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Long-term HIV Survivors' Beliefs about Aging and a Cure

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2016

Abstract

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by

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MA, California State University, Dominguez Hills 1999

BA, California State University, Long Beach 1976

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
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Abstract

Prior to 1996, the prognosis of HIV disease was near-certain death; however, biomedical advancements in the past 20 years established HIV as a chronic manageable disease with a nearly normal life span. Recent advancements suggest the potential for a cure. One outcome of current medical treatments is that 50% of all HIV positive individuals are older (≥ 50years), and a substantial number of those individuals are long-term (≥ 20 years) survivors. Existing research Qualitative research has provided little insight about what older long-term HIV survivors believe about their disease circumstances and aging with the disease. A qualitative method in the phenomenological tradition was used to explore older long-term HIV survivors' notions about aging with HIV and an HIV cure. The self-regulation model of illness representations and the preventive and corrective, proactivity (PCP) model of aging with HIV disease for older adults guided the study. Using strategically placed flyers in HIV services environments, 12 older long-term HIV survivors volunteered to describe their beliefs about aging with HIV and an HIV cure. Participants' statements were entered into discrete cells in an electronic spreadsheet (Excel) and were coded, sorted, and categorized. The categories were sorted for commonality, and emergent themes and subthemes were identified. Older long-term HIV survivors believed they had few issues aging with HIV, expected to live a long time, and believed that finding a cure would have little effect on their lives. These research findings may be beneficial to healthcare providers and researchers who provide quality of life interventions and information to older adults living long-term with HIV who are concerned about aging, longevity, and a cure.

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Dedication

The perseverance and outcome of this doctoral dissertation occurred, in part, because of the values instilled in me during my childhood and adolescence. My parents brought the best of what they knew to the family and have dedicated themselves to first nurturing and later supporting their children's dreams and endeavors. I want to thank Robert Lewis and Mary Jane Brewer for their continued encouragement during the time that I dedicated myself to the study of Health Psychology and the particularly the research of older long-term HIV survivors. In gratitude of your support Mom and Dad, this dissertation is dedicated to you.

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Chapter 1: Introduction

Since the first indication of the human immunodeficiency virus (HIV) in 1981, an estimated 658,992 individuals have died from HIV related illnesses (Chang & Lewin, 2014; Deeks, 2009; Halkitis, 2014). Even though health challenges associated with the side effects of antiretroviral (ARV) therapies and with the virus itself exist, many have survived the virus for 20 years and longer (Halkitis, 2014; Vergel, 2015). In fact, 50% of the total HIV population (1.2 million individuals) in the United States is 50 years of age and older (Moore et al., 2013; Vance, Bayless, Kempf, Keltner, & Fazeli, 2011; Vance, McGuinness, Musgrove, Orel, & Fazeli, 2011). From their lived-experiences with HIV disease, older long-term HIV survivors constructed their HIV disease beliefs as stressors and/or emotional responses (Anderson & Spencer, 2002; Halkitis, 2014; Kahana & Kahana, 2001).

Older long-term HIV survivors have developed internal and external conceptualizations of HIV disease, in part from the evolving psychobiomedical events affiliated with the HIV disease epidemic (Anderson & Spencer, 2002; De Cock, Jaffe, & Curran, 2011; Kahana & Kahana, 2001; Palmisano & Vella, 2011). As an illustration, 30 years ago the first events emerged that were eventually tied to HIV disease (De Cock et al., 2011). In the first cases of the disease that were observed, researchers portrayed the unnamed virus as a disease that predominately afflicted gay men and had an outcome of near certain death (De Cock et al., 2011). In contrast, the outcomes of widespread antiretroviral distribution have contributed to how older long-term HIV survivors experienced their disease. Most recently, the readily available information about HIV cure research could influence how older long-term HIV survivors represent their disease.

Further research by Barré-Sinoussi et al. (1983) and Gottlieb, Groopman, Weinstein, Fahey, & Detels (1983) led to describing the virus as acquired immune deficiency syndrome (AIDS) and naming it the human immunodeficiency virus (HIV). In 1996, the results of biomedical research efficacy (Palmisano & Vella, 2011) introduced antiretroviral medication therapies that dramatically reduced HIV-associated mortality and initiated the phenomenon of HIV patients living long-term with a chronic disease (De Cock et al., 2011; Halkitis, 2014; Palmisano & Vella, 2011). Recently, empirical psychological evidence has indicated that older HIV positive men presented with nearly equal psychological resilience scores compared to their age and gender associated HIV negative counterparts (Moore et al., 2013). In addition, a biomedical clinical procedure has reported one individual cured of HIV (Deeks & Barré-Sinoussi, 2012; Nema, 2015). Finally, older HIV positive adults have stated their interest in participating in HIV cure clinical trials regardless of the potential of personal harm that could occur during the clinical trial (Kall et al., 2015; Simmons et al., 2015).

Anderson and Spencer (2002) stated that individuals living with chronic illnesses develop cognitive perspectives of their disease which in turn influence their beliefs about their disease circumstances. Yet, there is little phenomenological information about older long-term HIV survivors’ beliefs of their long standing experiences in the evolution of HIV disease. In particular, there is a dearth of exploration of older long-term HIV survivors' beliefs about aging with the disease and the emergent possibilities of an HIV cure. Therefore, the imperative of the present study is to explore older long-term survivors' psychological experiences of aging with HIV disease and their viewpoints about a cure for HIV disease.

In chapter 1, I include a summary of the existing literature about the background of HIV disease. The problem statement informs the relationship between the designated variables and identifies relevant gaps in the literature. In addition, I introduce the conceptual and theoretical frameworks, research design and rationale, variables of interest, and assumptions, all of which further serve to rationalize the imperative of the present study. In addition, I provide information of the present study's scope, delimitations, limitations, and significance, which bound the study of aging with HIV and an HIV cure.

Background

The biomedical advancements in HIV disease management have influenced the beliefs of HIV positive adults (Anderson & Spencer, 2002). From interviews with a diverse group (*n* = 58; 41 men; 40% Black) of HIV positive adults (mean age = 42) with a disease history mean of nearly nine years, Anderson and Spencer (2002) codified 11 themes as viewing AIDS as death, destroying the body, and imaging HIV as simply a disease. Participants' responded to the circumstance of the disease by putting the disease out of their minds, wishing for the right drug (treatment or cure), and taking care of themselves. In the current paradigm of the HIV disease epidemic, many individuals 50 years and older living with HIV disease have been exposed to at least 20 years of internal and external HIV disease experiences. The present study will explore a diverse sample of older long-term HIV survivors' current beliefs of their HIV disease circumstances.

During the first 15 years of the HIV epidemic, individuals diagnosed with the virus experienced physical and psychological suffering and nearly certain death (De Cock, Jaffe, & Curran, 2012). However, in 1996 the widespread introduction of HIV antiretroviral medications transformed the HIV/AIDS disease paradigm from dying and death to surviving the disease (De Cock et al., 2011). In addition, many individuals not only survived the debilitating side-effects of the first variants of antiretrovirals but they experienced increased lifespans (American Academy of HIV Medicine & America, 2011; Burgoyne, Rourke, Behrens, & Salit, 2004; Johnston & Barré-Sinoussi, 2012). Recently, in the context of their lived-experiences, older gay male long-term HIV survivors were described as living and thriving with the disease (Halkitis, 2014).

The continued biomedical developments in HIV disease management have influenced the population characteristics of those living long-standing with HIV disease (Anderson & Spencer, 2002; De Cock et al., 2011, 2012). Since 1981, HIV researchers have identified and named the virus, identified HIV antibodies in the bloodstream, mapped the replication sequence of HIV, suppressed HIV replication capabilities, eliminated the human immunological virus (HIV-1) from the bloodstream in one individual, and proposed numerous proof-of-concept cure strategies (Chang & Lewin, 2014; De Cock et al., 2011, 2012; Deeks, 2013; Gant, 2012; Hütter et al., 2009). Of particular note are the phenomena associated with HIV disease management.

The numbers of HIV positive individuals aging with HIV disease have increased dramatically since 1995 (Centers for Disease Control and Prevention [CDC], 2013a; Emlet, 2006; Emlet & Farkas, 2001; Emlet, Gerkin, & Orel, 2009). At the end of 1997, one year after the introduction of the first antiretroviral medications, an immediate and significant decrease in HIV disease related mortality (64%) occurred and contributed to HIV positive adults surviving, then thriving and aging with the disease (Cahill & Valadéz, 2013; CDC, 2013b; Halkitis, 2014). The prevalence of HIV disease has grown to pandemic proportions (De Cock et al., 2012). One outcome of decreased HIV related mortality is increased heterogeneity in the HIV population (CDC, 2013a).

The rate of HIV prevalence is skewing toward older adults, long-term HIV survivorship, ethnicity, and gender (Johnson, Wray, Goulding, & Reynolds, 2012). Older adults (≥ 50 years) represent approximately 50% of the entire HIV population (Moore et al., 2013; Sankar, Nevedal, Neufeld, Berry, & Luborsky, 2011; Vance, Bayless, et al., 2011; Vance, McGuinness, et al., 2011). This cohort of adults 50 years and older includes individuals who have survived 20 years and longer with HIV disease (Halkitis, 2014; Vergel, 2015).

The rates of new HIV diagnoses are increasing among older African Americans and Hispanic/Latinos and particularly women in both of these ethnic/racial groups (CDC, 2013a). The increase in HIV diagnoses and prevalence among older adults living with

HIV disease elucidates the increasing number and heterogeneity of older long-term HIV survivors (Abrass et al., 2013; CDC, 2013a; Vance, Bayless, et al., 2011). Now, this diverse group of older adults aging long-term with HIV is experiencing the possibility of an HIV cure.

After a clinically-based HIV cure research procedure was published in 2009 that identified one 40 year old male cured of HIV disease, there has been an increase in biomedical HIV cure research strategies but little psychological information published on the topic (Brown, 2015; Chang & Lewin, 2014; Deeks & Barré-Sinoussi, 2012; Simmons et al., 2015). For example, empirical biomedical research includes stem cell transplants, gene therapy, latent HIV activation, viral replication reduction, and increased immune response (Chang & Lewin, 2014). Recent phenomenological research of an HIV cure from a population sample of older HIV positive adults indicated an HIV cure was important to them, and they expressed interest in participating in HIV cure clinical trials despite the potential for personal risk (Kall et al., 2015; Simmons et al., 2015).

Problem Statement

Currently, older (≥ 50 years) HIV positive individuals are estimated to be 50% of all HIV positive adults in the United States (Moore et al., 2013; Vance, McGuinness, et al., 2011). Some individuals who have survived long-term with HIV disease and have also aged into the category 50 years and older have escaped death, survived medication toxicity, and experienced aging with chronic illness (Halkitis, 2014). In fact, today in the diverse spectrum of older long-term HIV survivors, many identify themselves as thriving while living with HIV disease (Halkitis, 2014). Adults living with chronic illness have developed representations of their disease which influence their coping strategies and individualized perceptions of their disease circumstances (Anderson & Spencer, 2002).

Currently in the evolution of the HIV epidemic, many HIV positive adults 50 years and older have been aging long-term with HIV disease. Additionally, an HIV cure appears attainable (Deeks & Barré-Sinoussi, 2012). However, there is little information about older long-term survivors' views of aging and an HIV cure. In this growing and increasingly diverse population of older long-term HIV survivors, an exploration of older long-term survivors' beliefs about aging with HIV disease and an HIV cure will add to the existing information about this vulnerable cohort.

Purpose of the Study

The present study is grounded in two psychological health models. The first of these health models, self-regulation illness representations, suggested that adults living with chronic disease developed images and beliefs about their disease circumstances. The second model, the preventive and corrective, proactivity (PCP) model of aging with HIV disease for older adults, theorized that older HIV positive adults can experience successful aging with HIV disease. Both models posited older HIV positive adults choose coping mechanisms based on their assessments of their images and beliefs.

The PCP model of aging with HIV disease for older adults serves as the framework for understanding aspects of individuals aging and living long-standing with HIV disease (Kahana & Kahana, 2001). Second, in an era replete with HIV cure research, the self-regulation model of illness representations will be used to understand the older long-term survivors' cognitive perceptions of their disease (Anderson & Spencer, 2002; Leventhal, Leventhal, & Cameron, 2001).

Currently, there is a dearth of information about the beliefs that older long-term HIV survivors harbor about aging with HIV and the emergent HIV cure research. Thus, the purpose of the present study was to explore and consequently describe older longer-term HIV survivors' beliefs about aging and an HIV cure. The results from this phenomenological exploration were intended to add additional information about the psychological experiences of older long-term HIV survivors. The resultant information will benefit the health care providers who provide services to older long-term HIV survivors.

Research Questions

Studies related to individuals' beliefs about an HIV cure have included HIV positive individuals in their 40s (Anderson & Spencer, 2002), and more recently an older subgroup of HIV positive individuals were participants in a study of their beliefs about participating in HIV cure clinical trials. Yet, much of the phenomenological research about older HIV positive adults' lived-experiences with aging has focused on older gay men (Halkitis, 2014). In the present study, a broader spectrum of older individuals surviving long-standing with HIV was explored. Older long-term HIV survivors were asked open-ended questions about their beliefs of aging with HIV disease and their viewpoints about the current biomedical advancements of an HIV cure. Responses from the study participants were used to answer the following research questions:

RQ1: What beliefs do older long-term HIV survivors maintain about aging with HIV disease?

RQ2: How do older long-term HIV survivors' experiences of aging with HIV disease relate to and contribute to their current life experiences?

RQ3: What beliefs do older long-term HIV survivors maintain about an HIV cure?

RQ4: How do older long-term HIV survivors view an HIV cure as a part of their long-term HIV survival?

RQ5: How do older long-term HIV survivors view a cure in their future?

RQ6: How do older long-term HIV survivors resolve their lived-experiences and beliefs about a cure for HIV disease and aging with HIV disease?

Conceptual Framework and Theoretical Foundation

Conceptual Frameworks of Aging

Ancient philosophers who observed the process of aging expressed altruistic and pragmatic viewpoints. Aristotle (Rackham, 1947; Ryff, 1989) proposed that aging was a necessary process to reach the apogee of human capacity: divine connection and intellectual vigor. According to Baltes, (1987), two hundred years later Cicero noted the importance of aging successfully required an accounting of the physical, cognitive, and spiritual dimensions of human existence.

From the 1950s to the present, social scientists' characterizations of aging have evolved from observations that older adults experienced detachment from life activities in preparation for death (Cumming & Henry, 1961) to aging successfully which was expressed as freedom from disease and disability (Rowe & Kahn, 1997). In addition, researchers of older adults and their aging defined aging outcomes as an idiosyncratic value expressed only in the terms of an individual's own experience (Havighurst, 1961; Moore et al., 2013).

Theoretical Foundation of Self-Regulation Illness Representations

The first theoretical framework for the present exploration is the self-regulation illness representations model (Leventhal et al., 2001). Leventhal et al. (2001) noted that individuals in illness-disease situations possessed inherent characteristics to solve problems. During the time an individual has lived in an illness-disease situation, individuals used an iterative process to understand, cope, and regulate their disease circumstances (Anderson & Spencer, 2002). Additionally, an individual's emotions will contribute to the images and beliefs and influence any action to be taken. During the iterative process of self-regulating illness images, individuals reevaluated, reshaped their images of, refined their beliefs about, and experienced emotional reactions to their illness-disease circumstances (Leventhal et al., 2001).

Theoretical Foundation of Successful Aging with HIV Disease

The second theoretical framework for the present investigation is the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001; Kahana, Kelley-

Moore, & Kahana, 2012). Kahana and Kahana (2001) proffered that older adults living with HIV disease could achieve successful aging outcomes such as self-confidence, life meaning, continued activities involvement, and supportive relationships. Furthermore, Kahana and Kahana (2001) stated the achievement of successful aging among older adults could be achieved when individuals' pre-emptively employed hope, selflessness, self-worth, positive well-being, deterrent-mitigating, and take-charge behaviors (Martin et al., 2014). The present study used the PCP model of aging with HIV disease for older adults to understand older long-term HIV survivors' descriptions of aging with HIV disease.

Nature of the Study

Design Tradition and Phenomenon

The present study employed a qualitative research design and methodology in the phenomenological tradition. Underlying the present study is the assumption that participants have different beliefs about similar experiences (Anderson & Spencer, 2002; Chang & Lewin, 2014; Creswell, 2007; Moustakas, 1994). Using a telephone interview technique, older long-term HIV survivors were asked to explore their attitudes about aging with HIV disease and a cure for HIV disease. Their responses were recorded and transcribed verbatim (Moustakas, 1994).

Since the existing literature offers scant information about the phenomenon of older long-term survivors, older long-term HIV survivors themselves and health care professionals can increase their understanding of two vectors in the HIV disease paradigm (Anderson & Spencer, 2002). The first is aging and living long-term with HIV disease. The second vector is the emergent research toward an HIV cure. The present exploration included only older (≥ 50) self-identified men who experienced living 20 years or longer with HIV disease, and therefore are aging with HIV disease and having lived-experiences with HIV biomedical antiretroviral treatment and a single instance of an HIV cure. Therefore, HIV support environments such as AIDS Services Foundation (ASF) and clinical HIV specialists' offices were carefully chosen for recruitment of individuals representing the heterogeneity of older long-term survivors.

The design of the present study facilitated an in-depth phenomenological exploration of two constructs in the evolving HIV epidemic: aging with HIV disease and an HIV cure. As noted by Creswell (2007) and Moustakas (1994), a qualitative design with phenomenological intent is applicable because the aim of the study was to explore a phenomenon, and describe the common themes from the compilation of the participants' experiences, beliefs, and actions. In addition, participants had the common characteristic of living ≥ 20 years with HIV (Creswell, 2007; Moustakas, 1994). These factors in the approach afforded an opportunity to discover and describe prevailing beliefs from the older long-term survivors' experiences with the phenomena of aging with HIV and HIV cure scenarios (Moustakas, 1994).

Definitions

Antiretroviral medications: Drugs prescribed to control the human immunodeficiency virus. Often several antiretroviral drugs are prescribed to control the virus. Different types or classes of antiretroviral agents interrupt the HIV life-cycle at different stages (Moore & Chaisson, 1999).

Centers for Disease Control and Prevention (CDC): The national epidemiological agency tasked to protect the United States of America and its six dependent areas from foreign and domestic health, safety, and security threats. The CDC (2014a) combats the effects of disease and provides communities and citizens with tools such as epidemiology, guidelines, and critical science research.

Dormancy or Latency: A reversible and nonproductive infection. Dormant infected cells are not capable of initiating an infection virus but retain the capacity to do so with various stimuli (Chang & Lewin, 2014; Eisele & Siliciano, 2012).

HIV biomedical advances: In this current study, indicates the pharmacological (e.g., Truvada), surgical (e.g., stem cell transfusion) and proof of concept research (e.g., RNA HIV splicing) techniques used to decrease viral transmission and virus replication. These advances are also referred to as *HIV cure strategies*.

HIV Cure –functional: A state of long term (5 years) health in the absence of combination antiretroviral medications. Low levels of HIV RNA are present at < 50 copies/mL (Chang & Lewin, 2014; Eisele & Siliciano, 2012).

HIV Cure –sterilization: When all HIV-infected cells and infectious virus are eliminated from an individual (Chang & Lewin, 2014; Eisele & Siliciano, 2012).

HIV infection Stages:

- *Stage 0:* The HIV infection stage is unknown with no reported information on AIDS-defining conditions and no information available on CD4 count or percentage. (CDC, 2013a, p.11).
- S*tage 1:* No AIDS-defining condition and either CD4 count of ≥ 500 cells/µL or CD4 percentage of total lymphocytes of ≥ 29.
- S*tage 2:* No AIDS-defining condition and either CD4 count of 200–499 cells/µL or CD4 percentage of total lymphocytes of 14–28.
- S*tage 3:* (AIDS): Documentation of an AIDS-defining condition or either a CD4 count of < 200 cells/µL or a CD4 percentage of total lymphocytes of < 14. Documentation of an AIDS-defining condition supersedes a CD4 count or percentage that would not, by itself be the basis for a stage 3 (AIDS) classification.

Human Immunodeficiency Virus (HIV): The retrovirus generally agreed to cause acquired immunodeficiency syndrome (AIDS); symptoms of HIV infection can include opportunistic infections, developmental regression, and immune system dysfunction; comorbid factors associated with pharmaceutical management of viral replication is considered a separate issue (See *HIV Disease Stages,* this section).

Long-term HIV Survivor: A term used in social science literature to define a person who has lived with HIV in two timeframes, either 15 years (Halkitis, 2014) or ≥ 20 years since diagnosis (Kahana & Kahana, 2001). There is no consensus on the period of time used to define a long-term HIV survivor. However, Halkitis (2014) noted that definitions of long-term HIV survivorship have been contingent upon the period in which survivorship was discussed. With the introduction of antiretrovirals, the definitional timeframe increased. Biomedical factors also influence the definition of long-term survivorship. In addition, there is no consensus or empirical data about the number of long-term HIV survivors (Vergel, 2015).

Recently, a group of individuals exhibiting a disparate course of clinical disease were identified as "discordant controllers" (Groves et al., 2012). In addition, definitions based upon the "normal range" of CD4 T-cell counts can be misleading because natural diversity among CD4 T-cell count within and between ethnic populations exists (Imami, Westrop, Grageda, & Herasimtschuk, 2013).

Men who have sex with men (MSM): Men who may self-identify as heterosexual, straight gay, homosexual, or bisexual (Halkitis, 2014).

Older adult (≥ 50 years) living with HIV Disease: A definitional category promoted by the CDC and used by most social science researchers, epidemiologists, and healthcare providers (CDC, 2013a). Although age 50 is not a typical definition of an older person, particularly in the gerontological literature, there is an historical precedent for this age distinction. At the onset of their surveillance reporting, the CDC stratified all individuals with AIDS more than 49 years of age into one age category. The scientific literature has also adhered to this classification, routinely referring to individuals 50 years and older who are infected with HIV as "older adults" (Kirk & Goetz, 2009). The age 50 and older demarcation may have reached its zenith as stated by Vance, Struzick, and

Masten (2008). In addition, Vance et al. (2008) noted that despite the long-time use of the term older adult (≥ 50 years), it may now reflect ageism, and despite its history of delineating accelerated aging associated with HIV disease, it may no longer be important to bring attention to the cohort. Furthermore, Moore et al. (2013) concluded older HIV positive men's psychological resilience approaches that of older HIV negative men.

Reservoir: A population of HIV infected cells that can persist in patients prescribed combination antiretroviral treatment. A reservoir can exist in the blood stream, as a cellular (e.g. resting memory T-cells or macrophages) entity, or in an anatomical location (e.g. the central nervous system, testis, or lymphoid tissue). Another reservoir is a compartment or an anatomical site where there is limited exchange of viral genetic information with other sites (Chang & Lewin, 2014; Eisele & Siliciano, 2012).

Sanctuary: An anatomical location, a sanctuary has less than optimal levels of antiretroviral medication compared to the blood stream (Chang & Lewin, 2014; Eisele & Siliciano, 2012).

Seroconversion: The point in time when an individual was either aware of or given a diagnosis indicating conversion from HIV negative to HIV positive (infected with the human immunodeficiency virus).

Virion: A structural aspect of retroviruses that have the ability to assemble particles inside a host cell and leave the cell to further replicate itself in other cells. The virion lifecycle has three stages: after a mature virion binds and inserts itself in the host cell (i.e., CD4); particle assembly occurs inside the host cell (i.e., CD4); then budding occurs when the virion leaves the host cell; and maturation occurs outside the host cell and the virion becomes infectious. The human immunodeficiency virus (HIV) is a retrovirus (Klimas, O'Brien-Koneru, & Fletcher, 2008).

Assumptions

Data collected from older long-term HIV survivors was self-reported, and it was assumed that participants answered truthfully about their lived-experiences, viewpoints of aging with HIV, and their beliefs of an HIV cure. It was possible that participants over or under reported their overall psychological well-being related to aging with HIV disease because of circumstances on the day of the interview. In addition, it was possible participants reported their knowledge about HIV from casual conversations rather than cure strategies available from scientific resources. In addition, it was assumed that participants' knowledge of HIV cure research may have been influenced by interest level, research skills, and access to information. As noted by Anderson and Spencer (2002), individuals' approaches to illness are formed, in part, from available information sources.

Scope and Delimitations

Participants for the present study sample were recruited from Orange County in southern California. It was expected the sample represented a fraction of the number of older long-term survivors available in these geographically adjacent counties. Additionally, the participant sample was bounded by age and length of HIV disease exposure. Therefore, participants were all older (≥50) long-term HIV survivors (≥20 years), of any gender identity, and of any ethnicity/race. Participants were not disqualified to participate based on self-identified or perceived gender or sexual identity, or ethnicity/race. This study employed the telephone to conduct interviews (Creswell, 2012; Creswell, Hanson, Plano-Clark, & Morales, 2007; Shenton, 2004).

In addition, recruitment flyers were displayed at HIV/AIDS service and health related venues such as AIDS Services Foundation (ASF), HIV physicians' offices, and counties' clinics providing HIV treatment. However, not everyone in the population of older long-term survivors obtained assistance from HIV/AIDS organizations. Some individuals could be excluded from the study if they did not access social services organizations such as ASF because an individual may have self-sustainable wealth, speak only Vietnamese (at the time of the study ASF did not have Vietnamese speaking case workers), or be without access to transportation. Finally, it is unclear whether individuals in the ≥50 age demographic responded to a passive flyer to participate in an academic study of HIV disease. However, it was possible that recruitment was assisted by verbal reference to the study from case workers or health care providers in the venues where the flyers were available. It is important to recognize neither the former nor latter providers suggested or encouraged participation to this study.

The present study was designed and the interviews were conducted by me. It is worth noting that I am 66 years old and have been diagnosed with HIV disease since September 1997, which indicated a similarity to the participants who were recruited for the present study. In response to the potential for researcher bias, I suspended my experiences from the present study constructs to ensure objectivity in the identification and synthesis of the common themes from the representative voices of older long-term HIV survivor sample (Anderson & Spencer, 2002; Creswell, 2007; Halkitis, 2014). My biases and how I addressed them are identified in greater detail in chapter 4 in the section entitled Setting.

Limitations

A limitation of the present study was external validity. There is limited comprehensive empirical information about older long-term survivors' and their beliefs about aging with HIV disease and a cure for HIV disease (Kall et al., 2015; Simmons et al., 2015). In addition to limited phenomenological data about aging and biomedical HIV advancements, definitions of self-reported successful aging often lack specific input from the study participants (Cosco, Prina, Perales, Stephan, & Brayne, 2013; Karpiak, Shippy, & Cantor, 2006; Moore et al., 2013). Although qualitative investigations have left successful aging to be defined by the participant, individuals' lived experiences describe idiosyncratic characteristics of successful aging (Emlet, Tozay, & Raveis, 2011; Halkitis, 2014). In the present study, participants described their beliefs about aging with HIV disease and their viewpoints of a cure for HIV disease.

Lastly, I am an older adult living long-term with HIV disease. My experience does not include a perspective or experience with disease vulnerability, stigma, or oppression. I monitored my judgement of those whose perceptions and experiences were different from mine. I expressed my biases in my journal and verbalized these experiences in support group forums associated with HIV disease and aging.

Significance

Recent HIV cure clinical trials excluded some older HIV positive adults (Sax et al., 2014). For example, cure scenarios for each cure treatment required a specific patient strategy or a definition of the likelihood of achieving a positive cure outcome or each patient (Anderson & Spencer, 2002; Sax et al., 2014). Factors for consideration in HIV cure treatments included patients' capacity to endure the toxicity of the cure treatment, decreases or increases to an individual's quality of life associated with both toxicity and the compliance requirements the treatment, and finally, the overall specific post-treatment intervention costs associated with long-term HIV antibody testing.

There are few germane health models corresponding to the changes in the HIV paradigm that included adults aging long-term with HIV disease who may face exclusion from HIV cure scenarios (Sax et al., 2014). Qualitative results from a recent international population sample (*n* = 982; 49% aged 45-64) of HIV positive adults, indicated that if participation in an HIV cure clinical trial required HIV medication treatment interruption, 59% would participate in the HIV cure research (Kall et al., 2015). Next, effective social change includes empowerment opportunities for individuals to participate in their future (Baumgartner & Niemi, 2013). In addition, according to Frankl (1984) and Kahana and Kahana (2001), meaningful living can exist in the presence of adversity. Lastly, Vance et al. (2011) noted that in the evolutionary continuum of HIV disease, individuals' experiences uniquely influence decision-making. Thus, the present qualitative study will serve to encourage participation in and use of phenomenological data to describe older long-term HIV survivors' aging with HIV disease and HIV cure related perspectives.

Summary

Chapter 1 established the HIV disease epidemic emerged abruptly and was identified in the early 1980s, HIV disease management began with the introduction of antiretrovirals in 1995, and individuals with HIV disease continue to experience stressors and live effectively with the disease. Additionally, adults living with chronic illness created images and beliefs about their disease circumstances, revised them, and used those images as part of the activity of selecting coping mechanisms. In particular, a subgroup of HIV positive individuals has emerged who have long-standing experience with HIV disease. They are 50 years and older living long-term (≥ 20 years) with HIV disease. Individuals in this subgroup would have sero-converted prior to or at the beginning of the widespread availability of HIV antiretroviral drugs in the mid-1990s.

Notwithstanding, older long-term HIV survivors have been influenced by biopsychosocial events associated with the HIV epidemic. For example, older long-term HIV survivors may have observed the transition of HIV disease from diagnoses of dying and death to increased lifespans that occurred from the HIV biomedical advancements of HIV antiretroviral therapies. Now, in the current period of the HIV epidemic older long-term survivors experience an increasingly greater likelihood that a cure for HIV will become available before they die. Thus, it is important to describe the beliefs individuals in this cohort harbor about aging with HIV disease at the dawning of an HIV cure.

Also, chapter 1 established that there is limited phenomenological exploration about older long-term HIV survivors' viewpoints of aging and an HIV cure. Furthermore, research questions were presented that will inform the gap of information in the existing literature. As a means to understand the results of the present exploration, historical conceptualizations of aging were introduced. Next, two theoretical models, the self-regulation model of illness representations, (Anderson & Spencer, 2002; Leventhal et al., 2001), and the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001) were introduced.

In chapter 2 the experiences of older long-term HIV survivors is discussed. Chapter 2 is anchored by an historical discussion of the conceptualization of aging and aging successfully. Next, the self-regulation model of illness representations (SRIR) is reviewed; SRIR served to frame the iterative process of forming beliefs about illness and disease and coping responses (Anderson & Spencer, 2002; Leventhal et al., 2001). In addition, the PCP model of aging with HIV disease for older adults presented the concept of successful aging outcomes using adaptive behaviors (Kahana & Kahana, 2001). Then, a discussion of biomedical events that influenced long-term survivors' lives is presented. Next, the literature of older adults aging with HIV disease is reviewed and an HIV cure literature is discussed.

In chapter 3 an overview of the qualitative methodology is provided, and the phenomenological approach of the study is discussed. Next, the research questions are introduced. Then, the role of the researcher is discussed. Lastly, the proposed sampling procedure, recruitment process, data capture method, pilot study procedure, and the data analysis plan are discussed.

Chapter 2: Literature Review

Introduction

Since 1996, the widespread use and efficacy of HIV antiretroviral medications has contributed to individuals aging with HIV disease. Notably, HIV positive adults 50 years and older are estimated to represent 50% of the overall population of adults living with HIV disease (Moore et al., 2013). In addition, it is estimated that a substantial number of individuals in the older HIV positive cohort have lived at least 15 years or longer with HIV disease (Vergel, 2015). Individuals in this subgroup are identified as long-term survivors (Halkitis, 2014). Furthermore, individuals in the 45-49 age group (CDC, 2013d) will contribute (e.g., 175,591 in 2010) to an increase in the number of older long-term HIV survivors. Subsequently, an estimated 500,000 older long-term HIV survivors (Appendix A) aging with HIV disease are poised to experience the next biomedical advancement in the evolution of HIV disease: a cure.

Problem Statement and Purpose

During the evolution of the HIV epidemic, many older long-term HIV survivors had varied experiences that influenced their beliefs about their disease situation. Notably, Anderson and Spencer (2002) described the variability and complexity that HIV positive adults maintain about their disease state and the influence on their disease circumstances beliefs. Some participants in the Anderson and Spencer study (2002), viewed their disease situation as simply an illness, while AIDS survivors believed AIDS was decimation and death (Anderson & Spencer, 2002). Since the results of this exploration of HIV positive adults were published, epidemiological and biomedical changes in the HIV paradigm have occurred.

The population of HIV positive adults over 50 years of age has increased and has become more diverse (Anderson & Spencer, 2002; CDC, 2013a). For example, 50% of the total number of adults living with HIV disease is 50 years and older (Sankar et al., 2011). From 2007 to 2009 the estimated percentage of older adults living with a diagnosed case of HIV disease increased 14.3% (CDC, 2013a). In addition, the disparity of HIV diagnoses is noticeable among older African American (12.6 in 100,000), Hispanic/Latino (5.0 in 100,000), and White (3.9 in 100,000) populations (CDC, 2013a) and has influenced the demographics of the HIV disease epidemic.

The feasibility of an HIV cure has become more probable. HIV cure research has increased since one individual was identified as cured of HIV in 2009. Over 100 HIV cure clinical trial studies are in the National Institute of Health (NIH) queue (Peay & Henderson, 2015), the International AIDS Society (IAS) identified an HIV cure as its preeminent global strategy (Deeks et al., 2012), and HIV positive adults have self-identified themselves as willing to be involved in HIV cure clinical trials (Pebody, 2015; Simmons et al., 2015). Despite the increased emphasis on HIV cure studies there is little phenomenological information about what older long-term HIV survivors believe about aging with HIV and their viewpoints about an HIV cure. The purpose of the present study is to provide additional understanding of older long-term HIV survivors' beliefs about their disease circumstances. Healthcare providers who serve the older HIV positive community will have more information about the older cohort aging with HIV disease and their viewpoints about an HIV cure.

Synopsis of the Literature to Establish Relevance

Three constructs have been used to establish the social relevance of the present exploration of older long-term HIV survivors aging and HIV cure beliefs. First, relevant epidemiological data has established the effect of HIV disease. Furthermore, relevant literature established that there is little information about older long-term survivors' beliefs about aging with HIV and their viewpoints of an HIV cure. Finally, the relevance of the aging and HIV cure constructs are linked with two theoretical frameworks. First, the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001) suggests managing stressors (e.g., aging and a cure) with adaptive behaviors will improve successful aging outcomes. Second, the self-regulation illness representation model (Leventhal et al., 2001) posits individuals living with chronic illness develop images and beliefs about their illness situation from their experiences. Thus, older adults aging long-term with HIV disease have formed beliefs about their disease circumstances in a period when an HIV cure has been identified as viable (Anderson & Spencer, 2002; Leventhal et al., 2001).

In the United States, the introduction of medications that manage HIV disease contributed to the dramatic increase of persons aging with HIV disease (CDC, Division of HIV/AIDS Prevention, 2016). Within 20 years of the widespread distribution of antiretrovirals, 50% of the total HIV population was adults over the age of 50 (Vance, McGuinness, et al., 2011). In addition, many of the individuals 50 years and older have been living 20 years and longer with HIV (Halkitis, 2014; Vergel, 2015). Finally, the diversity of the older long-term HIV survivor population has become more diverse (CDC, Division of HIV/AIDS Prevention, 2016). The epidemiological data about older long-term HIV survivors demonstrated the relevance to explore the cohort of older long-term HIV survivors.

In the present exploration of older long-term HIV survivors aging with HIV, I discuss the historical conceptualizations of successful aging. A review of the literature empirically established the transformation in the understanding of successful aging. Early successful aging viewpoints described individuals as aging successfully when they lived without illness or disability, were active and happy (Baltes, 1987; Havighurst, 1961; Rowe & Kahn, 1987). Continued research of successful aging included definitions and characterizations of the acquired immune deficiency syndrome (Baltes & Baltes, 1990; Ryff, 1989). In addition to researchers' observational research of successful aging, input from older adults began to be included in the criteria for successful aging (Bowling, 2007; Havighurst, 1961).

In parallel with the research of successful aging, antiretroviral medications had begun to be widely distributed in the United States in 1996. One outcome of the availability of antiretrovirals was the dramatic increase in HIV positive adults surviving and living longer with the disease. In 2001, Kahana and Kahana (2001) published a theoretical model that identified how life stressors influenced the adaptive coping mechanisms of older HIV positive adults. In addition, Kahana and Kahana (2001) posited that older HIV positive adults could prevent, correct, and proactively change the outcomes of the life stressors.

Examples of successful aging were reported among older HIV positive adults. In 2014, Halkitis (2014) reported that most individuals within the study sample (*n* = 14) of older HIV positive gay males living long-term with HIV disease were thriving. In addition, Moore et al. (2013) published qualitative data from a controlled study of HIV negative and positive older men (*N* = 166), which identified that the strength of psychological adaptability between HIV positive older men was statistically significant (*p* = .007). However, information about the viewpoints older adults have about aging with HIV disease is limited. In addition to positive outcomes of aging and improved psychological resilience from the widespread distribution of antiretrovirals in the United States, another HIV biomedical advancement, an HIV cure, is emerging in the HIV disease paradigm.

HIV cure research strategies are increasingly more visible in the media (Davies & Fox, 2015; Joint United Nations Programme on HIV/AIDS, 2004). Several proof-of-concept HIV cure strategies have been published since 2009 (Chang & Lewin, 2014; Sax et al., 2014), although only one individual has been identified as cured of HIV disease (Chang & Lewin, 2014). In spite of the propensity of readily available HIV cure information, it is estimated that a implementable cure is 15 years in the future (Davies &

Fox, 2015). In addition, the parameters of HIV cure research have been identified by HIV researchers (Deeks, 2012).

The standards for developing a cure included cost consciousness, minimally invasive treatment, outcome expectations of an HIV cure, HIV cure clinical research participation, and ethical guidelines. Deeks (2013) defined the need for less costly treatment and less intrusive HIV cure options. Examples of lesser cost and less invasive cure treatments included activation of latent HIV in the blood stream and boosting the natural immune response to HIV (Chang & Lewin, 2014; Deeks et al., 2012). Outcomes of an HIV cure included determining whether eradication of the virus in the human body is the only outcome (Deeks, 2013). Lastly, HIV cure research has achieved sufficient progress that the guidelines for clinical trials are being investigated (Peay & Henderson, 2015). Despite the biomedical research for an HIV cure, there is minimal information on beliefs about an HIV cure from those who have been living for over 20 years and consequently aging with HIV disease. The following sections expand and codify the spectrum of older long-term HIV survivors aging at the beginning of HIV cure research.

Literature Search Strategy

The research and scholarly literature material was accessed from Pubmed, CINAHL, Medline, ERIC, ProQuest, and Health Star databases using the search engine Scholar.Google.com. The following keywords for the primary search were used to initiate a search of successful aging among older HIV positive persons: *successful aging, self-reported successful aging (SRSA), 2011-2015*. Additional search criteria variations were used to investigate other constructs of the primary topic: *HIV/AIDS, older adults,* and *successful aging; self-reported successful aging (SRSA),* and *HIV; aging, HIV,* and *resilience; aging, HIV, adults over 50, self-reported successful aging (SRSA),* and *qualitative; HIV/AIDS, adults over 50,* and *resilience; HIV/AIDS, adults over 50; long term survivors of HIV/AIDS, older adults,* and *qualitative.*

Prominent themes required additional search criteria necessary to define the issues older adults experience when living with HIV/AIDS. These search criteria included: *HIV disease epidemiology; HIV/AIDS psychological characteristics; HIV/AIDS;* and *demographic characteristic of HIV/AIDS, including race, ethnicity, region, gender,* and *transmission routes*. Next, search criteria were necessary for the HIV cure segment of the study: *HIV Cure, HIV biomedical prevention, older adults,* and *HIV cure.*

Lastly, in order to be apprised of the most recent publications about the subject matter, the alert utility in Scholar.Google.com was implemented. Three search criteria strings were established for the years 2011-2015. They were: *HIV Cure, qualitative,* and *older adults; long-term survivors, HIV,* and *older adults;* and *HIV cure, phenomenology, qualitative, survivor, older adults, long-term survivor, non progressor, and exclusions for Africa, Argentina, Asia, Australia, Brazil, India, Philippines, and Taiwan.*

Conceptual Framework and Theoretical Foundations

The first discussions about aging were philosophical in nature with the earliest written discussion attributed to the 4th century BCE and then in the 1st century BCE. However, scientific discussions of aging did not emerge until the mid-20th Century.

These mid-century discussions described aging outcomes. Aging discussions reemerged again in the late 1980s with an emphasis on an olio of processes and theories dedicated to aging successfully. In the 1990s successful aging research included individuals living with disability (Ouwehand, de Ridder, & Bensing, 2007). By 2001, the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001) was published. Lastly, the self-regulation model of illness representations (Leventhal et al., 2001) is presented. The discussion of aging begins with Aristotle's conceptualization.

Ancient Notions of Successful Aging

Aristotle. The oldest known written accounts of aging successfully occurred before the Common Era (BCE). Aristotle (384 – 322 BCE) and Cicero (106 BCE – 43 BCE) observed and identified the notions of aging outcomes in their eras. Aristotle posited happiness was a process of achieving the pinnacle of human achievement, communion with the divines, and achievement of the highest human capacity - the intellect (Aristotle, 1893). Moreover, Aristotle stated cognitive activity is awareness, and the acknowledgement of the mortal, the noble, and the divine aspects of living (Aristotle, 1893; Ryff, 1989). Aristotelian ideals included belonging, helping others, thriving, and striving for excellence (Aristotle, 1893). Furthermore, the philosopher reasoned that achievement of happiness (eudemonia) or well-being in older age was the outcome of deliberate activities to merge the mortal being with the divines (Aristotle, 1893; Ryff, 1989).

Cicero. Three centuries later, Cicero characterized the unhappiness of aging emanated from withdrawal of one's pursuits, a weaker physicality, diminished physical pleasure, and the recognition of mortality (Cicero, 1909). The factors necessary to preserve vitality in older adulthood (Baltes & Baltes, 1990; Rowland, 2012) required awareness of a holistic perspective emphasizing the achievement of high functioning states of body, mind, and spirit (Rowland, 2012). Additionally, Cicero viewed aging as an adaptive mindset to facilitate positive aging and aging outcomes (Baltes & Baltes, 1990). Aristotle's rationalistic philosophy of deliberate action to achieve deliberate outcome, and Cicero's prescriptive holistic body, mind, and spirit health statements are the foundation for modern conceptualizations of successful aging (Baltes & Baltes, 1990; Bowling, 2007; Depp & Jeste, 2009; Ryff, 1989).

From the philosophical discussions of Aristotle (Aristotle, 1893) and Cicero (1909), two overarching aging themes emerged. First, Aristotle (1893) proffered engagement in life-long intellectual endeavors led one to participate in developing divine ideals of community, charity, thriving, and self-betterment. Life-long learning served as the underpinning to achieve the greatest of the positive aging outcomes: happiness (Ryff, 1989). Second, Cicero (1909) noted that aging successfully required the preservation of vitality, which was the result of the deliberate dynamic actions of exercise and diet in the body, mind, and spirit framework (Baltes & Baltes, 1990). Aristotle and Cicero suggested that aging is set of interrelated activities pursued for the long-term and with purpose.

Contemporary Conceptualizations, Theories, and Models of Aging

In the second half of the 20th century emergent aging conceptualizations contributed to an interest in the aging phenomenon. The first contemporary notion of aging suggested aging characteristics of older individuals included preparation for death (Cumming & Henry, 1961). However, other contrasting aging conceptualizations surfaced and empirical researchers indicated successful outcomes of aging occurred when older adults engaged in continued social involvement (Havighurst, 1961; Kahana & Kahana, 2001; Ryff, 1989). In response, other researchers concluded one dimension of the aging paradigm was inclusive of several processes.

Yet another new aspect of the aging paradigm emerged as researchers in the same period emphasized highly functioning corporeal and intellectual capabilities differentiated aging successfully and aging normally (Rowe & Kahn, 1987). Lastly and in contrast to the former notion of aging successfully, HIV positive individuals were identified as living successfully (Halkitis, 2014).The following four discussions detail the evolutionary contemporary explorations of aging.

Disengagement Theory. Cumming and Henry (1961) proffered one of the first theories of aging (Achenbaum, 1995) as a process. For example, an older adult prepared for death using complex reciprocating tacit agreements among entities that could involve the older adult and family. In addition, several assumptions underpin the theory of disengagement. According to Cumming and Henry (1961), the unstated agreements in the process of disengagement include older adults' recognition and acceptance of the inevitability of death, diminished social activities, recognition and acceptance of the changes in one's social role (e.g., breadwinner to grandfather), and the influence of societal infrastructures (e.g., social security). Furthermore, disengagement is influenced by an individual's ethnicity, economic status, sex, and gender). In the same time period, a coincident notion, the Activity Theory, countered the assumptions of passive acquiescence to the structures and pressures of a social framework.

Activity Theory. Havighurst (1961) proposed delayed aging and improved quality of life occurred if an individual actively pursued self-affirmation; retained and continued midlife beliefs, activities and attitudes; developed and embraced new life roles (e.g. from parent to grandparent); and preserved and invoked friendships. In addition, Havighurst (1963) expanded the original notion of the activity theory beyond social interaction, and included the characteristics of inner happiness and life satisfaction as successful aging characteristics. Havighurst (1961) noted that documenting older adults' viewpoints about aging adds depth and breadth to any definition; older adults' viewpoints created different outcomes than the results received from qualitative assessments. Thus, the activity theory emphasized the existence of a positive relationship between social activity and happiness. However, the activity theory, like the disengagement theory, failed to explicitly acknowledge individuals living with disease and disability when aging. Yet, both the disengagement and activity theories acknowledged the influence of the institutionalized retirement and individuals' understanding, willingness, and acceptance of the aging process (Schulz, 2006). After the introduction of the

Disengagement and activity theories, a noticeable time lapse occurred in the research of aging (Ouwehand et al., 2007).

Usual and Successful Aging. Rowe and Kahn (1987) distinguished usual aging from successful aging. Usual aging, according to Rowe and Kahn (1987) incorporated normal losses in physical and cognitive domains. In contrast, these researchers (Rowe & Kahn, 1987) promoted three essentially discrete factors comprised successful aging. The first factor was to avoid disease and disease associated disability that disrupted the achievement of healthy living standards. Next, an older adult must be highly engaged in mental and physical activities. Lastly, seniors need to pursue social involvement and activities. The usual and successful aging (Rowe & Kahn, 1987) construct received several responses from aging and gerontology research communities.

The usual and successful aging construct was challenged by researchers in the aging and gerontology communities. First, the usual and successful aging construct described a static state of successfully aged rather than a series of processes in which individuals participated in their lived experiences to achieve successful aging (Pearlin & McKean Skaff, 1996). Next, because the aging criteria had been fixed, Rowe and Kahn's (1987) aging construct failed to account for heterogeneous patterns of aging (Baltes & Carstensen, 1996). Lastly, the aging criteria in the usual and successful aging (Rowe & Kahn, 1987) construct were solely representative of westernized archetypes in a specific period (Holstein & Minkler, 2003).

Psychological Well-Being. In the late 1980's, a literature review by Ryff (1989) consolidated the extant aging literature about positive psychological behaviors. From Ryff's (1989) amalgamated review of aging literature, a model of aging processes emerged. Using the Aristotelian viewpoint of happiness as the theoretical basis, Ryff (1989) proposed that personal growth culminated with happiness or psychological well-being as the core of life satisfaction. In addition, the results of the review of existing aging literature suggested that personal growth involved six independent and interdependent processes (self-acceptance, positive interaction in relationships, autonomy, environmental responsibility, purposeful living, and personal growth) contributed to successful aging (Ryff, 1989). In addition, Ryff (1989) concluded that directing the potential of one's undeveloped self toward meaningful living created happiness (Aristotle, 1893; Ryff, 1989; Waterman, 1984). The factors of psychological well-being (Ryff, 1989) and the activity model (Havighurst, 1961) recognized two complementary facets in the process of aging: self-acceptance and self-affirmation respectively. Additionally, the characteristics of relationships and the influence of environmental mastery were relevant in the activity and psychological well-being propositions (Havighurst, 1961; Ryff, 1989).

Selective Optimization with Compensation (SOC). The selective optimization with compensation (SOC) model identified successful aging as a group of processes used to adjust one's assumptions, preferences, and objectives (selection); focus on high priorities (optimization); and implement resources to work around limitations (compensation; Baltes & Baltes, 1990; Freund, 2002). SOC described the relationship between age-related changes within individuals (Baltes, 1987). In particular, Baltes and Baltes (1990) promoted the notion that as a person progressed through the circumstances of life, age-related choices appeared as cognitive decisions, and behavioral resources diminished. Therefore, individuals employed adaptive behaviors to compensate for diminishing capabilities. Thus, the responding adaptations manifested capabilities that had greater ability to respond to increasing short-falls (Baltes & Baltes, 1990). Furthermore, Baltes (1987) suggested older adults employed fewer adaptive behaviors less frequently, developed replacement behaviors that required time, effort, and motivation.

The SOC model was described as a process where older adults discarded less effective behavioral styles and to begin to positively effect and enhance their decision making with the use of discrete selection, optimization, and compensation capabilities. Additionally, the SOC model supported the notion that high degrees of resilience or adaptation were acquired through the process of recovery from repetitive experiences of adverse circumstances like chronic illness and the balance between gains and losses during aging (Baltes & Baltes, 1990; Dyer & McGuinness, 1996; Smith-Bell & Winslade, 1994; Smith & Hayslip Jr, 2012). In other words, the selective, optimization with compensation model emphasized the significance of older adults creating environments in which success is possible (Ouwehand et al., 2007).

Summary and Transition

This section established the progression of understanding the empirical notions of aging. The conceptualizations began with ancient philosophers' altruistic and pragmatic discussions, to the identification of aging processes, and finally to the notion that individual's living with chronic illness could achieve successful aging outcomes. The earliest known conceptualizations of aging emerged as altruistic images (e.g., communing with the divines and preserving vitality) and pragmatic activities such as learning and holistic maintenance that are facilitated by self-motivation, adaptation, and discipline (Cicero, 1909;Aristotle, 1893). In the 1960s, an observed social construct, disengagement, hypothesized that older adults prepared for death by participating in tacit dynamic agreements with the familial-social circle and with the socio-cultural norms (Cumming & Henry, 1961) in a culture. However, the description of aging was countered with the notion that older adults' well-being and satisfaction were desirable aging outcomes and were achieved with active social engagement and self-affirmation (Havighurst, 1961, 1963).

By the 1980s, although successful aging definitions highlighted the absence of disease and disability (Baltes & Baltes, 1990; Rowe & Kahn, 1987), Ryff (1989) recognized the presence of life satisfaction with the presence of self-acceptance, positive interaction in relationships, autonomy, environmental responsibility, purposeful living, and personal growth. In addition, successful aging was hypothesized to be the result of life-long difficult problem solving activities, which in turn promoted a determined activity of selecting and optimizing one's resources in an optimal fashion (Baltes & Baltes, 1990).

Until the mid-1990s, successful aging theories excluded those living with disease and disability, and it has been noted that definitions emphasizing unhindered physical functioning and ability suggest many individuals age unsuccessfully (Jeste, Depp, & Vahia, 2010). However, studies in which older adults rate their aging success using criteria in terms of adaptability or resilience, older adults living with HIV disease have similar scores to their age related HIV negative counterparts (Kahana & Kahana, 2001; Moore et al., 2013; Vance, Struzick, et al., 2008). In addition, input from interviews of older adults living with HIV disease described individuals living successfully (Emlet et al., 2011; Halkitis, 2014). In the Theoretical Foundations Section, the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001) is introduced. In addition, I will describe the self-regulation model of illness representations (Leventhal et al., 2001). Lastly, I will describe how the data from the present study added information to the current understanding of older long-term HIV survivors' aging with HIV disease.

Theoretical Foundations

The Preventive and Corrective, Proactivity (PCP) Model of Aging with HIV Disease for Older Adults

Stress theory forms the basis for the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001). Individuals experienced stressors (e.g., depressive states) in the physical, psychological, social, spiritual domains. According to

Kahana and Kahana (2001), stressors, regardless of their origin, are cumulative. Notwithstanding, stressors (physical, psychological, social, spiritual) have been identified in the lives of HIV positive individuals (Storholm et al., 2013; Vance, Brennan, Enah, Smith, & Kaur, 2011; Vance, McGuinness, et al., 2011; Vance, Struzick, & Childs, 2010). In response, Kahana and Kahana (2001) defined a proactive stress mitigation framework for older HIV positive adults.

Kahana and Kahana (2001) posited preventive and corrective behaviors could mitigate the effects of normative life stressors such as sickness, loss, and change in environmental circumstances (Martin et al., 2014; Ouwehand et al., 2007). In turn, employing proactive and corrective behaviors such as planning and engaging one's personal network empowered older HIV positive adults in their quest to negotiate better health care maintenance and psychological well-being (Kahana & Kahana, 2001; Kahana, Kahana, Wykle, & Kulle, 2009; Kahana et al., 2012).

Kahana et al. (2012) hypothesized that life stressors, such as chronic illness, on-going or recent illness, functional limitation, and social loss, which are associated with aging impede quality of life outcomes among older adults. In addition, Kahana and Kahana (2003) hypothesized older adults who experienced stressors could benefit from social and psychological resources, and engage in proactive efforts to help normalize their lives. For example, the positive relationship between the use of proactive preventive actions (e.g., health promotion and planning ahead) and proactive corrective actions (e.g., gathering support, changing life role, and environment modification) have been attributed to persons aging successfully and living with HIV disease (Kahana et al., 2012; Vance, Burrage Jr., Couch, & Raper, 2008).

In a quantitative investigation related to the present study, Emlet et al. (2011) noted older HIV positive adults' resilience and lived-experiences supported the hypothesis of the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001). In a review of older HIV positive adults, Vance et al. (2011;2008) concluded that HIV positive individuals confronted stressful circumstances by using proactive techniques of disease management identified in the PCP model of successful aging among older HIV positive adults (Kahana & Kahana, 2001). In interviews of older HIV positive gay men, Halkitis (2014) stated that study participants, older gay men, demonstrated personal health promotion behaviors and attitudes of resilience that were conducive to thriving. In these aforementioned studies, the data supported psychological dispositions of proactivity and adaptation (Kahana & Kahana, 2001).

The present study explored older long-term HIV survivors' beliefs of successful aging and their viewpoints of HIV cure strategies. The open ended construct of the research questions provided older long-term HIV survivors the opportunity to address the wide horizon of current HIV biomedical cure advancements. Since few phenomenological successful aging inputs (hopeful attitude, planning behavior, life meaning, and resilience) have been captured from older long-term HIV survivors in the context of forthcoming or current HIV biomedical advancements, the PCP model of aging with HIV disease for older adults provided a framework to explore participants' beliefs in both constructs (Emlet et al., 2011; Halkitis, 2014; Kahana & Kahana, 2001). A thorough discussion of related studies about aging with HIV disease is presented in the Literature Review and Key Concepts section entitled Successful Aging among Older Long-term HIV Survivors.

Theoretical Frameworks Summary. Leventhal et al. (2001) posited an amalgamation of several factors contribute to individuals' behaviors, beliefs, and adaptations to disease or illness. For example, individuals retain beliefs and are vulnerable to illness and disease, make choices to respond to health threats, and employ emotional resources to respond to the illness threat. In addition, they use their lived-experiences to determine healthy and risky behaviors, and revise their behaviors based on their intentions and personal beliefs about the hurdles and benefits to engage the threat, and they employ personal beliefs and capabilities to take the necessary actions to minimize or mitigate illness outcomes.

In the PCP model of aging with HIV disease for older adults, Kahana and Kahana (2001) posited that older HIV positive adults' quality of life outcomes were influenced by their responses to stressors (e.g., illness, loss, and the relationship between an individual and the environment). According to Kahana and Kahana (2001), older HIV positive adults' responses include dispositional characteristics (e.g., hopefulness, altruism, self-esteem, life-satisfaction), preventive adaptations (e.g., promoting personal health, planning, and helping others), corrective adaptations (networking, adjusting to new roles, changes in the environment), and external resources (e.g., finances). The state of older long-term HIV survivors' psychological health is reflected in their mental, affective, and behavioral processes, which affected their views of their health and illness circumstances (Anderson & Spencer, 2002; Leventhal et al., 2001; Schroder, 2014).

The Self-Regulation Model of Illness Representations

Leventhal et al. (2001) introduced the self-regulation model of illness representations as a health psychology theory to understand the relationship between health and behavior. In addition, the authors of the self-regulation model of illness representations sumarized and valued the input of individuals lived illness-disease experiences (Leventhal et al., 2001). Additionally, the self-regulation framework characterized individuals as effective problem solvers who continually change their image and beliefs about their illness-disease circumstances (Leventhal et al., 2001). Leventhal et al. (2001) noted the contributions to the complexity of illness-disease management included awareness of illness, creation of mental images of an illness, adaptation to circumstances, regulation of the self, and common-sense characterizations of the threat of illness.

Individuals who experienced illness-disease circumstances continually engaged in understanding and managing their illness-disease images. Influencers that contributed to adjusting an individual's illness-disease experience included health stressors (e.g., illness changes), emotional responses from personal (e.g., illness symptoms), sociocultural (e.g., illness mythology), and/or other outside (e.g., laboratory results) information sources (Leventhal et al., 2001). Adults in illness-disease situations develop information from lived-experiences (e.g., family beliefs) and construct images of the illness-disease circumstance and formulated solutions and beliefs necessary to adapt to their situation (Leventhal et al., 2001).

Self-regulation is shaped by cultural and family experiences of illness that contributed to unique and common self-regulation actions, adaptations, and assessments (2012). Additionally, emotions contributed to the formation of the images of the illness-disease circumstance to encourage or discourage action (Leventhal et al., 2001). The emphasis an individual placed on an influencer (internal or external) affected the selection and effectiveness of a coping mechanism (Leventhal et al., 2001). In the final event of the process, individuals assessed the coping outcomes and used the information in future common sense decision-making activities (Leventhal et al., 2001).

Individuals' images of their illness-disease circumstances were influenced by available disease information, family and friends and their own experiences. Anderson and Spencer (2002) used the self-regulation model of illness representations (Leventhal et al., 2001) to describe the relationship of HIV positive adults' (≥ 18 years) HIV disease images and their beliefs and behaviors. A detailed discussion of the Anderson and Spencer (2002) study and its relevance to the present study is discussed in the Literature Review and Key Concepts section of the present chapter entitled HIV Cure Strategies.

Literature Review and Key Concepts

Few studies of older long-term HIV survivors exist. In addition, individual voices from older long-term HIV survivors are less prevalent than the descriptive data (data from self-reported instruments) describing the cohort (Emlet et al., 2011; Halkitis, 2014). In addition, the voices of older long-term HIV survivors enhance the understanding of the qualitative descriptions of older long-term HIV survivors (Halkitis, 2014; Moustakas, 1994). Lastly, in the process of describing their lived-experiences, long-term HIV survivors contributed to their self-awareness about their beliefs (Anderson & Spencer, 2002). Therefore, the present Literature Review of the HIV literature included a discussion of the ongoing era of HIV disease that framed the lived-experiences of older long-term HIV survivors. In addition, the following discussions included the epidemiological literature for the older long-term survivor cohort, phenomenological data of resilience when aging with HIV disease, and finally a discussion of HIV cure strategies.

A Brief History of HIV

Beginning in 1982, evidence of compromised immune system function appeared simultaneously in the United States and France among a discrete cohort, and global awareness of the potential for an unknown viral disease vector emerged; the recognized era of HIV disease had emerged (CDC, 1982; De Cock et al., 2012).). In a period of 14 years (1981 -1995), HIV biomedical identified the virus, detected the viral antibodies in the blood stream, defined the viral lifecycle, and disrupted the replication capability of HIV, which partially restored the efficacy of the human immune system (Chang & Lewin, 2014; Deeks, Lewin, & Havlir, 2013; Fernández-Montero, Vispo, & Soriano, 2014). Furthermore, between 1995 and 1997 AIDS related mortality decreased significantly (i.e., 64%). Morbidity rates have remained stable in the past decade, which, in turn has contributed to a shift in the demographic characteristics of people with HIV disease (CDC, 2013a; de Aguiar Pereira, Palta, & Mullahy, 2010; De Cock et al., 2011, 2012). Additionally, individuals with long-standing HIV disease have experienced the outcomes of HIV disease transition from dying and death to surviving and thriving (Halkitis, 2014). Finally, in 2007, a serendipitous proof-of-concept clinical procedure yielded the first HIV positive patient in the world to be bio medically cleared of the virus in the bloodstream (Hütter et al., 2009).

An Overview of Events in the Evolution of HIV Disease. Abruptly in 1981, respiratory illness symptoms from an unknown pathogen surfaced in the United States in a group of individuals with common demographic characteristics. Cases of Kaposi's sarcoma and pneumocystis carnii appeared simultaneously in San Francisco, Los Angeles, and New York City (De Cock et al., 2011, 2012). In short order, discretionary factors like cancers, geographical locations, and populations reflected the HIV disease circumstance as a salacious and pernicious scourge (Gay Men's Health Crisis (GMHC), 2010; LaVail, 2010). The initial epidemiological disease information associated gay men, prostitutes, and injection drug abusers with the outbreak of HIV disease (Deeks, 2011, 2012; Morbidity and Mortality Weekly Report (MMWR), 1982), which in turn informed a fomented public discourse about those infected with HIV (Lagitch, 2012).

Early in the HIV epidemic, a symbiotic epidemiological and biological framework emerged that affected HIV positive individuals permanently. For example, Halkitis (2014) noted before the terms HIV and AIDS were designated mainstays of the biomedical and psychosocial sciences' lexicon, biomedical science and demographic epidemiology of the time were employed to identify the disease phenomenon. Notably, the early designators of HIV disease were gay related-immune deficiency (GRID); Kaposi's sarcoma and opportunistic infections (KS/OI); gay cancer; gay plague; and community related immune deficiency (CRID). These terms emphasized the emerging epidemiological data of HIV disease, which identified the first and most impacted cohorts: male homosexuals, injection drug users, and sex workers (De Cock et al., 2012; Halkitis, 2014). The scientific focus of the biological impact of the newly identified immune system overload syndrome was eclipsed by the demographics from the early cases in the United States (Halkitis, 2014). This information suggested the disease was confined to gay men, injection drug users, and sex workers; the stigma of the disease was cast (De Cock et al., 2012; Halkitis, 2014).

It was estimated that 61% of the mortality from HIV/AIDS related illness was among gay men (De Cock et al., 2012). Consequently, the initial characterization of HIV was associated almost exclusively with homosexual men. As early as 1983, epidemiological evidence from the United States (CDC, 1983) and Haiti (Piot et al., 1984) identified heterosexual sexual intercourse as a source of HIV infection transmission (De Cock et al., 2012). Notably, biomedical data from Haiti in the form of patients' frozen hepatitis plasma samples existed as early as 1979 (De Cock et al., 2011). Analyses of these samples were conducted as early as 1983, and there was evidence that

AIDS existed outside the United States predominately among heterosexuals (De Cock et al., 2012).

Biomedical Research. The discovery of the human immunodeficiency virus (HIV) and the identification of third stage HIV disease, AIDS (Barré-Sinoussi et al., 1983; Gallo, Shaw, & Markham, 1985), established one direction of HIV research: to understand the replication cycle of the virus and eradicate it from the body. Another research path developed around understanding the impact of the virus in society. In 1985, HIV antibody testing (Enzyme Linked ImmuniSorbent Assay [ELISA]) became widely available (De Cock et al., 2012; Landesman, Ginzburg, & Weiss, 1985). HIV antibody testing provided the basis for a surveillance mechanism that established the ability to estimate HIV incidence and prevalence (CDC, 2012c). In addition, HIV disease data capture and analysis accuracy improved and emphasized the heterogeneity and discrete impact (e. g., disparities of life expectancy among ethnicities and gender) of HIV disease (Pfeiffer, 2002; Psaros et al., 2014). Ten years subsequent to HIV testing, the biomedical discovery of antiretrovirals (ARV) and antiretroviral therapies (ART) that actually disrupted the human immunodeficiency viral lifecycle was introduced into the realm of HIV clinical treatment (Klimas et al., 2008).

Antiretrovirals (ARVs). Widespread availability of HIV antiretroviral medications, for many HIV positive persons, altered the outcome of HIV disease from dying and certain death to survival (Stoff, Khalsa, Monjan, & Portegies, 2004; Vlassova, Angelino, & Treisman, 2009, pp. 158-159). At different stages of the HIV replication cycle, antiretrovirals interrupted the viral proliferation lifecycle (Klimas et al., 2008). With fewer virus in the bloodstream, the immune system is able to ward off infectious pathogens detrimental to human health (Klimas et al., 2008). Consequently, the number of individuals living with HIV disease increased and HIV positive individuals began aging beyond previous lifespan time frame estimates (Cahill & Valadéz, 2013; Vance, Bayless, et al., 2011).

Widespread distribution (1996-1997) of antiretrovirals in the United States contributed significantly to decreased (64%) HIV disease related mortality (CDC, 2013b). After the widespread introduction of antiretrovirals, HIV disease infection incidence and prevalence began to shift toward the cohort of adults 50 years and older. HIV positive individuals were aging with the disease (CDC, 2013a). For example, in 2006 Karpiak et al (2006) stated that 27% of the total prevalence of those infected with HIV disease were ≥ 50 years of age and older. By 2015, it was estimated the number of older HIV positive adults would be 50% of the total HIV population (Moore et al., 2013; Sankar et al., 2011; Vance, Bayless, et al., 2011).

HIV Cure. Between 2005 and 2007, a significant, yet serendipitous, clinical HIV biomedical advancement developed (Brown, 2015). The outcome from a series of clinical research (e.g., HIV resistant stem cell transplantation into bone marrow) procedures (Hütter et al., 2009) rendered one 40 year old HIV positive individual free from replicating HIV in the blood stream (Brown, 2015). Results of a biomedical surgical treatment cured one individual of HIV disease (Chang & Lewin, 2014; Deeks & Barré-Sinoussi, 2012; Gant, 2012; Peay & Henderson, 2015).

Older HIV Positive Adult Population. Within the overall HIV population, the number of older (≥50 years) adults aging with HIV disease is estimated to be half of the estimated 1.2 million HIV positive persons in the United States (Sankar et al., 2011; Vance, McGuinness, et al., 2011). In addition to the estimated prevalence of older adults living with HIV disease, HIV infection incidence contributes to the category of 50 years and older. It is estimated that older adults (≥ 50) represent 28% of the overall number of annual HIV infections. In addition, at the end of 2010, individuals living with HIV disease age 45–49 represented 22% (192,058) of the total prevalence of those living with HIV disease (CDC, 2013b). As evidenced above, the increase of older adults living with HIV disease is affiliated with HIV infection incidence numbers for adults 50 and over, and the group of HIV positive individuals aging into the category of 50 and older. In sum, HIV infection incidence and prevalence are dynamic factors and influence HIV disease management (Carnegie et al., 2015; Hinkina et al., 2004).

More discrete epidemiological evidence indicates the differences of HIV prevalence among older adults living with HIV. Illustrative of the differences is that the estimated prevalence of older black/African Americans living with HIV (1,225/100,000) was greater than for older Hispanic/Latinos (536/100,000), and greater than for older whites (144/100,000; CDC, 2013a). For women, the CDC (2013d) identified the estimated rate of black/African American women living with HIV was 667/100,000 compared to 240 for Hispanic/Latina Women and 30 for White women. In the period between 2008 and 2010, the number of deaths among those living with HIV decreased in the 50-54 age group and was stable in the age group 55-59, but for age 60 and older there was an increase in the number of deaths (CDC, 2013d).

In 1981, a 20 year old man could expect to have a two year lifespan from the point of HIV disease diagnosis (Halkitis, 2014). However, in 2014 a 20 year old diagnosed with HIV can expect a 30 – 40 year lifespan from the point of HIV diagnosis (Halkitis, 2014). Life expectancy after diagnosis for black males was shortest (19.9 years) followed by Hispanic males (22.6 years), and 25.5 years for White males (Harrison, Song, & Zhang, 2010). In the category of sex, lifespan estimates from 2005 for HIV positive women (Harrison et al., 2010) indicated a nearly 2 year increase in lifespan than their HIV positive male counterparts (23.6 years for women 21.8 years for men). However, the cumulative (all categories) average life expectancy after HIV diagnosis increased 12 years between in the 10 years after 1996 (Harrison et al., 2010).

Empirical evidence demonstrated that HIV infected individuals are achieving lifespans near that of their HIV negative counterparts (van Sighem, Gras, Reiss, Brinkman, & de Wolf, 2010). Lifespan has become an important dimension in the lived experiences of HIV positive adults. An additional illustration of HIV disease epidemiology among older adults is the stage of the disease across the cohort. At the close of 2009 in the United States, the CDC (2012a) estimated 784,701 individuals, including those who do not know they are living with HIV are in Stages 1 (Acute; ≤ 6 months) and 2 (Chronic; 1-9 years). Additionally, another 476,732 were identified as living with acquired immunodeficiency syndrome (AIDS; Stage 3). Notably, many HIV positive individuals in the 45-49 year old group (192,058) will age into to the 50 and older age category. Consequently, the prevalence of HIV positive individuals 50 years and older living 20 years and longer with HIV will increase (CDC, 2012b).

The estimated number of long-term HIV survivors is unofficial and the empirical infection incidence and prevalence data suggest the number of individuals categorically positioned as older adults overall is stable, decreasing, and increasing. From the most recent (2008-2011) HIV infection incidence data from the CDC (2013c), the number of infection diagnoses among older (≥50) HIV positive adults was estimated to have decreased (55–59; 60-64) and been stable (50-54). On the other hand, prevalence for 50-54 year olds at the end of 2010 among HIV positive older adults aged 50–54 was 18% (157,138) of those in treatment HIV prevalence (872,990; CDC, 2013c). Consequently, the HIV population is skewing toward older adults, long-term HIV survivorship, ethnicity, and gender.

Adults living with HIV disease were designated by the CDC as older adults who were 50 years of age and older. However, Vance et al., (2008) challenged the use of age 50 as a differentiator for an older adult living with HIV disease. The term “older adult” and the age designation ≥50 years might reflect an ageist orientation, and might continue to inappropriately describe a psychologically and physically robust cohort (Vance, Struzick, et al., 2008). However, the designation for HIV positive adults as an older adult

(≥ 50 years) is used frequently in biopsychosocial research and can be affiliated with individuals who have survived with HIV 20 years or longer.

There is little formal or scientific estimation of the numbers of long-term HIV survivors (≥ 20 years), an informal estimate in the form of an uncollaborated mathematical model has been proffered (Vergel, 2015). An informal model (Appendix A) estimating the number of older long-term HIV survivors includes definitional criteria of long-term. The informal estimate is discussed in the Successful Aging section, which identifies the most recent peer reviewed demographic data of older adults living with HIV disease. There are older long-term survivors and individuals newly diagnosed or infected with HIV who have different needs, although in both groups many individuals have experienced the historical events of the HIV epidemic (Halkitis, 2014; Rosenfeld, Bartlam, & Smith, 2012; Solomon, O'Brien, Wilkins, & Gervais, 2014).

In the present section, epidemiological data established the emergence of a growing and heterogeneous group of older (≥50 years) long-term (≥ 20 years) HIV survivors aging with HIV disease (Halkitis, 2014; Moore et al., 2013; Solomon et al., 2014). Individuals in this cohort have had lived-experiences that precede and begin with the widespread distribution of antiretroviral medications. In other words, a phenomenon of individuals aging with HIV disease emerged. Yet, little phenomenological information exists about older long-term HIV survivors’ experiences of aging with the disease (Halkitis, 2014). Thus, there exists an aging group of individuals whose voices need to be heard (Anderson & Spencer, 2002; Creswell, 2007; Halkitis, 2014; Kall et al., 2015; Moustakas, 1994; Peay & Henderson, 2015; Simmons et al., 2015).

After the widespread introduction of HIV antiretrovirals, phenomenological and qualitative studies of older HIV positive adults identified individuals in the cohort with successful aging behaviors (Emlet et al., 2011). For example, Halkitis (2014) and Moore et al. (2013) noted that older gay long-term HIV survivors described their physical and emotional lived-experiences as vibrant, active, and worthwhile. Notably, successful aging and resilience emerged as relevant constructs that describe older long-term HIV survivors (Emlet et al., 2011; Halkitis, 2014; Moore et al., 2013).

The evolution of HIV biomedical and psychological research has identified an aging group of older long-term survivors with substantially different lived-experiences than their counterparts in the era before HIV antiretrovirals. Two theoretical models, the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001) and the self-regulation model of illness representations (Leventhal et al., 2001) frame the discussions in following two sections. The extant literature of the constructs of older long-term HIV survivors' beliefs about successful aging with HIV and an HIV cure is discussed respectively.

Successful Aging among Older Long-Term HIV Survivors

By 1994-1995, HIV mortality rates reached a peak (50-55 per 100,000) and not surprisingly there was little consideration in the scientific literature for successful aging for those living with HIV disease (CDC, 2013b; Kahana & Kahana, 2001). However, by

1998 the widespread distribution of HIV antiretrovirals among HIV positive persons contributed to HIV disease management and the HIV associated mortality rate dropped to roughly 17 persons in 100,000 individuals (CDC, 2013b). Subsequent to the increase of older persons living with HIV disease, Kahana and Kahana (2001) published the PCP model of aging with HIV disease for older adults. Kahana and Kahana (2001) proffered that psychological dispositions, preventive, corrective, and proactive coping characteristics are employed by older HIV positive adults to achieve quality of life and successful aging.

Successful aging was regarded as the capacity of older people to thrive (Depp & Jeste, 2009), or live happier, healthier, and satisfied (Holstein & Minkler, 2003). Halkitis (2014) suggested the terms “survivor” and “thriver” reflected the lived-experiences of older gay-male long-term HIV survivors. Even though successful aging definitions remain disparate and without general accord among researchers (Cosco et al., 2013; Emlet et al., 2011; Van Wagenen, Driskell, & Bradford, 2013), it is from self-reported lived-experiences of a cohort of older gay men who are long-term HIV survivors that adaptation and successful aging characteristics become apparent (Halkitis, 2014).

Emlet et al. (Emlet et al., 2011) investigated the adaptive experiences among older HIV positive adults (age *M* = 56.1 ± 5.75; 17 men; 8 women) aging with HIV disease. In this phenomenological research, one participant (male; 52 years old; 21 years from HIV diagnosis) was identified as a long-term survivor. However; 76% of the participants were identified as living with Stage 3 (AIDS) HIV disease at the time of the study. Thus, the results for the aforementioned population must be considered as older adults who may or may not be long-term survivors.

From participants' direct descriptions of aging with HIV disease, Emlet et al. (2011) identified that a majority of the older HIV positive adult participants expressed adaptive viewpoints, attitudes, and activities. In addition, the analysis of the results from participants' responses to aging with HIV disease indicated common experiences of optimism, life fulfilment, and attitudes of charity and self-worth comparable to those suggested in the PCP model of aging with HIV disease for older adults (Emlet et al., 2011; Kahana & Kahana, 2001). Emlet et al. (2011) surmised successful aging indicators among HIV positive older adults were identified as adaptive to their lived experiences, the will to live, and invoking support from their informal and formal networks.

Halkitis' (2014) analysis of the interviews conducted with older gay men (*n* =15; long-term survivors) revealed that the most common theme in aging successfully was adaptation or resilience to life circumstances. Furthermore, Halkitis (2014) noted the participants continued to adapt to the affiliated assaults of aging with chronic HIV disease. On the other hand, evidence of resilience among gay men, African Americans, and undocumented Hispanics was present before exposure to HIV. Illustrations of resilience included gay men with lived experiences of discrimination, secrecy, and heteronormativity (Halkitis, 2014); African Americans identified structural factors such as education (Nevedal & Sankar, 2015); Puerto Rican women identified aspects of race, gender, and poverty (Carrion, 2010). Halkitis (2014) suggested discussions of resilience must include the historical context of the individuals' lives experiences, speculating that the lack of reflection on broad spectrum life events could result in orienting scientific investigations toward the medical model of deficits.

Halkitis (2014) emphasized that conversations with older long-term survivors should reflect individuals' entire life experiences and that survival and resilience indicated that HIV disease is more than a biological intrusion into the body. Accordingly, older long-term HIV survivors' life experiences add depth to the biomedical qualitative data (Creswell, 2007; Halkitis, 2014; Moustakas, 1994). As such, the information in chapter 2 of the present study will serve as a touchstone to understand older long-term HIV survivors' beliefs about successful aging and HIV cure.

HIV Cure Strategies

A cure for HIV is the primary strategy of global HIV disease research (Deeks et al., 2012). In this discussion of the HIV epidemic, I will review the scope of literature about an HIV biomedical cure and the emerging focus of older HIV positive adults' beliefs about an HIV cure. During the 35 plus years of HIV disease history, there has been an ebb and flow of interest and research for an HIV cure (Johnston & Barré-Sinoussi, 2012). Notably, a recent audit of the National Institute of Health Clinical Trials database indicated there are over 100 HIV cure clinical trials either completed or in process in the United States (Peay & Henderson, 2015; Forum HIV Cure Project, 2014). For those living with HIV disease, the scope of HIV cure research is focused on functional and eradication cure strategies (Chang & Lewin, 2014; Deeks, 2013; Gant, 2012; Peay & Henderson, 2015).

Clinical HIV Cure Research. Hütter et al. (2009) reported that a 40 year old man, (aka, the Berlin Patient; Timothy Brown) presented with an 11 year history of HIV disease and acute leukemia. Beginning in 2006, Hütter (2009)seized a serendipitous clinical opportunity to test whether elimination of HIV-1 using a stem cell transplantation procedure of donor HIV replication resistant cells with the CCR5-Δ32 protein could achieve long-term elimination of HIV in the plasma, bone marrow, and rectal mucous membrane (Deeks & McCune, 2010; Hütter et al., 2009). In a second attempt to quell the leukemia, Hütter orchestrated the acquisition of unique HIV resistant stem cells known as CCR5-Δ32, and using a bone marrow graft procedure successfully completed the stem cell transplant (Brown, 2015; Younai, 2013). After three years of successful viral suppression in the patient's blood stream, Hütter and his team published the results of their clinical procedure and its outcome (Hütter et al., 2009), which identified the Berlin Patient as functionally cured of HIV disease (Brown, 2015; Gant, 2012). Additionally, other researchers indicated the importance of defining the parameters of an HIV cure (Chang & Lewin, 2014).

Functional Cure. It is generally agreed that the stem cell transplant procedure coordinated and performed by Hütter and colleagues achieved the definition of a functional cure (Chang & Lewin, 2014): long-term absence of HIV RNA in the blood stream without the assistance of antiretroviral medications. However, HIV biomedical researchers (Deeks, 2013; Gant, 2012) questioned the comprehensive viability of cost and procedural pain associated with the stem cell transplant procedure (Hütter et al., 2009). In fact the stem cell transplantation procedure established a proof-of-possibility scenario for an HIV cure (Deeks, Drosten, Picker, Subbarao, & Suzich, 2013; Gant, 2012), validated the plausibility of an HIV cure (Deeks, Drosten, et al., 2013; Gant, 2012), and informed HIV cure research about issues of HIV reservoirs and chronic inflammation from a constant immune response (Gant, 2012).

To date, the Berlin Patient is considered the first and only patient who has achieved a successful functional cure for HIV, which resulted from a bone marrow transplant of stem cells in 2006 (Barré-Sinoussi, 2009; Brown, 2015; Chang & Lewin, 2014; Deeks, 2012; Hütter et al., 2009). The clinical experiment exacerbated the need to pursue a cure outcome where it could be proven there was no virus in the body (Chang & Lewin, 2014; Johnston & Barré-Sinoussi, 2012).

Viral Eradication. A variety of approaches to eradicate HIV in dense organ (e.g., liver) reservoirs included editing genes, vaccines to stimulate immune response, and dormant cell awakening strategies called the “kick and kill” strategy (Chang & Lewin, 2014; Peay & Henderson, 2015). In addition to eliminating HIV entirely from the human body, there is evidence that HIV-associated diseases such as arteriosclerosis and heart disease persist despite the long-term capabilities of highly active antiretroviral therapy (HAART) that suppress the replication of HIV (Chang & Lewin, 2014; Deeks, 2013). Consequently, HIV eradication investigations must include at least two strategies.

First, there must be elimination of HIV cells that have the capability to replicate but do not (i.e., HIV virion; considered dormant) and reside in the dense organs (e.g., brain) and are dormant in the blood stream (Chang & Lewin, 2014). Second, there must be consideration for the restoration of individuals' health that has been associated with HIV disease (Deeks, 2013). An illustration for both strategies, as noted by Deeks (2011), is the importance of quelling chronic inflammation associated with HIV disease.

In the context of HIV infected individuals prescribed highly active antiretroviral treatment (HAART), which is a combination of anti-retroviral medications, eradication is defined as sterilization or complete elimination of HIV in all blood and anatomical parts of the human body (Chang & Lewin, 2014). In other words, replication competent HIV is completely eliminated in the body (Deeks, 2013). However, Deeks (2013) reported the unlikely potential for a complete elimination of HIV in the known reservoirs (e.g., dense organs, gut mucosa, macrophages, and monocytes). Notably, researchers have yet to achieve consensus in defining the characteristics of a sterilized cure or a functional cure (Chang & Lewin, 2014; Deeks, 2013).

Achievement of an HIV sterilization cure state requires resolution of numerous factors. As an illustration of the factorial complexity of a sterilized HIV cure state for long-term HIV survivors, the longstanding persistence of dormant HIV in identifiable and unidentifiable reservoirs is elemental (Stevenson, 2012). In addition, HIV infection clearly induces generalized and persistent CD4+ T cell activation and inflammation, which most likely has a role in the long-term persistence of HIV infection incurred from

HIV reservoirs (Barré-Sinoussi, 2011). Highly active antiretroviral therapy (HAART) elevates inflammation in gut mucosa, an HIV reservoir environment, which provides opportunity for increased HIV replication where localized inflammation is a response to an elevated immune response (Chang & Lewin, 2014; Deeks, 2013). According to Deeks (2013), the potential for high levels of tissue inflammation and immune cell activation could, in turn, increase the number of potential HIV target cells, CD4+T cells, which are susceptible to infection. Thus, HIV eradication strategies must include identifying all reservoirs, the elimination of HIV in these reservoirs, eliminate intense immune activation, and inflammation (Deeks, 2013; Stevenson, 2012). Lastly, an established protocol to ensure a continuing state of sterilization is necessary.

Functional Cure and HIV Eradication Summary and Segue. According to Deeks (2013) an HIV cure therapy must be able to eliminate HIV completely from the human body for a timeframe greater than or equal to 5 years, and prove there is no dormant virus in known reservoirs. To date, there are no technologies that can identify all reservoirs or determine whether an identified reservoir is void of dormant HIV. The complications associated with achieving sterilization and restoring the health of HIV infected individuals is considered unattainable by many HIV researchers (Deeks, 2013). At present, Deeks (2013) concluded the most attainable outcome is a functional cure with the criteria to achieve HIV suppression without antiretroviral treatment for ≥ 5 years. Many of these varied strategies will evolve to clinical trials and require human subjects to test the laboratory results. Characteristically, participation in these clinical trials requires demonstrated viral suppression and eventual eradication over a specified period. In addition, some studies require controlled interruption of antiretroviral treatments in order to investigate the effects of a proposed cure (Peay & Henderson, 2015). For some long-term survivors, this scenario may be too great a risk and contribute to stress (Kahana & Kahana, 2001).

Psychosocial HIV Cure Research. Specifically, Chang and Lewin (2014) identified the first considerations necessary to achieve an HIV sterilization cure state. Identification of the known impediments to a sterilization cure state should be the first order of research. Next, clinical trials must be inclusionary; for example, length of time living with HIV disease should not be a disqualifier. Lastly, biomarker testing to track long viral activity once combination ARV therapy is discontinued; new models to identify dormant HIV infection activity; and tests that identify replicating and dormant HIV in anatomical and blood environments. Lastly, Chang and Lewin (2014) identified the importance of innovative research collaboration and involvement of individuals living with HIV disease. Recently, participation of older long-term HIV survivors about their viewpoints of an HIV cure has emerged in HIV research (Kall et al., 2015; Peay & Henderson, 2015; Simmons et al., 2015).

The qualitative portion of a mixed methods study (n = 982; median time from HIV diagnosis was 7 years with a range of 2-17 years) of HIV positive persons investigated their interest level to participate in HIV cure research (Kall et al., 2015; Peay & Henderson, 2015; Simmons et al., 2015). Additionally, respondents were also invited to provide written comments. Explicitly, these same researchers wished to understand HIV positive persons' motivations and decision-making influencers if asked to participate in HIV cure research (HCR).

Comments provided by 26% (81% male; 71% MSM; 71% white; 49% aged 45-64; 90% on ART) of the respondents indicated most of the respondents (86%) supported an HIV cure and HIV cure research (Kall et al., 2015). Furthermore, most respondents (95%) identified their willingness to participate in HIV cure research even if asked to accept the risks associated with terminating their antiretroviral treatment (Simmons et al., 2015). In addition to their support and alacrity for cure research, participants expressed interest in alleviating themselves of treatment fatigue, concerns for long term effects of HIV, stigma, self-esteem, and relationships (Kall et al., 2015).

Coping with Illness and Disease. When individuals assess their health and illness events, such as self-observed symptoms or blood draw results, individuals with illness-disease conditions tend to define illness attributes and employ those attributes to select coping responses such as seeking care or waiting and observing diseases symptoms, and assessing outcomes (Leventhal et al., 2001). Illness-disease symptoms lead individuals to seek labels for the situation and the existence of labels leads to a search for symptoms: the symmetry rule (Leventhal et al., 2001). One outcome is the creation of a series of constructs that shape an individual's beliefs about the illness-disease circumstance.

One construct defines the disease as a stressor (Kahana & Kahana, 2001; Leventhal et al., 2001). Other illness-disease beliefs are defined by time line information (e.g., time to a cure or date of diagnosis versus date of infection), causes of the illness as external factors (e.g., viral or weak genetics), behavioral (e.g., exchange of body fluids), illness consequences (e.g., poverty, stigma, death), and efficacy (e.g., antiretrovirals) treatment (Leventhal et al., 2001). Thus, the experiences and images an individual maintains about living with an illness-disease condition are assumed to influence beliefs, selection and performance of one or more coping procedures. Emotions influence the formation of illness representations and can motivate or dissuade a person to take action. Appraisal of the consequences of coping efforts is the final step in the self-regulation model of illness representations model and provides feedback for further information processing.

Anderson and Spencer (2002) employed the self-regulation model of illness representations (Leventhal et al., 2001) to describe HIV positive adults' images of their illness-disease circumstances. Results from the phenomenological study of individuals (*n* = 58; age mean = 42; time from HIV/AIDS diagnosis = 8.8 years) living with acquired immunodeficiency syndrome (AIDS) identified a range of beliefs about their disease situation (Anderson & Spencer, 2002). Eleven themes were identified (inevitable death, distress of body disintegration, living life to the fullest, anticipation of the best new drug, self-care, simply another disease, controlling the beast, detachment, accepting the disease, building one's faith, and getting better in time), and these themes introduced the variability and complexity of beliefs HIV positive adults maintain about their disease state. For example, contrasting themes from participants included beliefs that their disease situation as simply an illness while AIDS survivors believed AIDS was death and decimation (Anderson & Spencer, 2002).

Summary and Conclusions

In the present chapter, the HIV literature elucidated pertinent biomedical factors that contributed to early perspectives of and the management of HIV disease. Initially in the United States, HIV disease was first defined by the very first individuals identified with the disease, gay related immune deficiency (GRID). During the period of stigmatized categorization associated with the virus, Barré-Sinnousi et al. (1983) isolated the human immunodeficiency virus and two years later it was widely characterized as the acquired immunodeficiency syndrome (AIDS) caused by the human immune deficiency virus (Gallo et al., 1985).

Next, the biomedical research community created a testing protocol to identify HIV antibodies (De Cock et al., 2012; Landesman et al., 1985). As a result of antibody identification, individuals exposed to the virus could be identified and treated. In addition, HIV testing contributed to the ability of the Centers for Disease Control and Prevention (Fleming, Ward, Janssen, De Cock, Valdiserri, & Gayle, 1999) scientists to scope the heterogeneity of those infected by HIV. In 1996, widespread antiretroviral medications disrupted the lifecycle of the virus and stabilized the immune systems of many HIV infected individuals. By 1997, it was apparent that the widespread distribution of antiretroviral medications significantly contributed to the decrease of HIV mortality (De Cock, 2011).

In the aftermath of the widespread introduction of antiretroviral medications in the United States, epidemiological evidence validated the number of older individuals aging with HIV disease is increasing (CDC, 2013a; Sankar et al., 2011; Vance, Bayless, et al., 2011; Vance, McGuinness, et al., 2011). Subsequently, some older adults experienced the phenomena of long-term survival, aging successfully, and inclusion in the next stage of HIV biomedical research (Chang & Lewin, 2014; Desai & Landay, 2010; Halkitis, 2014; Hütter et al., 2009; Kahana & Kahana, 2001; Sankar et al., 2011; Sax et al., 2014; Vance, Bayless, et al., 2011; Vance, McGuinness, et al., 2011). Additionally, a model for successful aging for older HIV positive adults (Kahana & Kahana, 2001) provided a touchstone to identify behaviors to identify aging outcomes.

Support of the PCP model of aging with HIV disease for alder adults (Kahana & Kahana, 2001) has emanated from qualitative and quantitative investigations that identified successful aging characteristics. For example, the existence of resilience among older HIV positive adults emerged as an adaptive behavior to address difficult situations in their lives (Emlet et al., 2011). Additionally, phenomenological literature revealed older HIV positive adults who examined the full array of their lived-experiences expressed preventive and corrective, proactivity characteristics such as a will to live and vitality (Emlet et al., 2011; Halkitis, 2014; Moustakas, 1994).

Lastly, the first studies of HIV positive adults interested in participating in HIV cure clinical research studies have emerged (Kall et al., 2015; Peay & Henderson, 2015; Simmons et al., 2015). The phenomenological data from a sub-group of the participant sample of older HIV positive adults was examined. The sub-group study (Kall et al., 2015; Simmons et al., 2015) results provided a glimpse of the viewpoints older adults harbor about their willingness to participate in HIV cure clinical trials. The present study will explore beliefs about an HIV cure from a cohort of self-selected older long-term HIV survivors aging with the disease.

The framework of the present study examined HIV disease history and epidemiological information and the constructs of aging and an HIV cure. Two theoretical models, the PCP model of aging with HIV disease for older adults (Kahana & Kahana, 2001) and the self-regulation model of illness representations model (Leventhal et al., 2001), were presented and demonstrated that the relationship between successful aging and biomedical advancements impact the beliefs of individuals in an illness-disease circumstance. However, available information of older long-term HIV survivors' beliefs about their illness-disease circumstance is minimal. In addition, the present study used a phenomenological methodology, which created an opportunity for older long-term HIV survivors to explore and decipher the impact of aging and biomedical advancements in their lives (Halkitis, Kapadia, Ompad, & Perez-Figueroa, 2014; Kahana & Kahana, 2001; Moustakas, 1994).

The present study used the contributions from a homogeneous and mature group of individuals who experienced living long-term with HIV disease. More discretely, the present exploration created opportunities to understand the older long-term survivors' beliefs of aging with HIV disease whose lives have been influenced by the biomedical advancement of HIV antiretrovirals, and the next stage of the epidemic, an HIV cure. This study intended to provide information useful to those who work with older long-term HIV disease survivors.

In chapter 3, I report the rationale for the use of a qualitative approach of phenomenological discovery to describe the beliefs of older long-term HIV survivors. An explanation of the research framework and explanation for choosing this design is revealed in chapter 3. Additionally, I discuss the burden of the researcher, matters of trustworthiness, and ethical considerations.

Chapter 3: Research Method

Introduction

In the United States, HIV disease is in its third decade (Chang & Lewin, 2014; Gallo et al., 1985; Gottlieb et al., 1983). In the earliest days of the HIV plague, there were no biomedical interventions, and by 1983 at least 150,000 people had been infected (CDC, 2005). An AIDS diagnosis in the first 15 years of the epidemic had a prognosis of near-certain death (De Cock et al., 2012). In 1995, the widespread introduction of antiretrovirals contributed to increased physical and psychological survival with HIV disease, and aging became a phenomenon of the HIV paradigm (Brennan & Eady, 2011). By 2015, 50% or more of the total population of 1.2 million persons estimated living with HIV disease are anticipated to be 50 years of age and older (Moore et al., 2013; Sankar et al., 2011; Vance, Bayless, et al., 2011; Vance, McGuinness, et al., 2011).

Antiretroviral medications have contributed to an increasing number of older long-term HIV survivors who refused to give up living despite myriad challenging factors such as medication side-effects, sociopolitical bias, and aging (Emlet et al., 2011; Halkitis, 2014, pp. 191-217). Importantly, older long-term HIV survivors have identified ardent characteristics of well-being, optimism, and resilience as themes of successful aging (Emlet et al., 2011; Halkitis, 2014, pp. 190-217; Kahana & Kahana, 2001). Moreover, despite the challenges of social stigma, regimented medication requirements, and suicidal ideation, long-term HIV survivors demonstrated nothing less than triumph (Halkitis, 2014; Vance et al., 2010).

A recent qualitative study of resilience among older long-term HIV survivors defined resilience using psychological traits. In a comparison of two groups of older men (*n* = 83), HIV negative men (*n* = 83; age *M* = 60.4, SD = 6.3; age range, 51-83) and HIV positive men (*n* = 83; age *M* = 59.3, SD = 6.7; age range, 48-84), Moore et al. (2013) concluded that older HIV positive individuals' psychological attributes contributed to their successful aging. In their study, older HIV positive adults self-reported their successful aging (SRSA) was associated to physical health (Moore et al., 2013). In addition, this sample of older HIV positive adults indicated positive psychological traits as an absence of depression, peace of mind, resilience, positive outlook, continuous life improvement, less perceived stress, and positive attitude about one's own aging.

Notably, the cohorts of the two studies of aging among older HIV positive adults accounted for individuals with bounded socioeconomic characteristics. The qualitative study cohort (*n* = 15) of older HIV positive men participating in the Center for Health, Identity, Behavior and Prevention Studies Project Gold (CHIBPS; Halkitis, 2014) were ethnically diverse living in a metropolitan environment (New York City). On the other hand, the quantitative study conducted by Moore et al. (2013) was predominately white (HIV-, 89%; HIV+, 79%), well educated (bachelor's degree; HIV-, 43%; HIV+, 42%), and participants in an on-going academic study (HIV Neurobehavioral Research Program at the Stein Institute for Research at the University of California, San Diego).

In addition to psychological resilience associated with aging long-term with HIV, there are new biomedical advancements that may offer new opportunities for older HIV positive persons. Up to the mid-1990s, HIV patients were resigned to death as an outcome of the disease. However, today antiretroviral medications have afforded older long-term survivors the opportunity of protracted life expectancy. Importantly, recent clinical proof-of-concept procedures and outcomes conferred the possibility of an HIV cure (De Maria, Persaud, Gay, & Ziemniak, 2014; Hütter et al., 2009; Persaud, 2013).

Currently, there is little information about older long-term HIV survivors' beliefs about aging and their viewpoints regarding the emergent biomedical cure strategies. Emerging biomedical events in the era of HIV suggest health related stressors might influence older HIV long-term survivors' beliefs about successful aging (Kahana & Kahana, 2001). Currently, there have been three clinical procedures that indicated a proof-of-clinical-concept for a successful HIV disease (De Maria et al., 2014; Hütter et al., 2009; Persaud, 2013). However, only one outcome of the three HIV biomedical cure protocols indicated a promising outcome for some long-term HIV survivors (CDC, 2014; Deeks, 2012; Deeks et al., 2012). Yet, despite the biomedical possibility of an HIV cure for long-term survivors, there is little understanding about long-term HIV survivors' beliefs of the materializing HIV cure possibilities.

Older individuals aging long-term with HIV are poised to encounter yet another milestone in the evolution of HIV disease. In addition to coping with a history of aging that included short and long-term HIV antiretroviral medication' toxicity, social stigma, and personal losses of loved ones or profession, older long-term survivors are experiencing a plethora of information about HIV biomedical cure strategies

(Ananworanich & Fauci, 2015). For example, there are the outcomes from clinical research procedures, the Berlin Patient, and laboratory research strategies such as "kick and kill" (Daly, Hartz, Stromquist, Peek-Asa, & Jogerst, 2007; Gant, 2012). Currently, long-term HIV survivors' beliefs about aging and emergent HIV cure strategies have yet to be examined. Thus, the purpose of the present study is to explore older long-term HIV survivors' viewpoints about aging and their beliefs about an HIV cure.

Major Sections of Chapter 3. Chapter 3 begins with a restatement of the events in HIV history and their influence on the purpose of the present study of older long-term HIV survivors' beliefs of HIV cure strategies. The key notions and context of the present study are identified. In addition, the choice of the qualitative research tradition is delineated and rationalized. Next, I identify the actions to mitigate my biases, associations with the present study's participants, and ethical conflicts with corrective actions. I discuss the parameters of the study that affords other researchers the ability to replicate the present exploration of older long-term HIV survivors including the sample selection and saturation processes. Finally, I present a discussion of the data collection instruments used to assess the researcher developed interview questions.

The present qualitative exploration employed a pilot study. I describe the recruitment, participation, data collection, and pilot assessment, and identify any corrections necessary to the main study methodology (Lee, Whitehead, Jacques, & Julious, 2014). The main study section delineates the processes of recruitment, interview participation, informed consent, and the data collection mechanism. Immediately following the description of main study processes, a data analysis plan is presented. Next, I outline the internal and external validity, qualitative data reliability, and coder reliability. Prior to the summary of chapter 3, a discussion of ethical dimensions addresses the specifics associated with a group with compound vulnerability. These factors for older HIV positive adults include: participant access, anonymity, participant treatment, data protection and security, and contingency plans.

Research Design and Rationale

Research Questions

The present study explores older long-term HIV survivors' beliefs about aging and the current biomedical HIV cure advancements. Responses from the study participants are intended to add breadth and depth of understanding to the following research questions:

RQ1: What beliefs do older long-term HIV survivors maintain about aging with HIV disease?

RQ2: How do older long-term HIV survivors' experiences of aging with HIV disease relate to and contribute to their current life experiences?

RQ3: What beliefs do older long-term HIV survivors maintain about an HIV cure?

RQ4: How do older long-term HIV survivors view an HIV cure as a part of their long-term HIV survival?

RQ5: How do older long-term HIV survivors view a cure in their future?

RQ6: How do older long-term HIV survivors resolve their lived-experiences and beliefs about a cure for HIV disease and aging with HIV disease?

Central Concepts and Phenomena of the Study

A series of studies (e.g., Project Gold) about older gay men living with HIV disease, initiated between 2010 and 2012 (Halkitis, 2014), provided the methodological and topical concepts for the present study. These studies investigated the lived-experiences of middle aged (≥ 45 years) gay men living long-term (≥ 20 years) with HIV disease (*n* = 200). Project Gold employed an in-depth exploratory interview approach to gather details of the lived-experiences of older adults living with HIV disease; the lived experiences of the researcher were integrated into the research (Creswell, 2012; Halkitis, 2014). From the Project Gold participant population (*n* = 220), the most recently published study (AIDS Generation; Halkitis, 2014) considered a subset (*n* = 15) of participants, long-term HIV survivors. The research legacy served to understand, preserve, and extend the understanding of the lived-experiences of those individuals who have survived long-standing with HIV disease.

For many older long-term HIV survivors, their experiences (e.g., dying, death, and surviving) with HIV disease occurred during their 20s and 30s (Halkitis, 2014). Thus, their normative living experiences in areas such as relationship building were truncated and redirected (Halkitis, 2014). Long-term HIV survivors’ experiences are unique as they have adapted and managed their lives through dying, the deaths of others, surviving, and thriving (Halkitis, 2014). Now, the current biomedical advancements provide another opportunity to explore the impact of the HIV disease in the evolution of this aging cohort. For example, will a cure be universal and applicable to all HIV positive adults (Sax et al., 2014)? Descriptions of older long-term HIV survivors' beliefs about the emergent HIV cure events adds an understanding of this cohort and may cue medical professionals' awareness about long-term survivors' lived-experiences with aging and HIV biomedical advancements (Simmons et al., 2015).

Research Tradition. The research convention of the present study was a qualitative phenomenological exploration. Therefore, interview questions were used to obtain data from the participants. Creswell (2009, 2013) suggested the interview questions begin broadly using one or two inquiries central to the topic. For each of the broad guiding questions, five or more prompts or questions were asked. For the present study, two central or broad questions guided the discussion, and three to four specific or topical subquestions were used to follow-up where answers were lean, opaque, or off topic.

Available HIV cure information evoked a visceral response and required additional questions that assisted the participant to find meaning or closure from the experience. Thus, the research and interview questions evolved during the pilot or main study sessions. The interview questions intended to explore the current HIV cure information in the lived-experiences of older long-term HIV survivors.

Rationale for Research Tradition. Little phenomenological information exists about older adults' beliefs of existing and emerging HIV cure strategies. Few studies have examined the HIV cure strategies among older long-term HIV survivors (Simmons et al., 2015). Accordingly, understanding a new phenomenon begins with exploring individuals' lived-experiences, their viewpoints about the emergent phenomenon, how affected individuals personalize the phenomenon, and identifying the common themes expressed by the cohort (Creswell, Hanson, Plano-Clark, & Morales, 2007). Finally, the philosophical basis is rooted in the exploration of individuals' daily lived-experiences and delivering individual and compiled descriptive elements of the experiences rather than analysis or commentary (Creswell, 2007; Moustakas, 1994).

Role of the Researcher

My role in this study was that of facilitator-observer as participants described their lived-experiences during the primary interview of the qualitative research (Moustakas, 1994). For example, within the context of active participation in one's health, participants described their beliefs about aging with HIV and their beliefs about biomedical advancements for which there is little academic research. Emergent HIV biomedical advances were described by participants (e.g., medications' side effects) during their long-term lived-experiences with HIV disease; participants described the beliefs acquired about the emerging biomedical advancements. The researcher explored, rather than directed, older long-term HIV survivors' lived-experiences and beliefs of past and emergent HIV biomedical advancements.

The idea for this study surfaced during a series of HIV community educational presentations that I designed and presented. The topic was Quality of Life and Living with HIV Disease. The presentation series was tailored for adults in the HIV community aging with the disease. The venue was a not-for-profit organization that provides services to individuals living with HIV/AIDS. Most participants who attended the presentations were 45 years of age and older. During the course of the presentation series, participants requested information about pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PeP), and HIV cure. Presentations were provided for each of the topics, and although the information and Q&A were biomedical in nature, few older adults expressed their beliefs about HIV cure strategies. I became intrigued that the impact of or the experience of an HIV cure could be construed as applicable to all persons. I became curious about what other beliefs older long-term HIV survivors harbored about an HIV cure. Consequently, I wanted to explore scientifically the beliefs about an HIV cure among older long-term HIV survivors.

At the beginning of my presentations about HIV disease, I disclosed three biographical aspects about myself. First, I sero converted in July of 1997 and my personal diagnoses was confirmed in September of 1997. I began and have been continuously treated with antiretrovirals since September of 1997. Lastly, I disclosed in my biography my experiences with HIV medication compliance, physician and laboratory appointment adherence, and practices of disclosure living with HIV disease.

My close association with the experiences of the participants will require attention to managing my biases (Moustakas, 1994). In order to control for predilection, I formulated five self-awareness raising questions to remind me of bias. The self-interview questions are listed in Appendix B, Managing Personal Bias. The answers to the questions were addressed in my journal.

Methodology

Participant Selection Logic

The study population was older (≥50 years) HIV positive adults who had lived with HIV disease before or since 1995 (Halkitis, 2014). The population was recruited in Orange County, California. The estimated number of individuals living with HIV disease in Orange County was 6,215 (Orange County Health Care Agency, 2013). The heterogeneity of HIV in Orange County, California is reflected in the infection numbers. For example, of the 275 HIV infections in 2013, 22.9% were older adults 46 years of age and older; 90% were males, 52% were Hispanic; 30% white, 4% Black, and 13% Asian (Orange County Health Care Agency, 2013). In this population, the transmission route ratio (i.e., infection vector) between men who have sex with men (MSM) and individuals who identify as heterosexual is 8:1.

Participants' told their life stories, which were used to grasp, explore, honor, and acknowledge that their lives may have been compartmentalized and partially obscured. Thus, their lived experiences with HIV disease may have been expressed only in specific environments unaffiliated with family and friends. The present study reinforced the value of the voices of the participants as a method to capture data and identify common themes. Their stories revealed numerous aspects of their disease circumstances.

Some individuals of the older cohort of long-term HIV positive adults in Orange County avail themselves of local, state, and federal resources and non-government organizations (NGOs) to support their day-to-day living and medical needs. Specifically, the non-profit services used by older long-term HIV survivors provided food through food banks, no cost HIV medical treatment (e.g.,17th Street Clinic, Santa Ana, CA), temporary shelter vouchers, case worker services, rent subsidies, transportation vouchers, daily meals, and education. In addition, some older long-term HIV survivors seek assistance for temporary housing in substance use recovery facilities and obtained and maintained rent subsidies vouchers to live in alcohol and drug free environments. In the present study interview process, no participant was asked to disclose present or historical substance use or receipt of services.

Purposeful sampling was used acquire a participant sample that is inclusive of the individuals who are in the cohort of older long-term HIV survivors in Orange County. Thus, recruitment of older long-term HIV survivors occurred at a not for profit and partially federally funded HIV services agency and at the offices of two infectious disease physicians in Orange County. Study recruitment began when an interested participant self-selected to respond to recruitment flyers posted in HIV services venues. Snowballing also occurred before and after a participants' interview (Simon & Goes, 2012).

In this study, all participants self-reported that they met two study participation criteria. First, each participant was vetted for the study age requirement by stating a birth date on the day and month of the study in 1996 or before. Second, each individual was asked to state the month and year of HIV diagnosis (1995 or before) to verify a disease duration of 20 years or longer.

Pilot Study. For the pilot, two participants who met the age and HIV diagnosis criteria were recruited from my personal circle of HIV positive individuals to participate in the study pilot. The pilot was the vehicle used to test the informed consent process, my interview skills, the efficacy of the questions, and the effectiveness of the interview recording process and questions (DiCicco-Bloom & Crabtree, 2006; Erlingsson & Brysiewicz, 2013). The results of the pilot interviews were coded (Appendix E) and formulated in writing into themes and provided to my Dissertation Chair for comment. In addition, the interview recordings were submitted to the chair as part of the study pilot package.

Main Study. For the main study, study participation recruitment flyers were posted in the ASF lobby and two physicians' offices where HIV positive older adults obtained services. The flyers provided a statement of the purpose for the study, the time allotment, and a brief statement concerning participant confidentiality (Appendix C). Interested participants were instructed to contact me at the number provided if they were interested in participating in an academic study of older long-term HIV survivors' beliefs about aging and an HIV cure. Participants were considered potential candidates until each had been screened for the two participation criteria.

Interested participants self-selected to be interviewed and used the contact information on the flyer. In addition, interested individuals were screened for meeting the participation criteria of age (≥ 50 years) and disease diagnosis date (≥ 20 years). Once the participation criteria were verified, an interview date and time was scheduled. Forty-five minutes were allotted for the interview. Twelve interviews were conducted to achieve the target sample size. In addition, data saturation was supported because the interviews ascribed to consistent questions, participants had verified similar backgrounds (e.g. age 50 and over and long-term HIV survivor), the study investigation was specific (e.g. beliefs about HIV cure strategies), and the goal was to identify and describe common themes rather than analyze or interpret the themes (Emlet et al., 2011; Guest, Bunce, & Johnson, 2006; Moustakas, 1994; O'Dwyer, Moyle, & Van Wyk, 2013). The data were recorded, transcribed, and a first draft of codes and themes was completed.

Instrumentation

The responses from the interviewees were captured on a digital recording device. In addition, a discrete note page was used to record nuanced responses such as voice tone associated with a question and the prompt. As a guide to avoid speculation in later analysis, the note page was used as a reminder to the researcher to describe participants' answer styles, voice intonations, and voice volume changes.

The phenomenological tradition was the method of data collection and occurred using open-ended interview questions in a telephone interview setting (Ayling & Mewse, 2009; Creswell, 2009; DiCicco-Bloom & Crabtree, 2006). Moreover, when an event or information was vague, imprecise, or unclear additional open-ended questions were asked to ferret out detailed information. The purpose of the in-depth interviews was to achieve detailed and nuanced descriptions of participants' experiences from their own viewpoint (Moustakas, 1994). I did not initiate follow-up questions with any of the participants.

Researcher Developed Instruments

The interviews explored the substance of participants' beliefs about successful aging and viewpoints of the current HIV cure research. As a guide, aspects of the *AIDS Generation* (Halkitis, 2014) interview (*n* =15) framework were used as a template to explore the participants' lived histories as long-term HIV survivors. For example, the framework allowed for the free flow of participants' stories, which relieved the researcher of guiding the interviews toward his agenda and alleviated the potential for participants to be facilitated or influenced by the researcher (Halkitis, 2014; Moustakas, 1994). This approach encouraged freedom of expression and unguided comprehensive storytelling. Notably, Halkitis (2014) stated meaningful phenomenological information was acquired because the focus was on the narrative rather than the researcher agenda. Consequently, content validity for the present study was established with the provenance of the NYU studies (Halkitis, 2014) which included the sample size (*n* = 200) of older gay men with HIV disease, the themes established from NYU study, and the long-term HIV survivor sample size (*n* = 15).

For the present study, the interview questions were developed from legacy studies of older long-term HIV survivors (Halkitis, 2014). In addition, this study expanded the qualitative understanding of long-term survivors' views of aging (Moore et al., 2013) in the current period of the HIV epidemic continuum. For example, at a time where a cure for HIV has become plausible, this study provided new information about individuals with specific circumstances such as medication efficacy history, and experimental medication toxicity, study relapse rate, costs, and quality-of-life thresholds (Sax et al., 2014). Specifically, the interview questions for the present study initiated discussions about older long-term HIV survivors' beliefs about their lived aging experiences with HIV and their viewpoints regarding an HIV cure. Thus, the content validity for the present study was established as an extension of the historical qualitative research for older long-term HIV survivors.

Pilot Study Procedures

A pilot study was conducted to gain skills in the process of participant recruitment and vetting, determining themes, and verifying the efficacy of the interview questions (Lenth, 2000, 2007). In addition, the pilot study established clear processes to achieve reliable and valid results (Lenth, 2000, 2009). The pilot study was administered after the dissertation proposal was approved by the Walden Institutional Review Board (IRB; Approval # 01-04-16-0176986).

Two participants for the pilot study were recruited who live in Los Angeles County, California area to minimize population homogeneity that can occur from candidates contacting friends who are similar to themselves (i.e., Snowballing) because the recruitment sites were in Orange County, California. The pilot study participants were asked to participate through my non-profit network. The pilot interviews provided information and feedback about the criteria for participation, the clarity of the questions, the appropriateness of the prompts, and clarity of the informed consent process. I conducted information gathering from the pilot study participants in a follow-up call within 48 hours of the conclusion of the interview. The purpose of the follow-up calls was to gather insights from the pilot study participants about their interview experience that could assist in developing my interview skills. Follow-up calls were not conducted for the primary study interviews.

The pilot interviews were recorded as well as the feedback discussions with the pilot interview participants. After an acceptance to participate was acquired from the pilot interviewees, the salutation, informed consent, interview questions with prompts, and closing (Appendix D) were be read aloud by the interviewer to the pilot study participant. After the pilot interviews were completed, they were, and an assessment was written about the interview process. The interview recordings, the interview script, the transcripts, and my written assessment of the interview process were provided to my Dissertation Committee Chair for review. My Dissertation Committee Chair and I had a conference call and recommendations were incorporated into the primary interview sessions for the 12 primary study participants. My Dissertation Committee Chair provided the authorization to continue to the primary study interviews as I had addressed all issues and concerns discussed about the pilot interviews.

The pilot interview process with the two volunteer interviewees was inclusive of the informed consent process, oral consent was recorded, and clearly stated primary questions and follow-on prompts were recorded. I provided a concise conclusion statement and warm statement of gratitude to the pilot interview volunteer for his participation. The data from the pilot interviews was summarized and reviewed separately from the feedback session with my dissertation committee chair.

Recruitment, Participation, and Data Collection

Recruitment. Participant recruitment flyers were placed at ASF, and in the offices of two infectious disease physicians, which were all located in Orange County, California. The contents of the recruitment flyer (Appendix C) identified the subject and purpose of the study, participant eligibility criteria, and the participation process. Additionally, the flyer stated participants' identities were protected. Specifically, at no time were participants' names requested or used (participants chose pseudonyms), and phone numbers were erased from the researcher's cell phone log. Furthermore, the solicitation flyer requested that participants call the researcher's phone number to identify interest in participating in a two question interview.

At the time of the initial call to me from interested parties identified an interest to participate in the study interview, I asked the interested participant to self-report his birth year and the year of HIV diagnosis. With the participation criteria validated, I repeated the participation time commitment requirement and asked the participant to identify a 45 minute time period when we could speak uninterrupted about the participant's beliefs of a cure for HIV. I clarified there would be only one interview, no follow-up calls or discussion. Finally, I stated that all information collected was confidential and the individual's name would not be published. I also asked for a phone number that I could use to contact the participant at the time of the interview. This statement was followed by a verbal commitment to the participant that the phone number would not be given, sold, or used by me for any purpose but to contact him for the study interview.

At the beginning of the scheduled series of interviews, if it appeared the participation response had been too lean to meet the required (< 13) number of participants for the study, interviewees were asked if they would be interested in contacting individuals' in their circle of influence to participate in an interview (Waters, 2014). If the participant responded with a yes, the interviewee was reminded of the participation criteria and thanked for their additional support of the study. I then asked the individual if he needed any additional information for his discussion with his contact. If the response for a friend's participation was no, I moved to the interview-exit portion of the script.

Participation. For the present study data collection activity, a one-on-one telephone interview was used to administer open-ended questions. During the salutation portion (Appendix D) of the telephone interview, participants were notified of the presence a digital recording device that was used to record the interview. At this point, the recording integrity of the device was tested. During a brief introduction, the participant was notified that the conversation was to be recorded. Next, the individual was asked to very his understanding that the interview would be recorded, if the answer was yes, the participant was asked for a verbal agreement to proceed with a test recording to ensure the device and the environment were in order. After the test recording, the digital recording device was rewound and the recording device capability (the interviewee's voice) was verified by the interviewer.

Next, the participant was informed the digital recording device had been turned on and recording had begun. All participants confirmed that he understood he was being recorded and that a recording session was in progress. At the beginning of the interview, the informed consent agreement (Appendix D) was read aloud to each participant and all participants agreed to the conditions of the Informed Consent statement.

Two questions were used to re-confirm the participant met the criteria of long-term HIV survivorship. The participation criteria were re-confirmed (date of birth is ≥ the year 1965; date of diagnosis is ≤ 1995) In addition, each participant was asked to self-identify gender. Then, each participant was informed that additional questions could be asked during the interview and it may be necessary to request clarification of a general or vague word or statement. Next, each participant was asked the two open-ended questions which were the vehicle to elicit detailed lived-experiences and beliefs from each participant.

First, participants were asked to discuss her/his beliefs about aging with HIV disease. Second, participants were asked to discuss his/her beliefs about a cure for HIV disease (Appendix F). None of the participants asked any additional questions after the interview was concluded. Finally, each interviewee was thanked for his participation in the study.

Data Collection and Preparation. The digitally recorded interviews of the participants were stored in a Sentry brand safe owned by me, and I am the only individual with the combination to the safe. Transcripts from the tapes were stored in the same safe. Interview tapes and transcripts will be destroyed five years after the publication of the dissertation (Walden University, 2010a).

The beginning of each recorded interview contained the date, the participant's self-assigned designation for gender, his date of HIV diagnosis, and his birthdate. In no instance was a participant asked to self-identify a gender status. For example, no individual was asked if she/or he was transgender or his/her stage of transition. Proper names were not used in order to ensure the anonymity of the participants' identity.

The recorded interviews were transcribed from the recording device verbatim into a word document and converted to a PDF file on a password-protected computer and a password-protected file. Responses acquired during the one-to-one interviews were coded (Appendix E) for distinctions among the current HIV cure strategies, which reflected the cure strategies available to HIV infected persons. For example, cure strategies available to HIV positive persons included bone marrow transfusion, stem cell transplants, and functional cures (Dieffenbach & Fauci, 2011; Evans, 2012). In addition, the interviewee’s beliefs were assigned to an emerging common theme.

Operationalizing the HIV cure data occurred in three areas. One area was participants' beliefs that may be identified in common themes. Next, participants' viewpoints about the biomedical advancement of an HIV cure that constitutes a thematic thread. During this portion of the interview, an open-ended prompt was employed to further explore the participant's understanding of an HIV cure. One final area was the participant's viewpoints of the beliefs about aging with HIV and an HIV cure. In chapter 2, the existing literature for older long-term HIV survivors aging successfully and biomedical aspects of an HIV cure were discussed. The studies in chapter 2 were used to assist in developing descriptions of participants' beliefs about aging and an HIV cure.

As an example, participants' beliefs of successful aging with HIV disease and the biomedical factors of an HIV cure were coded (Appendix E) and categorized by the number of times a theme occurred in the sample. Next, the biomedical themes were mapped to the existing HIV cure information in chapter 2 that was identified in the extant literature. More specifically, biomedical categories reflected the HIV clinical and research categories associated with the difference between a functional cure and HIV eradication. Another opportunity for describing the beliefs of older long-term HIV survivors occurred in participants' views of the relationship of an HIV cure and aging successfully. The potential for the overlap between data collection and data analysis exist (Moustakas, 1994). Therefore, in the present phenomenological investigation design, the overlap was mitigated with interview practice sessions (e.g., the pilot) and the use of open-ended questions and prompts (Moustakas, 1994).

Data Analysis Plan

In the present study, data collection and data analysis occurred at the same time during the research process (Neal, Neal, VanDyke, & Kornbluh, 2014). To analyze the transcribed interview data, I used a constant comparative coding sheet (Appendix H) to highlight important statements or comments in order to understand how the participants experienced the phenomena of aging with HIV and an HIV cure (Creswell, 2012; M. Vaismoradi, Turunen, & Bondas, 2013). Despite the laborious nature of this approach, I immersed myself in the data to become more knowledgeable of the nuances of older long-term survivors' lived experiences, beliefs, and the emerging themes of aging with HIV and an HIV cure.

Next, I coded the information, which included unique beliefs, from each overarching research question by identifying smaller portions of the data (Appendix H), which assisted in the achievement of a more granular analysis (Erlingsson & Brysiewicz, 2013). In addition to coding, my notes from the interviews identified the non-verbal language cues (e.g. hesitation or excitement) that presented themselves during the interview. Lastly, I kept a researcher's log to document my thoughts and feelings during the interview process (Mojtaba Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Because of my own long-term HIV disease experiences and my background as an HIV disease educator the researcher's log served to reveal additional insights of the essence of the phenomena being studied (Halkitis, 2014).

Issues of Trustworthiness

Credibility

Objectivity and truthfulness are critical in the qualitative research tradition. The criterion for judging a qualitative study, first and foremost, is for the researcher to seek believability, based on coherence, insight and instrumental utility and trustworthiness (Lincoln & Guba, 1985) through a process of data verification rather than through the qualitative traditions of validity and reliability (Creswell, 2012). In the present study, the truth in findings were addressed in two ways.

First, the interviews were anticipated to be 45 minutes in length on the telephone. I established and built rapport and trust by briefly disclosing my HIV disease status and aging experience. Second, because the data capture method was recorded and I verified with the participant what I had heard and documented using the method of repeating what I had heard and obtaining validation from the participant that I had heard his words as spoken or intended. This method did not restate or use the method, "what I heard was…" In this method, the participant's words were repeated back to him exactly as spoken. Ostensibly, this method gained the participant's trust through identification and validation of the participant's words. Thus, a safe environment developed, which was necessary to achieve truthfulness in the findings (Erlingsson & Brysiewicz, 2013).

Transferability

Rather than generalizability or applicability in the realm of psychological treatment, the expectation of the outcome of the present phenomenological research was that the forthcoming information would be helpful to add descriptive information about older long-term survivors' beliefs and about their health. In order to encourage use of the findings of the present study, I documented and presented vivid descriptions of the participants' beliefs about surviving HIV long-term, aging with the disease, and an HIV cure (Erlingsson & Brysiewicz, 2013). Although the present research focused on individuals living with HIV disease, the outcomes of the study may be transferable to other individuals who experience the possibility and uncertainty of a cure for other chronic diseases. The beliefs of older long-term HIV survivors presented common themes from their unique lived-experiences that added understanding to the phenomena of aging with chronic illness and the current biomedical advancements of an HIV cure (Halkitis, 2014; Kahana & Kahana, 2001; Kall et al., 2015; Moore et al., 2013).

Dependability

One goal of the present study was that the study could be repeated. Therefore, a pilot study was incorporated into the design. The pilot study was about information gathering and fabricating a solid interview process rather than confirmation of the results (Lee et al., 2014). Thus, the pilot portion of the present study included a review of all of the phenomenological design processes, data capture forms, and recording technology. Consequently, the exacting documentation provides greater opportunity for duplicating the study process, and increasing the likelihood of the dependability of the data.

Confirmability

The concept of not disturbing the data is demonstrated in the objectivity of the study (Erlingsson & Brysiewicz, 2013). The goal of the study was to describe the beliefs of successful aging and an HIV cure that were recorded in interviews with the study participants, rather than interpretations of participants' beliefs. In order to achieve accurate descriptions of the participants' beliefs, I completed a journal writing activity to unveil my own views of successful aging and an HIV cure; this was used as a compass to remind me of my biases and encourage me to focus on the participants' viewpoints. In addition, I reaffirmed my history with my Chair as a way of reminding myself of the biases I harbor. Finally, at the beginning of each interview I briefly revealed my own HIV status and aging information. For the latter, my introduction was neutral and avoided any commentary that I have acquired about successful aging as an older adult living with HIV disease and my HIV cure viewpoints acquired from research for this project.

Intra- and Inter-Coder Reliability

As noted by Neal et al. (2014) immersion in large amounts of data produced from interviews can be mitigated with a solid process. The process proffered by Neal et al. (2014) established themes preliminarily and included the following: concise definition of each theme in the codebook; identify theme code as positive, neutral, or adverse; refinement of codes in the codebook; discrete coding for each interview; description of voice tone; and identify common themes and thematic valence (Neal et al., 2014).

Ethical Procedures

The present research project required IRB approval from Walden University. Specifically, approval was required for the processes, anonymity, and safety of this unique sample of older long-term HIV survivors. In addition, the researcher in phenomenological research must be disciplined when interviewing vulnerable or invisible populations (Grossman, 2008; Trau, Härtel, & Härtel, 2013). In addition, participants were advised of the purpose of the study and their confidentiality in all aspects of the present study.

As a social science researcher, I conducted "research in a manner that minimizes potential harm to those involved in the study" (Bloomberg & Volpe, 2009, p. 76). Procedures to address ethical issues in this study protected the rights of the participants, protected the participants from harm, maintained the researcher-participant relationship, and ensured confidentiality. Prior to the beginning of each interview, I informed each participant of the purpose of the study, digitally recorded an oral informed consent, explained the voluntary nature of participation, and informed the participant he could leave the interview at any time without penalty or adverse outcome. In addition, I did not initiate data collecting procedures until approval had been emailed from the Walden University IRB. I assured the study participants that their confidentiality would be maintained during the interview portion, the analysis stage, and the reporting stage of the dissertation. In addition, I affirmed I would describe each participant's experiences, feelings, and attitudes accurately.

During the interview segment, I presented with a neutral posture toward participants' descriptions of her or his beliefs about aging successfully and an HIV cure. I will prepare for the interviews using mock interviews with individuals in my profession from the discipline of counseling psychology. Importantly, I practiced a nonreactive and nonresponsive posture toward participants that might have influenced his response to the questions.

When interviewing older long-term HIV survivors, I discarded my biases during the interviews and in the analysis segment of the study. Disclosing my personal experiences age and HIV disease status served to remind me that I had said enough on the subject. Additionally, I was particularly attentive to clarify vague or general responses from a participant. It was important to capture explanations that specifically characterized behaviors, actions, or feelings associated with a dimension of quality of life. Questions for clarification did not lead or cajole the participant to answer in such a manner as to bias the participant.

The study population sample included participants with several aspects of social, legal, and medical vulnerability. For example, individual participants experienced the phenomenon of being 50 years or older, living with HIV disease, aging with HIV disease, and living as a long-term survivor of HIV disease. In addition, some participants might have been living undocumented in the United States. Lastly, no participant identified as transgender. In no instance was any participant be required or encouraged to answer or disclose any detailed or explicit information regarding his health status, citizenship status, or gender identity. In summary, participation was voluntary. No individual participant withdrew his consent to participate at any time during the interview or after the interview.

Summary

In chapter 3, I presented the study's research design and methodology that was used to answer the proposed research questions. The use of a phenomenological approach to explore the lived experiences and beliefs of the long-term HIV survivors in the study was justified by the depth of experiences of the cohort and the limited information about their beliefs of an HIV cure. Lastly, the present phenomenological investigation explored the nuances of lived experiences among long-term HIV survivorship, successful aging, and a cure for HIV. The framework of the study was defined by an explanation of my role as the researcher, the selection criteria of the participants, the interview questions asked, researcher trustworthiness, as well as the ethical considerations of the study.

In chapter 4, there is an overview of the data analysis process with a discussion of the study's emerging themes. Aspects of the methodology that were continually audited throughout the study process included the research questions, key concepts, sampling and recruitment methods, procedures for data collection and analysis. The audits reinforced that the voices of the population sample were heard and represented accurately.

Chapter 4: Results

Introduction

There is little information about older (≥ 50 years) long-term (≥ 20 years) survivors of HIV disease. In 2015, this group represented 50% of the HIV disease population in the United States. The purpose of this phenomenological study was to describe older long-term HIV survivors' lived-experiences and beliefs about aging with HIV disease and an HIV cure. The study was guided by six research questions:

RQ1: What beliefs do older long-term HIV survivors maintain about aging with HIV disease?

RQ2: How do older long-term HIV survivors' experiences of aging with HIV disease relate to and contribute to their current life experiences?

RQ3: What beliefs do older long-term HIV survivors maintain about an HIV cure?

RQ4: How do older long-term HIV survivors view an HIV cure as a part of their long-term HIV survival?

RQ5: How do older long-term HIV survivors view a cure in their future?

RQ6: How do older long-term HIV survivors resolve their lived-experiences and beliefs about a cure for HIV disease and aging with HIV disease?

In chapter 4, I describe the pilot study and research setting; present the participants' demographic information; and provide an overview of data collection and analysis, evidence of trustworthiness, and the interview results. I conclude chapter 4 with a summary.

Pilot Study

The pilot study was used to evaluate the interview protocol. Two pilot study participants were recruited from my personal network. Both pilot study participants met the study age (≥ 50 years) and disease diagnosis duration (≥ 20 years) criteria. The pilot study interviews were conducted over the telephone. Each interview was recorded and each interview was typed by a professional transcriptionist. I reviewed each transcript with the original recording for accuracy and completeness. After the pilot study interview transcripts were completed and reviewed, the interview transcripts were forwarded to my dissertation Chair, Dr. Lee Stadtlander, for review. Recruitment for the main study commenced with approval to proceed by Dr. Stadtlander.

From the pilot process, it was determined that a poorly framed statement in the Informed Consent Statement required rephrasing. A revision to the informed consent statement was drafted and submitted to the Walden IRB. The change was approved (Approval #: 2016.01.04 16:22.01-061’00’) and recruitment of the main study participants commenced. Modifications to question prompts were identified and incorporated into the study interviews. Details are presented the Setting and Data Collection sections of this chapter.

Setting

Prior to obtaining IRB approval, I obtained agreement from a managing Director of an HIV/AIDS service organization and infectious disease physicians to display the main study recruitment flyers in their office lobbies. Upon receiving IRB approval, I immediately sought approval from each of the locations' managers to actually place the recruitment flyers in the three previously identified environments for a four week period with an option to extend. These settings were environments where older long-term HIV survivors were likely to seek out psychological, social, and/or medical support.

I advised all staff to allow the display to speak for itself and requested that individuals who asked questions be directed to call the phone number on the flyer. It was vital to the trustworthiness (i.e., credibility) of the study that the random sampling process allowed participants to self-select and that participants were not influenced by physicians, case workers, or administrative staff (Simon & Goes, 2012). I visited all three environments several times during the four week period to ensure there were sufficient telephone number tear-off tabs available.

At the end of the fourth week of the recruitment phase, 10 of 12 participants had been vetted and scheduled for an interview. In order to achieve a population sample of 12, at the beginning of the fifth week I telephoned the location managers and requested and received agreement that the recruitment flyer displays would remain in place for an additional two weeks. In the next two weeks two participants self-selected and were vetted, and an interview date and time were scheduled.

The recruitment flyer displays were retrieved, and location managers and staff were thanked for their contribution to this study. Two days later I hand wrote three personal notes to each of the key contacts who provided a location for the recruitment flyer displays. I expressed my gratitude and appreciation for the contribution to completion of this study. The notes were mailed the following day.

At the beginning of the telephone interview, each participant was thanked for his voluntary interest and willingness to participate in the study. I also thanked each participant for the time he devoted to the interview and assured him that his confidentiality could be protected.

All of the study participants (*n* = 12) were vetted for the study's criteria for age and disease diagnosis duration. All interviews were recorded after participants voluntarily agreed to be interviewed and audiotaped using a digital recorder. All interviews were conducted individually and privately. Each participant was asked to confirm that he was in an environment that was safe to speak about HIV disease. All 12 participants confirmed their environment provided safety and confidentiality. I provided a clear description of the purpose of the study, Next, I explained the interview process and procedures, and I assured the participants that their privacy and the confidentiality of their responses would be maintained. Each participant was read the informed consent statement; the informed consent required a clearly audible and discernable verbal "yes" or "no" acknowledging the informed consent had been understood. All twelve participants stated "yes."

The first interview question was posed to the participant. When clarification of any response was necessary, a prompt or follow-up question was presented at a convenient opportunity. The second question followed the same pattern as the first. No participants expressed any personal or interview process issues at the time of the interviews that might have influenced my interpretation of their responses.

Demographics

Table 1 illustrates the demographic information about the participants. The average age of the participants was 59 (range 51-72) years. All participants self-identified as male. In addition, the participants' average age at HIV disease diagnosis was 29.5 (range 21-52) years. As a group, the participants in this study have lived an average of 74% (range 38-93%) of their adult lives (≥ 18 years to age at time of interview) with an HIV disease diagnosis.

Table 1.

Older Long-term HIV Disease Survivors

		HIV Diagnosis			
Participant	Age	Age at	# Years	% Overall Yrs.	% Adult Yrs.*
Kevin	55	23	32	58	86
Richard	62	35	27	44	61
Paddy	66	41	25	38	52
Michael	64	30	34	53	74
Bob	54	23	31	47	86
Kirk	52	21	31	60	91
Ron	51	22	29	57	88
Sean	57	27	30	53	77
Danny B	57	27	30	53	77
Joshua	59	21	38	64	93
Sam	72	52	20	28	37
Steven	57	30	27	47	69

Mean	58.8	29.3	9.5	58	74
Range	51-72	21-52	20-38	28-64	37-93

Note. (*n* = 12). Particpant's names are pseudonyms. *Adult age = ≥ 18 years; (Yrs. Diagnosed/current age-18 = % of adult years living with HIV)

Data Collection

As noted by Neal et al. (2014), the overwhelming immersion in large amounts of data produced from interviews can be mitigated with a solid process. At the beginning of each telephone interview, the demographic information was collected from each participant (*n* = 12) and included birth month and year, the year each participant was diagnosed with HIV by a physician, and each participant's self-identified gender. I digitally recorded each of the 12 interviews, which lasted between 25 and 55 minutes. The length of each interview was determined by the amount of detail and description that each participant shared. During each interview I took notes, which I used as reminders to follow-up with prompts or additional questions.

All of the participants responded to both interview questions. Participants' locations at the time of the interviews were unknown. I conducted the recording of the interviews in my home office. I used two interview queries to answer the six research questions. The two interview queries and participants' responses were digitally recorded. Additional prompts were employed to address the research questions and to increase the acuity of long-term HIV survivors' lived experiences aging with HIV disease.

Immediately after each interview, the digital recording file was coded and electronically saved to three discrete locations. A file was also e-mailed to the transcriptionist. The transcripts were returned within two days. For purposes of backup security during the time frame that the 12 interviews were conducted, the transcriptionist retained a copy of the digital recording and an electronic copy of the transcript. After data collection and transcription were completed the transcriptions were imported into MS Excel for data analysis. Once the data had been imported into an Excel worksheet, several worksheets were created to capture individuals' demographic information; isolate participant's statements; and create a series of codes to delineate and summarize the themes (Neal et al., 2014).

After the last interview had been transcribed and forwarded to me, the transcriptionist deleted all files from the directory in which they were stored and from the recycle bin of her computer. Lastly, the files that had been deleted but in reality only moved to the Recycle Bin (Windows 10) were also deleted. I am the only person with copies of the digitally recorded interviews and the electronic files of the transcripts. There are no hard copies of the transcripts. However, my field notes remain in long-hand and have been stored in the same envelope with the electronic media.

All data that has been collected is in electronic files (audio, transcriptions, and Excel spreadsheets) and stored on a thumb drive and in an envelope marked "Confidential." The thumb drive is stored in my personal safe; I am the only person with access to the combination to the safe. Neither the audio files nor the transcribed files are stored on the hard drive of my laptop computer. In addition, a discrete jump drive that stored the audio and transcript files has been reformatted which permanently deleted the files and any directories. Data collection occurred exactly as described in chapter 3, and the data collection activity was smoothly executed.

Data Analysis

The data analysis included the use of electronic files of the 12 interviews' transcripts, which were imported from Microsoft Word into a Microsoft Excel Worksheet. The interview statements were read numerous times to formulate concepts, subthemes, major themes, and thematic relationships (Moustakas, 1994). The electronic files were also instrumental in the process of data interpretation. The spreadsheet assisted in the organization and analysis of participants' lived-experiences and beliefs about aging with HIV disease and an HIV cure. The interview statements were highlighted; descriptions were validated; and participants' statements were assigned themes and subthemes. This aforementioned process facilitated the management, clarification, and understanding of the interview data.

The researcher's notes were entered into the electronic spreadsheet and linked with participants' statements using terms or phrases of common English language. Parentheses were used to identify technical jargon or to clarify the themes and explain their meanings (Babbie, 2013). Themes were developed iteratively from reading and rereading the data. Next, themes were referenced to theoretical models 1) The self-regulation model of illness representations (Leventhal et al., 2001), and 2) Successful Aging with HIV Disease (Kahana & Kahana, 2001). Together, the themes enriched my understanding of the relationships among the themes and provided deeper meanings about them (Babbie, 2013). I used textual mining techniques (Shaw, 2012; Underwood, 2012) such as word searches to identify and analyze the content and meaning of the participants' interview statements.

In order to verify the themes' commonality to the research questions, electronic data sorting was employed to trace participants' statements. A subtheme was included in the final analysis if the number of participants who discussed the subtheme was ≥ 50% of the total number of participants. For example, the subtheme Accelerated Aging, under its prime theme Aging with HIV disease, was discussed by 6 of the 12 participants. Thus, Accelerated Aging was included in the results discussion.

All interview transcripts were imported into Microsoft Excel and the summarized themes were associated to each of the six research questions. In the spreadsheet, a participant's response or statement about a topic was contained in a single cell. Corresponding cells next to the participant's response or statement were used to reduce the participant's comments to succinct language, coded to a theme, and notes added where necessary.

The data were sorted on the column containing the themes. Common themes were delineated from the sorting of the data. The analysis activity was executed with sufficient rigor to establish 13 common themes associated to various research questions. For example, four themes (longevity; issues aging with HIV; taking care of one self; and accelerated aging) emerged in answer to Research Question 1. Lastly, themes for Research Question 6 were associated with themes that had been identified in Research

Question 2 (e.g., Medications and Physical Issues). Thus, the relationships among the themes materialized. In the Results section, I present the detailed variances, results, and themes developed and supported by the participants' responses.

Triangulation

Numerous electronic spreadsheets (Excel) were developed and the data were manipulated (e.g., sorted) to identify the themes and the most common themes. Themes identified as common were attached to each participant's statements on the topic. Statements were compared and assessed for similarities and differences. This process of data triangulation served to advise the researcher of bias. As a result of sorting the themes for commonality, the validity of the themes was established. The common themes were linked to the participants' statements and used to answer the research questions. The participants' statements validated the commonality of the themes. Lastly, the rigor of this process indicated the data sorting process is repeatable.

Evidence of Trustworthiness

Credibility, transferability, dependability, and confirmability were the qualitative criteria used to assess the trustworthiness of the interview results (Shenton, 2004). In this section, I present the actions taken to demonstrate trustworthiness. First, I established credibility with actions that ensured the presentation of an accurate portrayal of the phenomenon under investigation. Next, I ensured transferability and dependability by providing sufficient detail for another researcher to assess whether the results can be applied to another setting. Lastly, the processes used to demonstrate the emergent findings were clearly derived from the data and not my own biases, demonstrating confirmability.

Personal Bias

To achieve objective descriptions of participants' lived-experiences and beliefs, the interviews were recorded and transcribed. Objectivity was further developed by writing journal entries in which I acknowledged and discussed my age (66 years) and HIV disease duration (19 years). In these entries, I disclose my personal views of aging with HIV disease. In addition, I openly affirmed to colleagues the similarities between myself and the study cohort, which served to keep me aware of my biases. Finally, during the introduction segment of each interview I revealed my age, HIV status, and disease duration. Each introductory statement was matter-of-fact and provided no commentary about my beliefs of aging with HIV or an HIV cure.

Results

In the following section, I present the study findings. The data collected from interviews with older (≥ 50 years) long-term (≥ 20 years) HIV survivors were used to answer the six research questions. Additionally, I present the emergent themes, examples of participants' supporting and incongruent views. Also, in order to protect the anonymity of the participants, all the names associated with the quotes are pseudonyms, which were chosen by each participant. The participants' responses are direct quotes of their lived experiences and beliefs.

Themes

Each interview was carefully analyzed in order to answer each of the six research questions. During the interviews, I asked two open-ended questions and asked probing questions to ensure clarity and obtain more details. The themes from the two interview questions were identified to the six research questions. In the next six sections, the themes for each research question are defined and presented, and participants' statements that emerged as the themes are identified. In chapter 5, I present interpretations of the themes.

RQ1. The first research question was: What beliefs do older long-term HIV survivors maintain about aging with HIV disease? Four themes emerged from participants' responses about aging with HIV disease (Table 2). The beliefs most commonly reported were longevity, aging with HIV disease issues, self-care, and accelerated aging. Participants' beliefs that support this theme are presented below.

Longevity. The most commonly identified factor of aging with HIV disease was longevity or how long the participant believed he would live even with the circumstances of HIV disease. Most participants believed they would live long lives with HIV disease. In addition, most participants identified contributors to longevity such as diet, exercise, medication compliance, sobriety, not smoking, stress, and/or genetics.

One participant, Kevin (55 year old male diagnosed with HIV disease at 23 years of age), noted a relationship between longevity and stress as: "I think somebody who has a potentially compromised immune system, that just exacerbates the situation, the potential for stress to be -- I don't know if I'd go so far as to say life threatening, but certainly life shortening.” Ron (51 year old male diagnosed with HIV disease at 27 years of age) commented:

> I think I’m going to get old with HIV. So I think I’m probably going to live as long as everybody else. Many of my friends have fallen victim to the vices, and it changed them psychologically. And their outside appearance, it’s had an effect on them as well. And this includes something that’s as innocuous, you would think, as smoking, compared to harder drugs and some of the much more dangerous drugs. But, fortunately, I stayed away from all of those things, and I kind of reinforce it in myself that that’s had a lot to do with my longevity and my luck in never really having much problem with this disease.

Issues aging with HIV disease. Issues of aging with HIV were corporeal and psychological conditions such as early aging, medication side effects, and depression. Despite these corporeal issues, most participants reported few or no issues aging with HIV disease. Most participants stated they had few or no issues living with HIV disease. Paddy (66 year old male living 25 years with an HIV disease diagnosis) remarked that his lived-experiences issues aging with HIV disease were minimal. He stated “For someone who is 66 years old, I can compare myself to other people I know. I'm quite active. I consider myself almost perfectly healthy except for perhaps for the fatigue issue.” Joshua (59 year old male living 38 years with an HIV disease diagnosis) reported he had no issues aging with HIV disease. He remarked that “I'm aging normally. You know, I'm pushing 60 years old, so I get the physical aches and pains, but I've never had anything AIDS related, you know, Kaposi's sarcoma, pneumonia, any of the other defects."

Conversely, Sean (57 year old male living 30 years with HIV disease diagnosis) identified numerous issues associated with aging with HIV disease:

> So, I mean, I've been living with this disease for over 30 years, but yet I've got new chronic issues coming up as of now and again. My issues with my kidneys, I feel, are more because of dehydration because of the diarrhea, which is caused by the colitis, which is a side effect of, I believe, the HIV medicines. . . . My upper neck. . . . My shoulders have really bad arthritis in them, but I have it in my L—C5, C7. I don't know what the—lumbar 5. Anyway, it's my lower back, and what it is - I have spurs that are protruding out, and they're pinching my nerve. I have neuropathy… I lost my adrenal gland and my gallbladder that my body chemistry changed, again, nobody can say for sure, but something caused my routine that had been working for 12 years to finally fail or to stop working or to become toxic, I should say.)

Take care of one self. Most participants believed an aspect of aging with HIV disease included taking care of oneself. In particular, active involvement in handling one's healthcare (medication compliance) was a characteristic of taking care of oneself. For example, Kevin (55 year old male living 58% of his overall life with an HIV disease diagnosis) believed that "Well, the other thing that I think I've said quite a few times now is the only way you are going to age with HIV is if you're involved in taking care of yourself.” Danny B (57 year old male living 53% of his overall life with an HIV disease diagnosis) stated it in less direct terms as “So my belief is you take your medication, and you do what you can for yourself to live as positively as possible, and I think we have a very good chance of living quality lives for the long term.”

Accelerated aging. Participants were aware of the information that indicated older adults living with HIV disease experience age related illness earlier than their HIV negative counterparts, and many participants believed accelerated aging was a factor of aging with HIV disease. Participants’ beliefs about accelerated aging were framed in the context of their HIV negative age related counterparts, older HIV positive counterparts, family history, or corporeal circumstances. Kevin (55 year old male living 86% of his adult life with an HIV disease diagnosis) stated that “And, I mean, I guess that's the most primary thing that I've heard is that onsets of certain conditions happen like a decade earlier than our non HIV peers, and I personally have not had that experience yet…” Michael (64 year old male living 74% of his adult life with an HIV diagnosis) viewed accelerated aging from a scientific perspective and stated that:

> I believe that . . . "we" being the scientific community has come to realize that there seems to be an accelerated aging process in long-term HIV disease, and have indeed experienced that where I have gotten illnesses and symptoms and conditions that my parents don't –

Lastly, Bob (54 year old male living 86% of his adult life with an HIV disease diagnosis) stated his belief from lived experience as "I feel much older than I am. I have all kinds of joint problems, tissue problems, and with muscles."

Table 2

Themes (RQ1): Beliefs of Aging with HIV Disease

Themes*	# of Participants	% of Participants
Longevity	8	67
Issues aging with HIV	8	67
Take Care of One Self	7	58
Accelerated Aging	6	50

Note. * Participants (*n* = 12) could provide more than one response.

RQ2. Participants' responses provided answers to RQ2: How do older long-term HIV survivors' experiences of aging with HIV disease relate and contribute to their current life experiences? All but one participant began their stories of aging with HIV disease (Table 3) at the time of their HIV diagnoses (≥20 years ago).

Death sentence. Most participants characterized their HIV diagnosis experience with the most common prognosis before 1996: a near-certain death sentence. In addition, their early HIV experiences were punctuated with toxic side effects from HIV medications (e.g., AZT). Steven (57 year old male living 27 years with an HIV disease diagnosis) described his lived-experience during the time of his HIV diagnosis as:

> I was just 29, just before my 30th birthday. And back then when I was diagnosed it was a death sentence. People that were HIV positive were going to die within,

> you know, it could be months or even years, but here I am, 27 years later, somehow still alive.

Medications issues. Danny B (57 year old male living 30 years with an HIV disease diagnosis) explained his experience in terms of "they just threw a bunch of AZT at me, and it did everything from A to Z to my body, mentally and physically, and I think we've moved away from that, and I think it's completely manageable these days…"

Current health circumstances. Participants' stories of their HIV disease histories were illustrated by long-term HIV medication use and culminated with descriptions of their current health circumstances. Kevin (55 year old male living 32 years with an HIV disease diagnosis) explained his lived-experiences with his early treatment and his current treatment:

And so by the time I actually started on AZT, they had gotten the dosage right, but then even with that I stopped for a period of years and just didn't take any medication. And then I was on a regimen of Viramune and COMPLERA for a while -- Viramune and Truvada for a while... and was doing very well on that with virtually no side effects, and then my doctor recommended COMPLERA, which is one pill a day. Although it wasn't a stress inducer, when you're a chronic medication taker that, in my psyche, was constantly reminding me that I'm "sick." So to be just on one drug a day, that has helped considerably, at least for me.

Table 3.

Themes (RQ2): Experiences Aging with HIV and Current Life Experiences

Theme	# of Participants	% of Participants
Early HIV Diagnosis and Treatment	9	75
Current Health Circumstances	9	75
Medications' Issues	7	58

Note. Participants (*n* = 12) could provide more than one answer.

RQ3. All participants responded to RQ3: What beliefs do older long-term HIV survivors maintain about an HIV cure? From their responses, two distinct themes surfaced (Table 4).

No HIV cure exists. Participants have no confidence that a cure exists presently nor will a cure ever exist. Sam (72 years old and living 20 years with HIV disease) believed that “Well, so far, in my mind, if only in my mind, I don't think a cure will exist.” On the other hand, Bob presented the opposite belief.

An HIV cure exists. Participants believed a cure is forthcoming, while others believed a cure exists but is being withheld for financial reasons. Kirk (52 years old and living 31 years with an HIV diagnosis) stated that “So I believe that it will happen. I'm hopeful that it will be within the next 10 to 15 years.” Kevin (55 years old and living 32 years with an HIV diagnosis) stated that “I believe the pharmaceutical industry has it sitting on a shelf. I believe some powers that be are also -- I guess I've evolved into a conspiracy theorist to a certain point.”

Table 4.

Themes (RQ3): Beliefs about HIV Cure

Themes	# of Participants	% of Participants
No HIV Cure Exists or Will Ever Exist	6	50
An HIV Cure Exists or Will Exist	6	50

Note. (*n* = 12)

RQ4. Over half of the participants responded to RQ4: How do older long-term HIV survivors view an HIV cure as a part of their long-term HIV survival? A single theme emerged. Most participants believed a cure would have little or no influence on their lives (Table 5).

Little or no influence on survival . A cure will have little influence on survival because, for example, the damage from the virus and medications has already occurred and corporeal and psychological issues have stabilized. Sean (57 years old and living 30 years with an HIV disease diagnosis) believed "... me getting a cure for HIV is not going to change my life."

On the other hand, Ron (51 years old and living 29 years with an HIV diagnosis) explained the relationship between a cure and the source of his income would be compromised. He believed:

> So for someone like me who's had -- I had 4 T cells at one time. So when you have that low T cells, a lot of times it can't go that high. Know what I'm saying? So if there was a cure, I would still have that amount of T cells. In fact, it might

> even be detrimental to me if there was a cure, because I wouldn't be able to be on disability, you know, like that Berlin patient. He no longer has HIV, but he still has all the problems of HIV. I think he lost his disability or something like that, the last time I heard.

Table 5.

Themes (RQ4): Beliefs about HIV Cure as Part of Long-term HIV Survival

Theme*	# of Participants	% of Participants
Cure: Little or No Influence on Survival	7	58

Note. * Participants (*n* = 12) could provide more than one response.

RQ5. Half of the participants responded to RQ5: How do older long-term HIV survivors view a cure in their future? One theme surfaced. If a cure were available in the future, participants believed that a cure would affect them (Table 6).

Influence of a cure on one's future. Most participants believed that variations of external- and internal-group stigma (e.g., rejection and demonizing) from HIV disease would be positively altered with a cure. Richard (62 years old and living 27 years with an HIV diagnosis) believed:

Well, I think there's definitely a stigma going on in the world now that if you're HIV positive, you know, there's, you know, this reservation, you know, stigma. Some people hold back, and some people act that they don't even have it and they just go crazy. And I think if there is a cure, there would be a better way of dealing with all that.

Joshua (59 years old living 38 years with an HIV disease diagnosis) stated:

> But maybe you've heard of these places, (Grinder) or Match.com, and all these guys are hooking up bareback, but they're with HIV people, but then they never get tested, and they're hooking up bareback. So there's a whole social attitude out there that "It's not going to happen to me. It's not me. But if you are, you're the devil." And I think that stigma would go away.

On the other hand, Sam (72 years old and living 20 years with an HIV diagnosis) stated:

> I would feel really free like I was before. Like before this disease you feel just normal, but as soon as they tell you that you caught this virus, it seems like you're in a cage, and there's no way that you can escape. It keeps you right there, and it keeps you alive, but there's no way that you can get out of the cage. Well, like there is no way that you can escape. You know it's going to be there, and if there were a cure for it, you'd get out of the cage, and then you will be like a bird, out flying.

Table 6.

Themes (RQ5): Beliefs about an HIV Cure in One's Future

Theme	# of Participants	% of Participants
Stigma	6	50

Note. (*n* = 12)

RQ6. RQ6 asked: How do older long-term HIV survivors resolve their lived-experiences and beliefs about aging with HIV disease and a cure for HIV disease? Two themes emerged (Table 7).

No effect on one's life. Similar to RQ4 (Table 5), Cure: Little or no Effect on Survival, most participants expressed beliefs that the ramifications of the virus and medications has occurred and corporeal and psychological issues have stabilized, therefore a cure would be of little consequence in their lives. Fifty percent of the participants believed an HIV cure would have no effect on their life circumstances. Paddy (66 years old and living 25 years with an HIV diagnosis) stated his beliefs about a cure and his longevity as "I don't anticipate that a cure would extend my life."

Cure conspiracy. Over the past 20 years, the costs associated with HIV disease maintenance therapies have been thoroughly scrutinized by HIV activists. One hypothesis from the cost of research is that there is no incentive for pharmaceutical companies to invest in or conduct research for a cure of the disease (Table 7). In other words, an HIV cure would terminate pharmaceutical companies' revenue stream provided by maintenance therapies. Fifty percent of the participants affiliated their beliefs about an HIV cure to an economic conspiracy. Bob (54 years old and living 31 years with an HIV disease diagnosis) stated "I don't believe anything is ever cured, and the reason for that? There's no profitability in a cure."

Table 7.

Themes (RQ6): Older Long-term HIV Survivors' Beliefs of Aging with HIV Disease

Themes*	# of Participants	% of Participants
No Effect on One's Life	7	58
Cure Conspiracy	6	50

Note. * Participants (n = 12) could provide more than one response.

Summary

The purpose of this investigation was to better understand older long-term HIV survivors' beliefs about aging with HIV disease and an HIV cure. In chapter 4, I provided a review of the data collection, management, and analysis processes. The participants were selected based on random sampling techniques. An Informed Consent statement was read to each participant and the participant was asked to verbally affirm understanding of the Informed Consent before the interview was begun. The responses from the interviews were used to explore older long-term HIV survivors' beliefs and lived-experiences of aging with HIV disease and an HIV cure.

In response to the RQ1, most participants reported positive beliefs of aging with HIV disease (e.g., longevity, few or no issues, and self-care) but cited accelerated aging as a factor of aging with the disease. Answers to RQ2 revealed most participants identified their experiences aging with HIV disease to their HIV diagnosis (death sentence), early treatment (e.g., AZT), and current circumstances (e.g., accelerated aging, fatigue, HIV medications, depression, and sobriety). Answers to RQ3 indicated half of the sample believed that no cure exists or will ever exist while the other half believed a cure exists or will exist within their lifetimes.

Responses from participants to RQ4 showed that most participants believed a cure would have little or no influence on their long-term survival. Most participants' answers to RQ5 revealed they hoped that in the future a cure would eliminate varied aspects of stigma (e.g., rejection and demonizing). Participants' answers to RQ6 were framed in two dimensions: 1) older long-term HIV survivors' resolves of lived-experiences and, 2) beliefs of aging with HIV disease and older long-term HIV survivors' resolves of lived-experiences and beliefs of an HIV cure.

For the first dimension (aging with HIV disease), most participants stated positive resolutions (long life spans, few or no issues aging with HIV disease, and active self-care) to their lived-experiences and beliefs of aging with HIV disease. In addition, accelerated aging was recognized as a factor of aging with HIV disease. Answers to the second dimension of RQ6, the resolution of lived-experiences and beliefs about an HIV cure, revealed many participants reported a cure would have little or no effect on their lives and research and distribution of an HIV cure is controlled by a conspiratorial scheme.

Evidence of quality was identified in the last section in this chapter. All interviews were digitally recorded, which ensured the dependability and accuracy of the professionally typed transcripts. In chapter 5, an interpretation of the research study findings, limitations, recommendations, social change implications, and my experience will be provided.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Recent studies' results indicate that older long-term HIV survivors are resilient (Halkitis, 2014; Moore et al., 2013), aging successfully (Emlet et al., 2011), and altruistically motivated to participate in HIV cure research regardless of risks and benefits (Kall et al., 2015; Simmons et al., 2015). The purpose of the present study was to understand what older long-term HIV survivors believe about aging with HIV disease and an HIV cure. I employed a qualitative phenomenological approach to explore the beliefs of older long-term HIV survivors, which they characterized in terms of their past and present lived-experiences and their beliefs about the future. Several themes and sub-themes emerged from the participants' experiences and beliefs. Participants—50 years and older who have lived with HIV disease for 20 years or longer—self-selected to participate in one interview consisting of two open-ended questions with follow-on questions. The analysis of older long-term HIV survivors' beliefs revealed they were positive and pragmatic about aging with the disease. On the other hand, individuals' beliefs about an HIV cure indicated uncertainty, pragmatism, and optimism.

Interpretation of the Findings

Long-term HIV survivors' notions about aging with HIV have evolved over time. In the past 30 years of HIV disease medical advancements have contributed to a transformation of long-term survivors' beliefs from fear of dying with from the disease, surviving the disease, to living with the disease, to aging successfully or thriving with the disease, to the possibility of being cured of the disease. Halkitis (2014) noted that surviving not only the stigma of sexual orientation but HIV disease was an indicator of resilience. Although many long-term HIV survivors were devastated initially when told by healthcare providers that they had contracted AIDS (Anderson & Spencer, 2002), Emlet et al. (2011) noted many long-term survivors expressed a will to live. Recent phenomenological study results indicated long-term HIV survivors are flourishing (Halkitis, 2014); quantitative study results revealed HIV long-term survivors are adaptive, optimistic, and self-disciplined (Moore et al., 2013). In the present study, older long-term survivors' beliefs about aging with HIV disease indicated their resilience.

Over 30 years of corporeal and psychosocial difficulties suggested older individuals living long-term with HIV disease retain optimistic, uncertain, and pragmatic notions about aging with HIV disease and about disease-related medical advancements. Participants valued the importance of and participation in their well-being (e.g., exercise, diet, sleep, and medication compliance). In addition, individuals indicated they experienced few to no issues aging with HIV disease, and they expressed the conviction that they would live long lives. One participant living with several existing health issues (e.g., fatigue, neuropathy, colitis, sleep disorder, adrenal gland and gallbladder lesions, erectile dysfunction, and depression) was meticulous in scheduling and meeting all of his appointments, maintained a rigorous timetable of medical appointments and assessments, and pursued every avenue to improve his health circumstances.

When asked how their lives would be different if an HIV cure were available, individuals expressed pragmatic and uncertain beliefs. Participants were more polarized in their viewpoints about a cure than in their beliefs about aging with the disease. Half of the individuals believed an HIV cure would never exist nor would a cure have any effect on their present or long-term survival. Half of the participants believed that pharmaceutical companies gained greater financial benefit from treatment than from a cure. Simmons et al. (2015) and Kall (2015) concluded that older HIV positive adults' desire to participate in future HIV cure clinical trials was motivated by physical (e.g., treatment fatigue) and psychosocial factors (e.g., stigma), as well as scientific self-sacrifice. However, participants believed that if a cure were available, HIV disease stigma would be diminished or eliminated.

Conceptualizations and theories of aging, aging successfully, and aging with HIV disease encompass characterizations of purposeful living and divine alliance (Aristotle, 1893), body-mind-spirit integration (Cicero, 1909), life-detachment (Cumming & Henry, 1961), activities involvement (Havighurst, 1961), and avoidance of disease and disability (Rowe & Kahn, 1997). More recently, Leventhal et al. (2001) and Anderson and Spencer (2002) proffered the notion that adults living with chronic illness during the course of their lives continually assess and transform the images, beliefs, and responses (e.g., coping strategies) of their disease circumstances. The qualitative results indicated that during the course of aging with HIV, disease participants evolved their beliefs from surviving to beliefs that they would live long lives. Although, most participants stated they lived with at least one physical ailment (e.g., fatigue), they had no issues aging with HIV disease. Most participants discussed their aging and HIV disease experiences in terms of physical issues. Only one individual explicitly expressed beliefs about the integration of body, mind, and spirit. Another individual indicated his desire to detach from life.

Despite not being completely free of disease and disability (Rowe & Kahn, 1997), participants in the present study identified characteristics of resilience and optimism in their lived experiences and beliefs that indicated they were aging successfully (Moore et al., 2013). In the present study, only one participant indicated no interest in longevity and taking care of self. Although he stated he “welcomed” death, he identified being actively engaged with his work and partnered relationship. Conversely, one individual who was demonstrably affected by physical ailments identified the self-care strategies (e.g., medication compliance and exercise) he used to minimize his physical issues.

The PCP model of aging with HIV disease (Kahana & Kahana, 2001; Kahana, Kelley-Moore, Kahana, 2012.) illustrated that when older long-term HIV survivors proactively engaged in developing personal attributes (e.g., hope, selflessness, self-worth, well-being, planning, and zeal) positive outcomes ensued (self-confidence, life meaning, activities involvement, and supportive relationships). Participants’ lived-experiences and beliefs associated with aging with HIV disease included living a long life (hope) and taking care of self (self-worth, planning, well-being, and zeal).

Conversely, half of the participants' beliefs indicated uncertainty (lack of hope) for the existence of an HIV cure. In addition, half of the participants were negatively zealous about the priorities of pharmaceutical companies' research efforts. There were few examples or beliefs about selflessness identified by participants in this population sample. Two participants identified long-standing commitments at an HIV/AIDS not-for-profit support agency.

Participants' notions about aging with HIV disease transitioned from the volition to survive to the conviction of longevity and acceptance of their disease state. In response to the plausibility of a cure for HIV disease, participants' beliefs at the time of their HIV diagnosis indicated a will to live. In the present context, participants indicated they expected to live long-lives, and if available today, an HIV cure would have no effect on their lives nor would an HIV cure influence their survival. Participants in the present study accepted the notion that accelerated aging is an aspect of HIV disease among older long-term HIV survivors. They responded to this phenomenon by taking care of themselves.

Limitations of the Study

The outcome of the diversity of the population sample was different than expected. The study intended to recruit a sample populated with self-identified male and female volunteers. Subsequently, one recruitment location was chosen that provided services to all individuals living with HIV disease. However, two of the three recruitment environments were infectious disease physicians' practices with a patient roster predominantly populated with men who have sex with men (MSM). The demographic scope of the physicians' practices probably skewed participation toward men who have sex with men. In addition, the first participants who randomly self-selected identified they were male and members of the Fellowship of Alcoholics Anonymous. Because of the unique nature of support in the Fellowship, the early participants solicited other members of the Fellowship for participation (snowballing) who happened to have similar characteristics. Although the rigor of the study successfully provided a verifiable purposeful sample, the generalizability of the output is limited to men living with HIV disease.

The all-male population sample could be explained by the effects of the locations of the recruitment flyer displays and snowballing. In particular, the physicians' offices probably service a patient population skewed toward men. Also, random sampling was initiated by one male who probably contacted individuals in his social circle living with HIV disease. It is probable that individuals in the social circle of the first man in the snowball mechanism were male. Although, I was aware that older long-term female and transgender HIV survivors were clients or patients in physicians' practices, I am unable to account for the lack of female and transgender participation in the HIV/AIDS social services venue.

The population sample suggested the outcomes of the study may be transferable to males who have lived long-term with HIV disease. Additionally, any generalizations to other individuals with chronic illnesses may be limited in other populations. The background data, context of the study, and the detailed description of this study is sufficient for future comparisons to be made with similar populations in similar settings (Shenton, 2004).

Another limitation of the study may have been the construct of the interview questions and my limited experience with the follow-up questions. Three participants demonstrated difficulty with the open-ended question framework and my response was to ask numerous questions which may have lacked the benefits of the open-ended format. As a result, a pattern of questioning and answering occurred rather than a response of free-flowing lived-experiences and beliefs. This interaction might have biased the responses of the participants.

Another limitation is the extraordinary characteristics of older adults living long-term with HIV disease. These characteristics, similar to contemporary cancer treatments, included experiences associated with an HIV diagnosis as a death sentence; short- and long-term toxic medication side effects; internal and external stigma; and distrust that pharmaceutical companies are motivated to produce an HIV cure. Despite the same evolutionary disease characteristics (e.g. diagnosis and epidemiological experiences), one dominant discriminator of HIV disease is external stigma. Because of the intensity of external stigma attributed to HIV, transferability to other disease conditions is probably limited. Lastly, the unique population sample will likely restrain transferability beyond older MSM who have survived long-term with HIV disease.

Recommendations

This study increased the understanding of aging with HIV disease and an HIV cure among older men (n =12) living long-term (*m* =29.5 years) with HIV disease. In the upcoming years, the rate of new HIV diagnoses is projected to increase among older African Americans and Hispanic/Latino MSM, women, and white MSM (CDC, 2016). The increase in HIV diagnoses and prevalence among older adults living with HIV disease illustrates the heterogeneity of older long-term HIV survivors (Abrass et al., 2013; CDC, 2013a; Sankar et al., 2011; Vance, Bayless, et al., 2011). The expected increase from new infections and in those aging into the age category of 50 and older suggests the need for ongoing investigations of older long-term HIV survivors' beliefs about their disease circumstances. Furthermore, future investigations about aging with HIV and an HIV cure should be expanded to include greater demographic diversity (e.g., sex) within a population sample. In addition, future investigations' designs should be targeted to specific populations (e.g., ethnicity). Regardless of the characteristics of the population sample, it is imperative to continuously assess, refine, problem solve, and redefine (Leventhal et al., 2001) the relationship of aging with HIV disease and an HIV cure.

A common theme from this study indicated that individuals aging 20 years and longer with HIV disease showed optimism and pragmatism about their current disease circumstances. However, they were uncertain about the plausibility of a cure and the positive influence of an HIV cure on their current disease situation. Anderson and

Spencer (2002) concluded that adults living with HIV disease illness evolved their beliefs about their disease situation. In addition, despite the indication of pervasiveness of resilience (e.g., optimism and self-mastery) among older adults living with HIV disease, further explorations of resilience characteristics should be conducted with larger population samples and develop effective and practical interventions to promote resilience and well-being (Emlet et al., 2011; Halkitis, 2014; Moore et al., 2013).

Lastly, participants indicated uncertainty about the possibility of the development and distribution of an HIV cure and the ethical credibility of pharmaceutical research for a cure. These aforementioned beliefs suggest that generativity and altruism may be less important for older adults than has been previously identified by Halkitis (2014), Kall et al. (2015) and Simmons et al. (2015). Therefore, future investigations to assess aspects of generativity and altruism among older long-term HIV survivors related to an HIV would be beneficial to those conducting clinical research activities that might require participation from older long-term HIV survivors.

Implications

Older long-term HIV survivors' lived- experiences with the disease expanded beyond the scope of the biophysical (Halkitis, 2014). Characteristics of aging with HIV disease indicated a limited scope of HIV infirmity to thriving with the disease (Emlet et al., 2011; Halkitis, 2014). Older long-term HIV survivors reported a strong relationship between positive psychological attributes and characteristics of successful aging (Moore et al., 2013). Individuals' beliefs about disease circumstances changed over time

(Anderson & Spencer, 2002). Older HIV survivors defined the most favorable HIV cure outcome as improved health, diminished risk of disease transmission but not an HIV negative diagnosis (Simmons et al., 2015). In addition, individuals bespoke that participation in HIV cure clinical trials would require sufficient information, time, and medical advice (Kall et al., 2015).

This study has shown that in most cases individuals at the time of their HIV diagnosis focused on survival but after 20 years and more of living with a chronic disease they asserted they have few to no issues aging the disease. In addition, individuals opined they value self-care and anticipated a long life with little belief that their lives would change dramatically if an HIV cure became available. This suggested that although older long-term survivors responded effectively to some of the dynamic aspects (e.g., adaptability, optimism, self-mastery, and a will to live) of aging with HIV disease, when faced with a medical advancement, older long-term survivors' notions did not incorporate into their immediate circumstances such aspects as self-acceptance, relationships, legacy or generativity, or independence.

Social Change

Older men living long-term with HIV disease represented evolving notions about their existing and future HIV disease circumstances that were anchored in the time frame of their HIV diagnosis. Ostensibly, it appears the older men who have survived HIV disease for more than 20 years in this study have consigned themselves to living with a chronic illness; acknowledged that their corporeal issues have minimal impact in their lives; and expect little change in their lives from the development of an HIV cure. The potential for positive social change begins with appreciating and understanding the continuum of their notions about their disease circumstances.

Healthcare practitioners who strive to grasp the influence of the disease on older long-term HIV survivors can develop strategies and practices that enrich the lives of older long-term HIV survivors based on the findings of the current study. Strategies for consideration include emphasis of existing quality of life characteristics such as diet, exercise, and sleep. Additional emphasis should be directed toward aging successfully. For example, healthcare professionals can identify distinguishing factors that differentiate sadness and depression. Moreover, healthcare practitioners can provide opportunities to discuss adaptations (e.g., assisted living facilities) that are appropriate for individuals' unique aging circumstances.

Conclusion

The results of this investigation revealed that older long-term HIV survivors' beliefs evolved during the course of their disease timelines. After living long-term with HIV disease older long-term HIV survivors' experiences included aging with the disease and the plausibility of an HIV cure. At the time of their HIV disease diagnosis, individuals were hopeful that they would survive. After enduring years of chronic HIV disease circumstances, individuals' beliefs about aging with the disease reflected optimism and pragmatism, but uncertainty emerged in their viewpoints about a cure. Future research from the results of this investigation could be used to further understand the evolutionary development of individuals' beliefs as they age with HIV disease, the influence of medical advancements on individuals' beliefs about their disease circumstances, the tactics individuals employ to navigate their disease circumstances, and their experiences with internal and external stigma.

Despite near death experiences and years of corporeal challenges associated with aging with HIV disease, participants were optimistic that they would live a long time and pragmatic about their current health circumstances (e.g., fatigue and accelerated aging) and the importance of taking care of themselves (e.g., diet, exercise, sleep, and medication compliance). As older adults age with chronic illness, they may require a broader range of self-care mechanisms that will aid them in sustaining a self-defined level of quality of living. The value of additional data from adults aging with chronic illness could provide researchers with information about how individuals define and administer solutions to their age and disease associated circumstances.

Individuals indicated equally polarized beliefs that a cure would ever be implemented. When asked about the effect of an HIV cure in their lives, half of the individuals indicated a cure would have no effect on their lives or their long-term survival. Older long-term HIV survivors expressed uncertainty about the development and implementation of an HIV cure. Their uncertainty was further underscored by the notion that HIV treatments were more lucrative to pharmaceutical companies than an HIV cure. More research is needed to understand long-term HIV survivors' viewpoints and expectations about an HIV cure.

Stigma was not identified as a significant issue when participants discussed aging with HIV disease. However, when asked about their beliefs regarding an HIV cure, stigma emerged as a prominent psychosocial characteristic. Ostensibly, individuals were optimistic that stigma would be eliminated with the introduction of a cure. The data suggested that corporeal issues are of more importance to older HIV positive adults than psychosocial issues such as aging and stigma. Using the significant themes from the present research, future research could investigate older long-term HIV survivors' lived-experiences and beliefs about stigma and living a long life with a chronic illness. Additionally, researchers could explore older long-term HIV survivors' disease circumstances and their lived-experiences of internal and external stigma.

In the present current investigation, I explored older long-term HIV survivors' lived-experiences and viewpoints about aging with HIV and a cure for the disease. The information from the present study added to the existing literature of the adaptive characteristics that older long-term HIV survivors employ in their disease circumstances. Notwithstanding, the study provided emerging information about older long-term HIV survivors' notions about an HIV cure and its influence on their disease situations. This investigation exposed new areas of investigation to understand the disease circumstances of older individuals who live long-term with HIV disease.

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Appendix A: Informal Estimate of Long-term HIV Survivors

Vergel (2015) used 15 years and longer as the criteria to define long-term HIV survivor. Please note the following criteria to obtain the estimate were not referenced. In addition, the blogger suggested and estimated needed to be compiled by epidemiological researchers. Vergel (2015) informally estimated the number of long-term HIV survivors at 490,000 individuals.

The estimate and criteria logic and speculations begin with an estimated 1.3 million persons living with HIV in the US currently. The author then speculates there are 50,000 new infections every year for the past 15 years long-the period in which new infections might have occurred. Vergel (2015) arrived at a number of 750,000 new infections and subtracts that number from the current estimate of those living with HIV disease, 1,300,000. Thus, he speculates there are 550,000 long-term survivors in total. In addition, he calculates on average 8,000 deaths have occurred due to AIDS related illnesses over the past 15 years which equals 120,000. Vergel (Vergel, 2015) further speculates 50% of the 120,000 deaths were of people infected before 1999 (2014-15 years) and arrives at a number of 60,000. At the end of his calculation, Vergel (2015) subtracts 550,000 - 60,000 to arrive at 490,000 people still alive today who were diagnosed over 20 years ago.

Vergel (2015) speculated that fewer than 500,000 persons are HIV+ for more than 15 years. Many are 50 years and older, however many are in their late 30's and 40's and were diagnosed at a pre-adult age. In addition, Vergel assumed that fewer than 100,000

HIV+ adults have been positive for more than 20 years with fewer than 20,000 HIV+ for more than 25 years (we had no treatment options back then and the death rate was extremely high).

Appendix B: Managing Personal Bias

1. Describe how my personal biases about successful aging or HIV cure strategies, as the interviewer, might be directive.

2. What assumptions do I have about successful aging and living with HIV disease?

3. What assumptions do I have about HIV infection cure strategies?

4. Where do I obtain my information about aging successfully with HIV disease?

5. Where do I obtain my information about HIV cure strategies?

6. How will I address my assumptions that older long-term survivors experience HIV treatment fatigue and information overload?

7. What do I assume about older long-term HIV survivors?

8. How does my work as an HIV educator and learning facilitator contribute to the interview process?

Appendix C: Recruitment Flyer

RESEARCH STUDY

LONG-TERM HIV SURVIVORS NEEDED

I am conducting research to find out what older long-term HIV survivors think about 1) aging with HIV disease, and 2) an HIV cure.

Who can Participate?

Living with HIV disease for 20 years or longer

Male or Female

Age 50 years and older

When can you Sign Up?

September 1 to September 16, 2015

What you should know

- The interview is on the telephone and is anonymous
- The telephone interview is conducted in English
- The interview will take between 45 - 60 minutes

Please Contact:
Geary Brewer
(949) 566-1261
geary.brewer@Waldenu.edu

Appendix D: Salutation, Interview Questions, and Closing Interview Script

This script will be followed informally. The purpose of the introduction is to establish trust with each participant. In addition, the objectives are to create a rapport of respect, ease, and honesty.

The Researcher (Geary Brewer) phones the participant.

Salutation

Researcher:

Hello! This is Geary Brewer! Is this a good time to talk?

Participant response:

If No, ask the participant if he or she would be willing to reschedule the interview. Remind the participant the time commitment could be as long as 45 minutes.

If yes, proceed

Researcher:

We will be talking/chatting for about 45 minutes. I realize 45 minutes is a long time and a significant commitment? Will you be able to spend that much time?

Participant response:

If no

Participant response Can we reschedule? Conduct administrative calendaring activity to best meet the schedule of the participant.

If yes, proceed

Researcher:

Great! I am very excited about our discussion! I really appreciate that you are willing to take the time and energy to work with me on this study with which I am involved.

Researcher: To begin,

I need to test that the recording device is working properly. Then, when we have verified the recording device is working, I will read to you information about the study. Then I will ask for your verbal consent to proceed.

Participant response:

Yes. Proceed to test the digital recording device. If no, terminate interview.

Researcher:

I have turned the recording device on; please tell me what day of the week this is.

Participant response:

Researcher:

Thank you

Digital Recording Machine:

Replay recorded day and verify with the participant this is her or his voice. Repeat last two steps if necessary.

Informed Consent

I am turning on the recording device.

I am a student at Walden University School of Psychology, the college of Health Psychology. I am conducting a survey (research) about older long-term HIV survivors and their beliefs about aging with HIV disease and their beliefs about an HIV cure. Your participation is completely voluntary. This means that you do not have to participate in this survey unless you want to. The research survey will take approximate 45 minutes. There are two primary questions, and a series of clarifying questions or questions that will add to your answer will be asked.

Would you be willing to answer some questions about aging with HIV and an HIV cure?

If yes, continue.

If no, thank them for their time and end the call.

Thank you for agreeing to participate. I trust you will put forth your best effort and that you will do your best to answer all the questions. Please note that, complete or detailed and thorough responses to the questions will provide a rich and meaningful study outcome. However, you may find some questions are challenging or sensitive in nature and you may not want to answer a question, let me know and we will move on to the next question.

I appreciate and value the time you are giving to this project!

Do you have any questions up to this point? May I continue?

This is a formal study and I will be asking 10-12 people to respond to questions about their beliefs (lived-experiences) of successful aging and an HIV cure. It is possible that some of these questions may create discomfort for you or create distress; if so, please tell me as soon as you experience or realize any discomfort. You don’t have to answer those questions if you don’t want to. You also need to understand that all information that I receive from you by phone, including any information that identifies you (Carter-Pokras, Bereknyei, Lie, & Braddock), will be strictly confidential and will be kept under lock and key. No information published will be associated with any characteristics that could identify you.

I will not identify you or use any information that would make it possible for you to be identified in any presentation or written reports about this study. If it is okay with you, I might want to use direct quotes from you, but these would only be cited as from a person without a specific label or title. You may be assigned a pseudonym in the study. Your sex and gender will be retained as well as your age.

May I quote you directly without ascribing anything to the quote that could identify you?

If no, acknowledge and affirm no quotes will be in the published project.

If yes, continue.

There is no expected risk to you for helping me with this study. There are no expected alternatives or benefits to you either. When I have completed all of the interviews from those who have agreed to participate, I will group all the answers together in any type of report or presentation. There will be no way to identify individual participants.

Do you still want to continue with the interview?

Thank you! I want to remind you that your involvement is voluntary, and you do not have to complete this interview.

Do I have your permission to begin asking you questions?

The first three questions validate your age and the approximate time since your HIV diagnosis. Last, I will ask you to identify your gender.

1. First, please tell your birth date (MM-DD-YYYY)?
2. Next, what is the year of your HIV diagnosis? Please.
3. Lastly, would you be comfortable if I asked you to identify your gender? If yes, please tell me your gender. If no, move forward with the first open-ended interview question.

The next questions are specifically about the topics of aging with HIV disease and an HIV cure.

Do I have your permission to proceed?

At the end of the interview, please ask me any questions which you might have about the process or the two topics! During the interview, if necessary, please ask any clarifying questions that help you understand the question.

Interview Questions

As we discussed, this discussion is about your beliefs, or thinking, about two topics that might be of interest to older long-term HIV survivors. The first topic is to understand your beliefs about aging and living with HIV disease. The second topic is to explore your thinking about an HIV cure.

Aging Interview Question with Prompts

1. As a long-term HIV survivor, please discuss your beliefs about aging with HIV disease.

Prompts:

What have you done to promote your health?

Describe how effective you have been and are to adapting to the changing circumstances of your life.

Do you consider yourself aging successfully with HIV disease?

What are your success criteria for aging with HIV disease?

At this time, I would like to change topics. However, before we move to the topic of an HIV cure, would you like to add any additional comments to your beliefs about an HIV cure?

Thank you!

Are you ready to move on to talk about your beliefs about an HIV cure?

HIV Cure Interview Question with Prompts

2. As a long-term HIV survivor, what beliefs do you have about a cure for HIV disease?

Prompts:

Which of the beliefs you identified is most/least important to you?

Do you believe an HIV cure is the same for HIV positive and HIV negative persons?

For you, do you believe a cure for HIV is more a medical, psychological, social, or a spiritual important?

Is a cure for HIV disease the same as a cure for AIDS?

Are you familiar with the “Berlin Patient”? Do you believe the “Berlin Patient” has been cured of HIV disease?

Do you think or believe a cure for HIV will affect you negatively or positively?

Potential Prompts:

How important is an HIV cure to you today?

If a cure for HIV were available right now or within the next two years, describe how you believe an HIV cure would change your life?

What are your beliefs about when an HIV cure will be less important to you?

Closing

I want to thank you for your participation. Your responses were thoughtful and pertinent/relevant/meaningful. Frankly, your enthusiasm/interest/focus/contribution was noticeable. I appreciate your willingness to be so involved. This will certainly add depth and power to the study outcome.

Can I answer any questions before we conclude our time together?

Thank you once again for participating in this study about older long-term survivors' beliefs about aging and an HIV cure.

Appendix E: Data Coding Sheet

Significant Interviewee Statements	Condensation/ Meaning	Code	Category	Theme/ Essence

RESEARCHER REMINDER: Bracketing or Epoche	Researcher
Describing the act of the researcher taking a neutral standpoint (e.g., suspending judgment), collecting lived-experiences and viewpoints of the	

phenomenon from participants (data). The data are individually documented and reduced to significant statements (e.g., quotes) and percolates statements to themes. Next, the collection of experiences is developed into what participants experienced (what) and the experiences are described (how) the lived-experiences (conditions, situations, and context) were synthesized. Finally, the textual and structural descriptions are combined to formulate the essence of the participants' common lived-experiences.

Bracketing is also defined as a phenomenological activity of "unpacking" the lived-experiences of the phenomena. It is considered a systematic unlayering of participants' of symbolic meanings until only an unfettered description of the lived-experience remains. The outcome is a bracketed phenomenon (subjective) becomes available for examination and is viewed in pure state.

Appendix F: Interview Questions Related to Research Questions

Research Questions: HIV and Aging	Aging Interview Question with Probes (Appendix D)
What beliefs do older long-term HIV survivors maintain about aging with HIV disease?	As a long-term HIV survivor, please discuss your beliefs about aging with HIV disease.
How do older long-term HIV survivors' experiences of aging with HIV disease relate to, and contribute to their current life experiences?	Prompts: What have you done to promote your health? What are your success criteria for aging with HIV disease? Do you consider yourself aging successfully with HIV disease?
Research Questions: HIV and a Cure	HIV Cure Interview Questions with Probes
What beliefs do older long-term HIV survivors maintain about an HIV cure?	As a long-term HIV survivor, what beliefs do you have about a cure for HIV disease? Prompts: Which of the beliefs you identified is

	most/least important to you? Do you believe an HIV cure is the same for HIV positive and HIV negative persons? What are your beliefs about when an HIV cure will be less important to you?
How do older long-term HIV survivors view an HIV cure as a part of their long-term HIV survival?	Do you believe a cure for HIV is more a medical, psychological, social, or a spiritual important? Is a cure for HIV disease the same as a cure for AIDS? Do you believe the “Berlin Patient” has been cured of HIV disease? Do you think or believe a cure for HIV will affect you negatively or positively?
How do older long-term HIV survivors	If a cure for HIV were available right now

view a cure in their future?	or within the next two years, describe how you believe an HIV cure would change your life?
How do older long-term HIV survivors resolve their lived-experiences and beliefs about a cure for HIV disease and aging with HIV disease?	How important is an HIV cure to you today?