,” as a theme on her story. She believed that without this trust, she would not have taken medications and would not be in great health that she is now experiencing. She stated the theme, “Trust your doctor,” was critical to doing well when someone was diagnosed with HIV. She stated this act was not easy but was essential. Therefore, I added a seventh theme to her themes: Trust is Essential: “Trust your doctor.”

Participant 4 stated that she did not reveal her diagnosis when she worked as a nurse’s aide in a skilled nursing facility, but she did reveal her diagnosis now, as she worked as an HIV prevention counselor. She especially liked to do so when teaching others about their risky behaviors, as she believed no one would think *she* was living with HIV, which might make an impact. She did not ask me to remove the self-silencing theme; she just believed she revealed her diagnosis more often than she used to and “doesn’t care” who knows her status.

Overall, the women were satisfied and believed the stories and themes were accurate and authentic in reflecting their stories of living and aging with HIV. They all stated they were happy to be represented in their own words and excited to participate in this project. For example, Participant 2 said, “When you tell someone that you have the virus, their whole persona changes. They look at you in a different manner.” Not only did she not want to be judged, but she also stated she did not want to be pitied. These fears were especially prevalent when women thought about dating or finding a partner. Participant 9 stated, “I feel like leprosy when it comes to people dating.” Another said, “I was a plague, and I could never have sex again, normal sex again, with anybody” (Participant 008).

When they were younger, women did not obtain needed health care for fear of being identified as living with HIV and being subjected to the existing HIV stigma. As they aged, they realized the importance of health care and became more adherent, though some remained fearful of the experience. Several described humiliating, stigmatizing, inaccurate labeling, or inconsiderate actions by health personnel, which included the assumption that they were promiscuous or a drug user. Medical personnel exhibited fear of contact with a person with HIV despite the statistics for routine contact leading to the exposure being extremely rare. Participant 3 recalled a clinic doctor who was “very, very, rude. She made me feel like she didn’t want to touch me. She was just very nasty, the way she talked to me like she didn’t believe, like, like she was looking for tracks on my body or something.” Participant 6 stated, “Once they ask you the question and you tell them you’re HIV positive, it’s like a red light went off. Ooh.” She stated that they isolated her, and “they made it known that they don’t do HIV positive people.”

Medical providers are often unaware of their surroundings and the need for a higher level of confidentiality for certain situations, such as addressing issues of HIV. Participant 11 related a story about this situation, when the doctor, who was changing her HIV medication, came up to her and loudly said, “You’re HIV, you know, you’re undetected.” There was another patient sitting in the next seat who looked at her and moved further away from her. The participant was angry and upset: “I went to the bathroom, and I cried, you know because I was hurt.” She told the doctor, “You could’ve pulled me to the side or go in a room and close the door, and then you can tell me.” This strong, confident action left her depressed and drained; fearful her HIV diagnosis would now be known in the general community.

All participants advocated for increased education to communities, health providers, and patients. Most participants believed education would help to decrease HIV stigma in the community, as described in Theme 4, and was especially important for medical or health care providers. Participants suggested having classes for the community, creating television shows about current HIV facts, utilizing the Internet to spread awareness, and improving medical or health care provider education.

Table

Summary of Themes

Theme	Subtheme
Theme 1: Persistent HIV Diagnosis Related Trauma: “I Keep It All Bottled Up Inside”	1. Depression is ongoing / like I live in a box and the box ain’t no good / I still cry 2. Fear/ that someone will find out dx / living in a secret world 3. Shock & Disbelief / There was no way out / saddest day of my life 4. Isolation: I don’t go anywhere / I’m a private person 5. Mentally numb / Felt like killing myself many times 6. Substance use, I didn’t know what to do so I used / Recovery is of extreme importance /
Theme 2: Self-silencing Disclosure: “I Would Take It To My Grave”	1. It’s a “need-to-know” basis / Fear of inadvertent disclosure 2. I had to hide everything: living in the back of this shadow 3. Living in a secret world / it’s a hard, hard world 4. I keep my mouth closed / I keep it to myself 5. It hurts when I know I’m not telling the truth
Theme 3: HIV Stigma: “It’s Not Going Nowhere”	1. We are not people with leprosy / It’s like a plague / 2. There’s a lot of pointin’ / People are looking at you differently 3. The stigma is high. Keep away from the stigma 4. People will judge you / Please don’t judge me
Theme 4: Education: “We Can End the Stigma”	1. Knowledge is the best weapon 2. Need to educate on what HIV is now / Be on talk shows / Use the internet 3. People just need more education 4. You don’t have to be scared no more. There’s a lot of knowledge 5. Educating people – so that we can come out openly
Theme 5: Resilience Despite Challenges: “I Kick Rocks to the HIV”	1. Deal with it; it’s a part of who I am 2. Do what makes you happy 3. Me & that virus got a fight going on / I’m a survivor / I’m not goin’ nowhere 4. Use it as an Up-lifter / Smile / 5. Put it in God’s hands / God has a plan / 6. I’m happy I’m on this earth today / My health is my wealth

Intersectionality of Stigmas

HIV stigma was found to be an issue for all the participants in this study. The participants spoke freely and in-depth about the ongoing state of HIV stigma in the general community, in their families and with close friends, in the faith communities, and even in the medical community. However, they did not describe, on an individual basis, that aging, race, socioeconomic status created any issues of stigma. When questioned about age, they often responded that medical conditions, such as diabetes or hypertension, were difficult to control. However, mostly they replied that they were happy to be alive much longer than they expected, enjoyed their lives with their families, and did not give age much thought. The participants all said they felt that they looked great, even looked younger than their ages and that no one could tell they were living with HIV or even that they were older women, which might be why they did not associate any other stigma with their situation. The White woman in the study believed that race could play a role in how HIV was viewed and that it might be more accepted for one race than another but that she personally had not experienced any HIV stigma due to her race. The Black women did not associate their races or socioeconomic statuses with stigma but with the normative status of their lives. Although several participants described episodes of institutional or structural stigma, they did not identify this issue as anything other than HIV stigma. The participants could isolate their experiences of HIV stigma due to their statuses of living with HIV, however, they could not disentangle their own complicated identities comprised of all the stigmas that they experienced. The lack of findings around the intersection of stigmas of HIV, racism, sexism, ageism was surprising and certainly points to the need for further research.

Conclusion

This chapter presented the results of the dissertation study, including the individual analyses of the stories of 12 women over 50, living and aging with HIV, and their individual themes and subthemes. The overarching themes of the meta-story, including subthemes that emerged, were then discussed. The process was an iterative one with additional themes identified as the process proceeded. The outcomes of the interviews and themes that were reviewed by member check evaluations are discussed. In Chapter 5, I provide an overall discussion of the issue of HIV, aging, women, and stigma. Implications for clinical nursing, nursing leadership, nursing research, and nursing education are considered. The strengths and limitations of the study are examined.

Chapter 5: Discussion

HIV is now considered a treatable, chronic disease (Deeks et al., 2013). The rate of new infections is declining considerably, most likely due to improved medications, use of preventative strategies such as PrEP, and targeted education. Between 2010 and 2016, new cases of HIV in women dropped by 16% (CDC, 2019b). In women ages 45-54, there was a steep decline of 27%; however, the rate of new infections for women over 55 remained stable (CDC, 2019b). Even though the statistics for HIV cases has greatly improved HIV stigma has not dissipated and is still prevalent (Poteat & Wesp, 2019; Shen et al., 2019). Women, either aging with HIV or newly diagnosed with HIV, continue to feel the stigmatizing impact of the diagnosis of HIV infection. The HIV community, including people living with HIV, advocates, and HIV health care providers currently advocate a goal of working towards zero new cases of HIV infection, zero deaths due to HIV infection, and zero HIV related stigma by 2030.

Stigma has been an isolating, negative, and shameful force since early man, and first described in-depth as it referred to modern culture, by Goffman in 1963. Often associated with medical or physical conditions, especially ones with either contagious or notable physical variances, stigma is used to devalue and separate the “different” from the “normal.” It separates people into more and less powerful or valuable groups. HIV stigma is stigma directed toward people living with HIV. HIV stigma has been documented in early studies (Emlet, 2007, 2006; Foster & Gaskins, 2009) and again by recent studies (Jacobs & Kane, 2010; James-Borga & Frederickson, 2018; Shen et al., 2019), and the CDC (2019c). Initially, HIV stigma was focused on the contagious nature of the disease and later on the physical aspects such as lesions from Kaposi’s sarcoma. As MSM and people with substance use issues were the first to be identified with HIV, the force of HIV stigma was directed to them. HIV stigma then focused on social differences, such as sexuality, social status, promiscuity, and substance use, to isolate those living with HIV. As more women contracted HIV, stigma was directed at women through assumptions that all women living with HIV were either prostitutes, promiscuous or using substances. However, HIV is not transmitted through casual contact, and with the consistent use of medications, HIV is not transmittable through sex (U = U, PrEP); nonetheless, HIV stigma persists. As people are living longer and aging with HIV, it is important to understand the effect that HIV stigma has on their lives.

I used a thematic narrative analysis method and a feminist emancipatory social justice theoretical framework to explore the lived experience of women over 50 living with HIV. The 12 women who participated in the study told their stories in emotional and powerful narratives. They came from different backgrounds (African American, West Indian Black, Hispanic, and Caucasian), with different histories of contracting HIV (drug use, sex work, one partner, married), yet they identified many similar experiences and concerns around being HIV positive. They talked about their own feelings of not deserving to be burdened with this illness, of the central role it had in shaping their lives, and of how grateful they are to be alive and healthy today. Although not all had experienced HIV stigma directly, all of the women were aware of the existence of HIV stigma, and most all took steps to protect themselves from the experience of HIV stigma. Many had not told more than one or two people of their diagnosis, and this disclosure was always on a need to know basis. A variety of ways of stigma management were described. As Polkinghorne (1988) suggested, the women in the study took their experiences of becoming infected with the HIV virus and created culturally reflective meaning in their lives. The narratives they shared created a space for them to explore and understand this meaning.

Though each participant’s narrative was unique, there were necessary and sufficient commonalities and patterns to establish themes and an overarching mega-narrative. This finding gives strength and validity to the women’s narrative truths and completes the hermeneutic arc, moving between the parts and the whole and back, as suggested by Ricoeur (1975/1990; Ghasemi et al., 2011). Ricouer (1975/1990) also described the narratives of the participants, not so much as a memory but “as a reenactment of the past in the present” (p. 3), which might be why the participants felt the telling of their stories so intensely.

The study data revealed five themes regarding women over 50, living and aging with HIV: Persistent HIV Diagnosis Related Depression: “I Keep It All Bottled Up Inside;” Self-silencing: “I Would Take It To My Grave;” HIV Stigma: “It’s Not Going Nowhere;” Education: “So We Can End the Stigma;” and Resilience Despite Challenges; “I Kick Rocks To The HIV.” Theme, Persistent HIV Diagnosis Related Depression: “I Keep It All Bottled Up Inside, was common to all the participants. Two conquered their depression by using mental health services and one through her faith-based beliefs. Identifying the persistent effect of receiving an HIV diagnosis, even 30 years postdiagnosis, supports the process of providing immediate and potentially ongoing mental health care for all who receive new HIV diagnoses. At the same time, as researchers work to decrease stigma and identify HIV as a chronic disease, researchers must acknowledge that individuals receiving this diagnosis may have a different perspective. Addressing this issue at the onset of HIV diagnosis could prevent a lifetime of psychological distress.

In the second theme, Self-silencing: “I Would Take It To My Grave;” the women revealed that they often told no one other than a chosen health provider of their diagnoses. They either avoided intimate relationships, used protection for sex but did not reveal the true reason, or even lied to others about their status to evade the HIV stigma they feared would result from disclosure. Those who told close relatives sometimes had their secrets revealed to others without their permission and quickly learned not to share this information with anyone else. Others became acutely aware of the negative conversation about people living with HIV and were careful not to reveal their HIV diagnosis to others. These actions were formulated as methods to allow successful "stigma management," although they often made the participants feel uncomfortable, guilty, or ashamed that they did not speak out. Some have spent 30 years living with this secret, hiding their authentic selves.

This evidence led to the third theme, HIV Stigma: "It's not going nowhere." Many of the women stated they had not had HIV stigmatizing words or actions directed at them but were aware of this issue happening to others living with HIV. They heard conversations with negative connotations about HIV, including suppositions that women living with HIV were promiscuous or used drugs, that people living with HIV were contagious simply by being nearby, and that in general, people living with HIV were "bad" people and should be separated from general society. Sometimes they had to leave a gathering to avoid becoming entrapped in these conversations. Some felt that medical providers treated them differently because of their HIV diagnosis, although they could not delineate specifics of how this occurred, except in a few cases. They often thought it was just a lack of education or awareness on the part of the provider.

There was one action they felt that could end this HIV stigma, and that was the basis for the fourth theme, Education: "So We Can End The Stigma." All the participants thought that educating the community was critical to ending HIV stigma. Women felt that people were thinking about early HIV information, not believing new information, and often ignorant of any factual information. They supported having programs for local communities and faith communities, as well as the medical and nursing communities. Some women wanted to "go bigger" and contact national television programs such as The Oprah Show or other such programs. They felt HIV stigma could be decreased if people understood the ways that living with HIV had changed over time, including medications that resulted in a normal lifespan, U=U (undetectable equals untransmissible), and the availability of preventative medications (PrEP).

These four themes lead us to the last theme, Resilience Despite Challenges: "I Kick Rocks to the HIV." Having survived the earlier times of the HIV epidemic, these women display strength, courage, character, and faith. They have weathered fear, trauma, depression, stigma, and come forth with positive attitudes and fierce intentions. They have restructured their health behaviors by eating healthy foods, exercising, not smoking, and taking their medications. They value their families and spend time with their grandchildren as well as elderly parents. They enjoy and appreciate their lives despite all they have endured and believe things will be better in the future.

These themes are consistent with the past and current literature, including two previous dissertations. These two dissertations explored the same topic but from differing philosophical and methodological perspectives. James-Borga (2013) utilized van Manen's phenomenological approach with the theoretical framework of Merleau-Ponty, while Stoudmire (2008) employed an ethnographic methodology with African American feminism as the underlying theory. Both focused on the cultural aspects of being an African American woman in America and the impact that had on the stigma process. Obtaining consistent results with the use of different methodologies and philosophies to interrogate a similar query provides additional strength to each study. Additionally, the themes are consistent with previous studies that identified stigma management as critical to older women living with HIV leading full lives (McDoom et al., 2015; Poindexter & Shippy, 2010; Psaros et al., 2015).

Despite the ongoing stigma, the theme of resilience is found in almost all studies of older women living with HIV (Subramaniam et al., 2017; Warren-Jeanpiere et al., 2014). In addition to identifying the themes regarding HIV stigma, none of the women described any other form of stigma, such as stigma related to aging, to be female, to living in poverty, or to their race or ethnicity as factors in their stories of living with HIV. Though these stigmas have been identified in previous literature (McDoom et al., 2015; Sanaramoorthy et al., 2017) as common, they were not a finding of this study. Shen et al. (2019) did not find intersectional stigma to be recognized as a problem for aging women in the same way it was for aging men. Other stigmas, such as poverty, racial, ethnic, or structural stigmas, might be so integrated into women's lives, particularly African American women, that they are not individually recognized as stigmas or that the stigma of HIV is so powerful that it eclipses their consciousness of other stigmas that are occurring. More research is needed to clarify this notion.

Recommendations for Nursing Practice

The findings of this study are important to disseminate to nurses, nurse practitioners, physicians, and other health care providers, as these are the patients they care for now and may do so in even larger numbers in the future. Older women living with HIV who also have many other health-related issues will be needing more care for those issues. Increasing awareness of the behaviors and attitudes that represent HIV stigma beliefs may help to decrease their occurrence while providing care. This, in turn, will encourage women to attend their appointments and communicate more openly with their providers and receive appropriate medical care. There are many ways in which this study may be utilized by nurses in all aspects of nursing to enhance care for women aging with HIV.

Clinical Nursing

The findings of this study would be useful in educating nurses caring for women over 50, living and aging with HIV, in being more aware of how they may be unintentionally stigmatizing this population. Hearing the participant's stories could inform nurses of the need to provide a welcoming, non-judgmental space, assisting women in feeling comfortable attending appointments. Clinical nurses could develop an increased awareness of the possibility of underlying depression or PTSD related to the diagnosis of HIV and ensure that the women who show symptoms of this are evaluated and offered treatment. Several participants spoke of the significance of nurses, helping them with disclosing their diagnosis to partners or family members. Nurses could also provide a safe space for women to talk about their feelings regarding self-silencing and dealing with stigma.

The stories reveal that nurses could be essential in assisting women with medication adherence that is critical to their health and well-being. Participants also emphasized the importance of ongoing patient education for them, as well as for the community in relation to their HIV diagnosis.

Nursing Leadership

Nurse leaders are essential to all aspects of nursing about combatting HIV stigma. They set the tone, provide guidance, and support funding for programs, education, and research in their specific institutions. They could support benefits for all staff that encourage them to attend continuing education programs that address HIV stigma. Nurse leaders could provide support for programs that encourage aging women with HIV to be adherent to their care. They could seek grants and provide funding for incentives to aging women who stay HIV undetectable or to attending to other health care needs, such as cervical cancer screening or mammograms, which are especially important for women living and aging with HIV.

Nurse leaders could encourage and support community programs to educate the general population about HIV. HIV is often portrayed, at the present time, on television and film as it was 30 or 40 years ago. Nurse leaders could approach television, film companies, and social media programs about developing programs accurately addressing HIV as it is today. As nurse leaders, they could approach the legislature with bills to support stigma eliminating programs that required minimal funding. They could also provide testimony to support equal opportunities in employment, housing, education, and other areas for people living with HIV.

Nursing Education

At the present time, a preponderance of nursing degree programs devotes minimal time to education about HIV. Adopting curricula that include more HIV education and more than cursory references to women aging with HIV would allow nurses to develop a fuller appreciation of the experiences and particular needs of this population. The situation occurs similarly to medical and dental education.

Additionally, nurse educators could collaborate with nurse leaders to develop programs for the community that educates and updates knowledge about HIV, emphasizing the current changes. Nurse educators could encourage and participate in television programs and social media education programs focusing on HIV. They could also act as a consultant to media so that information is accurate. Much of the stigma identified by the women in this study related to lack of knowledge of the progress in HIV care, and it was generally felt that more community education could considerably combat this stigma.

Nursing Research

The findings of this study suggest that despite the current status of HIV as a chronic disease, more research is needed to address HIV stigma, particularly for the aging population living with HIV. Research on the many intersectional stigmas is currently inadequate and offers many opportunities for investigation. Qualitative and quantitative studies are needed to demonstrate the need for funding for nursing and medical, community, and patient education programs. Studies comparing various types of education programs aimed at combatting HIV stigma would also be valuable.

The identification of ongoing depression related to HIV diagnosis trauma suggests the need for more research to determine if this is a widespread issue, and if so, how it can be best addressed. It was not the purpose of this study to make clinical diagnoses using criteria from the DSM 5; however, this could be a potential future endeavor. This could support the need for mental health referral immediately after HIV diagnosis, and a study of patients attending mental health services versus those not attending mental health services might be revealing. Another possible study could address the use of EMDR or cognitive behavioral therapy for existing HIV diagnosis-related trauma, as those have been found successful in other types of PTSD. As more people with HIV are aging and being admitted to skilled nursing and long-term care facilities, studies on stigma and nursing care in this environment could be very revealing and significantly improve care.

Strengths and Limitations

This inspiration for this study was drawn from 40 years of providing nurse practitioner care for people living with HIV. I talked with my patients, especially women over 50, about their lives and concluded that many continued to have difficulty dealing with the HIV stigma that they said still existed. I also was able to experience first-hand the lack of knowledge and the unintended stigmatizing of older women by medical and nursing personnel. I discussed the idea for the study with women living with HIV and with other health care providers and found a consensus that such a study might reveal information that would be beneficial in the struggle against HIV stigma. I included these women in the development of the study as consistent with the emancipatory feminist social justice theoretical underpinnings of this study.

This study provided strong evidence for the ongoing status of HIV stigma for women over 50 living with HIV. The findings corroborated findings of HIV stigma, for women aging with HIV, in previous studies (James-Borga, 2013; Poteat & Wesp, 2019; Stoudmire, 2008) and, at the same time, looking to the future when HIV stigma might be an outdated concept.

As with many studies, there were limitations to this study. The study included a small sample (12) of women from the Northeast United States. Therefore, the results might not be representative of all women over 50 living with HIV. This potential issue with transferability was addressed with the richness or “thickness” of the data.

The themes may be reflective of “situated truths” (Riessman, 2008), which are influenced by the participants and the researcher. I did not attempt to bracket my knowledge of the subject but acknowledged this situation. I remained aware and endeavored not to comment or influence any participant’s story. Additionally, in analyzing the data, I remained aware of my own pre-existing biases, reflecting on these before making decisions about patterns and themes.

Conclusion

The narratives that the women related revealed that HIV stigma and HIV stigma management through self-silencing remained, even in the framework of the potential end of the HIV epidemic soon. Although all the participants were over 50 years old, stigma due to aging was not mentioned, and aging was not a major concern for them. They related that coping with the diseases of aging, such as diabetes and heart disease, often presented challenges, sometimes perceived as more difficult to manage than HIV. However, all the women articulated that they enjoyed their lives and appreciated living as long as they had. This dissertation study provides insight into a population that is often ignored and neglected in the literature of HIV. More research is needed to explore the effect of aging on those living with HIV to address the future needs of this growing population. This study showed the opportunities for nursing to be at the forefront of research and leadership in ending HIV stigma.

The narrative approach of this study allowed women to express their experiences in a format that was comfortable and known to them. Storytelling is a non-threatening way of sharing experiences that have been used for centuries and is accessible to almost anyone. The narrative approach can bring to light “the lived experience” as the women who lived it perceive it. It is consistent with feminist emancipatory social justice philosophy in that it is non-hierarchical and allows for focus on women’s voices.

The women in this study shared their experiences with honesty and candor, allowing me to enter into their world and feel some of their most intimate feelings. They shared their pain and their anger, their tribulations, and their joy and hopes for the future. They did not hold back and expressed themselves fully. They were proud, strong, beautiful women aging and living with HIV.

The participants suggested that I should create updated education programs for the community to combat stigma. One woman wanted to go on an Oprah television show to reach many women. Two women stated that they were happy that the study would show how things really were for them and that it would assist me in obtaining my PhD; however, they questioned its usefulness if it was not used to educate the world. I will do my best to fulfill their suggestions and match their strength and bravery.

There are many areas of HIV and women's issues that await investigation. I have outlined several in this dissertation. I hope that the next researcher who seeks the voices of women living and aging with HIV will find different themes. I look forward to the time when an HIV diagnosis does not initiate Post HIV Diagnosis Trauma, PTSD, or chronic depression. I look forward to the time when an HIV diagnosis does not force women to silence themselves and does not have women living and aging with HIV, living in fear and isolation. So, let's kick rocks to HIV together.

Chapter 5 reviewed the background of stigma imposed on women living with HIV, particularly aging women with HIV. The chapter then reviewed the findings of the narrative analysis study. The five overarching themes of the meta-story were reviewed, and I presented implications and recommendations for nursing practice, including clinical, leadership, educational, and research. The strengths and limitations of the study were discussed. The chapter concluded with the suggestions of the study participants to increase education for health providers and the community to eliminate HIV stigma.

Summary

I began by introducing the topic of aging women living with HIV. The background and significance were discussed, and the need for the research was identified. The existing literature was reviewed, and a gap in the literature was identified, justifying the need for this research. The background of narrative analysis was reviewed. Riessman's (1993, 2008) thematic narrative analysis process was delineated. The results of the analysis of the 12 stories of the individual participants were discussed, and individual themes were identified. A meta-story with overarching themes was then identified and discussed. The strengths and limitations of the study were reviewed. Implications for nursing practice, including clinical, educational, leadership, and research, were considered. I conclude by stressing the importance of nursing in participating in the fight to end HIV stigma.

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Appendix A: Characteristics of Individual Studies in the Literature Review

Author(s) & year	Discipline	Focus of findings	Design	Sample	Publication type
Emlet et al. (2002)	Social Work	Experiences: fear, isolation, acceptance	Focus group	7 women Age: over age 45	Journal
Plach et al. (2005)	Nursing	Attending to physical health, heart, mind & soul	Semi structured interviews. Analysis w Nvivo software	9 women Race: 4 African American, 4 White, 1 Latina Age: (*M* = 52)	Journal
Buseh & Stevens (2007)	Public Health & Nursing	Experiences of stigma, coping, resilience	Longitudinal qualitative study	29 women Race: African American Age: (*M* = 52)	Journal
Stoudmire (2008)	Nursing	Experiences of stigma, stigma management, resilience	Qual interviews based on VanManen's method with Black feminist theoretical underpinnings	22Women Race: African American Age: 45-60	Dissertation
Poindexter & Shippy (2010)	Social Service & Gerontology	Stigma management strategies & experiences	Focus groups with a grounded theory framework	14 women in 2 groups: Race: 8 African American and 6 other (not identified) Age: (*M* = 55) (Total groups included additional 20 men).	Journal
Teti et al. (2010)	Health Profesions & Public Health	Intersectionality of stigmas: HIV, poverty, gender leads to psychological distress	Intervention/Focus Groups	26 women: Race: 83% Black Age: (*M* = 43)	Journal
James-Borga (2013)	Nursing	Experiences of stigma, stigma management, self-transcendence	Phenomenological qualitative interviews	10 women Race: African American Age: over age 50	Dissertation
Warren-Jeanpiere et al. (2014)	Medicine & Sociology	How older women managed living with HIV	Focus groups w constant comparison technique of analysis.	23 women Race: African American Age: (*M* = 57)	Journal
Grodensky et al. (2015)	Public health	Stigma reduced social support, limited disclosure	Semi-structured interviews, open coding	15 women Race: 13 African	Journal

Author(s) & year	Discipline	Focus of findings	Design	Sample	Publication type
				American, 2 White Age: (*M*=57)	
McDoom et al. (2015)	Public Health	Stigma in the health care setting, social connections & support	Semi-structured interviews, grounded theory approach	20 women Race: Black Age: (*M* = 56.6)	Journal
Psaros et al. (2015)	Psychiatry	Experiences at diagnosis, uncertainty, acceptance, & living well	Semi-structured interviews, grounded theory approach	19 women Race: Age: *(M* = 56.79)	Journal
Sangaramoorthy et al. (2017)	Anthropology & Epidemiology	Intersectional stigma	Modified grounded theory approach with thematic coding	35 women Race: Black Median age: 52	Journal
Subramaniam et al. (2017)	Human Development & Family Studies	Self-acceptance, optimism, social supports, & spirituality	Grounded theory study w constructionist framework Womanist & resilience theoretical underpinnings	8 women Race: African American 7 were over age 40	Journal
Dale et al. (2018)	Psychiatry	Self-validation, self-care, dealing with adversities	Semi-structured interviews w thematic analysis	30 women Race: Black or African American Age: (*M* = 46)	Journal
James-Borga & Frederickson (2018)	Nursing	Stigma management, knowledge as empowerment, relationships, self-transcendence	Semi-structured interviews. VanManen's phenomenological framework.	10 women Race: African American Age: range 50-76	Journal
Rice et al. (2018)	Collaborative	Stigma experiences in health care settings, with family, or community.	Mixed methods: Qualitative interviews w Braun & Clarke's thematic analysis methodology Survey Questionnaires.	76 women including 50 women over age 46	Journal
Shen et al. (2019)	Medicine, Gerontology, Nursing	Stigma types, disclosure. Women did not experience stigma of aging as men did.	Focus groups	32 Older adults over 50 including 9 women in a separate focus group	Journal

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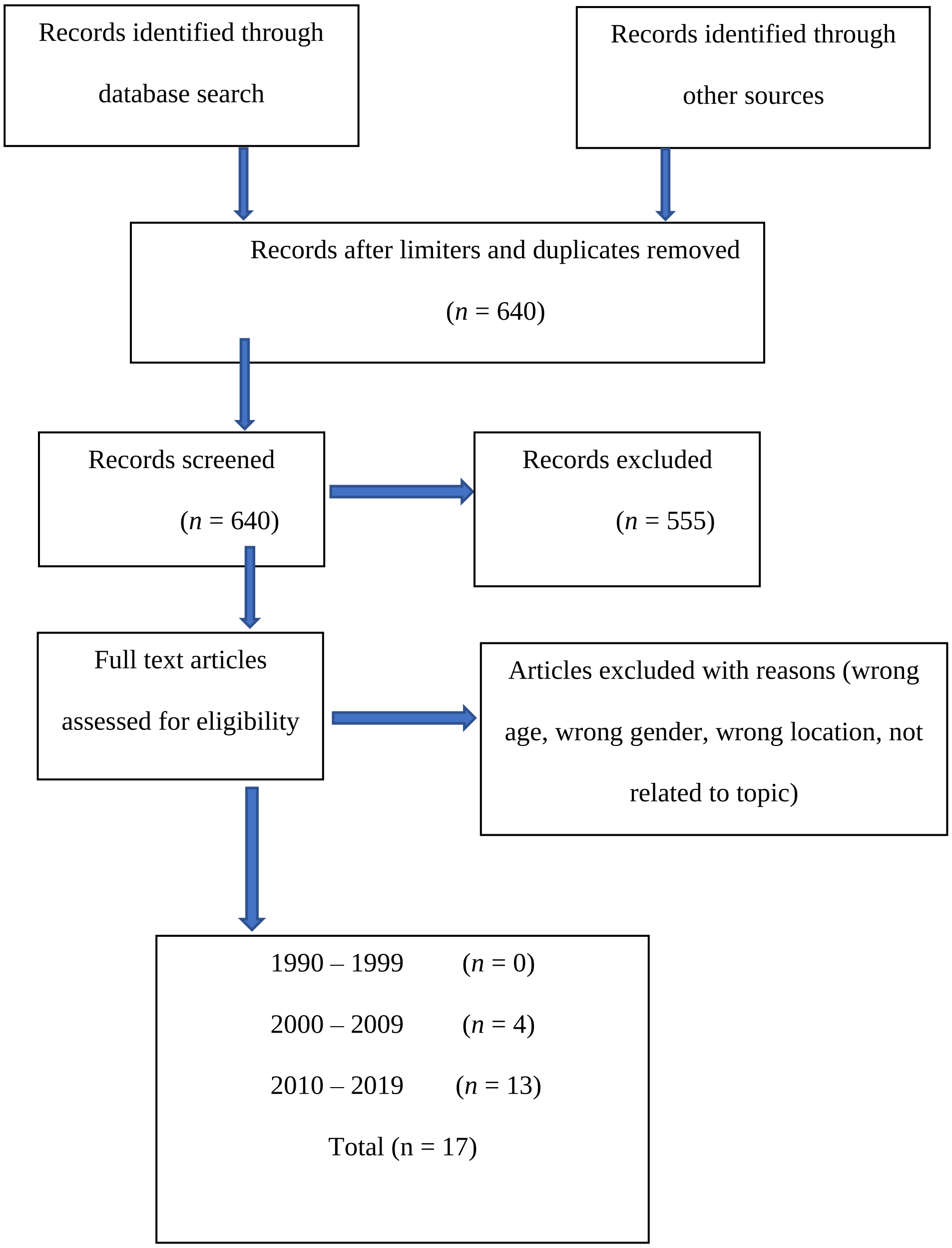
Appendix B: Prisma Flow Diagram



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