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Repurposing a Legacy: The Experiences of African American Women Receiving a Human
Immunodeficiency Virus Diagnosis at the Age of 50 or Older

A dissertation submitted in partial satisfaction of the requirements for the degree of Doctor of
Philosophy in Nursing

by

Ariel Rankin

2015

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ABSTRACT OF THE DISSERTATION

Repurposing a Legacy: The Experiences of African American Women Receiving a Human Immunodeficiency Virus Diagnosis at the Age of 50 or Older

by

Ariel Rankin

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2015

Professor Adeline Nyamathi, Chair

By the end of 2015, over half of all HIV/AIDS cases will be in adults aged 50 and older. One of the fastest growing older adult sub groups afflicted by the HIV epidemic is older African American women. At present, no studies have explored the unique experiences of older African American women who have received an HIV diagnosis at the age 50 and older.

A descriptive qualitative study employing constructivist grounded theory methodology was used to gain insights into the experience of African American women diagnosed with HIV at age 50 and older. In taking the constructivist approach, analysis stemmed from shared experiences and relationships with participants. Semi-structured interviews were conducted, audio-recorded and transcribed. A total of 16 interviews were used. Open-ended, non-leading questions and probes were developed from a literature review and community members' suggestions. Coding, mapping, analytic strategy usage, and memoing all assisted in creation of the grounded theory.

The results of this study demonstrated how older African American women utilized various strategies to repurpose a legacy, after an HIV diagnosis. The strategies used by the women included re-evaluating perceptions of HIV risk, learning lessons from tumultuous times, and reconciling past and present events. The women's lack of HIV risk perceptions and their provider's failure to assess risky behaviors resulted in delayed HIV testing. After being tested, the women embarked on a journey to resolve newfound issues, and in the process, learned various life lessons. This process allowed the women to make meaning of their HIV diagnosis and set out on a path to self-discovery. The results of this study can shape forthcoming research on the HIV trajectory of older African American women living with HIV/AIDS and at risk for HIV/AIDS.

The dissertation of Ariel Rankin is approved.

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2015

Dedication

To the 16 African American/Black women whose powerful stories made this study possible.

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CHAPTER ONE

Introduction

According to the Centers for Disease Control and Prevention (CDC), approximately 1.2 million people are living with Human Immunodeficiency Virus (HIV) in the United States (US), with approximately 14% of these Americans being unaware of their infection (CDC, 2014). With an estimated 50,000 people being infected with HIV annually in the US, strategies to decrease these numbers are needed (Prejean et al., 2011). In the 1980's, HIV/AIDS was seen as a fatal disease that affected primarily young, White, homosexual men and injection drug users (IDUs) (Goodroad, 2003). However, over the past 35 years, people of all ages, sexual orientations, social class and race have been affected by this epidemic (Curran & Jaffe, 2011).

Currently, African Americans, men who have sex with men (MSM), and individuals living in poverty have disproportionately higher rates of HIV infection than the general population (CDC, 2008a). However, older adults, defined as individuals aged 50 and older, are also a vulnerable population that is disproportionately affected by the HIV/AIDS epidemic (CDC, 2008b). Older adults accounted for approximately 15% of all new HIV infections in the US; with older African Americans fairing worse in terms of health outcomes (CDC, 2008b, 2013).

Older Adults and HIV/AIDS Diagnosis

By the end of 2015 over half of all HIV/AIDS cases will be in adults aged 50 and older (CDC, 2008b). There are two main contributing factors resulting in the increase of HIV in older adults (Goodroad, 2003). Firstly, after the advent of highly active anti-retroviral therapy (HAART), several classes of medications have dramatically slowed the progression of HIV; thus, persons with HIV began to live longer (Goodroad, 2003). Secondly, engagement in risky

behaviors continues, including unprotected sex and drug use (Goodroad, 2003; Vance, Struzick, & Burrage, 2009). These two factors have created two groups of older adults living with HIV/AIDS; those who were infected with HIV/AIDS at a younger age, and those who have recently become infected or diagnosed with HIV/AIDS in older adulthood (Goodroad, 2003). Thus, the diagnosis of HIV does not necessarily reflect when the person became infected (CDC, 2013). Individuals aged 50 and over are more likely than younger individuals to be diagnosed with HIV infection late in the course of their disease (CDC, 2013). African Americans have been shown to have significantly greater percentage of undiagnosed HIV infection compared with whites; which is associated with higher mortality rates (Campsmith, Rhodes, Hall, & Green, 2010). Moreover, one of the fastest growing older adult sub groups afflicted by the HIV epidemic is older African American women.

HIV and Older African American Women

Among women diagnosed with HIV at the age of 50 and older, African American women have the highest rates of HIV infection; accounting for over 60% of HIV new infections (CDC, 2013). Though older, African American women are diagnosed with HIV/AIDS earlier in their HIV disease trajectory; moreover, they account for the highest rates of death among older women. Mortality rates among older African American women diagnosed with HIV infection are higher than their younger female counterparts; accounting for approximately 62% of deaths among women (CDC, 2013). Exploring the factors driving the increase in mortality rates among older African American women can help to decrease the disparity between races/ethnicities. However, being of a specific race/ethnicity is not a standalone risk factor for HIV infection. Other factors such as perception of risk, risk behaviors, access to healthcare and utilization of health care services all influence timely treatment of HIV/AIDS (Campsmith et al., 2010). These

factors place older African American women at great risk for experiencing poorer health outcomes related to their HIV diagnosis as compared to their younger and White counterparts (Aberg, 2005).

Background

Over the last year, several studies have begun to explore the experience of women living with HIV/AIDS in older adulthood; however, at present, no studies have explored the unique experiences of older African American women who specifically received an HIV diagnosis at age 50 and older. This research study utilized Constructivist Grounded Theory methodology in order to provide older African American women with an opportunity to share the story of their HIV trajectory. These stories have led to the development of a situation-specific theory, grounded in the voices of women diagnosed with HIV/AIDS in later adulthood.

In order to create programming for this age group, data on new HIV infections and attitudes among women aged 50 and older is essential (Mahy, Autenrieth, Stanecki, & Wynd, 2014). The following sections will provide the reader with an introduction to various concerns older women diagnosed with HIV/AIDS in older adulthood experience throughout their HIV trajectory. A background on common HIV risk factors among older women will be discussed, followed by HIV screening and testing needs of older women. Secondly, a background on access and linkage to HIV healthcare will be discussed. Lastly, a background on social support and psychosocial needs of older women newly diagnosed with HIV/AIDS will be discussed.

HIV Risk and Need for HIV Screening of Older Women

The rising number of older women being infected with HIV can be attributed to biological and social factors (NIA, 2009). Biologically, as a woman ages, she is at an increased risk for vaginal dryness, which can lead to a greater risk of vaginal tearing during intercourse

(Corneille, Zyzniewski, & Belgrave, 2008). In addition, older women are less likely, than their younger counterparts, to use condoms, due to the belief they can longer become pregnant (NIA, 2009). The combination of decreased condom use and increased risk for vaginal tearing during intercourse places older women at greater risk for contracting HIV in older adulthood. The literature has also found that some older women have mistaken HIV signs and symptoms as symptoms of menopause or normal signs of aging (NIA, 2009). This misperception of risk places the older women at greater risk for later diagnosis. Not only are the older women's perceptions of their HIV risk lower than their younger counterparts, the perception of risk is also lower for their healthcare providers. This misperception exacerbates the already low numbers of older women being tested for HIV (Durvasula, 2014).

The CDC set forth a recommendation that HIV testing be offered to all persons aged 13-64 (Branson et al., 2006). Adults older than 64 are only counseled to receive an HIV test if they have perceived risk factors (Branson et al., 2006). In a group 12,366 adults, ages 50 and older, prevalence of HIV testing practices and perception of risk was assessed (Adekeye, Heiman, Onyeabor, & Hyacinth, 2012). Among this sample, only 25.4% of the older adults reported ever being tested for HIV and 84.1% believed they had no risk of contracting HIV. This lack of perception of risk was equated with only 3.5% of the sample planning to be tested for HIV in the next 12 months. Although many older adults report little to no risk of contracting HIV, studies surveying sexual behaviors find many older adults to be at risk (Adekeye et al., 2012).

In a study of 1,974 men and women, aged 50 and older, sexual risk behaviors and condoms use was explored (Schick et al., 2010). More than half of the sample reported being sexually active; however approximately two-thirds of the sample reported not using condoms during their last sexual encounter (Schick et al., 2010). It is important that strategies are created

and implemented to increase HIV screening in the older adult population regardless of perceived risk (Adekeye et al., 2012). This is especially true for adults 65 and older who are projected to be 20% of the US population by 2030 (Adekeye et al., 2012; Moody, 2009). By exploring the perspectives of newly diagnosed older African American women, this populations perceptions of HIV prior to testing, and their history of testing behaviors can be better understood. Once these women are tested and a positive diagnosis is assigned, linking and retaining these women into care is another important goal to decrease HIV-related health disparities.

Access to Health Care

In response to the rising number of Americans living with HIV/AIDS, under the Obama administration, the Office of the National AIDS Policy (ONAP) created the National HIV/AIDS Strategy for the United States (ONAP, 2010). One of the primary goals of the National HIV/AIDS strategy, is to increase access to care and improve health outcomes for persons living with HIV (ONAP, 2010). Survival decreases as age at diagnosis increases, particularly among older adults (CDC, 2013). Ethnic minorities and older adults are at greater risk for late diagnosis (Jenkins, Gardner, Thrun, Cohn, & Burman, 2006). Timely linkage and retention in care is needed to decrease morbidity and mortality rates among older adults. When HIV is diagnosed early, there is a greater chance that the patient can access health care and medication earlier and decrease transmission and morbidity and mortality rates (Duffus et al., 2012).

It has been seen that women are typically diagnosed with HIV earlier than men, primarily due to routine screening of HIV among women of childbearing age (Duffus et al., 2012). However, it is unclear if HIV testing occurs as routinely when the women are not within childbearing years. Is the late HIV diagnosis in older women related to delayed appearance for care or missed opportunities for these women to test early (Duffus et al., 2012)? In a study by

Ulett et al. (2009), it was found that older African Americans diagnosed with HIV/AIDS were more likely to have delayed linkage to care, primarily due to psychological distress. However, once the patient was linked to care, older adults were better retained in care in the following two years. It is essential that older African American women be tested for HIV in a timely manner and subsequently linked to medical care immediately after diagnosis, as they are at increased likelihood of presenting to care with higher viral load counts, lower CD4 counts, and increased susceptibility to opportunistic infections. In addition, addressing psychosocial needs is important to facilitate linkage and retention in care (Ulett et al., 2009).

Social Support and Psychosocial Needs

Receiving a new HIV/AIDS diagnosis can be a fear-provoking experience that invokes a multitude of thoughts and emotions (Anderson et al., 2010). The initial reaction to learning of a new diagnosis can be more overwhelming than the actual illness (Anderson et al., 2010). For older adults, these challenges can be multi-factorial (NIA, 2009). Older adults with HIV are faced with the double stigma of being older and having the virus, challenges of concurrently managing other chronic disease processes, decreased social support, and isolation (Goodroad, 2003; Vance et al., 2009). Unlike their younger counterparts, older persons may not have a strong network of friends or family who can assist with the psychological distress associated with an HIV diagnosis. Whereas younger adults can rely on parents, grandparents and spouses for financial support and emotional support, older women who may have been widowed or who serve as a primary caregiver may lack social support. While challenges experienced by adults aging with HIV/AIDS have been well studied, there is a paucity of studies that have investigated the specific needs of older African American women diagnosed with HIV in older adulthood.

Exploring how older African American women interact with their social networks after an HIV diagnosis can broaden our understanding of their support systems.

Purpose of the Study

A descriptive qualitative study employing constructivist grounded theory methodology was used to gain insights into the experience of African American women diagnosed with HIV at age 50 and older. Grounded Theory was selected for data collection and analysis. The exploratory nature of this study required a research methodology that would thoroughly capture the participants lived experiences.

Specific Aims

In a sample of 16 African American women diagnosed with HIV/AIDS at the age of 50 or older, the following aims were proposed:

1. Explore the women's perceptions of HIV risk prior to their diagnosis
2. Explore their interactions with their social networks before and after receiving the HIV/AIDS diagnosis
3. Describe the women's experiences in navigating the healthcare system throughout their HIV trajectory
4. Generate a theoretical framework of the processes involved in making meaning of and managing a HIV/AIDS diagnosis, by exploring the narratives of these women regarding their perception of HIV risk, social networks and navigation of the healthcare system

Significance of the Study for Practice and Research

There is a need for more research on the experience of becoming HIV positive in older adulthood. The current literature focuses on the segment of the older adult population who contracted HIV in young adulthood or middle adulthood. Much of the HIV/AIDS literature on

older adults has represented a fairly homogenous population of White, homosexual and bi-sexual men. With racial and ethnic minorities and women being disproportionately affected by this disease, further research geared towards helping these groups are needed (Coleman et al., 2006). This study explored older African American women's experiences upon receiving the HIV diagnosis, their perception of risk, and what this new diagnosis means to them in older adulthood. In order to tailor clinical interventions to this population, further exploration of problems specific to this population should be pursued. Further refinement of this phenomenon will assist healthcare providers and newly diagnosed HIV-positive patients in identifying and predicting coping behaviors utilized post-diagnosis.

Women's ability to manage psychological distress effectively can determine whether they are linked to medical services in a timely manner and whether they start medications promptly. Because HIV positive older adults are at a greater risk than younger adults in experiencing HIV progression, being linked to care earlier can result in better patient outcomes. This study serves as a foundation for determining vital services and skills needed to link and retain newly diagnosed older African American women in care.

Organization of the Study

Chapter one has discussed the introduction, statement of the research problem, and significance of the study. Chapter two will contain the review of related literature and research related to the problem being explored. The conceptual framework used to organize this phenomenon will be found in Chapter three. The methodology and procedures that were used to gather data for the study are presented in Chapter four. In Chapter five, the demographics of the participants will be discussed and the situation-specific grounded theory will be presented. Lastly, in Chapter six, a discussion of the extant literature surrounding older women living with

HIV will be explored in relation to the presented grounded theory. Also, implications for the health care provider, the healthcare system, and for older African American women will be discussed.

Summary

The outcomes of this research will shape future studies on the health and well being of older African American women living with HIV/AIDS and at risk for HIV/AIDS. Understanding the unique experiences, facilitators, and barriers to care that may arise with being diagnosed with HIV/AIDS later in life will lead to greater insights into management strategies for older adults living with HIV/AIDS.

CHAPTER TWO

Literature Review

This chapter will review the literature surrounding HIV/AIDS and older women as it relates to HIV testing, social support and access to care. The literature review was guided by the research aims of this study and developed through a synthesis and analysis of published articles found through PubMed and CINAHL.

In order to decrease the disparity between older African American women and their female counterparts of other races, interventions that target not only older African American women at risk for HIV but as well as older women living with HIV/AIDS are needed (Neundorfer, Harris, Britton, & Lynch, 2005). Much of the HIV risk literature has been done on community dwelling elderly women and women infected with HIV in young adulthood and middle adulthood (Gilbert & Wright, 2003). Exploring the perspective of women diagnosed with HIV in older adulthood may shed light on varying perceptions of personal HIV risk prior to diagnosis, experiences with accessing healthcare throughout the HIV trajectory, and the role various social support networks play throughout the HIV trajectory.

This review of literature will focus on examining factors that affect the HIV/AIDS rates and outcomes among older African American women, including perceptions of risk, social support and utilization of the healthcare system. First, an overview of the HIV risk factors older women face and the individuals who may influence this risk will be discussed. Secondly, the existing literature on perceptions of HIV risk held by older African American women will be discussed. Thirdly, the impact of social support networks on coping with a new HIV/AIDS diagnosis in older adulthood will be discussed. Lastly, a review will be presented of the existing literature on how older HIV positive adults navigate the healthcare system.

HIV Risk Influences

Biased media reports, deceptive personal experiences and other life gambles lead individuals to misjudge risks (Slovic, 1987). Whether risk is overestimated or underestimated, it begins with life experiences preceding the risk (Slovic, 1987). The HIV transmission routes among women, regardless of age, include injection drug use (IDU) and heterosexual contact (Kingsberg, Kellogg, & Krychman, 2010). Although the routes of transmission are the same among older and younger woman, there are several biological and psychological risk factors that place older women at greater risk for contracting HIV, including vaginal dryness, vaginal tearing, decreased condom use, decreased ability to negotiate condom use, and decreased perception of HIV risk, (Corneille et al., 2008; Grant & Ragsdale, 2008; Neundorfer et al., 2005)

Biological HIV risk

A common characteristic of menopause and aging, among women, is hot flashes and vulvovaginal atrophy (Kingsberg et al., 2010). Both characteristics are a result of lowered estrogen levels (Kingsberg et al., 2010). It is estimated that between 10% and 50% of postmenopausal women experience this vaginal atrophy, also known as vaginal thinning (Levine, Williams, & Hartmann, 2008). This thinning increases the risk for vaginal mucosal tearing during intercourse, thus increasing sites for HIV entry into the blood stream (Jacobs & Thomlison, 2009). Another common issue in postmenopausal women is vaginal dryness (Johnson et al., 2008). Due to this vaginal dryness, some women choose not to use condoms (Higgins & Hirsch, 2008). This reluctance to use condoms is also seen in older men with erectile dysfunction (Gracia Jones, Fenkl, Patsdaughter, & Chadwell, 2013).

In an descriptive study of 50 sexually active men aged 50 and older, 70% reported disliking condoms because they decrease sensitivity during intercourse and 46% reported losing

an erection when applying a condom (Gracia Jones et al., 2013). As a man ages, his likelihood of experiencing erectile dysfunction increases and his ability to achieve an erection with a condom can become problematic (Neundorfer et al., 2005). To combat this issue, older men may often begin sexual intercourse with female partners without a condom, and then apply a condom once the penis is fully erect (Gracia Jones et al., 2013). For some men, the use of condoms are excluded altogether out of fear they will not be able to perform sexually (Gracia Jones et al., 2013). The combination of vaginal thinning, dryness and tearing during sexual intercourse, and the reluctance of older women's partners to use condoms, increases older women's HIV risk (Corneille et al., 2008). Reluctance to use condoms is not only related to biological factors but also women's perceptions about condom use.

Condom Use

Another major HIV risk factor for women aged 50 and older is their lack of condom use (Hillman, 2007; Norman & Loue, 2015). Compared to their younger counterparts, older women were six times less likely to use condoms during sexual intercourse (Poirot, 2002). Often times, older women may not believe they are at risk for HIV because they can no longer become pregnant (due to sterility or menopause) (Chesney, Chambers, Taylor, & Johnson, 2003). This lack of perception of risk leads women to equate condoms with pregnancy prevention; thus, they may not consider using condoms for other reasons such as sexually transmitted infection (STI) prevention (Corneille et al., 2008). A study of 55 community-residing women aged 58 to 93 found many post-menopausal women engage in unprotected sex with the belief that their inability to become pregnant also protects them from contracting STIs (Lindau, Leitsch, Lundberg, & Jerome, 2006). This skewed self-perception of risk makes older women more susceptible to contracting HIV than their younger counterparts (Lindau et al., 2006).

The sexual risk factors, attitudes, and behaviors of a sample of 325 African American women between the ages of 18 and 61 were examined (Corneille et al., 2008). The authors found that age was significantly associated with the percentage of time condoms were used in the last three months ($p < .05$), condoms used at last sexual encounter ($p < .01$), and intention to use condoms ($p < .01$) (Corneille et al., 2008). Similarly, in a study by Paranjape et al. (2006), 155 women age 50 and older who were currently in a relationship were questioned about their safe sex practices. Although, 81% of the women reported being sexually active, only 13% reported using condoms frequently (Paranjape et al., 2006). Engagement in risk behavior can be mediated by social influences, such as friends, partners and respected public officials (Slovic, 1987). Women's use of condoms have been found to be influenced by their partner's preference and opinions (Neundorfer et al., 2005).

Condom Negotiation

Initiating a discussion with a partner about the need for condoms can be difficult. For older women, regardless of marital status, this discussion can be particularly complex when condoms are being introduced for the first time (Zablotsky & Kennedy, 2003). For older women who are newly single, issues arise in deciding when and how to propose condom use (Grant & Ragsdale, 2008). This can be particularly difficult if condoms were not used in their previous relationship or marriage (Grant & Ragsdale, 2008).

Older African American women have also been found to be less likely to initiate assertive conversations about a partner's past drug and sexual histories, compared to their white counterparts and younger counterparts (Dancy, 1996; Norman & Loue, 2015). Discussions with male partners about sexual behaviors and the initiation of condoms can raise the male partner's suspicion of possible infidelity (Wyatt, 2009). This suspicion can lead to anger and violence

from the male partner. Many women choose to maintain harmony in their relationships by not bringing up issues related to sexual protection (Wyatt, Forge, & Guthrie, 1998). Also, older African American women have been found to trust that being in a monogamous relationship will safeguard them from contracting HIV; as a result, condom use is less common (Wyatt, 2009). Due to a disproportionate ratio of available African American men to women, ensuing harmony, trust and stability in a relationship is important (Gilbert & Wright, 2003).

Maintaining Partnerships

The shortage of available African American men to partner with African American women has resulted in partner sharing (Gilbert & Wright, 2003). Sharing sexual partners within a small sexual network has led to an increased HIV vulnerability for African American women (Newsome & Airhihenbuwa, 2013). Unfortunately, many women may be infected with HIV after engaging in sex with a partner they believed was monogamous but may have engaged in risky behaviors outside of the relationship with other women and/or men. A growing phenomenon in the African American community is “down low” behavior among men, where men engage in sexual behaviors with other men secretly (Whyte, Whyte, & Cormier, 2008). A qualitative study to explore issues of down low sex in a group of older African American women whose long-term partner contracted HIV through an extramarital affair with a man was conducted (Whyte et al., 2008). The researchers found that when older African American women were involved in relationships in which down low sex occurred, but were unaware of it, the women unknowingly placed themselves at increased risk of contracting HIV by exposing themselves to their male partners multiple partners’ (Whyte et al., 2008). Perception of risk is also influenced by ones’ healthcare provider.

Healthcare Provider Perception of Risk

Healthcare providers are in unique position to assess sexual risk behaviors and educate older African American women about their HIV risk (Henderson et al., 2004). In a study conducted by Altschuler, Katz, and Tynan (2004), older adults stated that they would prefer to receive information about HIV/AIDS through educational programs, their physicians, and at senior citizen centers. Older women and healthcare providers differ in their perceptions of whose responsibility it is to initiate sexual health conversations (Grant & Ragsdale, 2008).

A group of 31 physicians and 44 newly single older women aged 45 to 68 were interviewed about sexuality and HIV risk (Grant & Ragsdale, 2008). The physicians believed it was both the patient and providers' responsibility to initiate discussions surrounding sexuality and HIV risk. However, the physicians' idea of "the patient will bring it [HIV] up if there is an issue" was identified. There was an unspoken responsibility of the patient to inform the provider of possible exposures to HIV. The physicians admitted to stereotyping many older women into a low-risk category without initiating a conversation to substantiate their claims; thus applying societal age and gender biases to their perceptions concerning the sexual activity and HIV risk of older women (Grant & Ragsdale, 2008).

Another misperception of HIV risk by providers is related to clinical manifestation of HIV (Durvasula, 2014). Many signs and symptoms linked with HIV can be misinterpreted as normal signs or symptoms of another condition (Siegel & Schrimshaw, 2002). If HIV is not considered a possible risk for the older women, the provider will not test for HIV (Henderson et al., 2004). The continuing increase in HIV cases among populations not traditionally considered at high risk of infection signifies that physicians and nurses may be missing opportunities to test and subsequently treat HIV-positive older adults. Healthcare providers' perceptions of older adults HIV risk can also influence whether an HIV test will be offered (Henderson et al., 2004).

HIV Testing Attitudes

A final HIV risk factor that older African American women face is related to negative attitudes towards HIV testing. In a study by Akers and colleagues (2007) with 514 primarily African American women, those who lacked interest in HIV testing were more likely to be older, African American, and sexually abstinent. In this same study, women who had no interest in testing often cited that they did not believe that they needed to be tested and felt they were not at risk (Akers, Bernstein, Henderson, Doyle, & Corbie-Smith, 2007).

In essence, older African American women face a number of unique barriers that may prevent the necessary precautions to protect their health; oftentimes contributing to engagement in risky behaviors that they may not identify as risky (Smith & Larson, 2015). Older adults have been found to have less knowledge about HIV, but perceive themselves to be at decreased risk for HIV compared to younger age groups (Corneille et al., 2008; Schick et al., 2010). A greater understanding of how older African American women perceive their HIV risk is needed.

Perception of HIV Risk

Individuals' perception of risk is seen as an essential element of most theoretical models on health and risk behavior, including the Social Cognitive Theory (Bandura, 1986), Health Belief Model (Becker, 1974), Theory of Reasoned Action (Fishbein & Ajzen, 1975), Theory of Planned Behavior (Ajzen, 1985), and Subjective Culture and Interpersonal Relations Theory (Triandis, 1977). A barrier to ensuring timely testing and diagnosis of HIV/AIDS is a lack of self-perception of risk (Corneille et al., 2008). This skewed self-perception of risk may increase older women's susceptibility to contracting HIV and subsequently forgo HIV testing (Maes & Louis, 2003; Rose, 1996). In a study by Setse and Maxwell, opting out of HIV testing was associated with older age and being a female (Setse & Maxwell, 2014). The assessment of

personal risk is one of the most powerful perceptions in encouraging individuals to adopt healthier behaviors (Napper, Fisher, & Reynolds, 2012). It is important to look at individuals' beliefs about their personal risk for HIV infection in order to understand what motivates individuals to engage in behaviors that decrease their risk of contracting HIV. While it is understood that perceived risk is not sufficient to motivate attitude or behavior change, it is considered necessary for change (Napper et al., 2012). Not only can beliefs surrounding HIV impact a person's perception of risk but also, their level of HIV knowledge (Henderson et al., 2004).

Older adults, specifically many older African American women, lack knowledge about HIV/AIDS, how it is transmitted, and how they are vulnerable to contracting the virus, compared to younger adults (Maes & Louis, 2003). In a study by Hillman (2007), 160 community-dwelling older men and women, aged 65 and older, completed questionnaires examining their attitudes towards and knowledge of HIV/AIDS. The study found that older women possessed little knowledge of HIV, or age-and gender-specific HIV risk factors (Hillman, 2007). Along with this decrease in knowledge less than 25% of the sample believed that HIV/AIDS is a problem among older people. Similarly, Henderson et al. (2004) examined age 50 and older urban women's knowledge of HIV/AIDS. The authors found that 63% of the sample believed that HIV could be transmitted through kissing, 76% considered oral sex as a high-risk activity, 13% of the older women identified condoms as a very effective means of reducing HIV transmission, and 44% of women said that abstinence was minimally or not at all effective in preventing transmission (Henderson et al., 2004). TV, friends, and family are common sources of information for urban older women regarding HIV (Henderson et al., 2004). Due to a lack of HIV education and awareness messages targeting older adults in general and older African American women in

specific, misconceptions and misinformation about HIV continue to be perpetuated (Linsk, 2000; Smith & Larson, 2015). Eliciting the perspective of newly diagnosed older African American women can shed light on this disparity and how they cope with a new diagnosis of being HIV positive.

Social Support

The experience of receiving an HIV diagnosis in older adulthood is not well explored. In the late 1980's and early 1990's, the experience of men and women infected with HIV was extensively explored and mental health and social support considerations were identified. In a qualitative study by Flowers, Davis, Larkin, Church & Marriott (2011), a sample of 14 gay men described their experience with learning of the new HIV diagnosis as both unsettling and confusing. Many participants in the study reported needing to grapple with the meaning of having HIV/AIDS in the 21st century. One participant described a conflict between the images once seen in the 1980's of emaciated hospitalized men and women and the treatments now available to prolong life in 21st century. Once participants learned more about the current treatments for HIV/AIDS and were able to establish a support system, they were able to cope with their HIV diagnosis (Flowers, Davis, Larkin, Church, & Marriott, 2011).

A mixed methods study of 147 HIV positive men and women explored the perceived antecedents and consequences of viewing a HIV diagnosis as a positive or a negative turning point in one's life (Kremer, Ironson, & Kaplan, 2009). Coping with a new HIV diagnosis was defined as experiencing a turning point, a dramatic transformation that has changed the person's attitudes, behaviors, beliefs and views of oneself. Such participants prayed daily, and maintained the belief that they were chosen to have this disease by a higher power. Praying daily was associated with viewing an HIV diagnosis as a negative turning point, $p < 0.01$, whereas, belief of

being chosen by God or a higher power was associated with viewing HIV as a positive turning point, $p < .05$ (Kremer et al., 2009).

As the number of older adults with HIV/AIDS continue to grow, strategies to support them during their disease trajectory is needed as increased level of distress is correlated with acceleration in disease progression (Chesney et al., 2003). Having formal or informal social support is a form of resilience in older HIV positive adults (Emlet, Tozay, & Raveis, 2011). Social support was described as special relationships, association with recreational activities, and support groups for HIV positive adults (Emlet et al., 2011).

Support Groups

Supports groups are a prominent strategy used to help HIV-positive older adults cope with their diagnosis. A telephone psych-educational support group for older persons living with HIV/AIDS was piloted in five gay men and one woman between the ages of 58 and 71 (Nokes, Chew, & Altman, 2003). Each participant was given a hotline number to contact the support group. During these phone conversations, participants were encouraged to share stories about living with HIV. Findings revealed that participants benefited from hearing about their peers' personal losses and how they coped. At the end of each support group session, some of the participants would exchange phone numbers in an attempt to continue the support group dialogue and to build their social support network (Nokes et al., 2003).

A randomized control trial was conducted with 295 HIV positive men and women between the ages of 50 and 76, to examine the effects of a coping improvement support group intervention on depression (Heckman et al., 2011). Participation in the intervention was found to increase HIV positive older adults' psychological well-being, and improve their efforts to cope successfully with HIV/AIDS. The support groups offered these older adults an opportunity to

share common HIV-related concerns with their peers (Heckman et al, 2006; 2011). In 1998, Malone, published one of the first descriptive studies that examined how HIV positive older women coped with their diagnosis. Malone created a support group for women 50 and older at an HIV clinic. The women all had very different personalities; however, their individual presence in the support group added to the support group's richness. The women reported that sharing their stories and listening to their peers' stories facilitated their healing process and enhanced their strength. Many of the women also identified having faith in a higher being as an important coping strategy for dealing with their HIV/AIDS (Malone, 1998).

Religion & Spirituality

Religion and spirituality are two strategies that some HIV positive older adults use to cope with their diagnosis (Vance, Brennan, Enah, Smith, & Kaur, 2011). A person uses spirituality to understand his or her own world, beyond concrete and earthly concepts. Being spiritual does not necessarily mean a person ascribes to a specific religion. In a qualitative study, 63 HIV positive men and women 50 and older were asked to describe how religious or spiritual beliefs helped them cope with their disease (Siegel & Schrimshaw, 2002). Almost all of the participants reported that having faith was a useful resource for coping with HIV/AIDS (Siegel & Schrimshaw, 2002), although many did not participate in structured religious services due to feeling uncomfortable with being in a traditional church setting (Siegel & Schrimshaw, 2002). Histories of drug use, living in poverty, or being homosexual were all reasons why the research participants did not want to attend traditional religious services (Siegel & Schrimshaw, 2002). Ethnic differences related to use of religion as a coping mechanism have also been seen among older adults (Speer et al., 1999). African Americans are more likely than their White counterparts to engage religion as a means to cope with their diagnosis (Speer et al., 1999). Social support

does not end at spirituality. Friends, family and significant others can also serve as a means of social support for HIV positive older adults.

Friends, Family and Significant Other

Older adults tend to disclose their HIV positive status to at least one friend or family member (Vance & Woodley, 2008). Friends, family members and significant others can console and support HIV positive older adults (Emlet et al., 2011). In a mixed method study of 75 HIV positive men and women, aged 45 and older, Whites were found to utilize more support from friends (Speer et al., 1999); whereas Blacks were found to utilize more social support from family members for emotional, financial and tangible support, than Whites (Heckman et al., 2000).

Research looking at sexual and romantic partnerships among individuals living with HIV has been focused primarily on men who have sex with men and IDUs, and not on women (Wilson et al., 2007). The extent to which HIV-positive women, aged 30 to 46, initiated new sexual relationships, disclosed their HIV-status, and used condoms with sexual partners was explored in a longitudinal cohort study (Wilson et al., 2007). Findings revealed that 70% reported disclosing their HIV status to their sexual partners (Wilson et al., 2007). In building a new relationship, honesty about HIV status can be an issue. Fears of stigma and loss of support from a partner can hamper these discussions.

Lack of social support from friends, family, peers, or the church and experiencing stigma are barriers to successful aging with HIV/AIDS (Vance, Brennan, Enah, Smith, & Kaur, 2011). Perception of stigma can cause HIV positive adults to isolate themselves or feel isolated from their networks of social support (Vance et al., 2011). The stigma associated with being HIV positive can be amplified by stigmas related to one's age, sex, and race (Vance et al., 2011).

Above, several seminal and germinal research studies that have changed the way health care professionals look at aging and social support was presented. With racial and ethnic minorities being disproportionately affected by HIV/AIDS, research geared towards exploring how social support networks are constructed and utilized among newly diagnosed older African American women is needed. Insight into these women's social support can assist in the development of interventions that cater to both the women's psychosocial needs and healthcare needs.

Healthcare Needs and Linkage to HIV Care

The National HIV/AIDS Strategy highlights the potential of the Affordable Care Act (ACA) to increase access to care and improve health outcomes for people living with HIV (Office of National AIDS Policy [ONAP], 2010). In 2010, the ACA was passed. Arguably, it is one of the most important pieces of health care reform legislation since Medicare and Medicaid enactment in 1965 (Greenwald & Killelea, 2011). With the implementation of the ACA, Americans will be offered a greater opportunity to gain access to affordable care, preventative services, and treatment. Starting in 2014, low-income individuals living with HIV will be able to qualify for Medicaid regardless of disability status. Currently, Medicaid designation is only given to HIV positive persons who are disabled by AIDS.

Continuum of Engagement

The goals of the National HIV/AIDS Strategy include reducing the number of people who become infected with HIV, increasing access to care, improving health outcomes for people living with HIV, and reducing HIV-related health disparities (ONAP, 2010). In order to accomplish the goals of the National HIV/AIDS Strategy, multiple elements along the continuum of engagement in HIV medical care must be changed (ONAP, 2010). This continuum begins with individuals who are unaware of their HIV status, which includes individuals who have

never taken an HIV test, or returned for the results of an HIV test (CDC, 2014). It is estimated that approximately 20% of individuals living with HIV are unaware of their HIV status (CDC, 2014). The total number of persons infected with HIV is 1,178,350; however after subtracting the number of individuals who do not know of their HIV status, the number drops to 941,950 (CDC, 2011).

Moving along the continuum, 725,302 individuals who know about their HIV status are actually linked to HIV care (CDC, 2011). Linkage to care is defined as seeing a medical provider within three months and before a maximum of six months following their HIV diagnosis (CDC, 2009). The next element of the continuum is retention in care, which is defined as having greater than two outpatient visits at least three months apart during each year. Only 480,395 (41%) HIV-positive individuals are retained in care (CDC, 2011). Once in HIV care, the goal becomes to start antiretroviral (ARV) medication and become viral load suppressed (CDC, 2007). Only 426,590 (36%) people are on ARV and only 328,475 (28%) have a suppressed viral load (CDC, 2011). The stark contrast between the number of projected HIV-positive Americans and the number who are viral load suppressed is astonishing.

A cross-sectional study was conducted with 113 HIV positive men and women, aged 17-61, to identify factors associated with the late diagnosis of HIV infection (Mugavero, Castellano, Edelman, & Hicks, 2007). Older adults were found to be more likely to be diagnosed with a CD4 count less than 200 (an AIDS diagnosis) $p=0.01$. Also, older persons ($p=0.03$) and women ($p=0.001$) were more likely to be diagnosed only when hospitalized (Mugavero et al., 2007). When older adults are hospitalized with HIV/AIDS related complications, extreme symptoms motivate them to seek out emergency services (Emlet & Poindexter, 2004).

Symptom Interpretation & Seeking Care

Typically, when a person is given a diagnosis, they will search for symptoms that match that illness (Siegel, Dean, & Schrimshaw, 1999). The individual's interpretation of symptoms, related to or not related to the illness, will influence their actions to seek healthcare or receive an HIV test. In a study of 67 men and women, 50 and older, who were interviewed about interpreting and appraising their HIV symptoms, many of the participants attributed their HIV symptoms to other causes. This led unfortunately to delay HIV testing and, after testing positive, delaying entry into medical care. One participant described denying medical treatment for HIV even after recognizing he had shared needles with friends who were dying from AIDS-related complications, and after receiving an HIV diagnosis. It was not until he began to experience symptoms he associated with HIV, that he was willing to initiate care. In another case, an older woman in the study reported delaying HIV testing for nine months due to ascribing the symptoms of night sweats, yeast infections, diarrhea, dry mouth, fatigue and swollen glands to normal aging and menopause. Due to the participant's perceptions that physical and cognitive declines were associated with normal aging, attributing HIV symptoms to other factors of aging was common (Siegel et al., 1999). Early identification of HIV-related symptoms in older women is necessary to ensure timely linkage and retention in care.

Linkage and Retention in Care

There has been little research on the factors associated with early linkage to HIV care among newly diagnosed persons (Anthony et al., 2007). This research is necessary in order to decrease the gap between testing positive for HIV and entering HIV care (Anthony et al., 2007). In a study exploring qualitatively the perspectives of providers referring HIV-positive persons to medical care after diagnosis (Gruber et al., 2011), the importance of linking patients to care in order to receive counseling on medication and prevention education on methods to reduce the

spread of HIV through sex and needle-sharing was discussed. The providers also described the disorganized and chaotic process of calling multiple persons in order to refer a client and fears that clients would not be able to navigate the complex system alone. After the implementation of a case management service, the providers found the referral process to be more clear and easier to navigate for the patients (Gruber et al., 2011).

Similarly, Naar-King et al. (2007) evaluated the care utilization and health outcomes of 104 newly diagnosed men and women (aged 19-42) in an outreach initiative. As a part of the outreach program, the participants received education and support to address financial and structural barriers. The newly diagnosed participants who were retained in HIV care and demonstrated an improved health status were more likely to have decreased insurance obstacles and decreased substance use and binge drinking issues (Naar-King et al., 2007).

In a retrospective cohort study with HIV positive men and women between the ages of 17 and 70, it was found that older adults (OR=1.31 per 10 years; 95%CI=1.06-1.62) and African Americans (OR=2.45; 95%CI=1.60-3.75) were more likely to have delayed linkage to care; primarily due to an inability to cope with the new diagnosis (Ulett et al., 2009). However, once the patient was linked to care, older adults were better retained in care. It is essential that older African Americans be linked to medical care immediately after being diagnosis, due to their higher viral load counts, lower CD4 counts, increased susceptibility to opportunistic infections, and depression. Providing services geared towards ensuring adequate coping after learning of the new diagnosis can aid in retention in care (Ulett et al., 2009).

Barriers to Retention in Care

Retention in care can be complicated by drug use, depression and other co-morbidities. Negative effects of drug use were found in a sample of 119 adults (aged 18 to 50+) newly

diagnosed with HIV (Mayben et al., 2007). Marijuana use was a predictor of lower CD4 cell count at diagnosis, $p=0.002$. Decision to reduce drugs and alcohol had a positive effect on retention in care. In the study by Naar-King et al. (2007), retention in care was significantly associated with reduction in substance use (illicit drug use or binge drinking) in the last 30 days. Depression is another deterrent to retention in care.

The impact of depression on 180 newly diagnosed men and women, aged 18-70, with HIV was explored in a prospective, observational cohort study (Bhatia, Hartman, Kallen, Graham, & Giordano, 2011). The researchers found that women who were unemployed, had a lower yearly income, and who reported drug use in the preceding six months were more likely to experience depression. Also, having decreased access to care, inability to obtain care, barriers to appointment adherence, and low self-efficacy were all related to depressive symptoms. This study highlighted the impact depression and depressive symptoms have on linkage to care among newly diagnosed persons. Similarly, in a study by Frontini et al., (2011) where 132 HIV positive men and women, age 59 and older, medical records were reviewed, depression was a common finding as well as the presence of numerous co-morbidities. Among the sample, 92% reported at least one co-morbidity other than their HIV diagnosis. The most common medical conditions included dyslipidemia, hypertension, diabetes and cardiovascular disease (Frontini et al., 2012).

Health-related issues, concerns and management strategies were explored in a qualitative study involving White women over the age 65 (Roberto, Gigliotti, & Husser, 2005). When having to cope with multiple health conditions, the complexity of health regimens increases. The cumulative effects of chronic conditions further compromise activities of daily living and overall quality of life in older women. The older women reported having difficulties identifying the difference between two conditions. A blending of problems and symptoms was common. The

findings of this study suggest the need for new health paradigms that look beyond a single health condition and adopt a holistic approach. This will assist practitioners in recognizing the interplay of multiple conditions with similar and unique problems. As the life expectancy of humans continues to rise, understanding the physical, psychological and social connections between chronic diseases is needs (Roberto et al., 2005).

Reorganization of Aging and HIV Services

AIDS service organizations were created with the goal of reducing stigma and offering people living with HIV/AIDS physical and mental health services (Shippy & Karpiak, 2005). However, for older adults, these organizations are seldom used, due to lack of programs that discuss aging-specific topics. In a study by Shippy and Karpiak (2005), aging HIV/AIDS populations were not able to depend on classic support networks, such as their spouse and children for social support as healthcare needs became more complex. Older adults living with HIV are at risk for falling between the cracks of aging services and HIV-related services (Emlet & Poindexter, 2004). Another consideration is that many healthcare providers who are specialized in the needs of persons living with HIV/AIDS are not also knowledgeable of unique needs of older adults (Emlet & Poindexter, 2004). Often older adults present to care with complex needs that cannot be addressed solely by an HIV specialist (Emlet & Poindexter, 2004; Greene, Justice, Lampiris, & Valcour, 2013).

Summary

A healthcare system that takes into account the needs of older adults, specifically older African American women for this study, is necessary for achieving the goals of the National HIV/AIDS strategy. Research exploring the perceptions, experiences, social support and healthcare utilization among newly diagnosed older African American women is needed. This

unique perspective can help researchers better understand testing behaviors, coping and barriers to care among this vulnerable population.

CHAPTER THREE:

Theoretical Orientation and Philosophical Underpinnings

In Grounded Theory (GT), the use of theoretical frameworks differs from traditional quantitative studies (Charmaz, 2006, p. 169) in that the theoretical framework is comprised of sensitizing concepts and theoretical codes that act as a starting point to help explain how ideas are conceptualized. The theoretical orientation influencing this Constructivist Grounded Theory (CGT) study has stemmed from Lazarus and Folkman's Cognitive Theory of Stress, Appraisal and Coping (Lazarus & Folkman, 1984), the Andersen Behavioral Model of Health Services Use (Andersen, 1968), and Symbolic Interactionism (Blumer, 1986). The Cognitive Theory of Stress, Appraisal and Coping has provided a useful conceptual lens of how older African American women utilize their social networks to cope more positively after receiving an HIV/AIDS diagnosis. The Behavioral Model of Health Services Use offered a conceptualization of various considerations inherent in navigating the healthcare system from pre-diagnosis to post diagnosis of HIV/AIDS. Both of these theories were used in the conceptualization and construction of the interview guide. Lastly, symbolic interactionism (SI) was used to guide the development and analysis of this CGT study. SI facilitated the examination of the history of actions, decisions and choices made by older African American women diagnosed with HIV/AIDS at the age of 50 or older that influenced their HIV trajectory.

The Cognitive Theory of Stress, Appraisal and Coping

Lazarus and Folkman published the Cognitive Theory of Stress, Appraisal and Coping in 1984 (Heckman et al., 2000). In the early 1950's, Lazarus began conducting numerous experimental studies on the adaptation of persons who experienced stressful problems (Lazarus, 1966). Between the 1960's and the early 1980's, the concepts of coping, appraisal and stress

evolved significantly. Within various disciplines, practitioners began to examine issues related to stress management, human emotions, and coping throughout the lifespan. In 1984, Lazarus and Folkman extended their work to include interdisciplinary research trends and created a new theory to explain this evolving phenomenon (Heckman et al., 2000). This theory has offered researchers a method to evaluate the relationship between an individual, their environment and their cognitive appraisal of the significance of a stressful situation (Heckman et al., 2000).

Stress

The Lazarus and Folkman Stress and Coping theory draws relationships among the concepts of stress, appraisal and coping (Lazarus & Folkman, 1984). The first concept in the Cognitive Theory of Stress, Appraisal and Coping is stress; first described in the 14th century as adversity or affliction (Lazarus & Folkman, 1984). As time progressed, the discipline of medicine started to describe stress as the basis of poor health. In the 19th century, a number of definitions of stress arose from researchers and theorists. Lazarus suggested that stress must not be simply defined by one definition; instead, stress should be used as an organizing concept that would allow researchers to gain a deeper understanding of a broad range of phenomena related to human adaptation. In order to demarcate the countless possible definitions of stress, Lazarus divided the definition of stress into three categories: stimulus, response, and definitions.

Stimulus. The stimulus aspect of a stressor highlights the effect a major life change or experience can have on an individual's life. These events can be internal, initiating within the individual, or external, originating from an individual's environment. Both internal and external experiences and changes can act as a stimulus (Lazarus & Folkman, 1984). Receiving an HIV diagnosis can be a life altering experience that requires subsequent changes in one's lifestyle. Managing an HIV infection involves day-to-day stressful encounters, including adhering to a

medication regimen, and dealing with medication side effects and other complications of the disease (Martin, Vosvick, & Riggs, 2012).

Response. Once the stressor is stimulated, the individual will respond or react to the stressor (Lazarus & Folkman, 1984). An HIV positive individual's response to the stressor of taking medications daily may be met with acceptance (adherence) or rejection (medication non-adherence). One's response can be complicated by their environment.

Relational. The relational aspect of stress emphasizes the idea that stress does not occur independent of an individual's environment (Lazarus, 1986). There is always a relationship between an individual's environment and their disease (Lazarus & Folkman, 1984). Coping with an HIV diagnosis can be complicated by environmental factors, such as housing. In a cross-sectional study, recently diagnosed HIV positive homeless individuals, were found to have worse medication adherence ($p < 0.001$), than their housed counterparts (Kidder, Wolitski, Campsmith, & Nakamura, 2007). Due to the fact some HIV medications have special requirements on how it should be taken and where it should be stored, homeless persons can experience barriers to medication adherence and added overall stress (Kidder et al., 2007). A qualitative study assessed the experience of 12 HIV positive injection drug using (IDU) men taking ARV medication in prison (Small, Wood, Betteridge, Montaner, & Kerr, 2009). Findings revealed that participants' ARV treatment regimen was interrupted by being in a prison environment; for example, prison transfers and the need to take ARV medications discretely caused delays in adherence (Small et al., 2009). Lazarus and Folkman combine these aspects to create their concept of stress.

Stress also takes into account the evolution of the medical model, which views illness as presence of a foreign agent, paired with the humans' susceptibility to a foreign agent. Lazarus and Folkman's meaning of stress is a connection between an individual and the event the

individual appraises as surpassing their level of resources or challenges their overall well-being (Lazarus & Folkman, 1984). For many adults, learning a new HIV/AIDS diagnosis for the first time can be a stressful event (Mack & Ory, 2003). To the extent that an individual experiences the event as stressful is based on the individuals' appraisal of the event. Because Lazarus and Folkman's meaning of stress requires the individual to appraise the situation or event as stressful, the concept of cognitive appraisal plays an important role in the Cognitive Theory of Stress, Appraisal and Coping (Lazarus & Folkman, 1984).

Cognitive Appraisal

The second concept in the Cognitive Theory of Stress, Appraisal and Coping is cognitive appraisal (Lazarus & Folkman, 1984). Environmental pressures are said to cause stress in most humans; however differences in reaction to a stressor are always seen between individuals and groups. One person's level of vulnerability to a stressful situation, understanding of the stressful event, and response to a stressor can vary considerably from that of another person's experiencing of the same stressor (Lazarus & Folkman, 1984). For example, one person can receive a HIV positive diagnosis and respond with anger, whereas, another person can receive an HIV positive diagnosis and respond with depression (Anderson et al., 2010). Because there can be vast differences among individuals experiencing similar stressors, theorists urge users of this theory to examine the cognitive processes that mediate the stressful event and the person's reaction to the event, as well as, external factors that affect their appraisal (Lazarus & Folkman, 1984).

Theorists describe the concept of cognitive appraisal as a subjective act, performed by the individual experiencing the stimuli or stressor (Lazarus & Folkman, 1984). The person is responsible for assessing the meaning of a stressor. The person is also responsible for permitting

this perception to shape their emotional and behavioral response to the stimuli or stressor. There are three basic types of cognitive appraisal: primary appraisal, secondary appraisal and reappraisal.

Primary appraisal. Primary appraisal of a situation can be considered irrelevant, benign-positive and/or stressful (Lazarus & Folkman, 1984). When an individual finds there are no consequences or benefits to a situation, the person appraises the situation as irrelevant (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). If a person views the product of the situation as preserving or enhancing well being, the appraisal is said to be benign-positive. In contrast, if a situation is appraised as causing harm, it is considered to be a stress appraisal (Folkman et al., 1986; Lazarus & Folkman, 1984). A qualitative study of 12 people living with HIV explored their experience of hope after receiving an HIV-positive diagnosis (Harris & Larsen, 2008). The men and women in this study appraised their HIV diagnosis as fear provoking and subsequently felt hope was unobtainable (Harris & Larsen, 2008).

Secondary appraisal. Secondary appraisal is defined as the act of assessing what can be done to manage a challenging situation (Monat & Lazarus, 1991). Secondary appraisal requires the person to determine which coping approaches are available for their use, the probability that a coping approach will be effective, the probability that the person can use the approach or the approaches effectively, and lastly, appraise the approach or approaches in relation to internal and external demands (Lazarus & Folkman, 1984). In the study by Harris & Larsen, the participant's secondary appraisal of how to cope with the HIV diagnosis stressor led to a decision to engage in high risk behaviors (Harris & Larsen, 2008). However, after reappraising their stressor, learning more information about HIV/AIDS and gaining hope, the participants stopped heavy drinking, IDU, having unprotected sex and reckless driving (Harris & Larsen, 2008).

Reappraisal. Reappraisal is the process of changing one's initial appraisal of a situation based on the gathering of new information from their environment or new information gathered from the individual (Monat & Lazarus, 1991). Reappraisal is often seen after a person implements a cognitive-behavioral coping approach (Folkman et al., 1986).

Coping

Lazarus and Folkman describe coping as frequently altering approaches to deal with specific inner and outer stressors that are deemed to be challenging to that individual (Lazarus & Folkman, 1984). This definition is one of many examples of how theorists draw relationships among the Stress, Appraisal and Coping concepts. Traditionally, the concept of coping was seen as the successful adaptation to a stressor or stimuli (Anderson, 1977); however, the theorists emphasized the importance of viewing coping as a behavior that can be successful or unsuccessful (Lazarus, 1966). Coping is any attempt to deal with a stressful situation, regardless of the outcome of the situation (Lazarus & Folkman, 1984). The only way to measure whether a coping strategy is effective is to examine the effects of an approach in a given situation and over time (Schwarzer, 1998). Two coping strategy are emotion-focused coping and problem-focused coping (Folkman & Lazarus, 1980).

Emotion-focused coping, also known as passive coping, is a cognitive method aimed at decreasing emotional distress (Folkman & Lazarus, 1980). Examples of emotion-focused coping, include avoidance, distancing, selective awareness, and deciphering helpful value from harmful events (Lazarus & Folkman, 1984). Individuals can use emotional-focused coping to sustain hope and optimism in a stressful situation, or the individual can use problem-focused coping to solve the problem at hand. The problem-focused coping, also known as an active coping approach, focuses largely on the person's environment, which is comprised of environmental

pressures, barriers and resources, or skill acquisition (Folkman & Lazarus, 1980). The individual targets the cause of stress, the problem itself, and attempts to change the circumstance (McLeod, 2010).

In a qualitative study exploring the experience of HIV-related stigma among nurses and men and women living HIV/AIDS, 43 focus groups were conducted with 251 participants (Makoae et al., 2008). The participants offered emotion-focused and problem-focused coping strategies. The most common emotion-focused coping strategy utilized was rationalization, which involved trying to make the diagnosis and the stigma less painful. Rationalization was accomplished through positive thinking and creating alternative explanations for their illness, such as “[it’s] just like TB, ulcer, and so on. It didn’t really hurt me that much.” In contrast, the most common problem-focused coping was disclosure. In an attempt to decrease gossip and stigma, some of the participants admitted to being open and truthful about being HIV positive (Makoae et al., 2008). Under the categories of emotion-focused coping and problem-focused coping, Lazarus and Folkman (1984) describe resources and influences that facilitate these coping processes. Several examples of resources and influences used include problem solving skills, material resources, and social skills (Lazarus & Folkman, 1984).

After Cognitive Theory of Stress, Appraisal and Coping was published, the use of the theory spread across the United States and then across the world (Campos, 2002). A reference search was performed on the database search engine, Web of Science, using Lazarus and Folkman as the cited authors, and 1984 as the cited year. The results of this search found that 386 articles cited Lazarus and Folkman’s theory (Lazarus & Folkman, 1984). This theory has been found in various settings, including, but not limited to research, administration, education and clinical practice. The authors anticipated that the theory would be used by sociologists, scientists,

medical researchers, anthropologists, and healthcare professionals, such as psychiatrists, social workers and nurses (Lazarus & Folkman, 1984).

Many researchers in the arena of HIV/AIDS have used this Stress and Coping theory to guide their social and behavioral interventions (Atkinson, Schonnesson, Williams, & Timpson, 2008; Braxton, Lang, Sales, Wingood, & DiClemente, 2007; Delmas, Delpierre, Cote, Lauwers-Cances, & Delon, 2008; Martin et al., 2012; Moneyham et al., 1998; Sikkema, Hansen, Kochman, Tate, & Difranceisco, 2004). Other researchers have used the Stress and Coping theory to create interventions to increase health and well-being of humans and decrease everyday stressors found in society (Sharts-Hopko, Regan-Kubinski, Lincoln, & Heverly, 1996). The use of Lazarus and Folkman's stress and coping theory in interventions serves two primary goals. The first goal is to assist researchers in describing variability in stress responses seen among their participants. Secondly, this theory provides a guiding framework for cognitive-behavioral interventions, aiming to effectively manage stressors (Brown & Venable, 2008).

In a cross-sectional study, Delmas et al. (2008) assessed factors associated with adherence in 115 HIV positive men and women who were on ARV. Potential risk factors found to affect adherence included ARV side effects, low social support, high levels of stress, low stress adaptation, maladaptive strategies of coping and low quality of life. The stress and coping model was utilized to analyze pathways by which factors could compromise adherence (Delmas et al., 2008).

In a randomized control trial testing an AIDS-related bereavement coping intervention among 235 HIV-infected men and women between the ages of 21 and 60, the stress and coping model was utilized (Sikkema et al., 2004). Based on this model, the intervention group was introduced to current coping strategies, adaptive and maladaptive, and asked to identify short-

and long-term goals related to coping with HIV/AIDS. Once the intervention education was provided, the participants were taught how to implement adaptive and appropriate ways of coping in order to decrease psychological distress (Sikkema et al., 2004).

The true test of a theory is its ability to describe, predict, and understand a phenomenon (Meleis, 2011). The Cognitive Theory of Stress, Appraisal and Coping theory was useful in conceptualizing the interview guide questions and probes related to dealing with a HIV diagnosis. Another sensitizing model that can organize the events that take place throughout older African American women's HIV trajectory is the Behavioral Model of Health Services Use.

The Behavioral Model of Health Services Use

The Health Services Use model was developed in the late 1960's by Ronald Anderson (Andersen, 1995). The model was created while he was completing his doctoral studies at Purdue University (Andersen, 1995). A nationwide social survey of 2,367 families was conducted in 1964 which explored the types and amounts of healthcare service utilized, costs of healthcare services, and how the families paid for their healthcare services (Andersen, 1968). Andersen used the family as his unit of analysis for the study; appropriate for studying consumption patterns of consumer services (Gochman, 1997).

The aims of his original model were to better understand why families utilize healthcare services, to define and measure equitable access to healthcare, and to assist in developing policies that would promote equitable access to healthcare (Andersen, 1995). In subsequent years, Andersen shifted his focus from families, as the single unit of measurement, to the individual (Andersen, 2008). This switch was necessary after Andersen encountered difficulties in accounting for the heterogeneity of a family unit (Andersen, 2008). The evolving models to

follow suggested that individuals' use of healthcare services is related to factors which enable or impede use of healthcare services and the individual's actual need for healthcare (Andersen, 1995).

Anderson described the ability of the model to both predict and explain (Andersen, 1995). The concepts within the model included predisposing characteristics, enabling resources, and need. Each individual concept can work independently or together in order to either predict healthcare use or explain healthcare use. When the concepts are used in combination, an explanatory process of healthcare use is seen (Andersen, 2008). This process involves the individual identifying predisposing characteristics, including demographic, social structure and/or health beliefs, enabling factors, such as family or community, and perceived needs by the individual which can lead to the use of health services (Babitsch, Gohl, & von Lengerke, 2012).

Predisposing Characteristics

The first concept is predisposing characteristics (Andersen, 1968). Some families have a tendency to use more health services than others. Andersen believed that this predisposition towards utilizing healthcare services could be predicted by family characteristics that existed before disease onset (Andersen & Newman, 1973). The key predisposing characteristics that greatly influence healthcare utilization included family composition, social structure and health beliefs (Babitsch et al., 2012).

Demographics. Family composition encompasses age, sex, marital status, head of the family, age of youngest and oldest family member and family size (Andersen, 1968). These characteristics are all related to health and illness. For example, being older or younger is not in itself a reason for seeking healthcare. Instead, individuals of different ages may experience varying types and degrees of illness, which results in a varying level of healthcare utilization

(Andersen, 1968). Once the model was changed to explore healthcare utilization of the individual, the sub-category of family composition changed to demographics of the individual (Andersen, 2008). Another sub-category of interest under predisposing characteristics is social structure.

Social structure. Social structure focuses on the family's location within society (Andersen, 1968). Measuring employment, social class, occupation, education, race, and ethnicity helped to explain the individual's or family's social structure and lifestyle (Andersen, 1968; 1995). This sub-category points to the physical and social environment that impacts usage of healthcare services. The variables employment, education and social class may all appear to be more suited for enabling healthcare services use because they are correlated to income and health insurance coverage. Just as family composition evolved, once the focus of the model moves to the individual, so did social structure. Social structure is now determined by an individual's social status within their community, that person's ability to acquire resources, ability to deal with problems, and the current character of the physical environment they live in (Andersen, 1995). Social structure is now measured typically through gathering data on the individual's education, occupation and ethnicity (Andersen, 1995). The last sub-category under predisposing characteristics is health beliefs.

Health beliefs. Health beliefs are attitudes, values, and knowledge that individuals hold about their health and healthcare services (Andersen, 1995). Beliefs about their healthcare provider and the disease are also housed under this sub-category (Andersen, 1968). Similar to demographics, health beliefs do not directly impact healthcare services usage, but it affects one's inclination to utilize healthcare services (Gochman, 1997). Andersen provides an example of the impact of health beliefs on health usage among families. When families strongly believe in the

effectiveness of the treatment put forth by their healthcare provider, they will be more likely to seek out care sooner and more frequently than families with less faith. Measurements of health beliefs include value of healthcare services, value of healthcare providers, value of good health, value of health insurance, attitude towards healthcare services, attitude toward healthcare provider use, and knowledge of disease. Although individuals have a predisposition to healthcare services, some reason must exist to enable them to do so; this is where the second concept of enabling components emerges (Andersen, 1968).

Enabling Resources

An enabling component allows a family to act upon a value or satisfy a need concerning healthcare service use (Andersen, 1968). These components help make healthcare resources available to the family. The family needs a way to attain the services (family resources) and geographic access to the service (community resources). Once both components are in place, the healthcare services can be utilized.

Family and community resources. Family resources are defined by Andersen as the family's capacity to obtain services for its members. These are measured by assessing economic resources and their source of medical care, including family savings, health insurance, regular source of care and welfare care (Andersen, 1968). Community resources are defined as the availability of services in that person's residential area (Andersen, 1968). When healthcare services are conveniently located, they can be utilized more frequently (Gochman, 1997). Community resources are measured by examining provider-population ratio, hospital bed-population ratio, residence and region (Andersen, 1968). Even when predisposing characteristics and enabling components are present, the individual must still perceive illness or possibility of illness in order for use of healthcare services to happen (Andersen, 1995).

Perceived needs. Need is the final component before healthcare services are utilized (Andersen, 1968). Need is measured by the magnitude of illness apparent to the family and by the way the family responds to their perceptions (Bradley et al., 2002). In Andersen's original model, illness was measured by self-reports of poor physical conditions experienced by the family member (Andersen, 1995). This subjective account represents what people think about a disease that can be clinically confirmed. An individual's level of health, type of symptoms, and disability days were used to assess for illness. The second sub-category that influenced need was response (Andersen, 1968). Perceiving poor health does not always equate to use of health services (Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006). When a person perceives symptoms of illness, they may or may not respond by seeking medical care. The response sub-category is assessed by the individual seeing a healthcare provider for symptoms and regular physical examinations (Andersen & Newman, 1973). Once the individual acknowledges their illness and decides to respond by seeking medical services, utilization of healthcare services is achieved (Andersen, 1968).

Adaptation of the Model

Over the years, the Behavioral Model of Health Services Use has been adapted to reflect new knowledge development surrounding healthcare utilization (Andersen, 1995). The model continues to assist researchers in discovering circumstances that enable or hinder utilization of healthcare services. In the 1970's, a revised model was put forth by Andersen and colleagues (Aday & Andersen, 1974; Andersen & Aday, 1978; Gochman, 1997). The revised model incorporated the health care system and highlighted national health policy, healthcare system resources and the healthcare system organization (Andersen, 2008). The health service-use measures in the original model were also expounded, including service type, site, purpose, and

coordinated services received in an episode of illness (Andersen, 1995). Finally, customer satisfaction was explicitly added as a branch from health services. The revised model now allowed researchers an opportunity to account for convenience, availability, financing, provider characteristics and quality when using the Behavioral Model of Health Services Use (Andersen, 1995) .

Between the 1980s and the 1990s, a third model arose (Andersen, 2008). This model strived to account for the need to maintain and improve the health status of a population. This maintenance and level of improvement is measured by both the perceptions of the population and the evaluation of the healthcare professional (Andersen, 1995). In addition to measuring health services, this model took into account external environmental factors and personal health practices (Andersen, 1995). The external environment components, physical, political and economic, strengthened the model by facilitating a better understanding of healthcare service use (Gochman, 1997). Diet, exercise, and self-care factors were added as personal health practices that influenced health outcomes (Andersen, 1995). The Behavioral Model of Health Services Use continues to be expanded and tested by researchers around the world (Wolinsky, 1994). An adaptation of the model by Gelberg, Andersen and Leake (2000) was created and tested for use with vulnerable populations. This Behavioral Model of Vulnerable Populations was used to conceptualize health service use, specifically intention to receive HIV testing in a group of minority women between the ages of 50 and 64 (Wigfall et al., 2011).

In the context of HIV healthcare utilization of older adults, the model has been shown to be a useful conceptual framework studying older HIV positive adults (Emlet & Farkas, 2002). In a cross-sectional study of 571 men and women living with symptomatic HIV, between the ages of 30 and 81, the role of age on service utilization among persons with HIV/AIDS was explored

(Emlet & Farkas, 2002). This study utilized a modified version of the behavioral model of service utilization revised by Andersen and Newman (1973) as a conceptual framework. The authors used predisposing, enabling, and need factors as independent variables (Emlet & Farkas, 2002). The study found that the majority of significant predictors of medical care services use were related to need characteristics, including level of functional impairment and having an AIDS diagnosis. Having a greater level of functional impairment ($p < .01$) and having an AIDS diagnosis ($< .05$) were significant predictors of seeing an MD (Emlet & Farkas, 2002).

The Health Services Use model and its adaptations influenced the researchers' questions created for the interview guide. These assumptions about health services use were deconstructed and used to create open-ended, non-leading questions about the participants' experience navigating the healthcare system. In remaining authentic to the qualitative methodology, these above two theories were not applied to data analysis. The concepts used to construct the grounded theory arose strictly from the participants' interviews. If at any time the assumptions of these theories or other assumptions of the research arose during data collection or analysis reflexive memoing was used to identify and isolate the assumptions. The last guiding theoretical framework that guided this study on older African American women's experience after an HIV diagnosis was symbolic interactionism.

Symbolic Interactionism

This study utilized CGT methodology to explore and understand older African American women's perceptions of HIV risk prior to diagnosis, ability to navigate the healthcare system, and interactions with social support networks post-diagnosis. The guiding philosophical tenant of pragmatism and the theoretical tenant of symbolic interactionism (SI) contribute to the primary assumptions of grounded theory (Wuest, 2012). SI demonstrates that human beings are active

actors in and responders to their environment (Plummer, 1991). Largely, people determine what they do, think and become (Charon, 2010). SI was used in this dissertation to facilitate an understanding of how older African American women diagnosed with HIV in later adulthood respond to a HIV diagnosis, and act throughout their HIV trajectory.

Philosophical Underpinnings of SI

SI is a theoretical perspective that was derived from pragmatism (MacDonald, 2001), which emerged at the conclusion of the American Civil War (Shook & Margolis, 2006). At this time, the United States strived to create a new intellectual culture and develop a way of thinking that would help Americans cope with the new, post-war conditions of modern life (Menand, 2002). At the forefront of this philosophical movement were three American philosophers, William James, Charles S. Peirce, and John Dewey (Menand, 2002). Together, James, Peirce, and Dewey offered Americans a method to solve intellectual problems and a philosophy regarding the types of knowledge humans are able to acquire (Popkin & Stroll, 1993).

According to Magee (2001), Peirce made the claim that knowledge is an activity. When a problem arises in everyday life and in the sciences, such as learning of a new HIV diagnosis, and which cannot be answered readily, human beings are motivated to learn more about the problem at hand. The “problem-situation” is then evaluated to try to identify what aspect of the situation is wrong. Lastly, the person thinks of ways to make this situation right (Magee, 2010). Human beings strive to use intelligence to achieve understanding of problems and situations (Chiasson, 2001). After receiving a new HIV diagnosis, an older adult assesses their current situation and then sets out to understand what the new diagnosis means to them. This on-going acquisition of understanding, through creating valid explanations is knowledge (Magee, 2010). As older adults and researchers acquire a greater understanding of coping strategies utilized after receiving a

new HIV diagnosis, they will be able to develop interventions to decrease psychological distress and increase linkage to care.

Dewey also presented a view of what knowledge is in the context of pragmatism (Hickman, 2009). According to Magee (2010), Dewey also viewed knowledge as a human activity. Dewey saw science as a self-critical type of enquiry with a logical composition. The first step in scientific enquiry is to identify the problem. The next step is to create possible solutions to the problem and then test the solutions in an experiment. The experiment could end in two different ways; one, the experiment could disprove the proposed solution and the scientist must then think of alternate solutions to solve the problem; or two, the experiment could confirm that the problem has been solved and the scientist can move on to another unsolved problem (Magee, 2010). Dewey saw that this problem-solving approach could enhance humans' knowledge and competence (Hickman, 2009). Once researchers can identify the coping strategies utilized by older adults and decipher the strategies that enhance linkage to care, they can test the usefulness of these strategies in an intervention. Pragmatism allows researchers to continuously test and re-test experiments until a practical solution for older adults is found.

The third influential pragmatist, James, presented pragmatism as a theory of truth (Magee, 2010). According to McCready (2010), James held that truth is an ontological issue and it is the destiny of the human mind to attain truth (McCready, 2010). According to James, the concept of truth includes big "T" truth and little "t" truth (James, 1910). Truths with a little "t" are estimates of truth with a big "T" (McCready, 2010). James uses the term "manyness-in-oneness," meaning there are many small truths in the journey towards reaching the ultimate big Truth (McCready, 2010).

Popkin and Stroll (1993) explained that James claimed truth was dependent on human experience; whereas early philosophers, such as Plato, claimed that a theory can be true, whether it is known by a person or not. From the pragmatist view, a theory, idea or belief is true if it works for the individual person. According to James, if the theory, idea or belief has “cash value”, it can be considered true (James, 1910). When determining whether a theory, idea or belief has “cash value”, one can evaluate the function of the claim, evaluate what difference it would make if the claim were true, and evaluate possible personal consequences for acting on that idea, belief or theory. If the idea, theory, or belief does not serve a purpose to the individual, does not affect an individual’s actions, or does not effectively solve an individual’s problem, the claim has no “cash value” (Popkin & Stoll, p. 275).

If a theory is found to deal successfully with the human lived experience, it is considered true; however, if the theory does not work in the human experience, it is considered false (Kimura, 2013). The only way to determine whether a theory is true or false is to evaluate it in relation to concrete aspects of life (Popkin & Stroll, 1993). When researchers explore the coping processes utilized by older adults, they pay close attention to what strategies work best for that individual. One older adult may rely on drugs and alcohol to cope with learning of a new diagnosis, whereas, another older adult may rely on spirituality to cope with the initial diagnosis. Pragmatism values the individuals lived experience and not a universal truth for all persons living with HIV/AIDS. James held that truth grows over time and it not stagnant (Popkin & Stroll, 1993). As humanity confronts new problems, solutions that once worked in the human experience and were true may no longer yield adequate results. Throughout time, as ideas, beliefs, and theories evolve, truths can become less or more true (Popkin & Stroll, 1993). As the

HIV/AIDS epidemic has, evolved, and the World's knowledge of what HIV/AIDS is, so has the coping strategies utilized by adults.

Pragmatism presents researchers with a useful approach to knowledge development (Cornish & Gillespie, 2009). The idea, belief, or theory that works best at that moment in time is what is used. Pragmatism is open to the use of pluralistic approaches to knowledge development (Watson, 1997). This approach allows for the uniting of a group of people with diverse ideas and provides them with the opportunity to learn different ways of being, doing, and knowing. This approach has been seen extensively throughout the HIV/AIDS coping literature in the form of support group interventions, for persons living with HIV/AIDS. By listening to the diverse views of a conversation, a new understanding of the topic of interest is gained. Using pluralism allows researchers to integrate multiple useful ideas in order to solve complex problems, create new knowledge, and unmask coping strategies effective at decreasing psychological distress among older adults (Popkin & Stroll, 1993).

Historical Background of SI

SI has an emphasis on the social nature of the lives of humans. Humans are the creators and active actors in the world they live in. One of the major players in the development of SI was George Herbert Mead who linked Charles Darwin's evolution with behaviorism (MacDoanld, 2001). Mead admired Darwin's work (Charon, 2010) as Darwin believed that the world should be looked at in naturalistic terms and not supernatural terms. Darwin looked at concepts, such as truth, self, mind, and symbols, and tried to understand them as qualities established by humans in our natural world (Benzies & Allen, 2001).

For example, freedom should not be looked at as something established through pure faith, but instead be examined as something that was established in nature by humans in

relationship with their environment (Charon, 2010). Mead adopted many of Darwin's assumptions related to humans living in the natural world where they continuously evolved (Perry, 2003). Human beings do not have a steady and structured personality; instead, humans are constantly changing actors who are in a state of becoming, unfolding, and acting (Charon). Truth is always evolving. As our symbols, rules, and environments change, so do our interpretation of truth.

In 1937, Herbert Blumer built upon the work of Mead to coin the term SI (MacDonald, 2001). Blumer identified three basic premises of SI to include:

“humans act toward things on the basis of the meanings they ascribe to those things”; “the meaning of such things is derived from, or arises out of, the social interaction that one has with others and the society”; and “these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters" (Blumer, 1986).

In SI, society is not a structure that exists apart from humans' actions and interactions (MacDonald, 2001). Instead, society consists of humans who interact on a symbolic level. People are responsible for creating their own actions during social and self-interactions (MacDonald, 2001). SI guides grounded theorists to see that meaning is created and constantly changed through interactions, which become implanted in a social context (Wuest, 2012).

Tenets of SI

In order to facilitate a discussion of the experience of newly diagnosed older African American women, the tenets of SI must be discussed. In the following section, the primary concepts of SI including the symbols, self, mind action, taking on the role of the other and social interaction will be discussed.

SI and symbols. Symbols are responsible for assisting humans in creating reality, in creating human society, and they are essential to what it means to be human (Charon, 2010). Through interactions, humans learn about and better understand their environments. Because of this, reality is socially constructed. This socially constructed world is comprised of social objects. Symbols are one class of social objects. Symbols are used to intentionally communicate or represent something. The actor communicating the symbol has an understanding of what the symbol stands for and the receiver of that communication must interpret its meaning. Through symbols, humans share their understanding of what they think, what they know, what they are and what they feel.

This understanding of the symbol is labeled and categorized into word-symbols to facilitate conversation between another human or within oneself. It is important to note that symbols are not universally agreed on. Symbols are arbitrary and established by and altered through interactions with others (Charon, 2010). An ethnographic study of women's meanings and symbolic representations of HIV/AIDS was explored (LeClerc-Madlala, 2001). It was found that a key symbol agreed upon by the women was that HIV/AIDS was synonymous with being a dirty woman (LeClerc-Madlala, 2001). In a study by Nzioka (2000), HIV was symbolized a punishment from God. Through interactions with other members of society, the symbols of dirty, wicked and gay can be labeled to persons living with HIV/AIDS. When sounds, gestures, and symbols are combined and used as language, meaningful statements can be created by the self.

SI and the self. In SI, the "self" is an object of an actor's own actions. In the same way an individual can act towards others or their environment, an actor can act upon himself or herself. Self is a social object that arises in interaction with members of society. The self also changes based on human interaction. An individual is able to look at their "self" and consciously

see where they exist in the universe in time and in space. As the individual interacts with others, the self continues to be defined and redefined. The social definition of who is the self is defined by everyday encounters. The individual's sense of 'self,' can be expressed as the 'I' or 'Me'. An individual may define himself or herself differently based on the social interactions with their environment (Charon, 2010). For example, an individual may define the 'self' as a grandmother when around grandchildren, a wife when she is around her husband and a black woman when attending an afro-centric event. The actions humans take towards the self is processed by the human mind. In a qualitative study exploring how women experience and deal with AIDS stigma in South Africa (Rohleder & Gibson, 2006), women described thoughts about living with a "spoiled" identity. Negative social discourses surrounding HIV were internalized by the women and became a part of their "self" (Rohleder & Gibson, 2006). As humans communicate towards self, they are able to see themselves in the situation and evaluate their own action in the situation.

SI and mind action. A primary component of social interaction is mind action. "Mind" is the silent conversations we have with ourselves (Charon, 2010). Most people consider this conversation to be "thinking;" however, this is referred to as mind action in SI; a covert action. The mind is always active while we are awake, but is not open to observation by others. Humans are conditioned and driven by forces, such as their past experiences, social structures, and culture. Through mind action, humans can use these forces to assist them in making decisions and directing their own actions. Also, through mind action, humans can problem-solve, control overt action, and process ideas and conversations with the external environment (Charon, 2010).

Mind action is present during all social interaction (Mead & Morris, 2009). Interactions between humans demand continuous understanding, implementation, and defining of other in the situation. Mostly, we are unaware of the fact mind action is occurring; however, when we are

forced to stop and figure out how to solve a problem, mind action appears to be more deliberate and obvious to the individual. Mind action allows us to plan an action, practice an action, and eventually engage in social interaction (Charon, 2010). For older African American women newly diagnosed with HIV, mind action was used at diagnosis, when deciding whether to disclose their HIV status to friends and family, and throughout the entire HIV trajectory. During this interaction with the world around us, we can also take the role of the other individual while in dialogue.

SI and taking on the role of the other. The concept of “taking on the role of the other” is another component of SI. Taking on the role of the other is similar to taking on the perspective of another individual (Charon, 2010). When taking the role of the other, the individual uses someone else’s symbolic framework in order to gain access to their perspective (Mead & Morris, 2009). Through this act, we can understand the people who are important to us, including our significant others, reference groups, and generalized others (a combination of several significant others who create a group or community).

By taking the role of the other, we successfully learn, teach, cooperate, act, control actions, lead and help. On the contrary, we can also force, manipulate and exploit others. We are not only able to take on the perspective of the other, but also take on the emotions of others. This ability allows us to feel as they do and in turn develop our own feelings towards them. Taking the role of the other is crucial for developing oneself. We are capable of taking the role of numerous types of people, some of which from our past or the future. A grounded theory study explored the experiences of married and widowed Thai women (Klunklin & Greenwood, 2006). Because of their culture, the women expected to experience discrimination from others in their village. The women were able to understand how others see HIV/AIDS by taking the role of the

generalized other and better understand how to communicate their HIV status to others (Klunklin & Greenwood, 2006). “Social intelligence,” our thought processes which inform how we act, allows an individual to refine their own sense of self and communicate it too others. This communication with others is one basis of social interaction.

SI and social interaction. Social interaction involves actors considering each other, symbolically communicating to one another, and in turn interpreting the actions taking place (Charon, 2010). This process involves taking the role of the other, utilizing mind action, and self. Once the actor defines the situation, he or she begins to engage in social action. An actors’ action becomes social when they consider another person as they act. As the situation develops, actions are exchanged back and forth. Each actor adjusts and responds based on what the other actor communicates.

Social interaction is important in the creation of a person’s human qualities, as well as their identity. As an actor takes into consideration the environment, he or she is interacting with the ‘self’ to “perceive, assess, judge, communicate to self, and establish” their identity (Charon, 2010). Social interaction is also a cause of action. How we react to a situation is based on our interpretation of the other actors’ action and the other actors action is based on our action. This on-going interaction is the basis for society. Through social interaction “society is formed, reaffirmed, and altered.” Without continuous social interaction, society would cease to exist (Charon, 2010).

Summary

This chapter presented a review of the theoretical backgrounds and philosophical underpinnings that have acted as a lens for carrying out this study. The Cognitive Theory of Stress, Appraisal and Coping, and the Behavioral Model of Health Services acted as guiding

theories to frame the researcher's thinking and organization of interview questions surrounding healthcare utilization and coping. Symbolic Interactionism and Pragmatism assisted in the operationalization of sensitizing concepts and theoretical codes that were relevant to this constructivist grounded theory.

CHAPTER FOUR:

Methodology & Design

This research study utilized a grounded theory methodology to explore perceptions of HIV risk, interactions with social networks, and experiences in navigating the healthcare system among African American women diagnosed with HIV age 50 or older. In addition, a theoretical framework grounded in the narratives of these women regarding their perception of HIV risk, social networks, and navigation of the healthcare system was developed. In the following chapter, the study's research methodology and design will be discussed.

Research Approach

Grounded theory is a qualitative, inductive, explanatory approach to conducting research (Schreiber & Stern, 2001). Constructivist Grounded Theory (CGT) was used for this study. In taking a constructivist approach, the researcher must recognize that both data and analysis is created from shared experiences, relationships with participants, and other sources of data (Charmaz, 2006). The interest of the constructivist is how and why individuals construct meaning and actions in particular circumstances (Mills, Bonner, & Francis, 2006). We are all constructivist (Schwandt, 2007). Humans construct their reality in order to make sense of experiences, and continuously adapt this reality as new experiences arise (Wallace & Wolf, 1999). This study utilized one-on-one interviews to elicit the stories of older African American women diagnosed with HIV at the age of 50 or older and their processes involved in making meaning of and managing a HIV/AIDS diagnosis.

Sampling

African American women diagnosed or infected with HIV age 50 or older and residing in California were purposively sampled. Adults aged 50 or older are not characteristically

considered elderly (Nguyen & Holodniy, 2008); however, they are considered as older if suffering from the chronicity of HIV/AIDS (CDC, 2006). The 50 and older cut-off is also used by the CDC in statistical reporting on HIV-infected older adults (Nguyen & Holodniy, 2008). The rationale for engaging this sample for this study is based on published statistics. According to the Los Angeles County division of HIV and STD programs (DHSP), persons aged 50 years and older represent 13% of the new HIV infections in 2011 (DHSP, 2014). Among persons living with HIV, those aged 40 years and older comprise 75% of cases; 13% of which are aged 60 years or older. Also, the proportion of AIDS cases diagnosed at age 50 years or older increased from 11% in 1995 to 21% in 2010. Lastly, among women, 38% of the newly diagnosed women were African American/Black (DHSP, 2014). Aside from the statistics, African American women age 50 and older were purposively sampled for this study because they had insight into this phenomenon of interest.

Purposeful sampling. In grounded theory, there is not a sample size requirement (Charmaz, 2006). However, various grounded theorists have offered recommendations for when saturation is typically met (Bertaux, 1981; Charmaz, 2006; Creswell, 2003). According to Creswell, 20-30 subjects are recommended for a grounded theory study (Creswell, 2003). Charmaz posits that 25 participants is adequate for a small grounded theory study (Charmaz, 2006). Finally, Bertaux, recommends a minimum of 15 subjects in a qualitative study regardless of methodology (Bertaux, 1981). Saturation was reached after interviewing 16 African American women.

Theoretical sampling. After the first interview was conducted, theoretical sampling was used. Theoretical sampling, a type of grounded theory sampling driven by gaps in properties and dimensions of a category, was used to recruit additional participants, as needed (Auerbach &

Silverstein, 2003). As categories surrounding the experiences of older HIV positive African American women developed, and gaps in the categories were identified, additional participants were recruited who could help build and give depth to the categories of the emerging theory. Once all of the categories of interest were thoroughly described, theoretical saturation was achieved. (Charmaz, 2006).

Eligibility criteria. To be eligible for this study, individuals must have met the following inclusion criteria: documented as being HIV positive based on a diagnosis form (an official document which denotes the individuals official date of HIV diagnosis and recent HIV-related laboratory results) from the participants HIV clinic or HIV provider; diagnosed or infected with HIV at the age of 50 or older; female; and able to read and write in English. The above eligibility criteria were used in order to ensure the recruitment of women who could articulate stories of receiving an HIV diagnosis at age 50 and older.

Recruitment site. Purposive sampling was used to recruit women for this study. After the initial recruitment of participants, each woman was asked to recommend other older women they know with similar or different stories to participate in the study. Women diagnosed with HIV at the age of 50 or older were recruited from an array of community-based health and social organizations, support groups, advocacy groups and drug treatment centers Los Angeles County Service Planning Areas (SPAs) 4, 6 and 8. The highest rate for HIV diagnosis in 2010 was reported among persons in SPAs 4, 6 and 8; more specifically, 62 per 100,000, in SPA 4 (Metro), 25 per 100,000 in SPA 6 (South), and 21 per 100,000 in SPA 8 (South Bay). In 2011, SPA 4, 6, and 8 also had the highest rates of newly diagnosed women, blacks, and persons 50 and older. The rates for women aged 50 and older ranged from 9-20 per 100,000.

Recruitment procedures. Institutional Review Board (IRB)-approved fliers succinctly describing the research study were given to selected agencies for posting (Appendix A). Relationships with prominent HIV clinics throughout California were established. The researcher used the Los Angeles, San Diego and San Francisco County's HIV directories to find clinics and healthcare systems. Once the HIV clinics were identified, the researcher set up meetings with the head HIV/AIDS provider, medical director or case manager. All agencies and organizations were briefed on the target population of interest and the purpose of the research study. A discussion was held about the racial, gender and age demographics of their center. In addition, their openness to allowing the researcher to post flyers about the study was discussed. The clinical and auxiliary staff were asked to refer potential participants to the study's flyer if they found women who would be good candidates for the study. Each potential participant was screened for eligibility to be in the research study by the PI over the phone (See Appendix B).

During the eligibility screening process, the PI described the purpose of the study, the expectations for research participants, methods to ensure participant confidentiality and privacy, and the voluntary nature of the study. In addition, the risk and benefits of the study were discussed with each potential participant. Once an eligible woman was identified, and verbally consented to participate in the study, meeting place and time for the interview were chosen. The PI administered a written consent form to the participant on the day of the interview date. Two copies of the consent form were completed, including a copy for the participant and the PI.

Incentive. An honorarium (incentive) of \$30.00 was provided to each participant at the conclusion of the interview. Also, at the conclusion of several interviews, as several participants requested results of the study, the PI sought permission from the IRB to distribute study results to the consenting participants. After acquiring permission from the IRB, a contact information

sheet (a document containing the participants phone number, e-mail address and/or home address) was collected from each participant, as well as, verbal consent for re-contact.

Semi Structured Interview/ Guide

The interview guide was developed through a qualitative course and a comprehensive review of the current HIV/AIDS literature on older adults, women, and African American women living with HIV. Open-ended, non-leading questions and probes were utilized in this interview guide as follows:

1. Perceptions of HIV before the HIV diagnosis
2. Learning about an HIV diagnosis for the first time
3. The effect HIV has had on the woman and her family/friends
4. What HIV means to the woman and their friends/family
5. Coping processes, social factors, and personal resources utilized before and after diagnosis
6. Interactions with the healthcare system after diagnosis

Qualitative Data Collection Procedure

A semi-structured interview guide was used to facilitate data collection for this study (See Appendix C). The topic of experiencing an HIV diagnosis at the age of 50 or older was the focus of the interview guide. Utilizing a semi-structured interview allowed the PI an opportunity to ask pre-set topic-specific questions, and also adapt follow-up questions to the participants' individual stories (Rubin & Rubin, 2011). As the categories developed, the guide became more focused on category description. A hand held audio-recorder, paper and pen was used to record the participants' responses to the interview questions.

Data collection took approximately 30 to 90 minutes. All participants engaged in one face-to-face interview. The interviews took place in a safe location that was agreed upon by the

PI and the participant such as, their home or a park. The participants were consented to the study, asked to complete a brief demographic form and present an updated HIV diagnosis form to the PI.

Socio-demographic Data Collection Procedure

Socio-demographic data pertinent to the study was collected from each participant and took approximately five minutes to complete. The questionnaire included: current age, diagnosis month and year, employment status, income level, educational level, religion, health insurance, CD4 count, viral load count, and current relationship status.

Approaching the Research from an Insider-Outsider Position

During the researcher's data collection phase, the PI encountered varying interactions with the participants. These interactions played an important role in establishing a rapport with the participants. The following section will describe the PI's unique journey in establishing trust and gaining entry into the women's lives.

All of the women contacted the PI via phone. During the pre-eligibility screening process, the PI began to notice a trend with the women contacting her. Most of the women, including all 16 participants interviewed, were very blunt and brash over the phone. Although the women agreed to participate in the study, when verifying details regarding the interview time and meeting place, several of the women appeared indifferent. Once arriving at the agreed upon interview meeting place, the women were very surprised to be greeted by the PI. Most of the women, 14 out of the 16 participants, bluntly admitted to believing the researcher would be "someone else." Later it was stated that "someone else" was a code for an "older white woman."

Throughout the interviews, the women's once cold demeanor on the phone turned warm and pleasant. The women would end the interview by walking the PI to her car in an attempt to

continue casual conversation. Other pleasantries would be exchanged and the PI and participant would part ways. It was not until the third interview that the PI began to notice this trend. It was at this moment, the PI realized that the women's perceptions of her and her membership in the "African American/Black" social group might have influenced their interactions.

An issue that arises in research is whether maintaining an "insider" or "outsider" status within the group being studied is helpful or detrimental to a study (Corbin Dwyer & Buckle, 2009). This relationship plays a key role in the collection of data and its analysis (Corbin Dwyer & Buckle, 2009). Some claim that maintaining an "insider" position and being closely linked to the field of study or social group can assist in creating genuine accounts of the phenomenon (Allen, 2004; Greene et al., 2013). However, others believe maintaining an "outsider" stance mitigates the potential for bias (Allen, 2004). In the case of this study, occupying an "insider" position may have facilitated relationships with the participants; whereas the "outsider" position could have evoked skepticism.

Before the participants would meet the PI, they believed she occupied an "outsider" position. Due to the PI's name, speech and UCLA affiliation, she was believed to be an "outsider." During the pre-eligibility screening process and before the interview, the women asked the PI various questions in order to gauge their willingness to continue with the interview or not. The following are several examples of questions: "what type of car do you drive; does it have anything about HIV on it?" "Are you Black?" "Why are you doing this study?"

Upon meeting the women, the participants described why they asked the researcher the above series of questions. The questions served as a means to protect themselves from harm and ensure the person coming to interview them would not alert their neighbors or community to their HIV diagnosis. Possible alerts included: driving a car with an AIDS service organizations

(ASO) logo on it or dressing in a manner that was atypical of their neighbors. Several of the women believed the PI could pass as a visiting granddaughter. One participant stated, “my neighbors are nosy... they are always wondering who is coming and going...with that book bag you look like you could pass for my granddaughter.”

One woman described how she received death threats once her community learned she was HIV positive. Another woman was forced to move from an apartment she lived in for 7 years once her landlord discovered she was HIV positive. The women conveyed if an “old white woman” were to arrive at their home or be seen walking with them, suspicion could be raised. This suspicion could lead to additional threats or stigma.

After the women met the PI and “ice breaker” discussions took place, the women disclosed their preconceived ideas of the PI. Once the participants were able to situate the PI in an “insider” position, she received a warm welcoming and was privy to rich data. Even as the interviews unfolded, the participants would show pictures of their grandchildren to the PI and state, “You remind me so much of my granddaughter” or offer words of encouragement to complete this study. For this study occupying an “insider” position facilitated rich discussions and assisted in building rapport. However, it is unclear if maintaining a different social group, such as someone of another race, gender, or age, could have influenced the interactions.

Data Analysis Procedure

Qualitative Study Data Analysis Procedure

Grounded theory is a methodology developed to assist in the construction of a theory about matters of importance in humans lives (Glaser & Strauss, 2009). As matters of importance to the participants were identified, the researcher then began data analysis (Crabtree & Miller, 1999). A continuous process of constant comparisons commenced until a story grounded in the

voices of the participants was evoked (Charmaz, 2006). It was important for the researcher to be reflexive as she collected and analyzed the data in order to be honest about biases and hunches (Charmaz, 2006).

Constructivists take a reflexive position toward the research process and the products of the research study (Charmaz, 2006). Both the participants and researchers interpret meanings and actions (Mills et al., 2006). The interpretation is situated in the time, place, culture and event. What the researcher sees and does not see in an analysis is a result of their values; therefore, constructivist must attempt to make themselves aware of their assumption and how it may affect the research (Charmaz, 2006). Being reflexive allows constructivist researchers to “come clean” about their predispositions (Guba, 1990). For this study, field notes, memos, codes, and analytic tools such as diagramming were used to form categories related to the experience of African American women diagnosed with HIV/AIDS at age 50 and older. Due to previous clinical work with patients living with HIV and societal stigma and beliefs regarding persons living with HIV/AIDS, it was important that the researcher wrote reflexive memos about preconceived beliefs that could be imposed on data collection and analysis.

Field notes

Data analysis began after the first interview (Rubin & Rubin, 2011). Once the interviews were conducted, field notes were written (Creswell, 2003). Field notes served as a shorthand, written re-enactment of events, observations and conversations that took place before, during, and after the interview (Van Maanen, 1988). The data that made its way into the field notes were subjective and varied based on the particular research context (Wolfinger, 2002). The field notes included mental notes and scratch notes taken while in the field (Thorpe & Holt, 2007). These highlights were further developed upon in various memos. A field note template developed and

adapted by the researcher in qualitative research seminars was used. The researcher wrote field notes promptly after each interview; this was essential to remembering specific details of an encounter with participants (Thorpe & Holt, 2007). Coding interviews was another way to remind the researcher of significant events that took place during the interview.

Coding

After the interview was conducted, it was thoroughly read and coded. Coding is the labeling of segments of an interview into concise terms (Charmaz, 2006). Gerunds, the conversion of nouns to actions by adding the suffix “ing”, were used to create the codes. When a participant’s voice is muffled by professional language, the resulting theory will be based in the narrative of the researcher and not the participants (Charmaz, 2006). Gerunds assisted in bringing the participants’ actions to the forefront of the analysis (Silverman, 2010).

Another method used to preserve the participants’ description of their experiences was utilizing in-vivo codes. In-vivo codes are special terms or phrases quoted from the participant (Corbin & Strauss, 2008). These codes captured the unique meanings behind the participants’ experiences.

The researcher used a Microsoft Word coding chart, created and adapted in her qualitative research courses, which included sections for codes created by the researcher, line numbers, and interview text. For each transcribed interview, the researcher copied, pasted and organized the text in the columns of “codes,” “line number,” and “transcription.” Grounded theory coding consists of both initial and focused coding (Marvasti, 2004).

Initial coding. Initial coding required the researcher to study, line by line, fragments of the data and name each line in succinct language (Charmaz, 2006). Line-by-line coding also allowed the researcher to remain open to nuances in the data. These nuances sparked new ideas

for the researcher to explore. Once initial coding was completed, focused coding began. Using the Microsoft Word coding template, the researcher read the adapted transcript, and added various codes that captured what the participants were communicating.

Focused coding. Focused codes captured important clues to “what is happening here” throughout the interviews (Charmaz, 2006). The researcher synthesized and explored larger segments of data, using the coding template. Based on the synthesis of the larger segments of data, a new code describing the segment was created. The most frequently occurring and significant initial codes were selected in order to facilitate the analytic process (Corbin & Strauss, 2008). Once the focused codes were identified, categories and subcategories were identified and labeled through axial coding.

Axial coding. Axial coding allowed the researcher to identify the properties and dimensions of several categories (Corbin & Strauss, 2008). The researcher created the axial codes through the synthesis and organization of earlier codes (Creswell, 2003). From these categories, subcategories were identified (Glaser & Strauss, 2009). Lastly, theoretical coding was used to validate the formed categories and assist in identifying relationships between categories (Morse et al., 2009). As codes and categories emerged, memo-writing aided in the theory development.

Memos

Memos allow the researcher to stop and analyze ideas about codes as the ideas emerge (Charmaz, 2006). Memos were used in this study to capture the researcher’s thoughts, capture comparisons and connections made, and develop questions and future directions for the data (Charmaz, 2006). Memos provided a space for the researcher to dynamically engage with the

data (Corbin & Strauss, 2008). From the beginning of the study to the end, memos guided the researcher's analysis. Another strategy that was used in data analysis was analytic tools.

Analytic Tools

Analytic tools are techniques used by researchers to facilitate a study's data analysis process (Clarke, 2005). Analysis involves taking coded data and raising it to a conceptual level. Each researcher has a set of tools that allow him or her to better understand their data set (Clarke, 2005). Several analytic tools that were used to facilitate the development of this study's categories were diagramming and constant comparison.

Diagramming. The first analytic strategy used in this study was situational mapping. This strategy assisted the researcher in articulating various human and nonhuman elements present in the data and exploring the relationships between them (Corbin & Strauss, 2008). Several examples of human elements found within the data included: support groups; gay men; children and boyfriend. In comparison, several examples of nonhuman elements included HIV medication and the healthcare system. These maps captured the intricacies of the various elements in the phenomenon (Corbin & Strauss, 2008).

Constant comparison. Secondly, the analytic tool of "making comparisons" was used. There are two types of comparison-making strategies, constant and theoretical (Clarke, 2005). The constant comparison strategy allowed the researcher to compare incidents with incidents in order to classify data and identify similarities and differences (Corbin & Strauss, 2008). The theoretical comparison strategy assisted the researcher in uncovering various properties and dimensions of a category. Both of these tools assisted the researcher in identifying and exploring possible perspective shifts and the acceptance of taken for granted perspectives (Corbin & Strauss, 2008). The combination of fieldnotes, memos, and analytic tools assisted in generating

this situation-specific theory of the lives of older African American women diagnosed with HIV at age 50 and older in California. Nvivo computer software was used to organize codes and quotes discovered throughout the data collection process.

Socio-demographic Data Analysis Plan

Sociodemographic data from the study participants was entered into a Microsoft Windows Excel spreadsheet and set up for data analysis. Descriptive statistics were run in order to underline and describe the participants' unique characteristics.

Ethical Conduct of Study

All participants were consented to the study. Participation in this study was strictly voluntary and participants could withdraw from the study at any time. Also, participation in this study did not subject participants to any physical risk, pain or emotional distress that required a counseling referral. To conclude each interview, the researcher answered any questions the participant had.

Information that was obtained in connection with this study will remain confidential. The recorded interviews and questionnaires were obtained confidentially, recorded confidentially and made anonymous during transcription. All recorded interviews were transcribed within a month of interview and later destroyed. Identifiable information, such as people, schools, and towns were replaced by pseudonyms. All confidential study data was locked in a secure place. Only the primary investigator had access to the study data.

Ensuring a Rigorous Study

In constructivist grounded theory an interpretive position is taken (Charmaz, 2006). The world is considered subjective and individuals' reality is socially constructed (Charon, 2010). In taking an interpretive position, the question of how a researcher can ensure the study's rigor and

quality arises (Lincoln & Guba, 2005). Qualitative research cannot be evaluated based on positivist notions of validity, because this worldview is incommensurable with the interpretive worldview (Lincoln & Guba, 2005). Instead, rigor can be established by ensuring confirmability, auditability, and authenticity.

Confirmability. Ensuring confirmability was the first step to ensure the quality of this study. Confirmability assisted in making sure the phenomenon being researched was represented clearly and not based on the beliefs or biases of the researcher (Gasson, 2004). Unlike positivist scientist who strive to maintain objectivity in a research study, interpretive social scientists recognize research findings will be influenced by the researchers own values and outlook (Mallalieu, 2002). The selection of significant data used in the theory emerged from an inductive process originating within the researcher and logically derived from participants' reported experiences. The researchers' outside experiences, knowledge, and biases played a role in influencing how the theory was formed. The researcher explored and acknowledged these biases and was reflexive through memo-writing (Charmaz, 2006). Extensive use of participants' quotes was used to confirm the categories and explanatory framework. Thusly, the categories emerged logically from the participants' experiences and were not solely based on the researchers interpretation. The second method used to enhance the rigor of this qualitative study was maintaining auditability.

Auditability. An interpretivist researcher cannot guarantee the reproduction of study findings (Gasson, 2004). Two sets of researchers can analyze the same data set and arrive at different conclusions based on their social construction of reality. In order to ensure the dependability of the research findings, the explicit process through which study findings were rendered is detailed. The data collection and data analysis procedures were described in detail, in

a matter that others can understand. This process leaves an "audit trail" of how the researcher arrived at the study's conclusions. By keeping a research journal and memoing throughout the data collection and analysis process, a seamless account of the research process is presented (Gasson, 2004). The researcher used the audit trail to note analytic decisions related to developing the grounded theory. The audit trail was also used to keep a record of conceptual maps, memos, field notes, coding and others notes that supported the creation of concepts. Lastly, the PI maintained the authenticity of the study in order to ensure its quality.

Authenticity. In order to demonstrate the authenticity of a constructed theory, all of the constructed concepts must be presented in a cohesive manner (Gasson, 2004). To accomplish this, the findings of the study were presented in a framework, with adequate details, to allow the reader to capture a holistic view of the participants' experiences with the phenomena. The author provided details on how data saturation was met. In addition, the process of collecting data from new informants, new sites, or new situations that are comparable to previous phenomenon is detailed. The researcher was as transparent as possible with the reader about the selection, collection and analysis of data that lead to the creation of the theory.

Summary

A constructivist grounded theory methodology guided the exploration of this research study. Grounded theory has the ability to examine social processes and human behavior in a social context (Munhall, 2010). In addition, grounded theory has been found useful for the examination of areas that are understudied. With the guidance of 16 older African American women diagnosed with HIV at age 50 or older, this study offers clear themes and a description of these older women's lived experience with HIV/AIDS.

CHAPTER FIVE

Results

The purpose of this constructivist grounded theory study was to generate a substantive theory that describes and explains the experiences of women diagnosed at the age of 50 and older with HIV/AIDS. The specific aims were to: explore the women's perceptions of HIV risk prior to their diagnosis; explore their interactions with their social networks before and after receiving the HIV/AIDS diagnosis; describe the women's experiences in navigating the healthcare system throughout their HIV trajectory (the path taken from pre-diagnosis to present day); and generate a theoretical framework of the processes involved in making meaning of and managing a HIV/AIDS diagnosis. The first section of this chapter describes the participants' socio-demographic characteristics (Table 1.1; Table 1.2). The second section presents the data representing the perspectives of the women.

Socio-demographic Characteristics

Of the 107 potential participants who were screened, 16 were eligible and enrolled. Over 90% of the women were not eligible because they were diagnosed with HIV/AIDS earlier than the age of 50. Many of the ineligible women were first diagnosed in their 20's and 30's. Women learned about the study primarily through their primary healthcare provider (88%) and snowball sampling (12%). The interviews took place in either the participant's home (81%) or a local park (19%).

The age of the women interviewed ranged from 54-71 years. The average age of HIV diagnosis was 55, and the average years living with HIV was 8 years. The educational level ranged from some high school to completion of 4-year college. The average income for 15 of the women was less than \$15,000/year and only one reported an average income between \$15,001-

\$30,000 per year. Fifteen women reported being currently unemployed and one was employed. Relationship status characteristics were as follows: 11 women reported being single, one was married, two were divorced, one was widowed and four were dating.

All women reported having health insurance, 82% had Medi-Cal/Medicaid, 13% belonged to HMOs, and 25% had Medicare. All of the women reported having children and maintaining a religious affiliation. Of special note, two core HIV measures, HIV viral load and CD4 count were collected from a HIV diagnosis form. Ninety-four percent of the women had an undetectable viral load. A viral load test was also used to monitor HIV infection over time. An undetectable viral load is between 40 to 75 copies. The second measure, a CD4 count, provides an illustration of how an individual's immune system is working. An average healthy adult's CD4 count ranges from 500 cells/mm³ to 1,200 cells/mm³ and a very low CD4 count is <200 cell/mm³ (an AIDS diagnosis). For this sample of women, the average CD4 count ranged from 222-1365 cells/mm³ (an average of 639 cells/mm³).

Repurposing a Legacy

For this group of HIV-infected older African American women diagnosed with HIV/AIDS at the age of 50 and older, the metaphor of "Repurposing a Legacy" is used to depict the end product of the participants' HIV trajectory. The word repurposing paints a picture of someone taking an item that is taken for granted and ridden with stigma, and utilizing strategies and tools to reinvigorate the item. In the "Repurposing a Legacy" Grounded Theory (Figure 1.1), the theory starts with the category of "Lack of Perception of HIV Risk." This perception of risk was impacted by the subcategories of Upbringing, Healthcare Providers and the Media. This lack of perceptions of HIV risk led to delayed HIV testing. After being tested and diagnosed with HIV/AIDS, the women began to "Find and Create a New Identity". The subcategories of this

category included Reaching a Turning Point, Learning Lessons and Reconciling the Past and Present. The following section will describe the various categories and subcategories that emerged from the data and will describe how these categories led the women to repurpose their legacies.

Lack of Perception of HIV Risk

Perception is defined as the act of apprehending by means of the senses or of the mind, cognition, an understanding (Dictionary.com). The category of lack of perception of HIV risk also describes the symbolic meanings the women ascribed to HIV/AIDS. The participant's "upbringing," media images, religious households, health advocates and past well-woman's visits influenced perceptions. Questions that arose for researcher were: What did these women know about HIV; are the images/depictions of HIV/AIDS relevant to these women; and how did perceptions of risk impact their timely testing and diagnosis?

These perceptions of risk led to late HIV diagnoses. Most of the women did not voluntarily seek out an HIV test. Various institutional buffers/safety nets were able to "catch" these women's HIV infection. Examples of the various buffers included hospitals, clinics, jails and drug treatment programs. Although the health care providers were ultimately able to discover the women's HIV status, the providers were initially stumped by the array of symptoms the women presented. Headaches, being tired, persistent flu-like symptoms, a cold that would not go away, and recurrent yeast infections were all symptoms cited by the women. When reflecting on the time period prior to their diagnosis, the women recalled these symptoms and they recalled visiting various healthcare practitioners. So, why were these women not tested? The women described textbook symptoms of a potential HIV infection. Was it because of their age? Did they not fit the profile?

What does the typical person living with HIV/AIDS look like? Are there any specific characteristics that can be attributed to a person at risk for contracting HIV? When the participants were asked to describe their perceptions of HIV risk, the women responded with various perceptions of not only HIV risk, but also perceptions of sexual health. The media, their upbringing and discussions surrounding sexual health all influenced the women's perception of HIV risk.

Influence of Media and Images

Media such as radio, television, newspapers, and magazines is a means of communication. Media has the potential to reach and/or influence large numbers of individuals at any given time. Throughout the HIV trajectory of the participants, media played a considerable role in influencing their HIV risk perceptions.

The images, surrounding HIV/AIDS, seen by the older African American women varied greatly. The women described media outlets that depicted celebrities, individuals from various sexual orientations and persons living across the world who were infected with HIV. What the women did not see was media images that represented them. Even when one of the participants described seeing images of "Black people" in the media living with HIV, she categorized this account as being "global" and affecting individuals "in Africa." However, the media accounts seen domestically only included images of celebrities and gay white men. One participant stated,

It's the first thing that came to my mind, you know, was gay white people.

Through the vine, you know...and then when they said global, Africa and black people. Man that's scary. Yeah so, that's the only people that I know [who] had it... I could think of ... Ashe and Magic.

All participants described similar perceptions of the typical HIV media icon. Gay men were the most prominent image. The older women described gay men as being a part of a particular “lifestyle.” This lifestyle involved having sex with various male partners and occasionally involved drug use. When asked to describe her perceptions of HIV prior to her diagnosis, one woman stated:

What did I think about it? That it was for just gay men. Gay men...Gay, homosexuals. But not straight people. Or drug addicts. Drug addicts, but more homosexuals. Because that's what they [were] pictured as,...they showed gay men, so that's all I thought it was.

The media helped to imprint an image of gay men as the primary recipients of HIV. As long as the participants only engaged in sexual acts with heterosexual men, they did not think they needed to worry about HIV. One woman stated,

Before I was diagnosed, I used to hear about AIDS, I never heard HIV. I heard people talk like it was a gay disease. Women didn't know. I just heard all men would get this disease. Until, I contracted it. And then I said “oh now wait a minute.” I am not GAY, so how in the world did I get this?

The belief that HIV was reserved primarily for gay men continued to be a recurrent theme of the perception of HIV risk category. Even when describing celebrities who were known to be HIV positive, the women suggested the celebrity might have secretly engaged in sex with men (on the down low). One woman described the first time she heard about HIV/AIDS:

The first time I heard about it, it was in college. I knew it was called AIDS. And lot of white people [had it]. And then...what's that tennis player's name...Arthur Ashe died with it. And that was interesting. We thought he was gay and we didn't

know... but he was married. You never know though. And as I go through life learning this stuff, maybe he was on the down low. But I don't know. He died of it then Easy E. And then boom, Magic came on TV and he had it. I would say "he shouldn't be out there playing with them guys." But see I didn't know nothing about it [then].

In the mid 1980's, the HIV status of public figures became public knowledge; beginning in 1985 with Rock Hudson and leading into the early 1990's with African American celebrities such as Magic Johnson (professional basketball player), Arthur Ashe (professional tennis player) and Easy E (musician). These celebrities also brought awareness to two additional HIV risk factors, unprotected sex between heterosexual partners and blood transfusions. The news stories reported on these public figures were the first time many of the women heard about HIV/AIDS.

Anna, 71-year-old, described her first encounters with HIV/AIDS:

Oh, I know Arthur Ashe who was a tennis player. Rock Hudson was an actor. And I was watching all the Rock Hudson stuff. I like to watch Tennis on TV. And all of a sudden, I hear Rock Hudson dies from it. So I said, oh, that's the disease they were talking about. Then I hear Arthur Ashe died from it too. I was young and I'd heard about this. But it was briefly. It wasn't where you could go to the computer or a magazine and read about this.

After being diagnosed, another participant, Heather, 69-year-old, could not figure out how she might have contracted HIV. She was able to think back to media stories on Arthur Ashe and was able to compare herself to this public figure. Heather stated,

So, I'm a recipient of HIV, um like Arthur Ashe. You know he had his HIV from a blood transfusion. Did you know that? His [got this] from a blood transfusion...yeah...it was from a blood transfusion...

Though well-known public figures like Arthur Ashe and Magic Johnson were known to have lived and one was living with HIV, several women could not relate to these figures and believed there was a lack of images and messages tailored to older women. One participant, 59-year-old stated,

There was nothing for older women. They showed faces that were young. Young faces. I couldn't relate to Magic...how am I going to relate to him? He's a rich man and to me, it was like okay you [are] rich, he can afford his medicine. Messages like, "you can live with HIV." Okay, I can live with it, but it didn't have [someone]... that looked like me. It didn't have [someone]... in [their] forties or fifties. I can't relate...Okay, you're twenty years old. You have different challenges than I do.

A lack of messages geared toward older women affected the participant's perceptions of risk. Though all of the women admitted to hearing about HIV/AIDS prior to their diagnosis, the lack of relevant media outlets prevented them from taking their potential risk seriously. As suggested above by one participant, the inclusion of older women in various media campaigns and messages could have helped shed light on the growing number of older women becoming infected with HIV. Another form of messaging described by the women was messages from their parents.

“Upbringing”

“Upbringing” refers to the women’s childhood and lessons they learned from authority figures, such as their parents. Several women described messages relayed by their parents that helped shape their perceptions of HIV risk. Candice, 59-year-old who was infected with HIV by her first husband, stated:

My first one went to the penitentiary system... To be honest, I was stupid with the first one. I was very naïve, preacher’s daughter, didn’t know nothing. I didn’t know anything. I was taught to be the wife, the mother. You do whatever your husband says. You never leave your husband. And the church said, if he hit you, you still stay.

Candice’s husband contracted HIV while serving a prison sentence. For Candice, messages from her parents reinforced the need to be a good wife, and subsequently led her to ignore her HIV risk factor. For Candice, her risk factor was having unprotected sex with her husband who engaged in unprotected sex with men in prison.

When another participant was asked to describe sexual health conversations she may have had in the past, Joni, 61-year-old, stated,

Really none. Maybe, I don’t even remember talking about it in school, in health class. Maybe a little bit and that was maybe eighth or ninth grade and I really wasn’t paying attention or any of that type of stuff. Other than that, no. Really there was no discussion about sex. As I was growing up, it just happened.

Another woman, Belle, 70-year-old, stated,

Yes, my mother would always... you know... We were minsters kids. She would said "oh alright, you know, you not suppose to be out there sexualizing with everybody; and keep your legs closed. Panties up.” And all that. [laughs]. She

would always talk to me and say you be healthy and keep yourself clean and don't do anything you are not suppose to.

For this woman, sexual health conversations were centered on staying “clean” and “healthy.” As the interview continued with Belle, it was clear that the messages provided to her as a child, molded her perceptions of HIV risk. When asked “what did you know about your risk for HIV,”

Belle stated,

Nothing, I really didn't think that unless you were a person that associated yourself with a lot of men, and you know...because we hear about gonorrhea and syphilis, and I thought by being promiscuous that [would] cause a lot of diseases and that's how I thought maybe this diseases or sickness was contacted. So I was very selective, I would never indulge with many, many men. If I ... had my husband... even after we separated and [went] through the divorce, I never had anything with anybody. I just... I just left it alone. I just didn't want to be bothered and there was a lot of offers and I said nope, I can't take that chance, I don't want to ...

For Belle, abstaining from having multiple sexual partners, as instructed by her mother, was thought to safeguard her from contracting STDs.

As these women aged, the sexual health messages from childhood stuck with them. These messages led the women to believe they were not at risk for contracting HIV; thus, making getting tested for HIV unlikely. The following will discuss the women's primary entry into HIV testing.

Initiation of HIV Testing

As women detailed their HIV trajectories, a common underlying story shared by women was their entry into HIV testing. All of the women described not perceiving themselves to be at risk for HIV. Also, all of the women, except for one, reported being tested at the suggestion of someone else. Darlene was motivated to take an HIV test by suggestion of her boyfriend. After feeling very sick for over a year, Darlene, a 55 year-old, decided to break-up with her boyfriend to focus on getting better. In response to the break-up, the boyfriend told her she should be tested for HIV. Darlene stated,

I told him I didn't want to see him anymore. And that's when he told me. He said, "well you better go get checked for it." I said what? He said "you better go get checked because I got uh, HIV, and I think you gave it to me." I said huh? "You must have got it from your husband." I said my husband, and I was thinking wait a minute. Did I get it from him?

Darlene later found out it was not her husband, but the current boyfriend who infected her with the virus. The boyfriend was aware of his HIV status seven years prior to meeting Darlene. If the boyfriend had not suggested she take a HIV test, Darlene, would not have been tested.

Although she didn't perceive herself to be at risk for HIV, Olivia, 54-year-old, she was the only woman to request an HIV test herself. She was open to being tested for HIV, because she became somewhat of an HIV advocate after caring for a brother who lived with HIV. Unfortunately, for Olivia, her primary healthcare provider refused to test her for HIV even though she was willing. Olivia stated,

I had a brother that was gay and he had HIV... so I didn't mind getting tested... I didn't think I had a risk, because I was married and I was with that person for 15 plus years. I didn't even think about me catching it because I knew I was okay. I

was at home. I was with one person. It never crossed my mind... It was like I was going in there not even nervous [about HIV testing] because I'm like I'm not doing nothing... and he's not doing nothing. We okay. You know. But I am just going to get tested.

Olivia asked her health provider about an HIV test. And the provider told her she was not at risk and could not be tested. Olivia explained:

They would tell me no, at first. And then umm... after the blood transfusion, I told them that I was at risk. That I needed to be tested. It was like seriously on my heart to be tested. Because they kept saying no, you need to be at risk and I didn't understand that at first. Like why they won't you test me? And my doctor, kept telling me no... and they don't pay... Medi-cal doesn't pay for you to just get tested. You had to say you were at risk or a drug addict or something like that. You were a gay male or messing with a gay in order to get tested. You had to say you were at risk for catching it. But when I told him I was at risk, he was like... well if you were at risk you can be tested. And that's when I was tested.

For Olivia, her healthcare providers' perceptions contributed to her late HIV diagnosis. If she were not an HIV advocate, she would not have challenged the healthcare provider to test her.

Women involved in drug treatment programs were also motivated by others to be tested for HIV. Faith, a 57-year-old woman, was tested while in a drug treatment program, in a jail.

Faith stated,

That time, I wasn't uh, I was on drugs. So I didn't, um, really think about it much. But I guess I really didn't think that it would happen to me. I had been in a few programs, and I uh, I really wasn't knowledgeable...I guess I did become aware

of how you can transmit HIV but...I just didn't take care of myself. I went to jail. And they tested me. It could have been anytime. In those days I was prostituting so...

For Faith, being incarcerated led to her being tested. Due to her drug use and lack of perception of HIV risk, she would not have sought out an HIV test on her own. Hospitals and clinics were the most common place for the initiation of a HIV testing.

After becoming very ill, many of the women sought medical attention. During their hospital or clinic visits, one of their healthcare providers finally tested them for HIV. One woman stated,

First of all, I was misdiagnosed for a long time. I didn't know what it was, you know. The doctors were treating me...I don't understand how all they had to do was do a blood test, you know, and have the blood, I guess, test for certain things. If you got high blood pressure or whatever, glaucoma, and different things like that...I didn't know how stupid sometimes society can be and maybe doctors can... to a certain extent, not [to] catch it. I constantly had a cough you know. A cough turned into a cold, a cold turned into pneumonia. And from there you know, I'm in the hospital. And that's when they had figured it out.

Another woman stated,

I was ill. I thought I had the flu. I wanted to find out because it wasn't, it wasn't going away. It didn't go away. I stayed sick. Didn't have a good immune system. And that's what motivated me...And I'm not going to say that I really thought I was getting tested, because they said, "We're going to run tests." They didn't say what that meant...then they come back and tell you, you have it. I'm married, I'm

not supposed to get it [yells]. So I didn't think I had it...why should you catch it? I've been married for thirty-something years...what you doing getting it? I thought it was odd. Married folk don't get it. And you go to a clinic and they tell you, oh, you're married. My perception was different because you got to remember if you're a woman and a wife, they're not going to think of you as the high-risk category. You're married; you're not supposed to be that package. Even today it's harder to get tested if you're a wife or a husband, because they figure there's no underlining danger when it is a danger. And it was a danger because I was married to somebody who was gay and I didn't know it.

Both of these women entered the clinic setting hoping to learn why they were sick, only to leave the clinic setting with an HIV diagnosis. Of note, most of these women did not know they were being tested for HIV, and in conjunction with their lack of perceptions of HIV risk, the shock and dismay that ensued was palpable.

These pre-diagnosis perceptions were radically changed after their diagnosis. In their journey to repurposing their legacy, the women carried this newfound information and used it to educate others. The women did not perceive themselves to be at risk for HIV, but neither did the media or the healthcare system. Learning from this and educating others served as a way to give a new meaning to, repurpose their legacy.

Finding and Creating a New Identity

After learning of their HIV positive diagnosis, the women reacted to their diagnoses with shock. In grappling with their diagnoses, the women searched for individuals like themselves (fitting the same profile) living with HIV. In their search, all they could find were gay men and male celebrities, such as Arthur Ashe and Magic Johnson. The women could not relate to the

struggles of gay men or “wealthy” celebrities. The women could not see themselves in these public figures/images. In speaking of their shock, the women’s responses varied from “I’m going to die” to “I’m okay with it, just tell me what I need to get better.” After a short time, weeks or months, of situating themselves within the clinical setting and starting HIV treatment, the women begin to work on themselves. While working on themselves, they began to “tie up loose ends” and reevaluated their life’s purpose.

Turning Point

“Reaching a Turning Point” was a major subcategory of “Finding and Creating a New Identity”. A turning point was an event or a decision that elevated the woman from hopelessness and confusion to the point where she was able to “do what I got to do.” One woman, Georgina, 63-year-old, stated:

I checked myself in a drug program because I was sick and tired of being tired. I was tired of being sick and tired. So I said, it’s time for me to change my life. So when I go into this drug program... we have to go to the doctor. To find out I had HIV was maybe... it’s not a good thing, but to me it’s like been a blessing. Because now I take care of myself much better, you know. I’ve been clean off of drugs for the last five years. I do realize I am getting old, so I do try to take care of myself better, you know rest and stuff like that. But yeah, I didn’t give a darn back then. I didn’t go to doctors you know. Only doctors where I can go get some drugs... were the only doctors I saw.

For Georgina, her turning point involved being “sick and tired.” She was ready for a change in her life and took the first step. Although this first step resulted in her learning of an HIV diagnosis, Georgina was able to see her HIV diagnosis as another turning point in her life.

Similarly, for Faith, drug use was a catalyst to change. Faith, 57-year-old, stated,

Each time I would go into programs, I would learn each time a little bit more about the nature of the disease...but the disease is powerful...and I'm, a what-you-call, a real addict. I had the Dr. Jekyll, Mrs, Hyde personality when I'd take a hit [of crack] or a drink. But I thought [there was] some way that I could successfully pull it off, that I could maybe get up one day or one night and it would be okay. Each time I'd lose my apartment, I'd lose my car. I'd lose everything. I lose my family and friends. And that has happened over and over again for 30 years until the last time I literally saw myself dying. And a lot of pain. And I just prayed to God to help me and I started recycling. I recycled my way out of that. And uh, I started doing what was suggested, and I got help. And I've been clean and sober since.

After being diagnosed Faith began moving away from crack use to recycling.

Another woman described her turning point involving crack use. Anna stated,

We separated, my friend and I separated for two years. He wanted to live the bachelor life. Okay. We had moved [to] Masseyton. He wanted to relive the bachelor life. That's when I got on the crack. For two years. I got on the crack. I went downhill. So I had to be shocked back into reality again. Through HIV case managers, psychiatrists, food bank people, the doctor, triage nurses. All of these people worked with me cause I went down. I don't like it because I had to go on this crack [starts crying]. I was hurting so bad. What did I do? I'm thinking why he walked off. I wasn't good enough. So I started doing crack for two years.

For Anna, having the support from her HIV healthcare providers and other AIDS service organizations (ASO) assisted her in getting back on track.

While, the HIV healthcare providers and ASOs helped some women get on track; for others, the HIV diagnosis itself served as a turning point. One woman, Eva, 66-year-old, stated,

Girl...I did a lot of praying. A lot of talking to God. ... It's true because if I hadn't had HIV, I'd probably been dead. I think it saved my life because I was doing a bunch of stuff—drinking, drugging, beating people out [of] their money. I knew when everybody's paycheck came. Everybody, the city, the county. I knew everybody's paycheck... I had a job. I had two jobs. But it wasn't enough, you know, how you get to the point, it's not enough. So that's how I was living. It's not enough. In real life it was enough. And I told my brother, I said I'm just churched out. I'm not going no more. That's when I got it. The devil came in. I was on the Lord's side. I was cool. But once I left that church, then I got sick.

The realization that she was HIV positive made her want to change her behavior.

Another woman saw her HIV diagnosis as a moment of truth delivered from God. Kayla, a 58-year-old, woman stated,

And by me, finding out at this age, maybe that's the way God wanted me to wake up and realize what I was doing wrong. See what I'm saying. Maybe it's a wakeup call for me to stop... I want you to stop doing what you're doing now. Enough is enough, you know...because I was getting high 24/7. I was happy go lucky, carefree. I didn't give a hoot...I still didn't want to believe it and I was weighing the pros and cons. Continue using and kill myself faster or let this disease take me over. Dr. told me...if I really wanted to stop using crack and start

getting healthy, to start taking medication to subside the virus... I thought about it and I thought about it and I thought about it, but street drugs and these drugs can't go together. They don't mix.

Kayla had to weigh the pros and cons of moving away from her past behaviors and moving forward with her recovery and treatment.

Reconciling the Past and Present

Reconciling the past and present was defined as strategies the women used to restore equilibrium to their lives. Through reconciliation the women did not always reach closure, but all were able to identify things in their lives they wanted to change and improve. Several issues the women attempted to reconcile were: decisions to date or not; to remain with the same companion or not; disclose their diagnosis or not; and coming to terms with the past behaviors.

In reconciling whether to date or not, the women came to a crossroads and decided how they would live out the remainder of their later adulthood. Some of the women decided to continue to seek out companionship in men (new partners or long-term existing partners). One woman stated,

So, uh, I've dated but the intimacy, I have not been intimate, and I miss that a lot. But you know, if I had a choice, yes I would be growing old you know with an older person ...beside me. And even, even if it was just for companionship.

Other women decided to "swear off men," usually due to issues with disclosure or being betrayed in the past. For the women seeking companionship (10 out of the 16 women), several codes emerged including: "keeping a man happy;" "staying with a partner regardless of chaos;" "avoiding being alone;" and "taking care of someone."

Deciding to seek out companionship or maintain a relationship required the women to make sacrifices. One woman described sacrifices she had to make to keep her partner around.

Anna stated,

For a while, I had low self-esteem. Because I'm thinking, here you got HIV you got to kiss a lot of butt. I thought about that...wait a minute...I can't kiss my own...why should I kiss yours...okay? From there, I became stronger. Okay so now I can kinda get on with my life. But I'm dealing with this sick person. We had a reclining chair in the living room. That man slept in that reclining chair for one year and 6 months. Never got up to go to bed. He would go and halfway make it to the bathroom. And the rest of the way, he was doing what he needed to do.... So I had to watch all of this. I had to help in there. Clean him up. Sit him back down.

Mary, a 59-year-old woman experienced a similar situation in which she had to care for a partner. Mary's partner, Bob, for whom she was caring, was also the man who transmitted his HIV infection to her. Mary stated,

They finally said he had you know [AIDS]. So they kept saying if he can't put on a pound, he's out of here. So what I decided to do was, he wouldn't eat the hospital foodso I started being there every day to feed him. And that's what kept him here you know because [he was having]...the wasting syndrome. So that's what I have. I guess that's what he got. He looks horrible. He looks like he lost 200 pounds.

While grappling with her newly discovered HIV infection and caring for Bob, Bob's new boyfriend (and his friends) confronted her. An altercation took place at the apartment Mary

shared with Bob. Mary was in disbelief that her partner would not only cheat on her with a man, but also allow the man to terrorize her home. The police were called. As Mary recalled the incident, she stated,

When they were all in here doing all this and had the helicopters and all these police here, [Bob] wasn't here. He didn't come up in here with that. Once them people leave, my baby comes home. And just like the police be like where's Bob and I said he's standing out there laughing at ya'll. I've been with [Bob] 30 years. Just like I told the police, if [Bob] wanted me out, how come he ain't here? I told him, when I leave [Bob] he'll be 6 feet under. One of us will, and that's the only way I'm leaving him. Nigga you done gave me this shit and you think you're going somewhere? Shit. No.

Mary could not believe the man who infected her with the virus and the man she cared for could betray her and date another man. The betrayal felt by Mary echoed throughout the stories of many women. In Mary's case, after her partner betrayed her by infecting her with HIV and cheating on her with another man, she decided to stay with him.

Candice was also betrayed by her husband of 30 years, but after his passing, she was able to fall in love and marry again. Candice stated,

Well he had children...how would I put it...I really didn't understand it. I really...I figured out by then he was funny. I mean gay—I should say, and the lifestyle. But I also understood that he was torn. You've given me this disease. You don't have a regard. And you're expecting me to not hate you, but understand you like you are. I don't think I was ready to deal with who he was. I knew but I really wasn't. And I think it was more anger of you giving me this

disease. I've been married to you over thirty years. I have children by you... What right do you have to take my life. It was more of you taking my life I felt. So no, I did not have good bon bons and candy bars. It was more of a...you get sick now I got to take care of your behind and my behind. And to be very honest, back then it was either I take care of you or I kill your ass. Um...I married a second time, and I married somebody who is positive so...

Candice was only able to separate from her first husband after he passed away from AIDS-related complications. Even with the turmoil she experienced in her first marriage, she was still motivated to date again and find a life-long companion.

Other women saw betrayal as a reason to break up and remain single for the foreseeable future. Darlene stated,

I think it's stupid that I fell for somebody...but then again, he was really, really, really nice and clean. I mean unbelievably nice, sweet, caring. I trusted him so...I'm like wow. After all that time being married, 32 years, and then I breakup and then get this? I just still don't believe it. It's still hard to believe. I thought I found a guy after marriage and I'm going to be happy now. I was feeling good and everything, and then I get a disease. It's kind of like um...it's kind of like, I don't really have a ...my life is over as far as having a romantic relationship. And now I'm not even interested in getting into a relationship. I don't trust no man at all. I don't trust nothing they say. Nothing. After that one, he was so good, he should have an Academy Award for the performance he put [on]...he should be getting an Oscar for that performance, of being such a good person. So, I would never be able to trust another man again and what he says to me.

Darlene could not envision herself ever dating again. After she divorced her husband, she vowed to finally begin to live her life the way she wanted, with a man who truly loved her. After her HIV diagnosis and the betrayal by a partner, she gave up on that dream.

In addition to choosing not to date because of past betrayal, the women also offered several other reasons for not seeking companionship, including “enjoying life/finding oneself,” “issues with disclosure,” and “not wanting to date men living with HIV.”

In an attempt to restore stability to their lives, some of the women choose to remain single after learning of their HIV diagnosis. Being single was an opportunity for them to get back to enjoying life, rediscovering themselves, and eliminating “drama”; all of which would help them live out their life’s purpose. One woman stated,

I’m not going to do it [dating]. I ain’t thought about it one day. Shit, I’m better by myself. If I had some crazy man, I’d be super stressed out. I don’t want nobody to stress me out, I know how men are. They are stressful. My shoes...my clothes ain’t ironed. I ain’t gonna iron it. And I ain’t gonna run no bath water for you. And I ain’t going to fix you nothing to eat. I cook when I want to.

Another woman, Georgina, stated,

Uh, my significant other died about 6 years ago. And I’ve been celibate ever since. We were married for 35 years...I just like getting to know me. I mean... you know I would like to... but it’s not... I’m not looking you know. If it comes, it comes. If it doesn’t, it doesn’t. I’m not trying to go find me a man. And I don’t need a man to validate me, you see what I’m saying. I like doing this because I finally get to know me. I was under his thumb like...see what I’m saying. I didn’t know me. Now I’m trying to get to know me...

Although Georgina was open to finding a companion, she enjoyed being able to focus on the things she enjoyed doing.

Along with attempting to get to know oneself better after an HIV diagnosis, some women decided to abstain from dating out of fear of being stigmatized. The stigma surrounding HIV prevented these women from disclosing their HIV status. One woman stated,

I don't want to tell other people you know. I don't trust other people knowing because not everybody can deal with it you know. I asked one guy, "How do you feel about HIV?" "Oh....I don't want nobody cook, I don't want nobody..." I said oh, I can't tell you [about my HIV diagnosis]. See what I'm saying? That's why I just be by myself. I don't date, you know, and there's a lot of guys... at the clinic.

I don't want another [guy] that got AIDS and HIV like me. I like being by myself.

For this woman, disclosure was not the only roadblock to seeking out companionship; issues surrounding dating another individual who was positive also hindered her ability to date.

However, the men available to older woman living with HIV were limited. One woman stated, "We are like...men are scarce for us. At 50, you gotta screen em. At 50, you gotta watch out." So not only were there a limited number of men available to older women, but for women not interested in dating a man living with HIV, they settled with being single. Ivy, a 63-year-old

woman, stated,

I'm talking about isolation as far as dating. I don't go out and meet nobody [be]cause I don't want to have to tell them... or give them nothing... or they have something and give me something. I'm very picky. Because I'm positive, I really don't want to meet a positive guy. They have parties for us to go [to], I don't want [to]. Why would I want somebody as sick as me? But I shouldn't be that evil.

They say you're mean and selfish. But I'd rather stick with negative guys.

But...now I might have to get me a positive man, because I don't like to be by myself too long.

For Ivy, she had no interest in dating a man living with HIV. However, because she disliked "being alone," she was coming to terms with possibly having to date a man who was HIV positive.

When envisioning their "golden years," the women imagined having a partner by their side with whom to share meaningful moments. The lack of available men and past betrayals derailed these plans. On the road to repurposing ones legacy, the women also grappled with coming to terms with other past events.

In coming to terms with their lives post diagnoses, many women went on a journey to reach a state of equilibrium. Leah, a 59-year-old woman stated,

Back to the grid and just trying to do better and pick up where I left off you know, back with my family you know. Trying to get it together and that's kind of where I am. I'm okay now. I mean it's only been what, what 3 years. But um, I'm still here for now. Of course I have this sickness, I have those ups and downs you know, when you get a cold it feels like you have pneumonia. But I'm still here you know. My kids are doing good. They're getting back up on their feet because they had fell too you know. When I fell they fell. I was on a journey.

After having to grapple with her diagnosis and the affects it had on her children and her life, Leah was able to arrive at a place where she was "okay."

Faith also described her journey to stability. Faith stated,

I'm in school. I go to Roma College just during the spring and in the fall. And uh, it was really hard for me at first, you know, because I had been on the streets and homeless on skid row. And my brain [was] practically gone from all the drug use... And it took me a while to get in the habit of exercising my brain and putting it back to use. I was misunderstanding, misinterpreting things and still I'm still struggling to overcome some obstacles mentally. It could be very damaging and HIV doesn't help. ...Yes, I've been managing to pass all my classes. But still I realize where the challenge lies. It's very important to take care of my health and try to attain whatever I want to attain; I need to work on it now... You need to push even harder.

“Pushing harder” was crucial to Faith for reaching a place of balance. By enrolling in school, Faith was finally living out her dream, but could not achieve because of her drug use.

The thing holding Anna back in her journey was her inability to disclose her HIV status. Anna stated,

That wasn't easy to have to disclose like that but I had to come out the closet because that will kill you quicker than anything else in the world. Being off into yourself... isolating yourself. You know that you have this virus and the stigmas behind [it]. You know, don't touch her. Don't eat behind her. Don't drink behind her. Okay. This is your spoon. Don't pick up my spoon. Don't use my bathroom. Okay. Those kind of things. So I pick and chose the people I go around. Those that I have educated on it myself that know I am positive. [I tell them] “Come on in here. I ain't poison. You'd of died a long time ago if I were poison.” You

know. Like that. I pick and choose the people who know that I am positive and who know my condition.

Anna, she was able to reconcile her issues surrounding disclosure and found a way to educate others about the stigma surrounding HIV/AIDS. Anna believed her inability to disclose to people she trusted stifled her. Through reconciliation, the women worked through challenges existing as a result of or in conjunction with their HIV diagnosis. The women prepared themselves, to achieve their “happily ever after” or accept there was no such thing as “happily ever after.” No matter the outcome of their reconciliation, the women were able to take away life lessons that they could teach to others. In relationship to “repurposing a legacy,” being able to teach others became a primary legacy to leave behind.

Lessons Learned & Educating Others

“Lessons Learned” was a category containing data that illustrated the women were able to take the unique lessons learned throughout the trajectory and use their newfound knowledge and life experiences to educate others. For most of the women, the education was intended for the “youth.” However, the knowledge was also bestowed on their peers, healthcare providers and the “system.” The women’s purpose was to ensure their grandchildren and future generations would not have to experience the same issues they did.

Educating the youth.

To ensure a safe and prosperous future for the youth, several women described life lessons they imparted or would like to impart to the youth. Belle referred to her children as follows:

Well, my loved ones don’t know, well my loved ones are the ones that I care about...my children, they do not know that I have HIV and I constantly talk to

them about it. You know they have this thought that the woman gives the man the HIV. I said no, come to the classes with me. And as we went along with the studies and going to meetings, they have all been tested. They all admitted or committed to being tested. And I'm glad about that. For a long time they didn't...

I said I want you to come to a meeting with me.

Some of the women refused to disclose their HIV status to their children, but did not let that barrier stop them from sharing anecdotal advice and wisdom.

Other women used their HIV diagnosis as an opportunity to educate others. Eva stated,

So, I don't have no problems. I explained to my kids what it was. This is a virus and you can't catch it by touching me. You can't catch it by sweat. The only way you can catch it is through blood, sex and milk. And I'm not [going to] give you no [breast]. And I'm not [going to] have no sex with you. So you need to sit down. So I explained to them.

Eva clarified and educated her children on the modes of HIV transmission. She did not allow stigma surrounding HIV to prevent her from educating them.

Another woman, Georgina, also described an attempt to educate the youth.

One day I was on the bus, Ariel, and then I don't do this. I swear to God I don't do this. But them youngsters saying that "B" got AIDS and I just turned around and said, what the hell do you know about AIDS? You know, and I had some literature in my purse. And I said, you know what, I don't think... you shouldn't be sitting up saying that. And I let them know, you guys can go to jail, sitting up there, putting that girl's business out in the streets like that. You guys shouldn't be doing that. And I said, "here. Take this. You need to read..." They didn't want to,

they didn't want to smoke cigarettes behind her. They didn't want to smoke their weed behind her. They didn't want to do.... woo woo woop. "Oh I might get it. I don't even want her to touch me." So I had the literature. I said, "Here. Here ladies. Why don't you read this?" I said, you bitches don't know nothing. You know. And they was looking at me like "ohh, she must have it." I said, "As a matter of fact, I do. Can you tell?"... You know and I look better than all ya'll. You see what I'm saying? I'm sharp than a mug. And I said I look better than all ya'll. And I do have it. I don't have AIDS. I have HIV. See what I'm saying. And that's the first time I ever did that. And I was loud. I said, Lord, when I came down from being mad, I said oh my goodness. I was shocked in myself.

Although Georgina was not entirely comfortable sharing her HIV diagnosis with strangers, she was motivated to do so in order to teach the "youth" a lesson.

As older women, many of the participants believed it was their duty to educate others. Candice, who witnessed a variety of uninformed decisions made by the "youth" believed she was required to educate them about their wrongdoings. Candice stated,

We're fifty, and we're trying to tell other women that are younger, you don't have to uh walk in our steps. We're trying to educate the women that you don't want to be like us. It breaks my heart when I see, even out here, young people that have the virus. They're not taking medicine. They're prostituting. And my mind says, okay, you're prostituting, but what happens if one of these gangsters figures out you got AIDS? You can be dead. And I sometimes want to say to them "baby, do you know what you're doing to your life?" But I have to leave them alone because they're on that stuff. So I kind of like look...and um...it saddens me to

see young people that are not as serious about HIV. I hear some young people say, “oh I can get AIDS and I can get section 8.” You don’t want section 8. They think you can get the benefit, the SSI. That’s not easy to live on. It’s not easy to, to be in a class of people where sometimes you’re only a number. Everybody’s on the bandwagon. If you got AIDS, it’s almost glamorized. It’s very glamorized. You even have in [The Valley] where some young people, where they call them “HIV parties” where the young people try and catch it. And why in the hell would you try to catch it? They have parties in [The Valley] where the young people think it’s glamorous so they try to catch it. Just like up in here on [Liam] Street, we have a house where if you’re a gay person, you pay twenty-five dollars and you try and catch it. Why would you try to catch it? So things like that.

After witnessing so many young women begin on a treacherous path, “hustling the system,” and abusing drugs, the participants hoped their words of wisdom could help steer other young women out of harm’s way. However, as seen in the above story, many youth and some of the women’s peers have found various ways to “hustle the system.”

Learning to “hustle” the system.

By “hustling the system,” a person had found ways to earn goods or services by illicit or unethical means. One woman, Leah, 59-year-old, described a conversation she had with a transgendered woman she met in a transitional home. This transgender woman shared with Leah how she had “hustled the system” by using her HIV diagnosis to acquire housing. Leah stated,

This was a disease for personal gain. I forgot what the conversation was about, but he said something like, well I want to be able to own a home one-day you know. Like this, was going to open up the door for him to get an opportunity to

buy a home you know, which for some reason I was on the housing list for [Edintown] like 20 years ago. I won that lottery thing and I never got it. But then after I got sick, right away I got it, you know. So people know the opportunity is there if you're ill to get it. And I think the younger people that get this are more opportunists. They don't understand the whole, the big picture on it. And uh, I think that's kind of sad. Um, because this disease isn't an opportunity. I think as far as like an older woman getting this sick, it's not really an opportunity. Of course you get a little help, but at this age, you know, if I was healthier, I wouldn't need this help. I would get out there and get my own, and have my own and do my own.

Leah was disappointed to learn that people were using their HIV diagnosis to acquire goods and services that would not typically be available to them. Leah also saw "hustling" behavior as more common among the youth and not older persons, like herself.

Housing was not the only "hustle" the participants claim individuals were utilizing.

Selling HIV medication was another "hustle." One woman stated,

The thing that bothers me now is I don't know if you know that people sell their AIDS medications. And that bothers me because the man who buys it, he's telling you...and they have people who are poor selling their HIV medicine. Okay, you get a hundred dollars for your meds. Then that man goes out in the street and tells somebody "you can buy HIV drugs and that'll cure you or either you won't catch it." That angers me when I see my peers selling HIV meds. I could remember a time when you couldn't get no HIV meds.

This woman was also disappointed by the use of goods and services for HIV positive persons' personal gain. While some individuals prided themselves in "hustling the system" and using the healthcare system to get the services they needed, other women described moments when the healthcare system betrayed them.

Betrayal by the healthcare system.

Overall, all of the women described having excellent encounters with the healthcare system. The women were able to find attentive physicians and clinics that best suited their needs. However, several of the women described moments when they found flaws in the healthcare system. One woman, Anna, stated,

After I accepted the fact that I was HIV positive, AIDS diagnosis, there was a nurse... from ABC clinic. One of them nurses came to my gate. She told me... she said "oh you Anna." I said yes. I walked over to her and stood at the gate. "I just wanted to inform you that you have hepatitis C." The woman would not even come in the house. I wanted to invite her in... "I just wanted to let you know that you need to get to the clinic as quick as possible." Okay, I am already twisted a little bit up here [points to head]. I wanted to tell her... humph... you know that words I wanted to tell her. Right?!? Go ahead on! There was another lady that came out to my house. I would never forget this lady. She was a sweet lady. Her name was Jane. [Jane told me] "Anna...can we go in your house and talk for a moment" I said sure. I let her in. She says "did someone come out here and tell you that you have hepatitis C." I said yes... yes they did. I broke down and went to crying. She said "don't cry, don't worry about that, you do not have no

hepatitis C. She went to the wrong gate and she's gone. She is in the process of now of being terminated from her job for disclosing in front of all your neighbors.

This embarrassing and traumatizing experience caused Anna to have issues trusting healthcare providers. Anna shared this story with others to make others aware of the careless mistakes members of the healthcare system make that lead to turmoil.

Mary also described a moment where she was betrayed by the healthcare system. This situation actually put her life in danger. Mary's HIV pharmacy delivered her medication to the wrong person's home. This incident happened numerous times, and each time, more of her neighbors discovered she was HIV positive. The people who lived in Mary's neighborhood were not very accepting of her HIV diagnosis. Mary stated,

Everything was going fine until [the pharmacy] gave out my medication and put my life in turmoil. I've been knowing these people [neighbors] for 10 years. They're thugs. They will kill you... especially the guy who said he would kill me...[he] is the head of the thugs over here. [I wondered] how the hell do you give somebody's HIV medicine [out] and just let anybody sign for it. So what they do different today, I have to show ID because they did it again... I had another pharmacy and they did it again. So it's like it's a joke [to the pharmacy].

Why would you give somebody's HIV meds to somebody you don't know.

After numerous calls and complaints to her pharmacy, Mary found a solution to her pharmacy issue and learned an important lesson from the experience. Mary educated others about the potential issues surrounding home delivery of HIV medication. The advice she offered to others was especially helpful to individuals living in unsafe neighborhoods.

An accumulation of various life lessons has made these women's story invaluable. Anna, described how it has taken her all of her life to acquire her wisdom and insight. Anna stated,

But like they say... I can see clearly now, the rain is gone. It took me 70 years almost 71 years to get to where I am at and I am not letting nothing or nobody to change me now. I'm not tightening any more nuts, bolts or screws. I will not adjust my life around nobody. Either you come up to my standards or you gotta stand on your own. You come up to where I am now. I'm leveled. Looking at leveled ground. And like Mr. Martin Luther King said "I am at the mountain now and I am looking over the promise land and I see what you doing out here and you ain't going to make it. I ain't going to make it either. At least I am up here where I can look at it. You still down here trying to make it. And everybody looked at me like... how did you learn all of this. I said, "experience BABY", okay, don't you see the snow on the mountain top.

Anna's years of life experiences made her a strong and wise person. These experiences have positioned her to not only educate the youth and members of the healthcare system, but also her peers. During the interviews, the participant's recounted various times they were able to offer their invaluable advice to others, including their peers.

Offering advice to peers.

The women's peers benefited from the advice they offered. For example, Anna described a conversation she had with a male friend. She offered him advice on dating younger woman and warned him of potential difficulties. Anna stated,

But now if someone my age... a man my age is looking for younger women, they don't want the younger woman. But those are the ones that destroy them. The

younger woman destroys that old man out there. All [the younger woman] know is money and the easiest way to get [the older man] off sexually. Okay and get on with the money. I've educated so many old buzzards like that myself. The men... look, this woman is 21 and you're 70. What can you do with that? As a matter of fact, you get your social security don't you... What! What! What old man... don't you get your retirement? Don't you get three checks in a month, man? Ain't that damn near three thousand dollars you getting. Look at the big picture... What do you think? It sure ain't your looks, because even with you being my age, I don't want you.

As Anna continued in her story she expressed how grateful her male friend was for her honesty and insight.

Having someone provide insight into a situation is essential to problem solving. Another woman, Georgina, stated,

Give back, you know, to those that have been good to me, and let me educate somebody. And I enjoy doing it, you know. I might not go in front of people, getting on camera and all that stuff, but, the homeless people and stuff and those women that are on drugs, you can't pull no wool over my eyes cause I was a druggie too. You see what I'm saying. You ain't gonna piss in my face and tell me it's raining because you can get tokens and it's a lot of little services that you can get and you misuse them. But I can understand that because I was a drug addict, you see what I'm saying. And I can talk with them. I've walked in their shoes and these people that they're trying to read textbook shit... you haven't

walked in these people's shoes. So you, really, all you know is what you read and those few that you deal with, you know.

Georgina challenged the knowledge base of healthcare providers. As a woman who had lived the life of "drug addict" and as an older woman, she believed she could offer more sound advice to women in her situation. Other women also offered advice to healthcare providers caring for older women living with HIV.

The women's stories recounted several co-morbidities and health concerns they shared. These anecdotes were messages they wished they could share with health care providers around the world. Candice described her frustration with attending support groups filled with individuals who could not relate to her and who did not look like her, such as young people. Candice stated,

You see all of us within the certain ages... but never an older Black person. We need that. And it's scary because we face more challenges. Like I hear my peers say, "How do you face arthritis?" How are you going to go to a support group and [relate to] somebody who is young...

Another women, Anna, suggested there needed to be more conversations about sexuality. Anna stated:

I would like to talk about sexuality. I haven't looked it up yet. But I have been hearing this from other women over 50 who say their sexual desires is not what it use to be. They now need to look at the big picture, since we are over 50.

Another woman described the need for more conversations on menopause, and stated,

I get up and take my medicine and go to the doctor like anybody else. But I do know that being a woman and being in your late 50's, it comes with challenges like menopause and different things that is different than a normal menopausal

woman. Like, when you're an HIV positive woman, they always don't want to give you the medicines for the menopause.

In addition to conversations about arthritis, sexuality and menopause, the women also believed that the healthcare providers and affiliates should address "how to live now." Candice stated,

You know, a lot of us joke and say, okay, here comes so and so and so and so from this pharmacy. We'll tell you what she's going to say today. That is good for newly positives. That is also good for people who may [have] those conditions. But tell people how to live now. And so, that is my thing I think should be a message today. How do you live? How do you get off SSI? How do you get an education? How do you not fall victim? How do you not get a man that might end up dead? So I think we think we need newer messages than what we're used to. We need uh, domestic violence messages. Things like that...we need to have the messages of why you need to get a pap smear. Okay, you tell me I need to get a pap smear, but why? You know some women have never had a pap smear. They don't understand what that means.

Candice described the need to expand the current discussion for older HIV positive women. Many of the participants described wanting to make sure accurate depictions of older women diagnosed with HIV/AIDS and their needs were presented to the world. The participants' dedication to educating others and advocating for the needs of HIV positive older women are all a part of their legacy, they will leave behind.

Building a Legacy- Finding my Purpose

By telling their story and educating others, these women were trying to build a legacy. Before being diagnosed with HIV/AIDS, the women described the type of women they were. Many of the women described the type of clothes they used to wear, the types of job they had, the types of parent or grandparent they were, and their overall plans for the future. Throughout this trajectory, these women's perceptions of what their legacy was, who they identified themselves as and what they would be remembered for, changed.

These women wanted to leave behind something to show that everything they had experienced was not in vain. For the women who disclosed to their family and friends, they described plans to update their legacy to include being HIV positive. For the women who grappled with what individuals might say about their HIV status, they saw HIV as a threat to their legacy. For some of the women, this was their primary reason for not disclosing their HIV status. They wanted to be able to carry on in life and die with their legacy intact. One woman, Belle, stated:

I didn't tell them [my children]. And I told the doctors that they don't know that I have HIV or AIDS. I know they [my children] would of just been crazy. And the doctor would always say... well if you need us to tell your [children]...I said I really don't want them to know. I really don't want them to know what I have. I want their minds to be focused on seeing that [I'm] human. People are human. Even the ones that have this condition.

Belle withheld sharing her HIV diagnosis out of a fear that her children would look at her differently. She feared her children would not identify her as the "knowledgeable, wholesome mother" anymore; something Belle worked years to instill.

In contrast, Eva, a 66-year-old woman, demonstrated that her relationship with her children and grandchildren could remain intact regardless of an HIV diagnosis. Eva stated:

And my kids know. And my grandkids know, all of them. And it really don't bother me because they know I would tear their ass off if they act like they don't want to do something [because of this] disease. They don't treat me no different. Just Granny. My little grand baby comes over, I'm just Granny. We hungry. Okay, sit down, I'm going to fix you something to eat. You know, we don't have no problems. I get up and go cook, everybody eats.

Eva was able to keep her “Mom” and “Granny” identity intact after her HIV diagnosis, something that many women struggled to do.. Although Eva was able to overcome the hurdle of disclosing to her family, she still believed plans for the future were deterred by her HIV diagnosis. Eva stated,

The only thing I hate about it [HIV], it happened in my golden years. Honey, I had plans for my golden years, do you hear me? Oh. I had plans. Going to retire at 55, going to travel and wear me a miniskirt. And I was thin like 130. I had plans. I ain't gonna say it was the devil. Whoever did it, they put a fork in that junk.

Eva envisioned her golden years to include her travelling and reaping the rewards of her years of hard work. The purpose of her years of hard work prior to her fifties was to earn the ability to relax and spend time with her grandchildren.

Other participants described additional ways their plans for the future were interrupted. Ivy stated,

Yeah, it kind of changed my goals because actually, I figured I'd be a little old lady working two or three jobs you know...just going from one job to another,

and going home, no kids to worry about nothing. I figured I'd be doing all that type of stuff. I'm doing some of the things now, but I'm thinking about going back to school right now. I'm thinking about writing a book that I've been thinking about writing for years. I'm just putting it all together in my mind. I just finally came up with a title, [Happily Ever After]. I thought I lived in a fairytale for a long time, fairytales, they don't come true. It's just a fairytale, but you live your life and sometimes you think it's a fairytale, and you pinch yourself. You know it's real girl, you better wake up and just cut the bull. Get to reality, but yeah. Just the things in life, life's work, God's work.

Ivy had to grapple with plans she once had for herself and her future.

Many of the participants had to grapple with adjusting past perceptions of self and past plans for the future in order to recreate a new legacy for themselves. During a family get together, one woman described an epiphany she had. Heather stated,

And I started crying because I didn't recognize myself. I looked like I was like 90 years old. My hair was totally gray. I didn't know who that person was sitting at a table. I was always a person that was, you know, conscious weight-wise... dressing, you know, basically never wore anything twice. I had shoes with tags on them you know. I used to work for the state, so when I went to work, I was a trendsetter. You know what I'm saying? I was a leader, not a follower. I was a trendsetter. And that's how I raised my family. I would go to work with a briefcase and my blue suit you know. And I worked hard too...I went to school. Finished high school, went to college for two years...became certified. I just felt that, you know, I had a good life. And when I got sick, it's like wow. It was just

devastating. Because the legacy, you know, I even went to doing drugs for a minute, because I was like, I wasn't worthy like....I'm useless. What can I do? I can't do nothing anymore. I can't work. I can't do anything you know. And um...it took me three years to recover. I went down sixty pounds. I lost my sight. I couldn't see, I couldn't walk, I couldn't talk, and I was in a diaper. That's really bringing a person down. And I said, my legacy, I want to...when I pass I want my family and friends to know that, hey, she didn't give up. She tried. She gave it her best, you know. Because I want them to know that whatever happens to you in life, don't give up. You know keep the faith.

Heather was able to take her adversity and begin to shape it into a promising legacy. Although her identity was altered due to the HIV diagnosis, she was able to find a way to change for the better.

Another woman, Mary, described being seen as a "brick house" before her diagnosis and being known as the "limo lady." Anytime there was a special event in the family or the neighborhood, she would get a limo for the family member or friend. This was her current working legacy she wanted to leave behind, until she learned of her HIV diagnosis. Mary stated,

So, when you get this here, your whole life changes. And then it becomes a secret. You know just like I say, I tell people, I say if this was cancer I could tell the world, but I can't tell them this. I would never tell. I got grandkids. I wouldn't tell nobody this. Because they've got to live their lives you know. I have a grandson going to college. You know I just got him a limo. He graduated in August. I'm the limo lady. I have limos out there all the time. Anytime a kid graduates, one of my grandkids, kindergarten, first grade, even remember [Tim] got killed. He was with

me. Limos. So I don't want nobody in my family to know that that's how, that's what happened. You know just like I said. We had a friend. We've been knowing him since he was a kid. But he happened to have HIV, and nobody wanted his furniture. How the hell are you going to catch it from the furniture? So if ya'll don't want his furniture, imagine knowing that I got it. They wouldn't have come around me. Shit. No. Hell no

Mary threatened, "when I really get too little, I'm going away where nobody can find me." Her HIV status served as a threat to her potential legacy. She believed that if she lost too much weight, people would know she was HIV positive and would no longer want her to provide them with limos (her legacy). Mary continued to grapple with whether her legacy would remain intact or be shattered by her HIV diagnosis.

When a legacy was in jeopardy of being dismantled, other participants found a way to repurpose their legacy and find a new purpose. One woman stated:

But uh, I think about God mostly all through the day, so that's what keeps me going you know. And I do believe I still have something to do in this world so I haven't given up. I just gave up maybe on having a man, but anything else. I have things to do to make people feel better in some type of way. The job I had, when I was working with adults and helping them to live on their own, I enjoyed that. So if I could get into somebody else's life and make them happy, I'll be okay. That makes me happy. I feel like I have a purpose you know. I'm going to get back into that very soon. I can't let him ruin the rest of my life. I was in a marriage for quite a while, kind of controlling, and I was not happy most of the time in that marriage. I came from a broken family, so I tried to keep my family together by

any means necessary really. I was not living my life, I was living his. I wasn't living the way I wanted to be. I was living the way he wanted me to be so I was not living actually.

This participant was able to restructure her life and begin to construct a new purpose.

Another woman, Patrice, 62-year-old, also described seeking a purpose. Patrice described how much she loved the jobs worked in the past, prior to her HIV diagnosis. For Patrice, her HIV diagnosis came along with various complications that left her unable to work. She expressed how finding a new job would give her a purpose again. Patrice stated,

I'd be so happy to have a job. That's the only thing that would make me happy. I don't even think about a man anymore. I just want me a job. It's like I have a purpose. And I want to take up some classes... but I don't even have money for that. So it's like somedays you don't feel like you have a purpose but I guess Jesus says, well whether you think you got a purpose or not I am your purpose... GET UP.

Until Patrice was able to find a job, she planned to continue to turn to God for support.

For these women, it was through reaching turning points, reconciling the past and present, and learning lessons from adversity, that they began to build a legacy and purpose for themselves (independent of or dependent on HIV/AIDS). Whether the women successfully repurposed their legacy or found their life's purpose, they all described being dedicated to accomplishing this feat in the near future.

Summary

The results of this study demonstrated how older African American women utilized various strategies to repurpose a legacy, after an HIV diagnosis. The strategies used by the

women included re-evaluating perceptions of HIV risk, learning lessons from tumultuous times, and reconciling past and present events. The women's lack of HIV risk perceptions and their providers' lack of perception resulted in delayed HIV testing. After being tested, the women embarked on a journey to resolve newfound issues and in the process learned numerous life lessons. This process allowed the women to make meaning of their HIV diagnosis and set out on a path to self-discovery.

CHAPTER 6

Discussion

This study explored the experience of African American women diagnosed with HIV at the age of 50 and older. This group of 16 women detailed unique stories and experiences not commonly seen in the current HIV/AIDS literature. Based on these stories, a situation-specific grounded theory entitled “Repurposing a Legacy” was generated (Figure 1.1). To repurpose a legacy meant to alter it, and make it suitable for a different purpose. These women worked to reconfigure their pre-diagnosis perceptions of self and the world around them, to construct a new legacy. “Repurposing a Legacy” had two major components: “Pre-Diagnosis” and “Post-Diagnosis.” This chapter will present an analysis of study findings and the “Repurposing a Legacy” grounded theory and discuss the findings in relation to the extant HIV/AIDS literature.

Major Study Findings

By using constructivist grounded theory to methodologically examine the unique experiences of older African American women diagnosed with HIV/AIDS, at the age of 50 and older, the researcher was able to describe their pre and post HIV diagnosis trajectory. Prior to their diagnosis, the study found that both the women and their primary healthcare providers lacked a perception of the women’s HIV risk. This lack of perception of risk, in conjunction with a failure to recognize early signs and symptoms of HIV, and an inability to navigate the HIV testing process, led to a late diagnosis (a CD4 count below 350 cells or an AIDS-defining event, irrespective of the CD4 count) (Antinori et al., 2011). After the women’s HIV diagnosis, they experienced few issues in navigating the healthcare system; however, they did experience personal identity issues and issues with their social networks.

Pre-HIV Diagnosis

To the researcher's knowledge, this study is the first to examine how 50 year old and older African American women diagnosed with HIV/AIDS at the age of 50 and older navigate the HIV testing process and make meaning of an HIV diagnosis. Recently, over the last several years, new literature on women living with HIV/AIDS, over a long-term, has emerged. While this development in the field is warranted, an advantage to studying this sub-group of older women, diagnosed at the age of 50 and older, is the ability to explore this sub-groups' specific perceptions of HIV risk prior to their diagnosis and actual HIV risks taken.

Lack of perception of HIV risk

Several studies have examined older women's perception of HIV risk (Hillman, 2007; Maes & Louis, 2003; Rose, 1996; Setse & Maxwell, 2014; Smith & Larson, 2014). The literature shows that older women do not perceive themselves to be at risk for HIV, and thus, leads this population to engage in risky sexual behaviors. In this study, the researcher asked the participants to think back prior to their diagnosis and describe their perceptions of HIV risk. This study found that the women lacked perceptions of HIV risk as well as elicited how these HIV perceptions were formed. Media sources, healthcare providers and childhood influences were cited as primary reasons why these women did not perceive themselves to be at risk for HIV. These influences led the women to underestimate their own HIV risk and perceive gay males as the only carriers of the HIV virus. For women who were taught at a young age to strive to date "clean" men, then marry them, and never leave them, they believed having sex with one man safeguarded them for contracting an STD. Similarly, in the existing HIV literature, decisions to use a condom and trust a partner was based on physical appearance and life experiences (Ludwig-Barron et al., 2014).

Being faithful to their husbands, seeing their doctors regularly and being selective of the

men they dated, were the cited HIV risk reduction strategies. In the current HIV/AIDS literature, sex with men “on the down low” and women attempting to maintain a peaceful partnership with their spouses, even though they were perceived to be unfaithful, were stated HIV risk factors for African American women (Gilbert & Wright, 2003; Whyte, Whyte, & Cormier, 2008). Similarly, in this study, the women reported being infected with HIV by men who were “on the down low” and not confronting their partners earlier, regarding potential infidelities, in order to “keep the peace” in the relationship. The women also reported that their healthcare providers impacted their perception of personal HIV risk.

This study found that the decisions of healthcare providers to not offer an HIV test or facilitate a discussion about HIV led the woman to believe they were not at risk. Congruent with the findings of others researchers, healthcare providers seldom viewed older women to be at risk for HIV (Grant & Ragsdale, 2008). Also, older female patients expected that their healthcare provider should initiate conversations about sexual health if a problem was perceived (Grant & Ragsdale, 2008). So when the older women and the healthcare providers lack a perception of HIV risk, the women go untested.

Initiation of HIV Testing

After weeks, months, or years of missed opportunities to test for HIV, the women described the metaphor of “hitting rock bottom.” Examples of “hitting rock bottom” included, needing to be hospitalized after feeling very ill (with a cough, cold, headaches) or needing to enter a drug treatment program. Once the women were hospitalized or entered the drug treatment program, they were tested and diagnosed. Most of the women reported not even knowing HIV testing was taking place. There were no conversations that took place, prior to the testing process, to indicate an HIV test was being administered. Initially, the women believed their

health care providers offered them the essential and needed routine health screenings. If they were to be at risk for HIV, the women believed their doctors would have recommended an HIV test; similarly to a doctor recommending a blood test to check for diabetes. If the doctor did not facilitate the discussion, the women did not see a reason to either. Although, the current literature suggests it is both the provider's and patient's responsibility to initiate discussions surrounding sexual health (Grant & Ragsdale, 2008), this group of women living with HIV/AIDS, relied primarily on their health care providers. The women all stated they would have welcomed an HIV test if it were offered. In contrast, the current HIV literature states older women do want to be tested (Akers, Bernstein, Henderson, Doyle, & Corbie-Smith, 2007). And when offered an HIV test, in one study, the older women were more likely than the younger men or women to decline HIV testing (Setse & Maxwell, 2014).

The combination of older women not wanting to be tested, and healthcare providers not assessing the need to test older women, resulted in delayed HIV diagnoses. Unfortunately, when the women are finally diagnosed, it is paired with varying co-morbidities and weakened immune systems (low CD-4 count), which is consistent with the emerging literature (Samuel et al., 2014). As the women grappled with this newfound diagnosis, they were faced with situating themselves within the world of HIV/AIDS.

Post-HIV Diagnosis- Finding and Creating a New Identity

Once the women were diagnosed, they began to search for a meaning behind their HIV/AIDS diagnosis. The participants used the metaphor of "getting my house in order;" a statement that denotes the need to rearrange priorities and affairs. This metaphor was synonymous with managing their diagnosis or coping with their diagnosis. Published research has looked at how older adults cope with an HIV/AIDS diagnosis (Chesney, Chambers, Taylor,

& Johnson, 2003; Coleman, Jemmott, Jemmott, Strumpf, & Ratcliffe, 2009; Emlet, 2006; Heckman et al., 2000, 2006; Lyons, Pitts, Grierson, Thorpe, & Power, 2010; Malone, 1998; Nokes, Chew, & Altman, 2003; Siegel, Brown-Bradley, & Lekas, 2004; Speer et al., 1999; Vance & Woodley, 2008); however, most of this literature has not focused on older African American women; and there is no literature that focuses exclusively on women diagnosed at the age of 50 and older. In line with the coping literature, the women utilized problem-focused coping (Lazarus & Folkman, 1984). In coping with their HIV diagnosis, the women targeted the stressful HIV diagnosis and its associated factors, in order to change their current situation (McLeod, 2010). The associated factors of particular consequence to the women included issues within their social network, personal identity issues, and a need to find a purpose.

Social network

The study found that older African American women pulled social support from their family members and significant others, which confirms what has already been published in the HIV literature (Emlet, Tozay, & Raveis, 2011; Heckman et al., 2000; Vance, Farr, & Struzick, 2008). However, a fear of being stigmatized by a family member or significant other prevented some women from disclosing their HIV status. A lack of disclosure has been associated with loss of social support and isolation among older adults (Grodensky et al., 2015; McDoom, Bokhour, Sullivan, & Drainoni, 2015; Siemon, Blenkhorn, Wilkins, O'Brien, & Solomon, 2013; Vance et al., 2011). Having a companion while aging with HIV/AIDS has been found to aid in decreasing the feeling of isolation and assist in illness management (Warren-Jeanpiere, Dillaway, Hamilton, Young, & Goparaju, 2014). Although this was true, for many of the women seeking companionship, they still grappled with whether to end or continue toxic relationships. After being diagnosed with HIV, the women were challenged with making tough decisions about their

roles in relationships, roles in their jobs and other roles they occupied.

Personal identity

Prior to their HIV diagnoses, these women occupied various roles including mother, grandmother, wife, girlfriend, “druggie,” and employee. However, after being diagnosed, some of their roles shifted or were eliminated. Shock to their personal identities motivated them to rediscover themselves and find their purpose. For the women who once used drugs, their identity no longer included the role of the “druggie.” Other women could no longer work after their diagnoses and felt as though their lives now lacked purpose. The impact of HIV on identity was described by Murphy and colleagues in a qualitative study of young and middle-aged mothers having an “empty nest.” An empty nest was defined as the segment of life when children become independent and move on with their lives. Fear of losing their identity as a mom, loss of social support and financial insecurity were several key findings in the study (Murphy, Roberts, & Herbeck, 2012)

While women in this study did fear changes to their roles, their reasons for fear were different. Before being diagnosed with HIV, they had already moved past the “empty nest” phase and had finally reached a place where they could begin to live their lives for themselves. The women envisioned themselves traveling and reaping the rewards of their hard work. An HIV diagnosis meant changing this plan, changing their roles and reevaluating their life’s purpose.

Finding a purpose

Erikson (1950, 1963) theorized that one’s psychosocial development encompasses eight stages. Consistent with gerontology literature, repurposing a legacy and finding a purpose falls into the stage of Generativity versus Stagnation (Coleman et al., 2006; Erikson, 1966; Maxfield et al., 2014; Rubinstein, Girling, de Medeiros, Brazda, & Hannum, 2014). In this phase adults

aged 40 to 65 strive to establish their careers and relationships and guide the next generation. As the women in this study worked through turmoil in their lives, they entered new or modified roles. For the women grappling with staying with or leaving a boyfriend or husband, they were on the cusp of entering the new role of a “single woman” or a “divorcee”; a role they never imagined they would occupy after the age of 50. For the women grappling with disclosing their HIV diagnosis to their children, they found themselves entering a new role as an HIV advocate or HIV educator. The women began to embrace these new roles and rediscover what hobbies or careers would make them happy. Activities the women settled on included being educators, advocates and/or counselors. These hobbies and careers served as a new purpose for the women and allowed them to assign meaning to their HIV diagnosis. While finding their purpose and making meaning of their HIV diagnoses, these women began to construct a legacy. They hoped their stories could serve as lessons to others. Their stories gave birth to a new subgroup of older adults living with HIV. Not only was this subgroup unique, to their over 50 counterparts, but their stories were not previously featured in the extant literature.

Conclusion

Presently, the HIV/AIDS literature has not addressed the barriers older women diagnosed with HIV/AIDS, at the age of 50 and older, experience. While the findings cannot be generalized to all HIV positive older African American women, this study has provided valuable insight into the HIV testing practices of older women and how older African American women make meaning of a recent HIV diagnosis. Understanding the HIV trajectory these older African American women embarked on will assist in the development of culturally-sensitive, age-appropriate qualitative and quantitative studies. Also, the “repurposing a legacy” grounded theory has great implications for nurses and other healthcare providers, as well as the

development of healthcare policy. The following section will discuss the nursing practice and policy implications of this study.

Nursing Practice

The National HIV/AIDS Strategy was created to decrease the incidence of HIV, increase access to care and decrease HIV-related health disparities (ONAP, 2010). The results of this study can assist in carrying out the above goals. One strategy to decrease the incidence of HIV, among this older African American female population, is to ensure nurses and other healthcare providers are not only aware of potential HIV risk factors and signs and symptoms of an HIV infection, but also educate their patients of potential risks. When older women enter the healthcare setting for a well woman's physical and assessment, this presents as a perfect opportunity to begin discussions about sexual health. Relying on the fact that an older woman is married should not stop dialogue regarding sexual health and HIV risk reduction. As seen in this study, all of the women did not view themselves to be at risk for contracting HIV/AIDS. They looked to their healthcare providers to initiate dialogue. Nurses are in a prime position to acquire a comprehensive sexual health history from patients and discuss any misconceptions of how HIV can be acquired. Based on the socialization of older African American women, certain preconceptions about HIV/AIDS prevented the women from seeking HIV tests.

It is essential that nurses and other healthcare providers seize every opportunity to assess and educate patients about potential HIV risk factors and to offer HIV tests. Common risk factors among this sample included having unprotected sex with a trusted heterosexual partner and sharing unclean needles with a partner. Unless an open dialogue is initiated between the women and their healthcare providers, there can be no true assessment of HIV risk. The U.S. Preventive Services Task Force (USPSTF) has made the recommendation that healthcare providers screen

individuals aged 15 to 65 years for HIV infection; and for individuals outside of this age range, it is recommended they are tested, only if they are deemed to be at “increased risk” (CDC, 2006).

As evidenced by this study, all of these women were at an “increased risk” for contracting HIV, but a lack of sexual health discussions hindered the risk from being discovered. The women made it clear that they perceived HIV as only a disease that impacted gay men. The women did not fit this risk profile. Thus, findings emphasize the need for healthcare providers to engage in sexual health discussions with all patients, regardless of preconceived notions. Further, there is a need to deconstruct the HIV risk profile and make it more inclusive. Providing updated information in the clinical setting, the media (billboards and television) and the community settings could aid in changing women’s perceptions of HIV. Community health fairs are another opportunity for healthcare providers to engage older adults in discussions on sexual health and HIV risk. Even if the woman may not perceive herself to be at risk, engaging women in discussions about the youth, their children and grandchildren’s HIV risk could assist in opening dialogue. Nurses and healthcare providers can also aid in educating older African American women living with HIV/AIDS.

Findings also revealed that African American women diagnosed with HIV/AIDS at the age of 50 and older had unique needs. Several of these unique needs included, issues with menopause, sexuality, and job placement. Throughout the interviews, the women described how they were in search of answers to questions surrounding menopause and sexuality. While their healthcare providers did offer them advice, they also searched for peers with whom to discuss these issues. The women attempted to seek out answers in their supports groups, but were unsuccessful. There is a need for additional programs geared towards older women. While support groups were cited as a great source of help, the women could not relate to the issues of

their younger female and male counterparts. Nurses and healthcare providers should be sensitive to the varying needs of older African American women and offer programs tailored to their needs. In regards to the women's need for job placement services or career counseling, they were left without assistance. Further, policies have the potential to ensure older women are tested in a timely manner and receive essential HIV care services.

Healthcare Policy

Over the last decade, there have been great changes to the policies surrounding HIV testing and treatment. For California, the legislation surrounding HIV testing supports routine HIV testing in medical settings. HIV screening is recommended for all patients in the healthcare setting. The law requires that the medical care provider inform the patient when an HIV test is planned and provide information about the test. The patient has a right to refuse testing. This approach is referred to as "opt-out" HIV testing. In contrast, opt-in testing requires the patient to ask their healthcare provider for an HIV test. Based on the results of this study, opt-in testing would offer another barrier for HIV testing among older African American women who do not perceive themselves to be at risk. It is important that all states adopt the opt-out HIV testing law.

Even with the opt-out HIV testing in place, in California, the women still reported delayed HIV testing. In many centers, an HIV test is not a laboratory test that is automatically offered. It is the healthcare providers' responsibility to ensure an HIV test is added to the women's list of laboratory tests and that discussions about potential risk takes place. In this study, when HIV testing was conducted, it was not paired with verbal consent or information about the test. Most of the woman (14/16) reported being tested "unknowingly" (learning of HIV test results without knowing they were being tested beforehand). This indicates another missed opportunity to talk to these women about HIV risk and ways to safeguard themselves.

Another barrier to receiving an HIV test is cost. One participant described her healthcare provider's reluctance to test her for HIV, since her insurer would not cover the cost. Although the cost of HIV testing is typically free, there are still some insurers who will not cover the entire cost of an HIV test. As a result of the Affordable Care Act, most of the new health insurance plans must cover certain preventive services, such as HIV testing. In order to decrease the incidence of HIV and increase the detection of HIV, healthcare providers need to offer all of their patients an HIV test. By offering an HIV test, the provider is also opening the opportunity for conversations regarding risk reduction. Nurses and healthcare providers must be equipped with adequate resources in order to facilitate the reduction of HIV incidence.

Recommendations for Future Research

This study has implications for both HIV prevention studies and studies centering on older African American women. Previous studies have not enlisted the opinions of newly diagnosed older African American women to help shape intervention studies, nor the influence of the media or healthcare providers in impacting perceptions of HIV risk among older women. Focusing future HIV prevention interventions on these barriers could assist in increasing older women's perceptions of HIV risk and willingness to be tested for HIV. Future studies can also utilize results of this study to create coping enhancement interventions.

The women described a need for support groups that included their peers. These coping interventions could benefit from discussions surrounding sexuality, menopause, dating, and chronic disease management. Lastly, future studies should include HIV educational trainings for older women living with HIV/AIDS who are interested in teaching others about HIV risk factors and ways to successfully cope with HIV. Many of the women studied, expressed a need to find their life's purpose and a job. Serving as an HIV peer navigator for other persons living with

HIV, would allow the women to share their wealth of knowledge and work to regain a life's purpose.

Summary

The results of this study can shape forthcoming research on the HIV trajectory of older African American women living with HIV/AIDS and at risk for HIV/AIDS. The process of learning of an HIV diagnosis for this population is unique. Targeted messages and interventions that are widely offered to other HIV sub-populations are not available to older women. Understanding the factors that influence timely HIV testing, and management of an HIV diagnosis, can facilitate the creation of culturally competent and age-specific programs. The stories shared by these women helped to illuminate how resilient older African American women can be. Although the women experienced some turbulent moments, along their trajectory, they were able to learn lessons and go onto repurpose a legacy. Older adults are often seen as a revered holder of valuable family culture, values and information. These stories have the potential to leave a lasting impression on future generations and assist in clarifying what it means to be an older African American woman diagnosed with HIV at the age of 50 and older.



Volunteers Needed for Study on HIV+ Older Women

WHO IS ELIGIBLE:

- 1) HIV Positive
- 2) Self-identify as an older (50+) woman

***All study participants must be able to read and speak English ***

ABOUT THIS STUDY:

- 1) This is a research study about the lived experience of women who received an HIV diagnosis in older adulthood and their thoughts about HIV risk, social support and the healthcare system.
- 2) You are asked to participate in a confidential interview for about 1 to 2 hours
- 3) You will be asked to fill out a brief questionnaire.
- 4) You will also be paid a **\$30.00** honorarium for the interview.

The interview and questionnaire will be kept completely CONFIDENTIAL.

INTERESTED IN VOLUNTEERING???

Contact: Ariel Rankin RN, MSN, CNL
UCLA School of Nursing
700 Tiverton, Factor Bldg.



Appendix B: Pre-Eligibility Screening Guide

Pre-Eligibility Screening Guide for Participants

This will be done over the phone

✓ **[I will state]:** Good [morning/afternoon/evening]. My name is Ariel Rankin. I am a doctoral student at the UCLA School of Nursing. It is my understanding that you are interested in this research study about the lived experience of women who received an HIV diagnosis in older adulthood. By being a participant in this study you will share your experience with HIV in a one-on-one interview with me. Women who participate in the study will receive a \$30.00 honorarium per interview. At this time, I would like to assess your eligibility for this study by asking a few questions.

✓ **[I will ask:]** Are you interested in participating in our study?

[THEIR REPOSE: YES OR NO].

[If yes, proceed].

✓ **[I will state]:** To assess if you are eligible to participate in the study I will need to ask you a few questions:

✓ **[I will ask the following questions]:**

- 1) Where do you currently live?
- 2) Can you speak and write in English? ***[If yes, proceed]***
- 3) How old are you? ***[If 50 or older, proceed]***
- 4) At what age were you diagnosed with HIV? ***[If 50 or older, proceed]***

[If the respondent is ineligible]

✓ [I will state]: Thank you for your time, however you are not eligible for this study, for the following reason _____ [state reason(s) based on questions 2-5]

[If the respondent is eligible]

✓ [I will proceed and ask:]

- 1) What time is convenient for you to interview and complete the questionnaire?
- 2) What is a specific place that is private and quiet where you will be comfortable being interviewed?

✓ ***[Note: I will retrieve the address and time for the interview meet time and place]***

✓ [I will proceed and state:]

- 1) Also, I will have a consent form for you to read and sign for your participation in the study.

- 2) Do you have any questions for me at this time?
- 3) Can I also have a phone number that is best to contact you at?
- 4) I look forward to your participation in the study and will see you at _____ (*the location*) at _____ (*date and time given*).
- 5) As a research participant you have the right to withdraw from this study at any time or refuse to answer any individual questions. Even after you sign the consent form, you can stop.
- 6) If you should have any questions or concerns feel free to me call me at 240-441-8140 or e-mail me at arankin@ucla.edu.

Appendix C: Interview Guide

Greet and introduce myself to participant and briefly discuss and describe the purpose of this interview

Hi, my name is **Ariel Rankin**. I am a doctoral student at UCLA School of Nursing. My research is on the experience of receiving an HIV/AIDS diagnosis at age 50 and older. A lot of research has looked at HIV/AIDS and aging, but the unique experience of newly diagnosed women has not been looked at. I am interested in learning about your HIV journey; starting with your perceptions before being testing, what it was like after receiving your diagnosis, and your relationships with loved ones and the healthcare system. I plan to use this information you provide me with to paint a clearer picture of what it is like to be a woman diagnosed with HIV in older adulthood.

I want you to feel completely comfortable during this interview so feel free to share whatever information you are comfortable with. If you feel uncomfortable at all during the interview, please let me know. Everything we discuss will be kept confidential unless you mention current plans to commit suicide or harm someone else. You will receive a \$30.00 honorarium after completion of this interview.

I want to make sure I depict your story clearly. Do you have any questions for me so far?

Okay before we begin. Let us review the consent form.

Do you agree?

Thank you

Let us begin. I will turn the tape recorder on now.

Begin Interview

Ms. _____, thank you so much for agreeing to participate in this study. Through this study, we hope to better understand the lived experience of women who received an HIV diagnosis in older adulthood. Let us begin.

Question 1: I would like to learn about your perceptions of HIV before you were diagnosed.

Probes:

- Thinking back before you were diagnosed,
- What did you know about HIV before you were diagnosed?
- What did you know about your risk for HIV prior to your diagnosis?
- Tell me about the last time a doctor talked to you about your sexual health and STD risk (before and/or after diagnosis)
- Who or what motivated you to be tested?

Question 2: Tell me about the day you found out about your HIV Diagnosis

Question 3: I am interested in learning more about your life now that you are living with HIV (your experiences with the disease and its impact on your loved ones)

Probes:

- Tell me about your journey to being linked to care. How were you linked to care?
- Tell me your first HIV- related doctor's visit?
- Tell me about obstacles that made this journey more difficult
- Tell me things that helped you find a doctor, helped you attend your first doctor's visit, return for a second visit
- Who linked you to care?

Question 4: I am interested in understanding what it means to you to be HIV positive in older adulthood

Probes:

- Tell me how having this diagnosis has or may change your interactions with
 - Family
 - Friends
 - Social Groups
 - "Boyfriend/Girlfriends"
 - Sexual Partners and/or Spouse
 - Tell me about your last sexual experience before receiving your diagnosis (conversations before and after, condom negotiation, etc.).
 - Tell me about your experience with (sexual) partners now?
 - Tell me about the relationship you had/have with the person who may have infected you
- Changes in roles (mother, grandmother, provider, etc.)

Question 5: I would like to learn more about the coping processes, social factors, and personal resources, you utilized after being diagnosed

Probes

- Tell me what you did to deal with your new diagnosis?
- Who or what would you consider to be a part of your support network?
- How did you cover your cost HIV care?

Question 6: Tell me about interactions with the healthcare system since being diagnosed

Probes

- Was there a delay between being diagnosed and attending the first clinical appointment? How long was the delay? Why the hesitation? Why the delay?

Concluding Remarks/Questions:

- Is there anything else you would like to tell me about being diagnosed with HIV/AIDS in your 50's, 60's, etc. (will tailor to participant). Is there anything you believe I missed?
- If there were one pearl of wisdom you would want me to take away from our talk, what would that be?

Thank you so much for your time; this has been great, you have given me a lot to think about. Is it okay for me to call you to clarify any information, after I have reviewed it?

Appendix D: Consent Form

University of California, Los Angeles

CONSENT TO PARTICIPATE IN RESEARCH

The Experience of Older Women Diagnosed with HIV/AIDS

Ariel Rankin, RN, MS, CNL, from the School of Nursing at the University of California, Los Angeles (UCLA) is conducting a research study.

You were selected as a possible participant in this study because you are a woman who was diagnosed with HIV/AIDS at the age of 50 or older. In addition, you speak English. Your participation in this research study is voluntary.

Why is this study being done?

This study hopes to explore the experience of receiving an HIV/AIDS diagnosis at the age of 50 or older. A lot of research has looked at HIV/AIDS and aging, but the unique experience of newly diagnosed older women has not been looked at. This study will explore your HIV journey; starting with your perceptions before being testing, what it was like after receiving your diagnosis, and your relationships with loved ones and the healthcare system.

What will happen if I take part in this research study?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Participate in a one-on-one, in person, interview
- The interview will be held at a safe place that is agreed upon by you and the interviewer
- The interview will take place after you consent to this study
- The interview questions will be about your perception of HIV before you were diagnosed, your interactions with your social support networks, and you interactions with the healthcare system
- The interview will last about one to one and a half hours
- After completing the interview you will be asked to complete a brief demographic questionnaire about yourself
- The items on the questionnaire will be about your employment status, income level, health status, relationship status, household type and age

How long will I be in the research study?

Participation will take between one and two hours.

Are there any potential risks or discomforts that I can expect from this study?

If you participate in the study, you will be asked about your life experiences and perceptions of HIV leading up to your diagnosis, relationships with friends, family, sexual partners, and other social network members, and experiences with the healthcare system post-diagnosis. Your participation will not subject you to any physical risk or pain, but, because some of the interview questions may be personal, you may experience some stress, embarrassment, or emotional

distress. In the event that you become upset and in need of additional health services, you will be referred to a health provider for support and counseling. It is up to you to either accept or refuse a referral for professional services.

Are there any potential benefits if I participate?

We cannot promise that your participation in this study will result in any direct benefit to you. You may find some therapeutic value in discussing the various issues related to living with HIV/AIDS in older adulthood and being a woman.

The results of the research may be helpful to other women, healthcare providers, science and society, by enhancing our understanding of the experiences of older women who were newly diagnosed with HIV/AIDS. The results of the study may also shed light on tactics to aid in the testing of older women and linking these women to care once they have been diagnosed.

What other choices do I have if I choose not to participate?

You may choose not to participate in this study. There are no consequences for not participating in this research study.

Will I be paid for participating?

You will receive a \$30.00 honorarium at the completion the interview. No further compensation will be provided for study participants.

Will information about me and my participation be kept confidential?

Any information that is obtained in connection with this study and that can identify you will remain confidential. It will be disclosed only with your permission or as required by law. You will not be identified with the information you give. No one but the interviewer, Ariel Rankin and her faculty advisor, Dr. Adeline Nyamathi, will know how you answered the interview and questionnaire questions. The interviewer and the faculty advisor have signed pledges to keep all information about you confidential.

For the recorded interview, the information will be obtained confidentially, recorded confidentially and later made confidential once it is transcribed. All recorded interviews will be transcribed within two weeks of interview and then the recording will be destroyed. All transcribed interview data will have identifiable information, such as people, schools, and towns replaced by a pseudonym (false name). The only connection between your participation in this study and the study itself will be the signed consent form and code list (maintained by Ariel Rankin). The coded list will be destroyed at the end of the study. Personal identifying information pertaining to the study participant will be destroyed within 3 years of the completion of the study.

The same confidential code assigned to the study participant during the interview will be assigned to the demographic data questionnaire completed by the study participant.

The confidential code linking your name to the study data will be locked in a secure place until data have been successfully entered into the computer. Only project staff will have access to the study data.

What are my rights if I take part in this study?

- You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
- Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.
- You may refuse to answer any questions that you do not want to answer and still remain in the study.

Who can I contact if I have questions about this study?

- **The research team:**
If you have any questions, comments or concerns about the research, you can talk to the one of the researchers. Please contact:

Ariel Rankin RN, MSN, CNL
UCLA School of Nursing
700 Tiverton, Factor Bldg.
Student Affairs Office Box 951702
Los Angeles, CA 90095-1702

- **UCLA Office of the Human Research Protection Program (OHRPP):**
If you have questions about your rights while taking part in this study, or you have concerns or suggestions and you want to talk to someone other than the researchers about the study, please call the OHRPP at (310) 825-7122 or write to:
UCLA Office of the Human Research Protection Program
11000 Kinross Avenue, Suite 211, Box 951694
Los Angeles, CA 90095-1694

You will be given a copy of this information to keep for your records.

Appendix E: Demographic Data Form

Instructions: Please provide a response for each of the following questions:

1. **Date of Birth:** _____ / _____ / _____
 mm *dd* *yyyy*

1a. **Current Age:** _____

2. **What is your relationship status?**

Single Married Separated Divorced Widowed Dating

3. **What is your annual income?**

Less than \$15,000 \$15,001 to \$30,000 \$45,001 to \$60,000

\$60,001 to \$75,000 \$75,001 to \$90,000 Greater than \$90,000

4. **Employment Status?**

Employed Unemployed

5. **What is the highest level of education you have completed? ("X" ONLY one with which you MOST CLOSELY identify):**

Less than High School

High School/GED

Some College

Two-Year College Degree (Associates)

Four-Year College Degree (BS/BA)

Masters Degree

Doctoral Degree

Professional Degree (MD/JD)

6. **With what denomination or faith tradition do you most closely identify?**

7. What was the month and year of your diagnosis?

 /
m m y y y y

8. Do you currently have Health Insurance ?

Yes No

8a. If so, what kind

HMO

PPO

Medicare

Medicaid/Medical

No Insurance

Other: _____

Not Sure

9. Ethnicity origin (or Race): Please specify your ethnicity.

Black or African American

Hispanic or Latino

White

Asian / Pacific Islander

Other

Appendix F: Results Dissemination Guide

This will be done over the phone

- ✓ **[I will state]:** Good [morning/afternoon/evening]. My name is Ariel Rankin. Thank you again for volunteering to participate in my study. I have completed the study and I now have results for you.
- ✓ **[I will ask:]** Are you interested in learning more about the study's results?

[THEIR REPOSE: YES OR NO].
[If yes, proceed].

- ✓ **[I will state]:** I have created a short handout describing the results of the study you participating in. Is the address you provided me with still correct [recite address]? If not, where would you like me to send this sealed handout?

[If the response is no]

- ✓ [I will state]: Thank you for your time and thank you again for participating in the study.
- ✓ ***[Note: I will retrieve the address]***
- ✓ The handout will include the following information:
 - 7) Purpose: This study hoped to explore the experience of receiving an HIV/AIDS diagnosis at the age of 50 and older.
 - 8) Background: Will describe relevant information related to older women and HIV.
 - 9) Results: Summary of themes and categories developed from the participants. List of several key quotes from participants. Diagram of grounded theory.
 - 10) Discussion: Will describe how the study's results can be used by women, patients, healthcare providers, and researchers.

****All information will be described using lay language.***

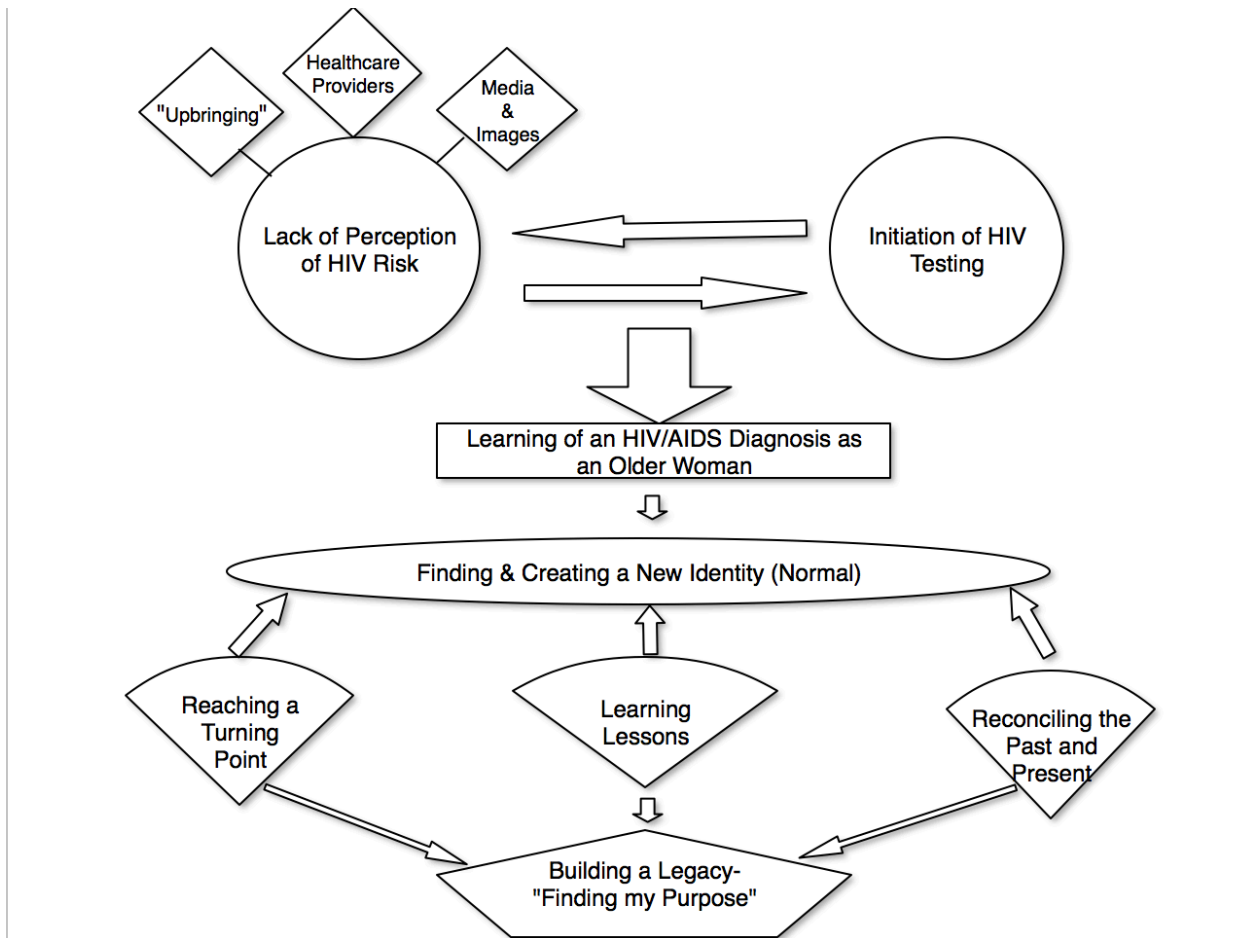
Appendix G: Table 1.1: Participant Characteristics

Table 1.1 Sample Characteristics, N=16			
Characteristics	Range	Mean	SD
Current Age	54-76 years	63 years	6.2
Age at Diagnosis	50-61 years	55 years	4
Years living with HIV/AIDS	1-17 years	8 years	5
CD4 Count	222-1365 cells/mm ³	639 cells/mm ³	349.3

Appendix H: Table 1.2: Participant Characteristics

Table 1.2 Sample Characteristics, N=16		
Characteristic	N	%
Education		
Less than High School	2	12.5%
High School/GED	3	19%
Some College	8	50%
2-Year College	2	12.5%
4-Year College	1	6%
Employment		
Currently Employed	1	6%
Unemployed	15	94%
Relationship Status		
Single	11	69%
Married	1	6%
Dating	4	25%
Health Insurance (yes/no)	16	100%
Annual Income		
<15,000	15	94%
15,001-30,000	1	6%
Viral Load Supression (yes/no)		
Yes (<48 copies)	15	94%
No (>200 copies)	1	6%

Appendix I: Figure 1.1: "Repurposing a Legacy"



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