Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention

Johnnie O'Neal
Virginia Commonwealth University

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Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University

by

Johnnie O’Neal
B.S.W. Limestone College, 2002
M.S.W. University of South Carolina, 2003

Chair: Elizabeth Cramer, Ph.D.
Professor, School of Social Work

Virginia Commonwealth University
Richmond, Virginia
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Abstract

OLDER MSM AND HIV/AIDS: A GROUNDED THEORY STUDY TO INFORM PREVENTION

By Johnnie O’Neal, Ph.D.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2013.

Chair: Elizabeth Cramer, Ph.D.
Professor, School of Social Work

This study sought to increase knowledge as it relates to HIV-prevention for older adults, especially for MSM who are HIV-negative. In participating in this study, participants shared their experiences, stories and feelings related to their exposure to HIV and HIV-prevention initiatives. Using a Traditional Grounded Theory method, 22 interviews with older MSM were conducted with the aim of producing a theory that explained how these men lived prior to HIV, the different ways they responded to the onset of the virus, how they have lived their lives over the last three decades, and the extent to which the virus continues to impact their lives.
Chapter 1

The Problem

The profession of social work strives to improve the quality of life of individuals, groups and communities by addressing problems each may encounter. These social problems that are the focus of social science research and social work practice are often influenced by morals, values, and ethics. Examples of such problems are substance use/abuse, poverty, unemployment, and sexually transmitted diseases or infections.

The human immunodeficiency virus (HIV) is a complex virus that attacks the human autoimmune system preventing the body from ridding itself of the virus and other life-threatening conditions (CDC, 2009a). As the virus strengthens and the body weakens, individuals are diagnosed with acquired immunodeficiency syndrome (AIDS). A more in-depth description of this process occurs later in this chapter.

As is noted later in this chapter and extensively in chapter two, HIV/AIDS is a social problem with an extensive impact on the United States resulting in the virus being the focus of many social science research initiatives. Individuals at-risk of contracting HIV are influenced by belief systems of family members, friends, community support networks, and their own. These factors may subsequently influence the individual’s decision to have open dialogues with pertinent individuals about safer-sex and HIV-prevention, seek and/or adhere to prevention strategies, and ultimately practice safer-sex. Agencies providing HIV-prevention are influenced by the communities they serve, governing and funding entities, and their philosophical underpinnings. These factors can lead to an agency changing the type of prevention initiatives they decide to offer the community.
Tremendous strides have been made in HIV/AIDS prevention in the United States leading to a decrease in the number of individuals diagnosed with HIV. These initiatives historically have focused on the groups with the highest infection rates, specifically gay males or men who self-report having sex with men (MSM), African-American females, and individuals with histories of alcohol and/or drug use/abuse. Within these high risk groups the primary target is youth or young adults.

The purpose of this dissertation is to increase knowledge as it relates to HIV-prevention for older adults, more specifically older MSM who are HIV-negative. This subgroup of the older adult population was young and middle aged adults during the onset of HIV/AIDS in the 1980s. Understanding how they have remained HIV-negative during the last three decades may offer insight into which HIV-prevention initiatives (or safer sex messages) may be successful in future prevention programs. Using qualitative interviews, MSM throughout the US were asked to reflect upon their experiences with HIV-prevention and to share their ideas for prevention initiatives for older adults. More specifically, research questions that guided this study were: What were the experiences of older MSM with HIV-prevention initiatives, specifically during their younger adult years? Given that the majority of their adulthood occurred during the AIDS epidemic, how do these men think they were able to remain HIV-negative? Furthermore, what thoughts do these men have about HIV-prevention messages that may be effective in decreasing the rising rates of HIV among their peers?

**Dissertation Structure**

Chapter one addresses the dearth of research regarding the experience of older MSM and their exposure to and suggestions for effective HIV-prevention messages. Given the role of the researcher and the importance of acknowledging and bounding one’s subjectivity in qualitative
research, a personal reflection about my experience with and commitment to this research topic is provided. Definitions of key terms are provided, as are a brief description of the population and an overview of the chosen study design.

Chapter two includes a review of relevant literature, starting with the historical complexities of HIV/AIDS and of HIV-prevention including epidemiological trends. The focus then shifts to older adults with an emphasis on psychological differences as they relate to other age cohorts, psychosocial issues, and HIV specific factors the cohort may encounter. A discussion of the demographics of older MSM is followed by a review of psychosocial issues experienced by this marginalized group. The final section of chapter two discusses HIV-prevention beginning with a definition and information about funding sources. The role of theories, a historical account of prevention, and a discussion of current and future trends within HIV-prevention follow.

Chapter three summarizes the proposed qualitative methodology including the history of grounded theory and justification for using traditional grounded theory in this study. Details about the proposed research including sampling, data collection, and data analysis strategies are provided.

Chapter four includes a review of the findings, starting with a review of the study, discussion of alternative questions that participants were asked, and then a description of the sample. The final section of chapter four is a detailed review of the study findings.

Chapter five begins with a discussion of each developed category which includes a discussion of theory involvement, when appropriate. The focus then shifts to implications for micro and macro social work practice and then research.
Personal Reflection

As a teenager, my devotion to HIV/AIDS began when I volunteered with Lowcountry AIDS Services (LAS), a local AIDS Service Organization (ASO) in Charleston, South Carolina. I assisted staff members in the office, stocked the nutritional pantry and clothing closet, but most importantly, provided direct services such as delivering groceries and offering transportation to medical appointments to clients. It was during this direct contact with people that I gained my most powerful insight into the social problems facing individuals living with HIV/AIDS and my interest in social work blossomed.

As a college student working on an associate of arts degree at Trident Technical College, I continued to volunteer with LAS with the hopes of one day working as a case manager for the agency. Emboldened by the encouragement of my academic advisor and the executive director of the agency, I pursued my Bachelor of Social Work (BSW) degree at Limestone College and later my Masters of Social Work (MSW) degree from the University of South Carolina. My advanced standing MSW internship was with LAS, where I was subsequently hired as a case manager, and then clinical social worker providing direct services.

As a clinical social worker, I worked with individuals of all age groups who stimulated my current interest in HIV-prevention. I quickly realized the role that stigma and other forms of discrimination play in the lives of this vulnerable population. While it was a privilege to work with the individual male clients and facilitate my weekly men’s support group, one female client catalyzed my interest in newly diagnosed older adults.

Mary (pseudonym used) was a female client who received her HIV-diagnosis in her 60s. Our first meeting consisted of completing a social work assessment including HIV risk factors and barriers often experienced by HIV-positive persons. For Mary, I identified barriers within
the healthcare system, her social network, and community based services that unfortunately included our agency. Our female support group focused on younger females and our referral database lacked information for agencies serving older adults. A review of the prevention programs offered by our agency revealed our initiatives focused exclusively on gay males between 18-30 and young African American females, leaving an older woman like Mary without relevant programs. This experience raised my interest in HIV-prevention with older adults.

Determined to increase my knowledge of healthcare and medical social work, I next worked as a hospital social worker, providing direct services to patients and their families in the Intensive Care Unit and on a medical/surgical floor. While my direct contact with individuals living with HIV/AIDS decreased, my interest in HIV-prevention grew. Still pondering the question, “What are we doing to prevent HIV/AIDS in older adults?” I surveyed discharge orders for older clients. A large number of older males were being discharged to nursing or rehabilitation facilities with prescriptions for male enhancement medications (e.g. Viagra). As a social worker I wondered whether there was a discussion between the patient and healthcare provider about safe sex. Were there policies in place in the residential facility regarding sexual relationships between residents? And are health care practitioners, including social workers, trained and comfortable discussing topics such as safer sex practices with older adults, and if not how does this contribute to their vulnerability? Questions such as these, informed by my practice experience have culminated in this study.

**Definitions of Key Terms**

Given the interdisciplinary nature of practice and research related to HIV/AIDS, definitions are provided to help promote clarity and consistency. Traditionally, the term “older adult” refers to those 65 and over; however, for the purpose of this paper, the term refer to adults
50 and older. Studies have shown significant changes related to the physical and psychological changes for older adults warranting the widening of the age group (Goodroad, 2003).

The term “human immunodeficiency virus” known by the acronym “HIV” is an autoimmune disease that decreases the number of healthy blood cells in the body leaving the body susceptible to infections that are often life-threatening. HIV is the virus that causes “acquired immunodeficiency syndrome” or “AIDS.” Individuals receive an AIDS diagnosis when their immune system weakens and they develop an opportunistic infection and/or their immune system cells are 200 or below (CDC, 2009a; CDC 1992b). It is important to note that being HIV-positive does not mean a person has AIDS. See chapter two for further discussion about the HIV process. The interchangeable terms “HIV-positive” and “HIV-seropositive” refer to individuals living with an HIV-diagnosis, while “HIV-negative” and “HIV-seronegative” correlate to individuals not having the virus.

Public health prevention programs fall within one of three categories: primary, secondary, or tertiary. The term “primary prevention” refers to interventions that attempt to prevent the occurrence of a disease or injury and to promote healthy decision making. Secondary intervention programs focus on decreasing the level of infection or the risk taking behaviors of individuals at risk of contracting a disease or already diagnosed with an early stage of a disease. These prevention modalities can come in the form of early diagnosis or treatment initiatives. The term “tertiary prevention” refers to programs that focus on minimizing possible side effects or preventing other conditions from developing because of a correlation with an existing diagnosis (Sable, Schild, & Hipp, 2012).

A final category of relevant terms relates to sexual orientation. The term “gay” refers to males who self-identify as being sexually attracted to males. The term “men who have sex with
men,” more commonly known as “MSM,” refers to males who may not necessarily identify as gay or homosexual, however, have had sexual intercourse with a male (Lieb et al., 2011b).

**Study Population**

**Complexity of Population**

According to the U.S. Census (2011), nearly 96 million adults 50 and older lived in the United States in 2010, which accounted for 31.5% of the U.S. population. Roughly 45 million of those were males, representing 30% of the overall male population. It is estimated that the population of older adults will continue to increase due to the continuing aging and anticipated increased lifespan of the Post World War II Baby Boomer cohort, increased health awareness and fitness of the aging adult, advances in medical care, and trends focusing on preventive care. Several of these factors have a direct correlation to the quality of life of those within this age cohort and are the focus of a growing trend within research. While affirming, these trends lack support for specific social issues important to older adults such as sexual behavior and HIV-prevention.

At least two forms of discrimination are relevant to the life experiences of this study population. Historically, ageism was the dominant experience of discrimination for the older adult, while older gay males’ experiences were compounded by internal and external homophobia. These experiences come from within individuals and from their family members, friends, and society. Recent literature reports an increase in internalized homophobia, HIV-ism, and AIDS apathy as growing forms of discrimination experienced by older gay males (Burns, Kamen, Lehman, & Beach, 2012; Emlet 2006b; Yi, Sandfort, & Shidlo, 2010).
Study Criteria

Inclusionary factors require participants to be male, 50 and older, identify as MSM, self-report being HIV-negative and having limited professional or volunteer experience working with HIV-prevention, and have means to communicate in English. Exclusionary factors include, transgender female-to-male individuals, those living with HIV/AIDS, and individuals with an extensive work or voluntary history focusing on HIV-prevention. Justifications for these inclusionary and exclusionary criteria are discussed in detail in chapter three.

Study Rationale

This section begins with a brief historical overview followed by the current state of HIV-prevention in the United States. The focus shifts to a brief discussion of the following four theoretical frameworks or approaches: (a) Health Belief Model, (b) Ajzen’s Theory of Planned Behavior, (c) Prochaska and DiClemente’s Transtheoretical Model/Stages of Change, and (d) the Empowerment Approach. The section concludes with a brief discussion of the methodology used within the study.

Historical Overview of HIV/AIDS in the US

In the early 1980’s when AIDS began to infiltrate urban cities, no public health initiatives were in place to halt the spread of the virus. In part, this was believed to be related to the fact that those testing HIV-positive were predominantly marginalized social groups such as gay males, intravenous drug users, and select groups of at-risk females (Kull, 2010). The concern about the virus began to broaden as it was affecting other social groups including individuals receiving blood transfusions, Haitian immigrants, and infants via maternal transmission. However, the initial fears and prejudice fostered discrimination and a lack of social support for AIDS patients as well as little understanding for the critical importance of funding for HIV/AIDS
prevention (Shilts, 1988). Advocates were confronted by a lack of support and funding for prevention programs offering HIV-testing and safer sex counseling in addition to services for those testing HIV-positive, such as, HIV-medications and social programs for victims of eviction, assault, neglect, and discrimination because of their HIV-status (Lieberman, 2000). To aid this vulnerable population, grassroots social service and advocacy groups began forming throughout the country (Kull, 2010; Lieberman, 2000; Shilts, 1988). Many of these organizations exist today providing advocacy for those affected and infected with HIV.

**Current State of HIV-Prevention**

As the world commemorates 30 years of the AIDS pandemic, HIV continues to impact all segments of the population, demonstrating the ongoing need for HIV-prevention. The Centers for Disease Control and Prevention (CDC) provides assistance for developing and implementing HIV-prevention programs. In their *HIV Prevention Strategic Plan: Extended Through 2010*, the CDC (2007) maps out the following four milestones focusing on HIV-prevention and bolstering quality of life for those living with HIV/AIDS:

1) **Milestone One:** decrease HIV infection rates nationwide by using evidence-based prevention interventions.

2) **Milestone Two:** increase the proportion of HIV-infected individuals who know of their seropositive status.

3) **Milestone Three:** increase the linking of community programs offering social support, prevention, and treatment to those HIV-positive.

4) **Milestone Four:** increase the capacity to monitor HIV/AIDS nationally and develop, implement, and evaluate effective prevention programs.
The CDC identifies at-risk and high-risk populations such as men who have sex with men (MSM) and African Americans. The CDC does not identify older adults as an at-risk population, perhaps missing an opportunity to intervene with a vulnerable group that is often overlooked and underserved by prevention initiatives.

In a review of guidelines and recommendations of CDC approved and sponsored prevention programs, none are designed to work exclusively with adults over 50. A more extensive search of programs focusing on specialized groups (e.g. African American females, MSM, and co-infections) indicates that most of the current programs are designed for adults under the age of 50. According to Orsulic-Jeras, Shepherd and Britton (2003), prevention programs exist for many at-risk segments of society; however, they are scarce in most regions of the country or they are not effectively reaching those adults with high-risk behaviors. Several socio-cultural issues affect older adults and their decision to practice safer sex. Among these are the adult’s knowledge of HIV, access to testing, and multiple forms of stigmatization. A detailed account of the historical and current state of prevention is discussed in chapter two.

**Relevant Theories**

Multiple theoretical frameworks or models serve as underpinnings for the various forms of HIV-prevention programs. With an overarching theme to foster change within an individual or community, these frameworks or models approach the process in a multitude of ways. Health Belief Model, Theory of Planned Behavior, Transtheoretical Model/Stages of Change Model, and the Empowerment Approach are representative of models found within HIV-prevention. A brief description of each theory is provided below to explain the connection to the study. Chapter two provides additional detail about the theories, including their effectiveness within HIV-prevention.
Health Belief Model

The Health Belief Model (HBM) originates from pivotal work by social psychologists working for the U.S. Public Health Services in the 1950s looking into why individuals opted to take part in screening or prevention programs relating to health conditions. Since its inception, the model has been proven effective while working with varying health related behaviors such as diabetes, smoking, and sexual risk behaviors (Janz & Becker, 1984; Rosenstock, Stretcher, & Becker, 1994).

As an individual-level theory, HBM implies that an individual will base his/her behavioral change decisions on his/her perceived threat of the health concern or disease and his/her understanding of the effectiveness of the suggested behavioral change. In other words, individuals take into account personal fear of the health issue and how reliable the recommended behavior change will be when deciding on making change. The model utilizes four constructs and two concepts to elucidate this relationship. One construct, perceived control, measures one’s level of self-efficacy. This is an individual’s belief in his/her own ability to comply with the recommended task.

Theory of Planned Behavior

Ajzen’s Theory of Planned Behavior (TPB) expands on the Theory of Reasoned Action (TRA) which was developed by Fishbein and Ajzen in 1975. The primary focus of the theory is to understand the relationships between an individual’s attitude, his/her intention to perform a recommended task, and possible outcome behaviors. In addition to applications regarding HIV, the theory has been proven effective while working with decreasing binge drinking (Cooke, Sniehotta, & Schüz, 2007; Norman, 2011) and intimate partner violence (Betts, Hinsz, & Heimerdinger, 2011; Tolman, Edleson, & Fendrich, 1996).
One construct found in TPB, intention, is an individual’s readiness to perform a task. The theory posits that an individual’s behavior is influenced by intention and perceived behavioral control, which is an individual’s self-awareness relating to his/her ability to perform the necessary task. A positive interaction between these two constructs leads to the individual taking on the behavior change. Conversely, a negative interaction may lead to the behavior change not occurring or failing if attempted (Ajzen & Madden, 1986; Connor & Armitage, 1998; Montano & Kasprzyk, 2008; Sheeran & Taylor, 1999).

Transtheoretical Model/Stages of Change Model

The Transtheoretical Model (TTM) or Stages of Change Model is the work of Prochaska and DiClemente (Prochaska, DiClemente, & Norcross, 1992). The focus of their research was on smoking cessation and alcohol and drug addiction. The authors suggest that an individual’s readiness to change, or attempt to change, toward positive behaviors falls within one of six identified stages. The stages are: precontemplation, contemplation, preparation, action, maintenance, and termination. A key concept of TTM is relapse. Relapse implies that the person digresses from a higher level of the theory to a lower level; therefore, the person needs more intervention or support for change. Since the theory’s implementation relating to the abovementioned behaviors, researchers have adapted it for use with additional behaviors such as infant feeding options for individuals living in lower income communities (Brophy-Herb, Silk, Horodynski, Mercer, & Olson, 2009) and the bereavement process (Calderwood, 2011).

Empowerment Approach

According to Rappaport (1987), “empowerment is a process, a mechanism by which people, organizations, and communities gain mastery over their affairs” (p.122). Extensive research has proven that empowering a person gives him/her the opportunity to make necessary
changes to better his/her life in areas such as mental health (Rappaport) and safer sex practices (Zimmerman, Ramirez-Valles, Suarez, de la Rosa, & Castro, 1997). How people gain empowerment varies and is studied by many disciplines and professions. Older gay men are often marginalized; therefore, those who are in need of sources should have the means to gain quality information. This may allow them the opportunity to make changes that have been recommended.

Each of the above mentioned theories contributes to the development of this research study. HBM addresses perceived threats, which encourages questions that relate to the participant’s exposure and recollection of current or previous HIV-related risk factors. From the TPB, intention implies that the individual is ready to make change. This is an underpinning to prevention research, therefore, relevant for this study. The TTM’s staging process will assist with compliance issues, because it acknowledges that individuals making changes may have relapses, therefore, validating concerns for individuals who are wary of taking part in programs. Finally, the empowerment approach provides a unique social work view encouraging individuals to make changes that may lead to a healthier lifestyle. Together, these theories serve as an underpinning for the study.

**Study Methodology**

This study sought to gather an in-depth understanding of HIV-negative men’s experiences with HIV-prevention and solicit suggestions for future prevention initiatives. Qualitative methodologies are appropriate for studies such as this seeking to learn from people who are experts on a certain lived experience (Creswell, 2013). Grounded Theory (GT), one qualitative research design, stems from Glaser and Strauss’s (1967) work on theory development within the social sciences. Their groundbreaking work focused on the experiences of patients
and nurses with the dying process. Differences relating to the researchers’ techniques during the data analysis process resulted in GT splitting into two variants. The original work is respectively referred to as Glaserian or Classical Grounded Theory (CGT), while the more recent version is known as Straussian or Traditional Grounded Theory (TGT) (Walker & Myrick, 2006). Charmaz developed a third GT approach moving from the social process focus of GT to “a conceptual analysis of patterned relationships” (Charmaz, 2006, p.181). Each variant has qualities that warrant their usage with this study; however, TGT will be applied, because TGT allows the researcher to be more rigorous with data analysis and the design supports validity (Creswell).

Individual interviews with 20-25 consenting males, or until saturation has been reached, was the data collection strategy (Creswell, 2013). The proposed population could have been difficult to recruit, because of complexities with recruiting older adults and MSM. Combining these vulnerable populations and presenting individuals with questions relating to their sexuality, sexual past, and their experience with HIV/AIDS may have exacerbated recruitment difficulties. Recruitment strategies and the design of the interview process were designed to decrease these barriers. Participants were recruited locally using gatekeepers to the aging and LGBTQ communities. The latter was chosen because men who behaviorally fall within the MSM category may identify as gay, bisexual, queer or heterosexual. Possible gatekeepers to older adults are social workers with senior centers, housing communities, faculty/staff with the School of Social Work and the Department of Gerontology, and members of local organizations or associations focusing on aging (e.g. Partnership for Education and Practice in Aging Services—PEPAS). Gatekeepers within the local gay communities may include owners and/or workers at local gay friendly bars/restaurants, and employees of local gay organizations or programs (i.e.}
SAGE, GCCR or Triangle Players). Nationally, recruitment could occur through websites frequently used by MSM seeking relationships or sexual encounters and through list-serves and websites accessible to professionals working within social work, HIV-prevention or older adult services.

Interviews were conducted in a traditional face-to-face format, phone, or via Skype. While preference was given to face-to-face and Skype, phone interviews were offered to participants who felt uncomfortable with or who lacked access to these forms of technology. Interviews took 45-90 minutes and focused on the participants’ exposure to HIV-prevention, their viewpoints on sexual behavior and HIV-risk within their age cohort, and their insights into effective means of HIV-prevention messages and initiatives beneficial for their cohort. From the interviews of MSM who lived during the start of the AIDS crisis in the early 1980s, during the rapid spread of the virus during the 1990s and 2000s, and now as 50 and older males whom the virus continues to impact, I developed a theory that informs HIV-prevention for older adults.

A thematic analysis using TGT was performed to analyze the data. During this process, peer review took place to ensure the themes and messages found within the interviews were properly interpreted.
Chapter 2

Historical Overview of HIV/AIDS in the US

HIV has an extensive, life changing effect and affect on society at local, national, and global levels. The first reported cases of AIDS in the United States were in 1981. That year, the CDC (1981) reported five known cases of homosexual males with Pneumocystis carinii pneumonia (PCP), a rare type of pneumonia usually seen in individuals with suppressed immune systems. These findings prompted an inquiry into possible causes for the rare pneumonia. At that time, the CDC felt that PCP may have had a correlation with being homosexual and/or sexual contact because the only similarity among the five individuals was their sexual orientation (CDC, 1981). The CDC labeled the condition the “gay-related immunodeficiency disease” (GRID), and throughout the country, many labeled it the “gay cancer” (Kull, 2010).

Shortly after the findings of PCP in men who have sex with men (MSM), doctors began seeing an influx of other illnesses normally seen in suppressed immune systems such as Kaposi’s sarcoma (KS) and Mycobacterium Avium Complex (MAC). KS is a rare form of cancer found on the skin, inside the mouth and in the lungs. The severity of the disease can range from a skin lesion to accumulation of fluids in the lungs, which, eventually, can lead to death (The Body, 2009a). MAC is a bacterial infection that can cause life-threatening problems with body organs such as the spleen, intestines and lungs (The Body, 2009b). These, along with other debilitating conditions, are opportunistic infections, meaning they normally do not affect an individual’s health unless his/her immune system is weak; such is the case with persons infected with HIV.

In 1983, the CDC noticed an increase of immunodeficiency infections similar to those found in homosexual men in females (CDC, 1983a) and male prisoners (CDC, 1983b), which raised concerns regarding transmission routes of HIV. These groundbreaking observations
prompted both medical researchers to broaden their search for a cause and social science researchers to begin to pursue prevention and public awareness initiatives.

The prison inmate report confirmed previous knowledge that AIDS was a blood borne infection and since inmates were in prison for a few months to several years before showing signs of illness, researchers concluded that the virus causing AIDS likely had a dormant period (CDC, 1983b). With continued research, scientists identified HIV as the cause of AIDS in 1984. The following year, testing became available for HIV, which allowed thousands of individuals to find out their HIV-status by measuring antibodies in their blood (Pear, 1985). With an identifiable cause and an available diagnostic test, concerns regarding who should receive the test were the next area of focus for researchers and advocates.

HIV also affected social groups other than homosexuals including: intravenous drug users, select groups of at-risk females, individuals receiving blood transfusions including hemophiliacs (CDC, 1982a), Haitian immigrants (CDC, 1982b), and infants (CDC 1982c) were also testing HIV-positive. However, as noted by Kull, “in the absence of a clear scientific understanding of AIDS, the disease readily became a metaphor for the ‘immoral’ behavior of gay men and drug users” (2010, p.4). These prejudicial thoughts led to an increase in discrimination and little social support for AIDS patients. Additionally, a lack of support and funding for HIV-testing and medications, compounded with a dearth of social and political support for individuals with HIV led to an increase in HIV-positive people who were victims of eviction, assault, neglect, and discrimination related to their HIV-status as well as minimal governmental investment in service or prevention programs.

Grassroots social service and advocacy groups developed throughout the country to assist these vulnerable populations (Lieberman, 2000; Shilts, 1988). With groups such as the AIDS
Coalition to Unleash Power (ACT UP) and Gay Men’s Health Crisis (GMHC) focusing on homosexual issues (Kull, 2010), and The National Black Leadership Commission on AIDS and the National Minority AIDS Council (Wright, 2006) focusing on Black issues, some HIV-positive individuals were able to access needed services while others had little access to such services. A noted concern for those affected and infected with HIV was the lack of support displayed by President Ronald Reagan (Kull). While federal agencies such as the CDC and the National Institute for Health (NIH) evinced concerns for the spread of HIV in the early 1980s, President Reagan did not mention HIV or AIDS publicly until 1987 (Rimmerman, 1998). In his speech occurring roughly six years after the CDC announced concerns regarding the virus, President Reagan remarked:

What our citizens must know is this: America faces a disease that is fatal and spreading. And this calls for urgency, not panic. It calls for compassion, not blame. And it calls for understanding, not ignorance. It’s also important that America not reject those who have the disease, but care for them with dignity and kindness (Barker & Simone, 2006).

Although the President’s speech expressed concern regarding the well-being of U.S. citizens, his previous reticence made a lasting impact on society’s views regarding HIV, which fostered increased discrimination of HIV-positive individuals. In 1990, the federal government acknowledged the severity of HIV/AIDS and passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This act provides medical, social programs and support for those affected and infected by the HIV virus (Marlowe, 2010). Examples of programs are housing, emergency financial assistance, medication assistance, case management, prevention programs, and medical care including dental and mental health.
In 1991, the CARE Act provided $220.5 million federal dollars in services and treatment needs for those living with HIV within the US (Health Resources & Services Administration, 2009). The Obama Administration’s 2013 budgeted amount for the CARE Act is 28.4 billion (Henry J. Kaiser Foundation, 2012). The overall budget consists of five categories: care and treatment (55%), global services (22%), cash and housing assistance (10%), research (10%), and prevention (3%). In a review of data from 2008-2012, ‘prevention services’ has continuously represented the lowest category of funding and had not reflected an increase in funding. The proposed 2013 prevention budget is $960,000, which reflects an increase of $60,000 from previous years (Henry J. Kaiser Foundation).

**Epidemiological Trends of HIV/AIDS**

HIV/AIDS impacts society at local, national, and global levels. There are over one million individuals living with AIDS in the US (CDC, 2011a). As the CDC reported in 2011, an estimated 663,000 people within the US were diagnosed with HIV/AIDS by the end of 2009. There were approximately 43,000 new HIV infections and 35,000 new AIDS cases in 2009. Viewing HIV prevalence rates by ethnicity, the CDC reports approximately 48% (979.9 per 100,000) were Black; 33% (131.3 per 100,000) were White; and 17% (369.2 per 100,000) were Hispanic/Latino. Aggregating prevalence rates of HIV positive individuals by age at the end of 2008, the 13-24 age group represented 29,746 (4.4%); the 25-49 age group had 440,896 (64.88%); and there were 208,947 (30%) adults 50+ older living with HIV (CDC, 2011a).

Though the terms “aging adult,” “older adult,” or “aging population” often refer to people over the age of 60, Goodroad (2003) notes “the HIV literature has included those older than 50 in this category” (p. 19). However, this is not always the case. In their HIV research, Dolder, Patterson, and Jeste (2004), identify older adults as 55 years of age or older. Situations
such as this complicate the process of researching HIV in older adults as well as comparing findings from previous studies. For the purpose of this literature review, Goodroad’s definition of those older than 50 was used.

Because the literature and statistics presented here shift back and forth between HIV, AIDS, and sometimes HIV/AIDS, prior to discussing epidemiological findings below, a brief review of how HIV and AIDS are related is provided. AIDS is a progression of HIV. There are three changes within the HIV-positive individual that will classify him/her for the AIDS diagnosis. The individual’s immune system weakens and he/she develops an opportunistic infection, his/her immune system cells drop to 200 or below, or a combination of both (CDC, 1992b; CDC, 2009a). So this literature review will be referring at times to each or both; at times the initial infection, at other times the progression of the disease.

The number of adults over the age of 50 impacted by the virus has increased steadily since 1981 with 5,097 (10.1%) of AIDS cases in the years 1981-1987; 20,724 (10.3%) in 1988-1992; 25,871 (10.0%) in 1993-1995; and 32,353 (12.3%) between 1996-2000 (CDC, 2001b). Current figures from the CDC (2008b) confirm HIV infection rates continue to rise in the older population. In 2007, roughly 10% of new HIV diagnoses in the US were adults over the age of 50 (CDC, 2008b). Of new AIDS cases, the CDC estimated nearly 7,550 (19.9%) were persons aged 50 and older (CDC, 2008a). The cumulative estimate for AIDS cases through 2009 for this age group was approximately 150,000 (CDC, 2011a). Zablotsky and Kennedy (2004) report “a consistent 10%-11% of all AIDS diagnoses have occurred in people in the 50 years old and older age group” (p.7). In a 34-state survey comparing figures from 2004 and 2007 an increase among the 60-64 and above 65 age groups was observed (CDC, 2009b). The 60-64 age group experienced a growth of 171 (771 to 942) new HIV/AIDS diagnoses, and the over 65 age group
experienced an increase of 107 cases (696 to 803). According to Schmid and colleagues (2009), “case reporting from 2003 to 2006 shows the proportion of older HIV-positive individuals has climbed from 20% to 25% and numbers of cases have risen in all 5-year age bands from 45 years to 65 years and older” (p.162). According to Funnye, Akhtar, and Biamby (2002), the percentage of HIV infection rates in older adults increases in communities with larger populations of older adults such as retirement communities.

Lieb and colleagues (2011b) analyzed HIV prevalence rates among MSM residing in 13 southern states with mature, confidential name-based HIV infection reporting. Such reporting connects individuals’ names with test results and requires that healthcare providers report the test results to county or state health departments (CDC, 1999). The 13 states were: Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia. There were 172,166 HIV-positive MSM identifying as Black, Hispanic or White living within the 13 states resulting in an estimated HIV prevalence rate of 7,280.4 per 100,000 MSM. The largest group, White, accounted for 76,168 (44%) cases, while Black/African Americans represented 72,223 (42%) and Hispanics 23,775 (14%) (Lieb et al., 2011b).

Conducting a thorough search for HIV/AIDS statistics for the older MSM population yielded one report. According to the 2011 CDC report, there were 28,250 newly diagnosed HIV-infected MSMs in 2009 of which 2,350 (8.32%) were males 50 and older. Whites accounted for 11,400 (40.35%) of cases; Blacks were in a close second with 10,850 (38.41%); followed by Hispanics with 6,000 (21.24%). Trends were different when looking at males 50 and older and race. Whites accounted for 1,600 (68.09%) of cases; while Blacks and Hispanics represented
smaller percentages with Blacks having 450 (19.15%); followed by Hispanics with 300 (12.77%) of cases (CDC, 2011b).

In summary, these findings show an increase of HIV infection rates for older adults compared to other age groups. Although this increase may not be as drastic as in other groups, it warrants attention because of the unique and complicating interactions of ageism and HIV-stigma related effects as addressed in the following sections.

**Study Population**

As noted above, older adults are at risk for being exposed to or contracting HIV and developing AIDS. The increasing population growth for this marginalized group, along with the continuing rise in HIV infection rates, warrants more aggressive attention from researchers and practitioners. This nationally based study highlights a subsection of the older adult population, MSM. To help frame this content, MSM is defined and explained. Lieb and colleagues (2011b) define MSM “as adult males who [have] ever had sex with another male, without regard to the type of sexual contact” (p.597). This definition focuses on the sexual behavior, but does not indicate the males’ self-identity. Men who fall within the behavioral category MSM can self-identify as gay, homosexual, heterosexual, or bisexual. While other definitions exist for this term, this one was chosen because of its simplicity, frequency of usage by others, and fit for the target population of the study. This section will focus on demographics, sexuality, HIV-transmission and risk factors for older adults and different forms of stigmatization experienced by this population.
Demographics of Aging Adults and MSM

A 2011 report by the U.S. Census Bureau estimates in 2010 roughly 309-million individuals were living in the US. Adults 50 and older accounted for nearly 100-million of that estimate and males 50 and older represented nearly 46-million (Howden & Meyer, 2011).

Determining the number of individuals who identify as either gay or MSM is more difficult because of inconsistent definitions and varying means of data collection (Bradford & Mayer, 2008; Gates, 2011; Rosenfeld, Bartlam, & Smith, 2012). In a review of six separate surveys, Gates reports that there are nearly 9 million (3.8%) individuals who identified as LGBT in the US, 1.5 million of whom are males who identify as gay. In a separate report, Lieb and colleagues (2011a) estimated that in 2007 there were nearly 7.1 million MSM over the age of 18 living in the US. Racially, slightly over 5 million (71.4%) were White; slightly over 1 million (15.9%) were Hispanic; 635,000 (8.9%) were Black; and 264,000 (3.8%) identified as another race/ethnicity. Again, determining the number of older LGBT adults has proven to be difficult. That being said, Cahill, South and Spade (2000) and Grant (2010) report approximately one to four million adults 65 and older living in the US representing the LGBT communities. Appelbaum (2008) reports a more conservative estimate, stating that there are roughly two million older LGBT adults.

Sexual Practices in Older Adults

A common misconception is that older adults are not sexually active (Lieberman, 2000). Cooperman, Arnsten, and Klein (2007) report “among men aged 60-69 [N=507], 25% reported nine or more sexual partners, and 15% reported 15 or more sexual partners [during a year time period]” (p.322). This study was conducted in New York City and may not depict a true representation of the typical older adult male residing in the US. However, these startling
statistical findings challenge some misconceptions about sexual practices among older adults and heighten awareness for HIV research with this at-risk group. In a study comparing risk factors of MSM in 1997 and 2002, Osmond and colleagues (2007) found increases in sexual partners, unprotected anal intercourse, and other risky sexual behaviors in HIV-negative MSM. While these results are for HIV-negative males ranging from 18 years to 50+ years, the authors conclude that males over 49 were major contributors to the increase in the findings. As with many HIV related studies focusing on HIV and males, the focus is on high-risk segments of the MSM population. Examples of such groups are highly populated gay communities such as San Francisco and New York, and MSM who frequent free health clinics and night clubs. Dolcini, Catania, Stall, and Pollack (2003) raise concerns that underrepresented segments of the MSM communities, including older males who may not frequent these social clubs or live in metropolitan areas, are being neglected.

The exponential growth of male enhancement medications has also contributed to the rise in HIV rates among males over 50. Karlovsky and colleagues (2004), report that men over the age of 60 account for nearly 39% of the 15.5 million prescriptions written in 2001 for the medication sildenafil, commonly known as Viagra. Because sildenafil is one of several medications used to treat erectile dysfunction, these findings represent only a portion of the entire population of men taking medication for the diagnosis. These medications have become readily available, receive funding from insurance companies, and are becoming more socially acceptable with the introduction of television and print advertisements. The risk for HIV transmission with the increased use of erectile dysfunction medications and the lack of knowledge among this population about HIV/AIDS heightens the importance of prevention.
Given that many older MSM remain sexually active along with an increase in both erectile dysfunction medications and risk-taking behaviors in older males, the promotion of safer sexual practices is critical. An effective means to safer sexual intercourse for males and females of all ages is the use of prophylaxis, such as condoms. Hart and Elford (2010) report “21% of men in their 20s and 30s reported unsafe sex, compared to 19% of men in their 40s and 18% in those over 50” (p. 42). This indicates that 18% of males over 50 surveyed are not practicing safer sexual practices, including the use of condoms. Many barriers to condom use exist including: condom fit, responsibility to provide the condom, or embarrassment purchasing condoms. With the lack of condom use as a barrier to achieving safer sexual practices, Crawford, Rodden, Kippax, and Van de Ven (2001) suggest more prevention programs relating to condom education and negotiation be made available.

Risk Factors for HIV Transmission for Older Adults

As with all segments of the population, older adults are at risk of contracting HIV because they take part in high-risk activities. Specific risk factors increase the likelihood of HIV transmission in the older population. For example “older adults face predicaments that are unique to their age group, such as few community support systems, the lack of older siblings or parents to care for them, the stigma of ageism, and the burden of various co-morbid conditions that often accompany older age” (Heckman, Kochman, Sikkema, Kalichman, Masten, & Goodkin, 2000, p.437). Adding to the complexity of understanding HIV and the older adult, there are different categories of prevention and treatments. Emlet (2010) identifies four groups of older adults impacted by the HIV virus: those at-risk of contracting the virus, those infected after the age of 50, long-term survivors, and those who are caregivers to someone who is HIV-positive. The Gay Men’s Health Crisis [GMHC] (2010) identifies three groups: those newly
diagnosed, newly infected, and long-term survivors. The goal of this study is to develop theory to help develop effective HIV-prevention initiatives based on the perspectives and experiences of HIV-negative MSM 50 and over; the group at risk of contracting the virus referred to by Emlet. This section will first discuss risk factors such as sexual transmission routes, intravenous drug use, inadequate housing, and other generalized risk factors. Next, the focus will shift to specific risk factors affecting the older adult such as limited HIV knowledge, late diagnosis, older adult relationship dynamics, and other generalized age-related risk factors.

**General risk factors.** Transmission of the HIV virus in the older population is similar to other populations through unprotected vaginal or anal sexual intercourse and contact with human blood through intravenous drug use or (in extremely rare cases) by blood transfusions (Kull, 2010). Studies reveal that the highest rates of HIV infections in older adults are due to risky unprotected intercourse (Gott, 1999, 2001; Winningham, 2006).

The second largest route of HIV transmission in older adults is drug use. Using substances can impact HIV transmission in older adults in two ways: first, by impairing an individual’s judgment resulting in inappropriate decision-making and second, when an individual uses a contaminated needle while consuming drugs (Johnson & Sterk, 2003; Kwiatkowski & Booth, 2003). Substantial research exists on the correlation between intravenous drug users and HIV infections; however, a limited number of studies discuss drug users who are over the age of 50. The reason for this, according to Johnson and Sterk, is “by the time youthful drug users reach midlife or beyond, most are believed to have ‘matured’ out of their illicit drug habit” (p. S229). This stereotypical view has fostered a belief that research and prevention are not necessary for older drug users. One example of older adult drug use is late-onset crack use.
There are three types of male late-onset crack users, the first being men who progress from using intravenous drugs. The second and third types are men with a history of alcohol use and men with no drug or alcohol use or abuse. These last two groups have one thread in common: connections with younger females with current histories of drug use (Johnson & Sterk, 2003). These relationships risk exposing older men to HIV through unprotected sex (which may be paid for), drugs they otherwise would not have access to, and multiple sex partners (Kwiatkowski & Booth, 2003). A major obstacle regarding prevention and research with this population is community discrimination in the form of ageism. Ageism is discussed in detail later; however, a parsimonious definition of ageism is discrimination experienced by an individual based on age. Older adults experience ageism from healthcare providers, community agencies, and family members. Small (2010) reports, “ageist ideologies among many health care workers contribute to the general lack of understanding and recognition of HIV in the older adult” (p.29). Regarding the family, HIV-positive older adults are more likely to hide their status because of fear of rejection or abandonment (Orel, Spence, & Steele, 2005). These issues need to be part of the foundation of an HIV-prevention program for older adults in order for newly diagnosed and at-risk adults to have access to services and receive appropriate care.

In addition to high-risk sexual behavior and drug use, lack of affordable housing is another risk factor for individuals, including older adults. HIV/AIDS statistics denote a large proportion of at-risk older adults live in low-income housing, alone, or in communities that traditionally have higher rates of drug use and sex workers (Schensul, Levy, & Disch, 2003). According to Ward, Disch, Levy, and Schensul (2004):

To prevent further acceleration of HIV infection in older minority adults, as well as older
adults in general, we must understand more about the conditions under which they are exposed to HIV and the attitudes, beliefs, and practices that promote or reduce the risk of transmission (pp. 571-588).

Using the biopsychosocial model, a basic social work approach, Ward and colleagues are discussing the ‘social’ component of the concept. To gain a better understanding of an at-risk individual, it is their recommendation that some of the focus be on the community in which the older adult lives.

Many social and psychological factors affect a person’s decision to seek medical care. Some factors have already been discussed, such as housing, low economic status, and age. Yet there is limited research regarding HIV and the older adult’s social support networks (Poindexter & Shippy, 2008). As with seeking HIV-testing, those in need of HIV treatment are prone to seek care only when symptoms dramatically affect quality of life (Siegel, Schrimshaw, & Dean, 1999). A recent study showed that roughly 40% of new HIV diagnoses progress to an AIDS diagnosis within a year (Bamford, Ehrenkranz, Eberhart, Shpaner, & Brady, 2010). Older age was a primary factor for delay in entering HIV care. Siegel and colleagues found that participants felt that treatment was not necessary if they were not sick, which statistically leads to a shorter time-period between an HIV and AIDS diagnosis and even shorter periods from diagnosis to death.

**Risk factors more specific to older adults.** There are specific risk factors that are age specific relating to HIV-prevention, transmission, and treatment such as a lack of HIV knowledge, health and aging factors, late diagnosis, relationship dynamics, and other generalized issues relating to aging. These age specific factors that warrant further research in prevention and treatment of HIV are explored below.
**HIV knowledge.** Studies indicate that older adults have limited knowledge regarding HIV transmission. In a study of women 45 and older, participants reported having unprotected sexual intercourse 84% of the time with primary partners and 25% with other sexual partners (Maes & Louis, 2003). While the article fails to indicate the characteristics of the ‘primary partners’ group in the first statistic, the latter shows the need for an increase in awareness of prevention within the older female population.

Henderson and colleagues (2004) note that, “people aged 50 and older scored lower on knowledge questions about HIV/AIDS than younger adults” (p.1549). In another study of older adults, individuals 45 to 64 were less knowledgeable about risk factors than those 18-44 years old, more specifically in categories of casual contact (Zablotsky & Kennedy, 2004). The same authors report that the older adult over 64 knew significantly less about safe sex practices than those under 64 years of age.

While a portion of the rise in HIV rates in older adults is due to generalized lack of HIV knowledge, their belief that they are not at risk is also a factor. This idea has been perpetuated by healthcare providers, the media, and the myth that older adults are not at risk (Maes & Louis, 2003). This fallacy is similar to the early beliefs that heterosexuals and women were immune to AIDS because it concerned only gay men.

In a senior initiative program in Florida, Agate, Mullins, Prudent and Liberti (2003) found that “health professionals were reluctant to conduct in-depth HIV risk assessments on their senior patients” (p. S239). These healthcare providers tended not to consider their patients to be sexually active and feared that discussing sexual health or education would frighten the patient away. The lack of sexual risk assessments and health care provider’s lack of confidence and
competence in conducting them can result in delayed diagnosis and treatment and severe consequences for the patient (Shippy & Karpiak, 2005).

**Physical and mental health.** The older adult experiences many physical and mental changes as he/she advances in age (Llorente & Malphurs, 2006). Research indicates that the effects of HIV can be more severe on the older adult compared to younger people living with HIV (Nichols, Speer, Watson, Vergon, Vallee, & Meah, 2002). The authors report, “a decline in immunological function with age . . . is largely responsible for age-related increases in life-threatening autoimmune diseases, infectious diseases, and cancers and may affect both disease susceptibility and severity” (p.94). Llorente and Malphurs state that “as a result of these changes, at time of HIV diagnosis, older adults have lower CD-4 counts than younger patients” (p.269). Though these age-related physical changes may affect the CD-4 levels of older adults at the time of diagnosis, as discussed later in more detail, late testing is another possible cause. Montoya and Whitsett (2003) encourage healthcare providers to cautiously distinguish between HIV/AIDS symptoms from other age-related health conditions to ensure early diagnosis.

According to Chesney, Chambers, Taylor, and Johnson (2003), “HIV-infected persons confront a unique set of challenges and chronic stressors, including stigmatization, alienation from family and friends, complex treatment regimens, and, often, debilitating side effects as they attempt to manage the psychological and physiological consequences of their condition” (p.S186). While these challenges affect most individuals with HIV/AIDS, they are more significant in older adults.

The stress of living with HIV can precipitate possible mental health concerns such as emotional problems, suicidal feelings, uncertainty, relationship problems, and interpersonal issues related to infections (Mancoske & Smith, 2004). In a study of 113 middle-age and older
people living with HIV, Heckman, Kochman, Sikkema, and Kalichman found that “29% reported moderate or severe depression on the Beck Depression Inventory” (as reported in Nichols et al., 2002, p.17). Several of the stressors that led to these levels of depression were “poor finances, lack of HIV-related information and support resources, and AIDS-related stigma and discrimination” (Heckman et al., p.119). Although this unique population is experiencing increased levels of depression, Emlet and Farkas report that “persons aged 50 and over with AIDS are only half as likely to use mental health and emotional support services as their younger counterparts with AIDS” (2002, p.318). To decrease participation in at-risk behaviors and to design relevant and effective prevention programs, researchers need to have a more comprehensive understanding of the knowledge base of the older adult (Carey & Schroder, 2002).

Late testing and diagnosis. A notable concern is late testing of older adults (Coon, Lipman, & Ory, 2003). In a 2009 study conducted by the CDC in 34 states, on average 45% of individuals met the criteria for late diagnosis, which is receiving an AIDS diagnosis within 3 years of testing HIV-positive. For the 50 and older population results were higher, with 57.5% of 50-59 year olds receiving a late diagnosis. The study’s results were even higher for those over 65, with 63.2% receiving a late diagnosis (CDC, 2009b). These results indicate the need to improve testing within all age groups with special attention focused on persons 65 and older. In the same report, the CDC acknowledges they only recommend routine screenings for individuals 13-64 years of age. It is also their recommendation that healthcare providers follow CDC recommendations regarding testing and aid in the efforts of early testing. The CDC’s omission of testing guidelines for those 65 and older suggests a lack of support for prevention in this vulnerable age group.
A late diagnosis often leads to an individual progressing from being HIV positive to having AIDS more quickly, often in less than three years. Individuals 65 or older make up nearly 56% of individuals in the late diagnosis category (Emlet, 2010). A 2006 report by Kohli, Klein, Schoenbaum, Anastos, Minkoff, and Sacks concludes that, “adults >50 years and at risk for HIV were one fifth as likely to have been HIV-tested than a comparison group of at-risk individuals in their 20s” (p.32). This number is alarming given that this vulnerable group is sexually active and is susceptible to the risk factors discussed elsewhere in this chapter.

**Stigmatization in Older Adults, Gay Males, & HIV**

Stigmatization is a social phenomenon in which individuals are identified as having a personal trait or characteristic that is different than others resulting in negative reactions or devaluing of the person (Goffman, 1963). Crocker, Major, and Steele (1998) explain that “a person who is stigmatized is a person whose social identity, or membership in some social category, calls into questions his or her full humanity—the person is devalued, spoiled, or flawed in the eyes of others” (as cited by Dovidio, Major, & Crocker, 2000, p.504).

Emlet (2006b) identified two types of stigma affecting the older adult: HIV/AIDS stigma and ageism. HIV stigma is “prejudice, discounting, discrediting, and discrimination directed at people perceived to have HIV or AIDS” (Emlet, 2006b, p. 782). HIV stigma has been associated with an increase in HIV, poor adherence to medication, decrease in quality of life, and mental health symptoms (Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007), and can prevent individuals from receiving HIV-prevention information, HIV testing, and using safer sex practices (Levy-Dweck, 2005; Nazon & Levine-Perkell, 1996).

One component of poor medical services, late testing, was discussed earlier in this literature review. Other components regarding biases from the healthcare field toward the HIV
positive individual are the fear of disclosing HIV statuses to providers other than the HIV specialist, receiving inferior care from healthcare providers due to diagnosis, and feeling that healthcare providers view HIV-positive individuals as being contagious (Sayles et al., 2007). In a recent study of the participants experiencing stigma, 77% report poor access to care as a problem (Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). The works of Coon and colleagues (2003) and Sayles and colleagues have identified concerns of the HIV-positive adult and the stigma attached to seeking healthcare and testing. These concerns reinforce the need for advocacy and supportive services for those living with, and at-risk of contracting, HIV.

Ageism is the “negative attitude toward aging based on the belief that aging makes people unattractive, unintelligent, asexual, unemployable, and mentally incompetent” (Emlet, 2006b, p. 782). Shippy and Karpiak (2005) have found that in addition to society and family members, healthcare professionals and AIDS Service Organizations (ASO) can be perpetrators of ageism; for example, a healthcare professional might assumes a patient is “too old” to be sexually active, or an ASO fails to provide prevention services to older adults. According to Mack and Bland (1999), “ageist assumptions concerning older persons’ sexual or drug use behaviors may mean that their risk for HIV/AIDS is often overlooked and elderly patients may die without ever being diagnosed as HIV positive” (p.697). Here, the author alludes to society’s reluctance to acknowledge that older adults are sexually active. Three years prior to the work of Mack and Bland, Nason and Levine-Perkell (1996) state, “popular misconceptions about older adults included beliefs that they are not sexually active, are monogamous, are neither homosexual nor bisexual, and were unlikely to be intravenous drug users” (p.23). Both research groups identify similar biases held by society regarding the older adult and sexual behaviors.
In addition to HIV/AIDS-stigma and ageism, older MSM may be susceptible to internal and external homophobia. One definition for homophobia is one who shows hostility towards or fear of individuals who are a part of a LGBTQ community (Herek, 2004). External forms of homophobia can come from family members, friends, community members, co-workers, and institutions such as governmental and other agencies via policy or treatment. As mentioned in chapter two, the history of HIV/AIDS is strongly tied to society’s views of homosexuals, especially gay men of the early to mid 1980s when the virus was newly identified. Gay males were thought of as being immoral and deserving of the virus. Today, homophobia remains and according to the CDC (2012), MSM still represent the largest group of newly infected individuals annually.

According to Dew and Chaney (2005) internalized homophobia is “the taking in or internalization of society’s negative attitudes and assumption about same-gender sexual orientation by gay and bisexual men” (p.261). While the authors mention gay and bisexual men, any member of an LGBTQ community can experience the phenomenon. The relationship of internalized homophobia with HIV/AIDS rates has been researched with varying results (Newcomb & Mustanski, 2011). While Ross, Rosser, and Neumaier (2008) did not find a direct correlation, they did find higher levels of internalized homophobia in men who fail to disclose their MSM status. The latter in return, represents a larger group of HIV-positive men who fail to report their HIV-status. Another correlation that the authors found was that those with internalized homophobia had lower levels of condom self-efficacy. These findings do not directly relate internalized homophobia and HIV/AIDS; however, they show strong correlations between it and risky behaviors that warrant further investigation.
In order to eliminate the abovementioned forms of stigmatization and decrease the stigma experienced by older adults regarding sexual activity, prevention programs need to be created focusing on this at-risk group (Strombeck & Levy, 1998). To date, research has shown that older adults have little contact with HIV-prevention programs or safer sex material (Auerbach, 2003). The effects of HIV-stigma and ageism are a major hindrance to combating HIV/AIDS prevention and interventions (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007).

**HIV-Prevention**

As more was learned about HIV/AIDS, society benefited from new prevention programs and methods of treatment. As previously mentioned, in the 1980s and 1990s, HIV was reported predominantly in MSM and intravenous drug users. To combat these transmission rates, prevention programs focused on the relationship of risky behaviors and HIV-transmission. Common intervention programs during that time were condom distribution programs, needle and syringe exchange programs, safer sex classes, case management and HIV-testing (Porche & Swayzer, 2003). Unfortunately, HIV-prevention programs targeting older adults continue to be scarce in most regions of the country or they are not effectively reaching older adults, especially those with high-risk behaviors (Linsk, Fowler, & Klein, 2003; Milaszewski, Greto, Klochkov, & Fuller-Thomson, 2012).

The first noted prevention initiatives in the United States date back to the mid 1800s and focused on mental health (Spaulding & Balch, 1983). Since then, researchers and practitioners in fields such as social work and public health have had an extensive history in creating and implementing prevention strategies for social problems for minorities (Bloom, 1983), improving parenting (Huxley & Warner, 1993), decreasing school based bullying (Drake, Price, Telljohann,
Prevention Categories

Prevention initiatives are routinely divided into three categories: primary, secondary and tertiary. Programs designed to prevent diseases or specific behaviors from developing are known as primary. Benotsch and colleagues (2006) note that AIDS Service Organizations with websites that increase awareness of risky sexual behaviors exemplify an effective primary HIV-prevention initiative. Secondary prevention programs focus on decreasing the level of infection or risk taking of individuals at-risk of contracting a disease or already diagnosed with an early stage of a disease (Sable, Schild, & Hipp, 2012). An example of a secondary HIV-prevention program for HIV-positive individuals residing in rural areas could be a telephone-delivered intervention with components that aid in decreasing psychiatric distress (Heckman & Carlson, 2007).

The final prevention category is tertiary. Programs in this category focus on minimizing possible side effects or other conditions from developing because of a correlation with an existing diagnosis. Individuals living with HIV/AIDS for long periods of time are susceptible to increased levels of cardiovascular disease (Jones-Parker, 2012). Parker suggests that older adults in this category have routine blood work monitoring conditions like cholesterol and triglycerides to prevent co-morbid conditions.

Prevention with Older Adults

Prevention initiatives exist for a variety of groups based on age, race, ethnicity, socio-economic status, geographical location, and/or healthcare needs (Teutsch & Harris, 2003). This section begins with a brief discussion of prevention initiatives targeting older adults and then
shifts to identifying barriers frequently noted by researchers and participants in studies focusing on the older adult.

The risk of falling is a major concern for older adults and their caregivers and healthcare providers. According to Chang and colleagues (2004), “In the United States one in three people aged 65 or more living in the community fall at least once a year. This proportion increases to one in two for those over 80 years” (p. 680). These rates have resulted in an increase in prevention initiatives to improve the quality of life for this population (Noonan, Sleet, & Stevens, 2011). Smith, Ory, Ahn, Bazzarre, and Resnick (2011) report that older adults can decrease their fall risk by increasing their level of physical activity.

In addition to fall precaution programs, older adult prevention initiatives exist with foci on changing negative behaviors such as cigarette smoking, which impacts an individual medically, financially, and socially. According to Sachs-Ericsson, Collins, Schmidt, and Zvolensky (2011), “older adults who are cigarette smokers have increased medical problems, health care cost, disability, a greater rate of cognitive decline and mortality rates compared to non-smokers” (p. 132). Therefore, the goal for researchers and prevention experts is to decrease (or cease) smoking in this population. Thomas, Supiano, Chasco, McGowan, and Beer (2008) developed and implemented an innovative seven week smoking cessation group program for older adults called “Smoking Cessation for Seniors.” At the yearly follow-up, the authors reported a combined cessation rate of 68% for the seven completed groups, which indicated a successful intervention.

Another older adult behavioral prevention program initiative focuses on dietary changes. Individuals who improve their dietary intake decrease their likelihood of receiving or worsening a health condition and increase their overall health (Dwyer, 2006). Changing negative dietary
habits can improve cardiovascular disease and osteoporosis (Dwyer), stroke and kidney related diseases (Robare et al., 2010), and cognition (Siervo et al., 2012). The “10-Keys to Healthy Aging Demonstration Project” is an example of a community-based prevention program fostering behavioral changes within the older adult population. Its premise was to “focus on long-term adherence to preventive therapies, screening and immunizations” (Robare et al., 2011, p. 379).

Creating an effective prevention program is a detailed oriented process. A key factor to being successful is having a knowledgeable developer or development team. Prevention designers focusing on older adults need to know the baseline for the target population and how much intervention is adequate for the desired outcome (Sleet, Moffett, & Stevens, 2008). Another suggestion for developers is creating alternative methods for delivering interventions (Conn, Minor, Burks, Rantz, & Pomeroy, 2003). In other words, it is important for those involved in creating programs to ensure the program is tailored to different subgroups, if necessary and feasible. For older adults, this may refer to location of the group (e.g. community center, nursing home, hospital units, or church), physical ability of participants, and access to the program (e.g. transportation). These factors can significantly impact a program’s recruitment and retention, which Sleet and colleagues indicate as being important factors to focus on in the design process. Burns, Deaton, and Levinson (2011) stress the importance of programs using specially designed recruitment and marketing campaigns when attempting to capture subgroups like older adults. This could mean using older individuals in advertisements, posting flyers in communities with higher percentages of older adults, and offering incentives that are age appropriate.
HIV-Prevention with Older Adults

Strombeck and Levy (1998) identified primary and secondary prevention strategies useful while working with older adults. Primary prevention identifies and works to reduce risk factors by educating the adult, healthcare providers, and preexisting senior community programs to help prevent infection. Secondary prevention programs focus on the prompt treatment of people who have already tested HIV-positives.

As early as 1998, Strombeck and Levy advocated for primary research for the older adults; in 2004 this population was still overlooked: “One explanation for the exclusion of older adults in targeted HIV/AIDS education and prevention programs may be existing societal attitudes, myths, and biases concerning elderly populations” (Orel, Wright, & Wagner, 2004, p.693). To address these forms of exclusions they recommended the development of age appropriate educational materials, governmental support for further research on HIV and the older adult, and the encouragement of distribution of HIV risk reduction material with erectile dysfunction prescriptions. Recently Orel, Spence, and Steele (2005) emphasized the importance of risk reduction literature for the at-risk older adult warning that “disseminating appropriate age-specific HIV reduction messages targeting people older than the age of 50 is imperative to curtailing the escalating HIV/AIDS epidemic among older adults” (p.490). They identify the following four recommendations for effective prevention programs: raise perceived sense of susceptibility to HIV/AIDS; provide factual HIV/AIDS information; incorporate risk reduction strategies; and emphasize early intervention.

These findings suggest further research is needed to address the level of access older adults, more specifically older MSM, have to safer sex education and HIV-prevention. Greater knowledge about possible barriers experienced by older adults attempting to obtain prevention
information and HIV-testing will help practitioners better understand the client holistically and may help improve adherence to safer sexual practices. This greater understanding of the psychological effects of this process will help researchers develop supportive approaches for healthcare providers with their older patients. The results could assist families with facilitating a safer-sex discourse with older adults, which typically is avoided. Finally, the findings of this research can be used to develop better communication skills, negotiation skills, and empowerment via specialized prevention programs for older adults.

**Relevant Theories**

Multiple theoretical frameworks or models serve as underpinnings for the various forms of HIV-prevention programs. With an overarching theme to foster change within an individual or community, these frameworks or models approach the process in a multitude of ways. Health Belief Model, Theory of Planned Behavior, Transtheoretical Model/Stages of Change Model, and the Empowerment Approach are representative of models found within HIV-prevention. While large scale HIV-prevention programs for older adults are currently non-existent, the proposed research aims to understand how well elements of these models can provide the same quality of outcomes for older adults.

**Health Belief Model**

The Health Belief Model (HBM) implies there is a relationship between an individual’s decision-making and one’s health related behaviors (Harrison, Mullen, & Green, 1992). The following four constructs and two concepts frame the model that explains this relationship: perceived susceptibility, severity, benefits, barriers; and the concepts are cues to action and self-efficacy (Champion & Skinner, 2008; Harrison, Mullen, & Green). Perceived susceptibility is the level of belief that an individual has that he/she can get a disease or health condition.
Relating to that disease or health condition, perceived severity is an individual’s thoughts about the seriousness of contracting said disease or condition. Thus far, the individual’s focus is on the implications of threat on contracting a disease or condition. The next step is when an individual begins to evaluate possible benefits of preventing a disease or health condition. In the HBM model, this is known as the perceived benefits construct. Perceived barriers are internal and external obstacles that impede an individual’s ability to take-on the necessary behaviors to prevent the disease or health behavior. To eliminate these obstacles, HBM uses the concept cues to action. The final concept, self-efficacy is an individual’s belief in his or her own ability to complete a behavior. These constructs and concepts comprise the HBM and help guide research that addresses behavioral change at the individual level (Champion & Skinner).

Coleman and Ball (2009) used HBM to identify how self-efficacy influences condom use of middle-aged African American males who are HIV-positive. A cross-sectional correlational design measured the relationship between self-efficacy to use condoms with the variables HIV knowledge, religious well-being, HIV symptoms, relationship status, and sexual orientation. Their goal was to evaluate these variables and determine which correlates offer a better prediction of self-efficacy to use condoms for this at-risk group of adult males (Coleman & Ball).

Given the dearth of data relative to older adults, a study of 130 African American men (ages 40-68, m=46) receiving HIV-care at two separate Mid-Atlantic outpatient infectious disease clinics is included (Coleman & Ball, 2009). The authors collected demographics and HIV symptom data using a checklist. Self-efficacy and health beliefs, AIDS knowledge, and religious well-being were measured by using pre-existing scales. The sample included 63% MSM and 37% heterosexual men. The authors did not conduct statistical analysis based on sexual orientation; therefore, the following results are based on all study participants. AIDS
knowledge scores ranged from 37-95% accuracy, and 46% report being non-condom users. Findings suggest that religious well-being and AIDS knowledge were significant predictors of self-efficacy relating to condom use. These data allow prevention researchers to better understand the at-risk population and to help develop more effective and relevant prevention initiatives (Coleman & Ball).

**Theory of Planned Behavior**

The Theory of Planned Behavior (TPB) is an extension of the Theory of Reasoned Action (TRA) developed by Fishbein and Ajzen (Ajzen, 1991). While both theories focus on understanding relationships regarding an individual’s attitude, intention to perform a task, and outcome behaviors, TPB has an additional construct that measures an individual’s perceived control over the action of performing the desired behavior (Montano & Kasprzyk, 2008). This construct mirrors Bandura’s self-efficacy theory in that the two evaluate the individual’s ability and willingness to take on the new behavior (Ajzen & Madden, 1986; Sheeran & Taylor, 1999).

The other constructs of TPB are behavioral beliefs, attitude toward the behavior, normative beliefs, subjective norms, control beliefs, intentions, and behavior. Behavioral beliefs and attitude toward the behavior both focus on the individual. Behavioral belief is the individual’s belief about the consequences of the behavior, while attitude toward the behavior is the positive or negative attitude an individual has regarding the behavior in question. Normative beliefs and subjective norms are influenced by the individual’s society. Normative beliefs are the perception an individual has about a behavior in relation to the influence society has on the perception. Subjective norms refer to how an individual believes society feels, either negatively or positively, about the behavior. The abovementioned constructs (attitude toward the behavior, subjective norm, and perceived behavioral control) all influence the next construct of TPB:
intention. In TPB, intention is an individual’s readiness to perform a task. The final construct, behavior, is influenced by intention and perceived behavioral control. A positive interaction between these two constructs leads to the individual adopting the behavior change. Conversely, a negative interaction may lead to the behavior change continuing to occur or failing if attempted (Ajzen & Madden, 1986; Connor & Armitage, 1998; Montano & Kaspryzk, 2008).

In 1999, Villarruel, Jemmott, Jemmott and Ronis (2004) conducted a study using TPB with Latino youth (N=141) taking part in a health promotion program. The study used multiple instruments to measure behavioral beliefs, control beliefs and intentions. The behavioral beliefs measures related to sexual intercourse and condom use. The researchers asked questions about parental pride, popularity, prevention, hedonistic beliefs, and partner reaction. The control beliefs also related to condom use; however, here the researcher sought to measure self-efficacy, condom availability, impulse control, and technical skills. Intention referred to the youth’s intention to use condoms over a specified time period.

Villarruel and colleagues (2004) report that there was a significant relationship between attitudes, norms, beliefs and intention to have sex and sexual intercourse behavior. For example, those youth who reported possibly having self-pride for restraining from sexual intercourse perceived that their parents would be pleased with their decision or thought that sexual intercourse would impede on their futures more likely restrained from intercourse. The study also confirmed that youth with positive attitudes toward condom use reported higher chances of obtaining and using them in the future.

A meta-analysis of 96 data sets that used TPB and/or TRA to predict condom use was conducted by Albarracin and colleagues (2001). Inclusionary criteria for the study were as follows: a) have a direct involvement with condom use behavior; b) measure condom use
behavior or intention; c) measure attitudinal and normative factors and perceived behavioral control (components of TPB/TRA); and d) report appropriate statistical analysis. Using path analysis, the authors concluded that “the theories of reasoned action and planned behavior are highly successful predictors of condom use” (p.155)

**Transtheoretical Model/Stages of Change**

The Transtheoretical Model (TTM) is a cyclical process used to predict and motivate individuals with identifying, accepting, and adapting a specific behavior. The model has been used with co-occurring drug abuse and severe mental health, smoking cessation, fall prevention in older adults and sexual risk reduction (Batra, Melchior, Seff, Frederick & Palmer, 2012; Fu, Fernandez, Pascual, Martinez-Sanchez, Agudo, Moncada, Nebot, & Borras, 2011; Nidecker, DiClemente, Bennett & Bellack, 2008). The model consists of six stages with no specific entry point. In the first stage, precontemplation, an individual has a specific behavioral problem, yet lacks intention to change the behavior. This lack of intention is generally the result of a lack of knowledge relating to the behavior and its risk. The next stage, contemplation, occurs when an individual knows about a condition and plans to adapt necessary change in the future to improve his/her quality of life. Next, preparation occurs when the individual moves closer to making necessary changes. Once the individual enacts the necessary behavior change consistently, he/she is officially in the action stage. The final stage, maintenance, allows the individual to monitor his/her progress and implement further changes if relapse occurs (Prochaska, DiClemente, & Norcross, 1992; Prochaska, Redding, & Evers, 2008).

In a study of 539 high school aged participants, Hacker, Brown, Cabral, and Dodd (2005) sought to evaluate a sex education program containing pregnancy and HIV/AIDS education that uses TTM. The researchers were interested in demographics, risk factors (e.g. age of first sexual
activity, type of sexual activity, number and type of partners, etc.), and target behavior and stage of change as it relates to pregnancy. Researchers separated data for the pregnancy prevention and disease prevention initiatives of the intervention and found that the majority of clients were in the preparation stage for both (pregnancy 41.7%, disease 31%). The authors report, “agency site, client’s gender, proximity of sexual activity, past month sexual partner status, level of partner support for target behavior, and target behavior were associated with [stage of change] at first visits for both pregnancy and disease prevention” (2005, p.S85). In other words, these variables all showed a significant influence on the client’s designated stage based on his/her response to questions within the questionnaire.

**Empowerment Theory**

Empowerment theory connects underserved, maltreated, or misinformed individuals or groups with knowledge, skills, or monetary resources allowing them to gain independence (Robbins, Chatterjee, & Canda, 1998). McWhirter (1991) expands this definition by emphasizing that the process need not infringe on other people and encourages those who have achieved empowerment to offer support to others in need. A basic assumption of the empowerment approach is that within societal structures, forms of oppression reside with negative implications on individuals and communities of all sizes (Lee, 1996). A primary goal of empowerment is to eliminate barriers and oppression faced by individuals or groups. Facilitation of this occurs on an individual level when clients take responsibility to build personal power and increase self-actualization through the creation of meaningful goals (Cattaneo & Chapman, 2010). On a community level, facilitation occurs when individuals work together to access resources and raise consciousness as a whole. According to Banyard and Goodman (2009), “collaboration with community members ensures a more accurate assessment of needs,
more effective interventions, greater buy-in from participants, and more sustainable programs” (p.272). An example of a primary HIV-prevention program situated within the community could be a mass condom distribution to at-risk individuals organized by an entity that has surveyed community need.

**Conclusion**

This literature review demonstrates the need for further work with HIV-prevention work targeted towards the population of older MSM. This qualitative dissertation focused on capturing information from HIV-negative MSM who are 50 and older. Participants were asked questions relating to their personal history with HIV and HIV-prevention, and their insight into how they have remained HIV-negative. In order to acquire this data, 22 interviews were conducted with members of this population throughout the United States using gatekeepers mentioned earlier in chapter 1. The following chapter details the rationale for and components of this chosen methodology.
Chapter 3

Methodology

Overview

The rate of new HIV/AIDS diagnoses is increasing in the older adult population, especially within the MSM communities. As noted in chapter two, HIV-prevention initiatives are scarce for this cohort. This study sought to increase knowledge as it relates to HIV-prevention for older adults, especially for MSM who are HIV-negative. In participating in this study, participants shared their experiences, stories and feelings as they relate to their exposure to HIV and HIV-prevention initiatives.

Since the goal of this study was to understand the participant’s lived experience, a qualitative design using Traditional Grounded Theory was chosen. As noted by Denzin and Lincoln (2011):

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning (p. 8).

Qualitative inquiry allows the researcher the opportunity to identify and describe meanings and patterns, and explore the processes of participants’ experiences (Creswell, 2013). The research process is inductive with an end goal of building or creating theory (Padgett, 1998). According to Creswell (2013), qualitative research is conducted when: (1) “a problem or issue needs to be explored;” (2) “we need a complex detailed understanding of the issue;” (3) “when we want to empower individuals to share their stories, hear their voices and minimize the power
relationships that often exist between a researcher and the participants in a study;” and (4) “to develop theories when partial or inadequate theories exist for certain populations and samples or existing theories do not adequately capture the complexity of the problem we are examining” (pp. 47-48). Currently, no studies have been conducted that explore the experiences of older HIV-negative MSM with HIV/AIDS, nor have data been used to address future prevention initiatives. This study explored these phenomena by means of the following research questions:

1. How have older HIV-negative MSMs’ experienced the first 30 years of the HIV/AIDS pandemic?
2. What are older HIV-negative MSMs’ experiences with HIV-prevention?
3. What factors influenced (if any) older HIV-negative MSMs from contracting HIV?

This chapter will describe the qualitative research design, Grounded Theory, access, ethics, data collection procedures, analysis approach, and the trustworthiness of methods utilized in the study.

**Grounded Theory**

Qualitative researchers have multiple theoretical approaches available to undertake their study; one approach is Grounded Theory. According to Nathaniel and Andrew (2010), “because of their real world orientation, grounded theories are particularly appropriate for health care research” (p. 65). Originating in 1967, Grounded Theory is the work of Glaser and Strauss. At that time, Glaser and Strauss sought to identify “social loss of dying patients” and the phenomenon’s impact on nurses (p. 42). Using the inductive design, they hypothesized and proved that patients experiencing greater levels of social loss receive higher quality of care from nursing staff compared to those with lower levels (Glaser & Strauss, 1964).
Over time, Glaser and Strauss developed two separate approaches for conducting Grounded Theory (Creswell, 2013). According to Walker and Myrick (2006), “It was a split that surfaced publicly when Strauss and Corbin (1990) released their version of grounded theory, which Glaser (1992) aggressively argued was not, in fact, grounded theory but a new method, which he called full conceptual description” (p. 547). Therefore, the original work is respectively referred to as Glaserian or Classical Grounded Theory (CGT), while the more recent version is known as Straussian or Traditional Grounded Theory (TGT). A third version of Grounded Theory originates from Charmaz, which is a constructivist approach (Creswell, 2013). This approach rejects the traditional positivistic and objective underpinnings of Glaser and Strauss and Corbin and Strauss’ work and encourages GT to be more interpretative and subjective (Charmaz, 2006; Mills, Bonner, & Francis, 2006). When discussing how her GT approach differs from CGT and TGT, Charmaz explains “data do not provide a window on reality. Rather, the ‘discovered’ reality arises from the interactive process and its temporal, cultural, and structural contexts” (2000, p. 524).

Each variant has qualities that warrant their usage with this study; however, TGT will be applied. Reasoning for this is twofold. First, TGT allows the researcher to be more rigorous with data analysis and the design supports validity (Creswell, 2013). Second, the end goal of TGT is theory development. Corbin and Strauss (2008) define theory as “a set of well-developed categories (themes, concepts) that are systematically interrelated through statements of relationship to form a theoretical framework that explains some phenomenon” (p. 55). The focus of this study was to develop a theory to explain the posed research questions.
Access and Ethics

**Access.** Identifying and accessing participants occurs in stages and required the researcher to be engaging and patient and to receive Instructional Review Board (IRB) approval. Recruitment occurred locally and nationally. Locally, participants were recruited from agencies who serve older adults and members of the LGBTQ communities with the assistance of social workers and other staff who served as gatekeepers to participants. Prior to the start of the study, the researcher had the opportunity to build a relationship with individuals working within senior housing, LGBTQ services, and HIV-prevention and services. Additionally, the researcher built a network of supportive social work, gerontology, nursing, and health psychology faculty who served as liaisons with community gatekeepers. Gatekeepers are usually members of the community or have high stakes within the community and serve as a link to other community members (Creswell, 2013; Taylor & Bogdan, 1998). Once identified, gatekeepers were notified by letter using traditional or electronic mail. This letter introduced the researcher, explained the study, and requested an in-person or telephone meeting to discuss the study and to address possible questions or concerns. Ideally, this rapport building with gatekeepers helped foster access to local participants.

**Ethics.** The ethical underpinnings within this study stem from the ethical beliefs of the social work profession. The National Association of Social Workers (NASW) provides standards and guidance for social workers. One specific guide, *NASW Code of Ethics* (2008), provides guidance about ethical dilemmas practitioners and researchers may encounter. The code consists of the following six core values: 1) service, 2) social justice, 3) dignity and worth of the person, 4) importance of human relationships, 5) integrity, and 6) competence (NASW, 2008). These values influenced all aspects of the study from the initial thoughts of the social
problem and research questions to the intricate study design, including sample selection, data collection and analysis, and dissemination of findings. The study is governed by Virginia Commonwealth University’s IRB, which ensured that the researcher had completed and received Collaborative Institutional Training Initiative (CITI) certification.

Participants & Sampling Techniques

Participants. This study explored the experiences of older HIV-negative MSMs’ with HIV/AIDS. The explicit inclusionary and exclusionary criteria included: being male, 50 or over, MSM, have a HIV-seronegative status, and not have an extensive work or volunteer history within HIV-prevention or treatment. Also, participants needed to be able to read and write in English or have access to means that allowed the ability to do so.

Recruitment took place locally and nationally. Locally, recruitment was facilitated through local list-serves and websites (e.g. Roanoke Community Center and Gay Community Center of Richmond), advertising through flyers at LGBTQ-friendly and LGBTQ specific agencies/businesses (e.g. Gay Community Center of Richmond, Fan Free Clinic, SAGE, Equality Virginia & ROSMY), and through word of mouth using personal and professional relationships. Gatekeepers were offered an opportunity to meet with the researcher to discuss the study aims, recruitment needs, and ways in which he/she could assist with the study. Interested participants were asked to call or email the researcher to set up a screening or to ask questions. With IRB approval and signed permission of potential participants, gatekeepers were allowed to provide the research with the names and contact information of potential participants.

Similar to local recruitment, national recruitment relied heavily on word of mouth through professional colleagues. Emails were sent to individuals who work with LGBTQ or HIV agencies or have access to list-servs that target these communities. Gatekeepers were asked
to send emails to their represented list-servs or personal and professional networks with the IRB approved recruitment script as the body of the message. As in the case of local gatekeepers, national participants were asked to contact the researcher with questions and screening.

The aforementioned techniques are supported within the literature (Creswell, 2013) and have been routinely administered by social scientists (E. Benotsch, personal communication, November, 2011). In this study, 36 individuals showed interest and 22 were enrolled. More information regarding sampling and data collection follows.

**Sampling Technique.** In this GT study, data collection occurred through theoretical and purposive sampling to help achieve maximum variation so as to hear from a variety of perspectives within the target audience. According to Glaser and Strauss (1967), theoretical sampling is, “the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (p. 45). In this systematic approach, the researcher conducts interviews or observations to collect data. Once collected the data are immediately analyzed to identify pertinent concepts. These concepts may generate questions or a different line of inquiry for the researcher that will be integrated in future interviews or observations. The goal of this strategy is saturation, the point where the data have provided the researcher with definitions and explanations for the concepts and no new concepts are heard that are relevant to the population (Corbin & Strauss, 2008; Morse, 1995). While the goal of TGT is to collect enough data to develop a theory, Creswell (2013) suggests a sample of 20 to 30 may be sufficient to do so; therefore, this study had a target sample size of 20-25 participants.

A second sampling technique focuses on recruiting participants. In research, there are two means of gathering a sample: probability and non-probability sampling. The primary
difference between the two is that the former includes random selection while the latter uses other means to collect participants. Qualitative researchers typically use non-probability sampling (Devers & Frankel, 2000; Miles & Humberman, 1994). One type of non-probability sampling is purposive sampling. The focus of this technique is to recruit participants based on a pre-existing plan. Several varieties of purposive sampling exist such as expert, homogeneous, and maximum variation (Patton, 1990). The latter was used within this study. According to Patton (1990), the aim of maximum variation is “capturing and describing the central themes or principal outcomes that cut across a great deal of participant or program variation” (p. 172). Maximum variation was used in this study to capture a wide range of perspectives from participants. A goal of the study was to ensure that participants were from diverse racial/ethnic backgrounds as well as some variety in relationship status and exposure to HIV/AIDS. With such a goal, maximum variation allowed the researcher to cease data collection when the sample began to mirror one particular group and allowed the researcher to target more diverse participants.

**Data Collection Procedures**

This study used demographic questionnaires and semi-structured interviews to collect data. At the conclusion of each interview, field notes capturing my thoughts and feelings about the interview experience were documented. Rodwell (1998) refers to this process as a “reflective conversation with oneself that investigates possible meanings from what is happening in relation to one’s own values and interests” (p. 134). In addition to documenting the researcher’s reflection of the interview, Creswell (2013) suggests notating on the physical environment. Interviews were conducted face-to-face, through the use of live video communication technology
(e.g. Skype), or telephone and lasted between 45-90 minutes. For that reason, the explanation of data collection is described based on each approach.

**Face-to-Face.** To qualify for a face-to-face interview, participants needed to live or work within a three hour drive of the researcher. A total of 16 interviews were conducted in this manner. Those showing interest in the study were screened using a scripted recruitment tool to ensure they met the inclusionary criteria. Screening took place through telephone or email communication. Those meeting criteria were scheduled for face-to-face interviews. Participants determined the interview location with preference being a quiet site that fostered a safe environment to discuss the research topic. One day prior to the scheduled interview, participants were contacted via phone or email to confirm the appointment. The interview began with a description of the study to ensure participants understood their involvement. Those expressing understanding then underwent the consent process. Since the only linkage with participants and this study was the consent form, a request to waive consent documentation was submitted to the VCU’s Office of Research during the IRB process. While all participants were made aware of the consent form and its content, the waiver permitted the researcher to not obtain or store a signed copy of the document. Participants interested in obtaining a copy of the consent form received one from the interviewer. Once consented, participants spent approximately five minutes completing a demographic questionnaire and 45-90 minutes being interviewed using the script. Notes were taken to ensure all non-verbal responses and exterior stimuli were captured. If permission was granted, interviews were recorded to assist with the data analysis stage of the study. Individuals who did not agree to the recording were still interviewed. In these situations, extensive field notes were taken. Recordings from those consenting were transcribed and field notes reviewed and assessed for accuracy and clarity.
Technology based interview. Interviews using live video communication technology (e.g. Skype) or telephone were available for those who lived or worked more than three hours from the researcher or for those within the three hour radius who preferred this interview format over face-to-face. A total of six interviews were conducted in this manner. Those showing interest in the study were screened using a scripted recruitment tool that was administered via email or telephone. This process ensured inclusionary criteria were met. Those meeting criteria were scheduled for online video or phone interviews. The latter option was for participants who were hesitant or lacked access to video methods. Participants were encouraged to ensure they were in a quiet location that fostered a safe environment to discuss the research questions. The researcher was either in a locked office or personal residence, with a guarantee that interruptions were avoided and the confidentiality of the interview was assured. One day prior to the scheduled interview, participants were contacted via phone or email to confirm the appointment. The interview began with a description of the study to ensure participants understood their involvement. Those expressing understanding were then consented using the abovementioned waiver process. Hard or electronic copies of the consent form could be mailed, if requested. Once consented, participants spent approximately five minutes completing a demographic questionnaire and 45-90 minutes being interviewed using a script. Notes were taken to ensure all non-verbal responses and exterior stimuli were captured. Interviews were recorded to assist with the data analysis stage of the study. The recordings were then transcribed and assessed for accuracy.
Data Analysis Methods

Grounded Theory data analysis commences during the initial participant interaction and continues into the analysis process (Corbin & Strauss, 2008; Creswell, 2013). The first stage is known as memoing. Creswell define memoing as:

The process in grounded theory research of the researcher writing down ideas about the evolving theory. The writing could be in the form of preliminary propositions (hypotheses), ideas about emerging categories, or some aspects of the connection of categories as in axial coding. In general, these are written records of analysis that help with the formulation of theory. (p. 289)

In other words, memos act as the researcher’s conceptual analysis of his/her thoughts on the process, participant’s statements during the interviews, the story the data are telling, and will later shape the theory.

In addition to TGT’s memoing process, the researcher begins analyzing participant data using several coding procedures. According to Creswell (2013), during this process “researchers build detailed descriptions, develop themes or dimensions, and provide an interpretation in light of their own views or views of perspectives in the literature” (p. 184). The outcomes of coding are concepts and categories. Concepts are “words that stand for ideas contained in data” (Corbin & Strauss, 2008, p. 159). The authors suggest that there are different levels of concepts, categories being broader. Glaser and Strauss (1967) advise researchers to be open-minded when creating categories by not focusing just on the research topic or those that are related. The computer software, Atlas.ti, was used to assist the researcher with data management.
Coding

The different variants and even editions of key authors who write about GT provide varying suggestions for conducting the coding process. Corbin and Strauss (2008) suggest using open and axial coding, which will be used in this study. Creswell (2013) suggests that open coding occurs prior to axial, while Corbin and Strauss indicate they are facilitated simultaneously. According to Corbin and Strauss (2008), open coding is “breaking data apart and delineating concepts to stand for blocks of raw data. At the same time, one is qualifying those concepts in terms of their properties and dimensions” (p. 195). Here the researcher reads each line, sentence, and paragraph to identify codes or categories. For the purpose of this study, coding began after interview four and continued once all interviews were completed. Charmaz (2004, p.507) suggests asking the following questions while conducting open coding:

- What is going on?
- What are people doing?
- What is the person saying?
- What do these actions and statements take for granted?
- How do structure and context serve to support, maintain, impede or change these actions and statements?

While the researcher performed the coding process mentioned here, he also compared and identified concepts or categories that had similarities, which is known as axial coding.

Theory Development

The abovementioned data analysis procedures occur continuously during the data collection stage, allowing the researcher to monitor for theoretical saturation. Corbin and Strauss (2008) describe this as “the point in analysis when all categories are well developed in terms of
properties, dimensions, and variations. Further data gathering and analysis add little new to the conceptualization, though variations can always be discovered” (p. 263). The next stage in the analysis process, integration, provides the researcher the opportunity to begin shaping the themes into a comprehensive framework of core categories. The current goal is to be able to weave the categories together into a story or framework that is moving toward theory development.

The process of theory development does not cease here. Corbin and Strauss (2008) suggest that the researcher “(a) check for gaps in the logic and rework those areas where there seems to be gaps and (b) begin to use all of the memos that [were] written and sorted to fill in the information under each major category” (p. 270.)

Steps to Enhance Rigor

A common term found in qualitative and quantitative research is rigor. Padgett (1998) suggest that rigorous studies assist researchers with reactivity and personal biases. According to Rolfe (2006) a study is rigorous when it has validity and reliability. Padgett advocates for trustworthiness as another technique to achieve rigor. Currently, a debate exists between researchers regarding which terminology is appropriate to use (Creswell, 2013; Lietz, Langer, & Furman, 2006). That being said, it is important to note that the terms used here were chosen by the researcher because of their strong connection to social work and qualitative research. Creswell (2013) summarizes validation as “an attempt to assess the ‘accuracy’ of the findings, as best described by the researcher and the participants” (pp. 249-250). Creswell and Corbin and Strauss (2008) suggest that qualitative researchers use one or multiple validation strategies such as 1) triangulation, 2) peer review or debriefing, 3) member checking, and 4) external audits. These are all examples of what Padgett refers to trustworthiness (Padgett, 1998). To increase the validity or rigor of this study, Justin Lee, a colleague with experience with qualitative studies,
served as peer reviewer. Dr. Lee reviewed the initial coding strategy and later reviewed the thematic framework and its accompanied conceptual map. This process included Dr. Lee offering supportive feedback, questioning outcomes, and facilitating discussion around proposed study findings, all of which Lincoln and Guba (1985) describe as validity within qualitative studies. Creswell and Miller (2000) refer to this phenomenon as credibility.

Dr. Pamela Kovacs, committee member, has extensive research with qualitative studies and has served on several grounded theory dissertations; therefore, served as a valuable resource with ensuring study validity. Reviews by Drs. Kovacs and Lee assisted the researcher in ensuring that all processes were understood and warranted the research design (Barusch, Grineri, & George, 2011).

Creswell (2013) suggests several techniques to enhance a study’s reliability such as quality recording devices, transcribing recordings, using computer software to aid with storing material and analysis, and using multiple coders. This study used an electronic recording device accompanied with software that eased the transcription process. Another characteristic of the study’s reliability was the use of Atlas.ti as a data management tool. Together these enhancements increased the study’s reliability.

Conclusion

In conclusion, this qualitative study used Traditional Grounded Theory to help understand the lived experiences of older MSM who are HIV-negative. Using theoretical sampling and maximum variation, participants were interviewed face-to-face, by telephone, or Skype. Study findings are presented in chapter four.
Chapter 4

Findings

This study used two formats to depict findings: conceptual model and narration. Conceptual models offer a visual representation of ideas and their interconnectedness, while a narrative provides the author the ability to describe findings in a richer and more in-depth fashion. Together, they inform researchers and practitioners about the experiences older gay males have had with HIV/AIDS including how they managed to remain HIV negative and how the virus impacted their relationships, as well as their thoughts about HIV prevention for the 50 and older population. For researchers, these categories may assist with the development phase of future qualitative and quantitative studies. Findings may help inform practice and policy, eliminate stigmas, and advance prevention initiatives. These implications will be addressed in the Discussion and Implications chapter.

Results

This study sought to increase knowledge as it relates to HIV-prevention for older adults, especially for MSMs who are HIV-negative. Attempts were made to recruit men of diverse sexual identities (MSM, gay, bisexual, etc.); however, after an extensive recruitment process, the study yielded only men who self-identified as gay. Therefore, within this and the subsequent chapter participants will be referred to as gay instead of MSM.

The 22 participants shared their experiences, stories and feelings related to their exposure to HIV and their knowledge about HIV-prevention initiatives. The questions guiding this study were:

1. How have older HIV-negative MSMs experienced the first 30 years of the HIV/AIDS pandemic?
2. What are older HIV-negative MSMs’ experiences with HIV-prevention?

3. What factors (if any) influenced older HIV-negative MSMs from contracting HIV?

To adequately approach the questions an open-ended technique was used. In other words, participants were presented with questions that allow for flexibility offering several benefits to the researcher, mainly, the opportunity to collect richer responses because participants are encouraged to explore and share their experiences (Creswell, 2013). The following nine primary questions and nine sub-questions guided the study, with sub-questions used as probes to further explore the participant’s response:

1. Tell me about the first time you heard about HIV/AIDS?
   - How old were you?
   - Where were you living at the time?
   - How did the experience make you feel?

2. How has HIV/AIDS affected your life over the past 30 years?
   - How has it impacted your relationships?
   - Have you lost any friends to the disease?
     - How has this affected you?

3. As a gay male or MSM, tell me about your experience with HIV-prevention?

4. What does HIV-prevention mean to you?

5. Tell me about your first HIV-testing experience?
   - What made you get tested?
   - Did you go by yourself?

6. What about HIV-prevention do you think is beneficial?

7. What about HIV-prevention do you think is not beneficial?
8. As an older HIV-negative gay male or MSM, what has influenced you to remain HIV-negative?
   
   - What about others you may know?

9. Do you have any suggestions for HIV-prevention strategies/initiatives that could benefit other gay or MSM males who are 50 and older?

If participants did not know exactly what “HIV-prevention” meant for question 3, the researcher provided a listing of common characteristics of HIV-prevention (e.g. condom distribution, safer-sex flyer distribution, & HIV-testing).

**Question alternatives**

Going into the study, the aforementioned questions and probes were designed to capture participants’ experiences. At times, changes were made to better capture responses. Over time it became clear that inquiry about participant’s HIV testing experience in question 5 was a better fit in tandem with or immediately following question 1 because of the questioning flow. Also, participants often answered question 5 without being directly asked.

Question 2 asked about the impact HIV/AIDS had on participants over the last three decades. Based on responses, the question seemed too broad and unfortunately somewhat repetitive, resulting in only the related probing questions being useful. Several changes were made to these probes to enhance responses. For example, the words ‘intimate’ and ‘non-intimate’ were added to the ‘how has it impacted your relationship’ probe, because responses seemed to only reflect on the former category at first. The noted changes increased participants’ responses with accounts from both groups of relationships. In addition to these changes, a final probing question was asked regarding the ramifications the loss of someone due to HIV/AIDS had on the individual’s sexual behaviors.
Questions 3 and 9 also required changes to enhance the interview and participant feedback. Question 3 required the use of its probing questions because apparently participants did not actually consider the events or programs they attended or witnessed as being affiliated with HIV/AIDS prevention. Question 9 was better asked as a two part question. Part one: “Tell me how I could reach your peers?” and part 2, “What messages should I use when trying to reach them?”

**Description of Sample**

Prior to the start of each interview, participants were provided a demographic form and asked to complete it to the best of their ability. The following information was collected:

<table>
<thead>
<tr>
<th>Age</th>
<th>Sexual identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race/Ethnicity</td>
<td>Current relationship status</td>
</tr>
<tr>
<td>Length of time in current relationship</td>
<td>Description of previous relationship(s) over the past 30 years</td>
</tr>
<tr>
<td>Number of previous relationships</td>
<td>Education level</td>
</tr>
<tr>
<td>Employment status</td>
<td>Date/year of last HIV test</td>
</tr>
<tr>
<td>Frequency of HIV testing</td>
<td></td>
</tr>
</tbody>
</table>

The age range for participants was 50-77 (M = 58.5). Each of the 22 participants identified as gay. Racially the sample consisted of white males of which two identified as Hispanic. Eleven participants reported currently being in a married/partnered-*closed* relationship; seven identified as single; and four chose married/partnered-*open* relationship. The vast majority (20/22) reported having earned a college and/or post graduate degree while other participants either completed high school or attended college without graduating. None had an education below that of a high
school graduate. Nineteen participants were presently employed while the remaining three were retired. Regarding HIV testing, two reported never requesting or obtaining a test, seven sought testing within the last two years, and a total of 14 have received testing since 2000. When answering the final question about the frequency of having been tested for HIV, six replied “never”; six “when I feel concerned”; four were tested “once a year”; and “when my healthcare provider inquires” was noted by three. See Table 1 for more details.

Although not captured on the demographic form, participants were asked during the interview process to report where they resided when they initially heard about the virus now known as HIV. Participants reported living in the following locations at that time: Arizona, California, Illinois, Massachusetts, New York, North Carolina, South Carolina, Texas, Virginia, and South Africa.

**Structure of Chapter**

The goal of this chapter is to present participants’ experiences as gay men during the HIV/AIDS pandemic so that these findings may help influence the development of relevant and effective HIV-prevention for older gay males. To achieve this goal, summaries of each category will be provided, followed by detailed accounts and explanations for each associated category and subcategory often with the participants’ own words.
Table 1: Description of Participants

<table>
<thead>
<tr>
<th>PT</th>
<th>Age</th>
<th>Hispanic</th>
<th>Current Location</th>
<th>Relationship status</th>
<th>Education</th>
<th>Employ Status</th>
<th>Last HIV Test</th>
<th>Testing Frequency</th>
<th>Interview Type</th>
</tr>
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<tbody>
<tr>
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<td>F</td>
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<tr>
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<td>post grad</td>
<td>employed</td>
<td>2012</td>
<td>once year</td>
<td>F</td>
</tr>
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<td>never</td>
<td>P</td>
</tr>
<tr>
<td>4</td>
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<td>no</td>
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<td>closed</td>
<td>some college</td>
<td>employed</td>
<td>never</td>
<td>never</td>
<td>P</td>
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<tr>
<td>5</td>
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<td>college</td>
<td>employed</td>
<td>1993</td>
<td>never</td>
<td>F</td>
</tr>
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<td>college</td>
<td>employed</td>
<td>2012</td>
<td>once year</td>
<td>P</td>
</tr>
<tr>
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<td>51</td>
<td>yes</td>
<td>NYC</td>
<td>open</td>
<td>post grad</td>
<td>employed</td>
<td>1992</td>
<td>never</td>
<td>S</td>
</tr>
<tr>
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<td>50</td>
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<td>2012</td>
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<td>employed</td>
<td>2010</td>
<td>Feel concerned</td>
<td>F</td>
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<td>53</td>
<td>no</td>
<td>South Carolina</td>
<td>closed</td>
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<td>self-employed</td>
<td>2009</td>
<td>never</td>
<td>F</td>
</tr>
<tr>
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<td>no</td>
<td>South Carolina</td>
<td>single</td>
<td>some college</td>
<td>retired</td>
<td>2008</td>
<td>once year</td>
<td>F</td>
</tr>
<tr>
<td>12</td>
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<td>no</td>
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<td>closed</td>
<td>post grad</td>
<td>employed</td>
<td>2011</td>
<td>HC provider</td>
<td>F</td>
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<td>employed</td>
<td>2012</td>
<td>once year</td>
<td>F</td>
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<tr>
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<td>no</td>
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<td>college</td>
<td>employed</td>
<td>2013</td>
<td>HC provider</td>
<td>F</td>
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<td>15</td>
<td>60</td>
<td>no</td>
<td>South Carolina</td>
<td>Closed</td>
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<td>1980s</td>
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<td>F</td>
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<td>F</td>
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<td>17</td>
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<td>post grad</td>
<td>employed</td>
<td>1999</td>
<td>Feel concerned</td>
<td>F</td>
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<tr>
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<td>no</td>
<td>South Carolina</td>
<td>closed</td>
<td>college</td>
<td>employed</td>
<td>1999</td>
<td>Feel concerned</td>
<td>F</td>
</tr>
<tr>
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<td>once year</td>
<td>P</td>
</tr>
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<td>once year</td>
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<tr>
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<td>HC provider</td>
<td>F</td>
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<tr>
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<td>no</td>
<td>Virginia</td>
<td>open</td>
<td>college</td>
<td>employed</td>
<td>2009</td>
<td>Feel concerned</td>
<td>F</td>
</tr>
</tbody>
</table>

Notes: PT = Participant number; Closed= partnered/married-closed relationship; Open= partnered/married-open relationship; Feel concerned= when participant feels concerned; HC provider= when healthcare provider feels inquires; F= Face-to-face; P=Phone; and S=Skype.
Emergent Results

During the thematic analysis phase, one theme emerged accompanied by four categories and subcategories. This central theme was the experiences of gay men during the onset of HIV and their relationships during the period since onset of the virus and how these experiences have influenced their current prevention practices. The categories were the following: Life Prior to HIV, Initial Reaction to HIV, Current Status of Participant’s Relationships, and Insight into Future Prevention. This section provides a brief account of each category and the corresponding sub-categories, followed by greater detail illustrating participants’ unique experiences.

Summaries

Life Prior to HIV. In this section, participants share stories of their lives prior to the onset of the HIV virus in the late 1970s and early 1980s. A common response by participants refers to how sexually active the gay community was, with little concern about STDs. Participants were in high school, college, or just starting careers during this period and some were dealing with the coming out process.

Initial Reaction to HIV. This section covers when participants first heard about HIV/AIDS, which for all was the late 1970s to mid 1980s. They heard about the virus in the media and within the community, primarily the gay community. Participants reported losing friends, acquaintances, and intimate partners early in the pandemic. Also mentioned in the section, was participants’ first experience with HIV testing. All but two of the participants indicated that they have requested an HIV test since their availability in 1985. This section concludes with self-reported behavioral changes implemented by participants to help assure not being infected.
Current State of Participant’s Relationships. In this section, participants provided responses to the question “why do I think I am negative?” Responses varied from luck to strategically seeking and staying in monogamous relationships. Participants also discussed dating and sexual relationships and risk factors related to sexuality after age 50, including communication with partners, friends, and healthcare providers.

Insight into Future Prevention. At the conclusion of the interviews, participants were asked to provide feedback to help inform future prevention initiatives for older adults. This section presents their responses starting with a discussion on stigmatization. The conversation moves to defining prevention followed by their opinions about existing prevention messages. The section and this chapter conclude with a discussion of how participants would design a prevention program for the 50 and older adult gay male.

Life Prior to HIV

This section reports the variety of attitudes and thoughts that gay men experienced, and the impact of geographical location during the era before HIV. Prior to the HIV scare, participants described a gay community that was sexual and minimally engaged in thinking about STD prevention. According to P18:

Most people who went through the 70s had a very active sex life and um, I mean it was a great time, and you just didn’t think about that. I mean the worst that would happen was you could get crabs, or syphilis, or gonorrhea, all very easily treatable.

During this time, gay men were meeting each other for sex in a variety of settings such as bars, bathhouses, bookstores, parks, and libraries (P10, P16, & P20). “In the late 70s, things were very, very wild!” stated P11, a resident from the Village, the heart of the gay community of New York City. He added “there were all the bathrooms bars [such as] the Vista Toilet and the Anvil.
There was a lot of S&M [sadism & masochism], lots of drugs, and nobody practiced safe sex, nobody- including me.”

When asked how he found men to have sex with in the late 70s and early 80s, P21 stated “I used to go down to a local island and also would do the block.” Both, he reported, were illegal events. The former was an isolated piece of land that required individuals to “repel up the side of a bridge, climb through a hole in a fence, and walk across an eight inch beam.” The latter was a common experience where gay men would walk, drive, or sit in their parked cars in anticipation of finding someone with whom to have sex. Participant 21 said “We would do things in our cars, go home with the guy, and some guys would even do things in the alleys.” Both of these events took place in a mid-size mid-Atlantic city and speak to the level of sexual frequency with unfamiliar partners in the gay community prior to the visibility of HIV/AIDS.

Another example of sexual experiences of gay men prior to HIV was from Participant 10. Here is his story:

I had begun to go to bookstores occasionally, and then I got up enough nerve in 87 to actually go to a gay gym. I wouldn’t go there very often cause I was scared to death I was gonna see somebody that I knew. Even in Miami, that was always a fear. So the reality of it was that my closeted situation, at the time, was causing me to involve myself in more dangerous behavior.

While many of the men interviewed discussed sex being easily available, some found that “scene” of no interest. Participant 7’s experience in New York City was different than that mentioned above by P11. He was just coming to terms with being gay and found himself trying to figure out where gay men found others to date. He said “I wasn’t looking for sex, therefore I felt naïve.” His goals were twofold: he wanted “to connect with other gay males and try to
understand the gay life.” He eventually responded to personal advertisements he found in the *Village Voice*, a local gay magazine.

Similarly, P16 only met men in bars. He said “I was a very shy person and the idea of going out there [bookstores, baths, and parks] was frightening to me, so I only met men through the bars. It just felt safer.”

Unlike these participants, several men reported not being sexually active for various reasons. Participant 4 who was in high school in the late 70s and early 80s and feared coming out explained:

I’ve known I’ve been gay all my life, probably since I was six. Being that it was the time it was, I was in high school in the late 70s, I graduated in 1980. So you really didn’t want to be out in high school then, so I dated one girl… I think it was my junior year. I then dated [another female] once I got out of high school, but I realized that it was just not where I wanted to be. It’s not what I wanted to do with my life, and I broke up with the last girl I was with, and just I didn’t go searching for anyone.

In summary, life prior to HIV was a liberating experience for the men in the study. Unfortunately, this changed as is noted in the next section.

**Initial Reaction to HIV**

In this section, participants reflect on their initial reactions to the disease and provide responses to the question “why do I think I am negative?” Responses varied from luck to strategically seeking and staying in monogamous relationships. Participants also reported on dating and sexual relationships and risk factors related to sexuality after 50, including communication with partners, friends, and healthcare providers.
First heard about it. When HIV/AIDS began appearing in the media it was known as the gay plague, gay cancer, and gay-related immune deficiency (GRID) (CDC, 1992a). Gay men responded differently depending on the delivery method of the message, geographical location, relationship status, and their stage in the coming out process. Participant 7 remembered the hysteria in the southwestern city where he lived. The take away message for P2 in the early onset of the epidemic was that promiscuity equaled getting AIDS. Participant 3 felt that “there was some talk about [the virus], but no one seemed terribly concerned about it.” “It was just another STD” recalled P12, a suburban NYC resident.

In the late 70s and early 80s, gay men acquired knowledge of their community by word of mouth or gay publications such as The Advocate. Participant 15 referred to the latter as “rags,” a phrase commonly used by gay men to describe gay related literature. These “rags” included calendars for happenings in larger metro cities, political articles, pornographic stories, and personal health advice. In addition to the aforementioned forms of media, participants (especially those in suburban or rural areas) reported accessing HIV/AIDS information through broadcast journalism and newspapers (P3 & P6). Participant 19’s knowledge of HIV was unique. While discussing sexual encounters that had occurred at local bathhouses, his therapist mentioned an illness affecting other gay men. He recalled, “It wasn’t long after that that people started talking about it in the local piano bars, and I started seeing people with thrush or Karposi’s.”

Many participants reported being in high school or college when they first heard of what is now known as AIDS. Participant 1, then a high school senior in a foreign country, reported knowing about the virus but believed that it would not affect him because he was dating women.
He said, “I didn’t liken [the virus] as being part of my life until I actually started being interested in men and that was basically about 1990.”

Upon graduating from college, P5 moved from South Carolina to Miami and subsequently broke up with his boyfriend, leaving him single and “scared to death to have sex.” Similarly, P10 was a college student and he recalled his experience as follows:

Well, thirty years ago I would have been in my second year of graduate school ... and we started hearing about, I guess I probably heard rumors about, this gay cancer problem and this Kaposi sarcoma that was coming up in uh gay men primarily in New York and San Francisco. I wasn’t out then. I was very deeply closeted at that point and in my mind it was NYC and San Francisco. I was concerned about it, but at that point it was NYC and San Francisco, so it was kind of distant.

Participants living in larger metro areas such as New York City, San Francisco, and Miami reported there being more organized gay communities and ‘out’ people and thus a greater likelihood they would know someone affected by HIV/AIDS. After graduating college and moving to Florida, P10 reported living on a street with other gay men, many of whom were HIV-positive.

As previously mentioned, responses to the virus varied. Participant 13, a pharmacist who resided in Los Angeles with his partner at the time, reported reading about the staggering number of deaths in San Francisco and New York and said it was “alarming.” Despite this, he continued, “It took a while to put the brakes on. We still went to the baths, periodically.” Another story from P13 revealed the complexity between early knowledge of the dangers of the virus and continued “risky” sexual activity. At the time, he and his partner lived in Los Angeles and the partner appeared to be moody. It was obvious to the participant that something was wrong, so he
told his partner to go visit the partner's parents who lived about two hours away. The area they lived in was known for its gay bed and breakfasts. Participant 13 felt that his partner needed to “blow out the pipes” (have sex), so the trip would help him do that. Unfortunately, P13’s partner died of HIV in the 1990s. He is currently in an open relationship with another man. As a pharmacist, the participant was well educated and in the medical field; these stories speak to the complexities of behavioral change and prevention.

Participant 2 who at the time was in graduate school had heard the many names used to describe the virus and knew that it was sexually transmitted. Thus, he concluded that the more sexual encounters one had, the greater the chance for being infected. He said “in general, if you were promiscuous, you were coming down with this, whatever ‘this’ was.”

Participants 7 and 17’s experiences also spoke to how individuals perceived HIV messages in the early years of the virus as well as the struggles related to safer sex. Participant 7, a New Yorker, was in a relationship with a man who also had sex with women. The boyfriend was a former drug user and P7 believed that he was now sober. Knowing all of this, P7 felt nervous about HIV because of the boyfriend’s actions, adding:

So, I was nervous, yes. Did it consume me? No. I mean, I really had feelings for him. I wanted us to be together. So, I was solely concentrated on him, not thinking about HIV, just trying to grasp having this relationship with this man that I thought was in love with me at 18.”

Participant 17’s experience was different; he was married to a woman and also having sexual intercourse with males. He said:

I guess the beginning, just the very beginning of the epidemic, in the early 80s, was a bad time for me because I was married to a woman at that time, and I had been having some
relationships outside the marriage. I was scared to death that I had infected her, so that was a really scary time for me.

Another example showing MSMs exposure to the virus comes from P11. As mentioned earlier, he felt the virus was only affecting larger cities. He lived in a southeastern city in which the virus did not appear to be present. This caused him to be “wary, definitely wary” he said, “when [he] was tricking out, picking up people and [taking] them home. [He] wasn’t comfortable.”

Finally, the story of P16 during the onset of HIV indicated a shift from fear to action. Like several other men in the study, P16 spent time volunteering with community based programs assisting those living with and dying from AIDS in the early 1980s. After visiting San Francisco and seeing the toll the virus had taken on the gay community, he returned to his home state in the southeast with a mission to educate his community. He and members of a support group he routinely attended that was affiliated with the local Episcopal Church partnered with state and county health departments and the regional medical school to begin community outreach. The goal, according to P16, “was to make sure that whatever information [they] had at the time was going out to the people.” For most, hearing about the virus went in tandem with experiencing loss.

**Loss.** With nearly 775,000 individuals being diagnosed with AIDS and approximately 448,000 dying between 1981 and 2000, it becomes paramount to acknowledge the impact this loss had on the surviving individuals (amFAR, n.d.). The men in this study, combined, lost hundreds of friends and acquaintances due to the virus. This section addresses the impact these deaths had on the survivors both emotionally and physically, and how it may have influenced their sexual behaviors.
When asked, “Did you lose friends during the onset of the virus?” Participant 14 began listing the names of friends who had died starting from the 80s and continuing into the 90s. Participant 13 cried while thinking and responding to this question, noting:

It was ... it was getting to be just painful. I only had one really close personal friend that died of it and it was devastating. Still is. I knew a lot of people. Friends of friends were dropping all over the place. It is easy to ignore when you don’t live through the painful parts. When you see your friends die it’s something you don’t ever walk away from unscathed. It’s never too far from the back of your mind.

He later revealed that the close friend who died was previously an intimate partner who he took care of when he was actively dying. “It was tough watching a lot of people die. And, I did not know as many people who died as a lot of my friends did,” stated P2. Participants 6 and 17 specifically mentioned losing classmates. Participant 17 somberly stated “I lost a lot of my best friends in medical school.” An interesting finding at this point is that even information and medical knowledge about the virus did not necessarily lead to behavioral changes.

The response of P5 was distressing and vivid. In 1987, the NAMES Project revealed the AIDS Memorial Quilt and P5 recalled reading an article about the founder, Cleve Jones. In the article, according to P5, Cleve Jones said “he could ride down the streets of San Francisco and point out houses where dead friends used to live.” Participant 5 thought, “this is such a gross exaggeration, he’s just trying to scare people.” Sadly, for P5, the scenario later became a reality within his mid-size mid-Atlantic city.

Of all the interviews, P10 provided the most profound recollection of the implications the deaths had on the individual, community, and society. As previously mentioned, P10 moved to Miami in the early 1980s after graduating from college in another southeastern state. In Miami,
he was a real estate agent and stated that his business was successful. Unfortunately, the success was due to an influx of HIV-positive men relocating after cashing in their life insurance policies, moving there to “die.” Participant 10 felt an obligation to help; therefore, he became active in the local gay community offering assistance to those infected and/or affected by the virus. He described the time as:

In the 80s, all of a sudden that wave of people dying who were perfectly healthy one day, coughing the next evening, and dead the next day. That was the way it was going and it was over and over and over again.

Immersed in selling real estate and helping those around him, P10 began dating a man who later was diagnosed with HIV. This shocked and scared them both. Because he loved his boyfriend, P10 stayed in the relationship which strengthened his commitment to those with HIV/AIDS. He described a time when he accompanied his partner to a doctor’s appointment and noticed that people who usually had appointments at the same time were no longer there. He knew this meant that they had died. After the death of his partner, P10 decided he had had enough and chose to leave Miami. Here is his account of his last days there:

I decided I didn’t wanna be in Miami anymore, so was going to sell my house. I went to church the Sunday before I moved. We are in the “prayers of the people,” and praying for the sick. Well, we knew who was on that list—it was half the people I knew. One person’s name didn’t come up. I thought “oh no, don’t do this to me as I’m leaving town.” Two minutes later, he was on the “list of the dead.” He died that morning and his partner was at the consul playing the organ ... I looked up at him and he was looking at me and I was just like “fuck, I gotta get out of here!” This had become normal. I wanted
to go somewhere where it wasn’t normal, where it was exceptional for that to happen.
And I was just tired of it. I couldn’t take any more of it.

With friends and family members dying, participants wanted to know their own HIV status; therefore, most of them went to get tested.

**First HIV Test.** In 1985, the Food and Drug Administration (FDA) licensed the first HIV antibody test, enzyme-linked immunosorbent assay (ELISA) and in 1987, the Western Blot test was sanctioned by the FDA and became the standard for diagnosing the HIV virus (FDA, 2009). The majority of men interviewed for this study received their first HIV test between 1985 and 1990.

In order to understand participants’ experiences with their first HIV test, it helps to know about the testing process. Generally speaking, it took two weeks, consisting of a blood draw, analysis period, and then result notification. Participants agreed that the 10-14 day waiting period was difficult to manage emotionally. Participants 12 and 20 referred to it as nerve rattling and unnerving. Participant 12 and his partner bought a new car during their waiting period. He stated “It was one of those stupid things people do. You know, what if one of us was to die we wouldn’t have to pay for the car, kind of thing. Participant 10 also expressed anxiety about the waiting period. After his boyfriend’s disclosure that he was positive, P10 went for testing. While recalling his experience, he said “I think I went immediately and got tested. And I tell ya, the ten day waiting was the most excruciating thing I’ve ever been through in my life!”

Two forms of testing existed at the time of participants’ experiences discussed here: confidential and anonymous. In both cases, statistics about positive results are reported to the CDC and for practical reasons, both tests can be considered confidential; that is your test results are not public knowledge and your identifying information is kept private. However, anonymous
testing utilizes non-identifying information such as a randomly assigned number that allows subjects to receive their results without ever having to disclose their name or other identifying information to the testing agency.

Participant 17 had his first test at a county health department in a southern state that did not offer anonymous testing. Here is his recollection:

Going to the health department and filling out the forms and the woman [completing the assessment] said “if I called this phone number and asked for the name you provided, is there any chance I’d find you?” and I said “of course not!”… Everyone was doing that. This participant spoke to a common practice of those in anonymous testing jurisdictions providing incorrect or insufficient contact information to testing locations in order to prevent direct notification.

Another resident in that state, P18 had his test results processed in another state because his did not offer anonymous testing. According to the participant, he and his partner contacted a friend who was a physician with access to a laboratory in a neighboring state. Their blood was drawn in their home state and sent and processed in the neighboring state. Describing the situation, P18 said “We were numbers or something… at the time, there was no anonymous testing in [our state]. You had to register, so they would know who was HIV-positive.” As a physician himself, the participant knew the importance of being tested, yet he was afraid of possible consequences if he tested positive such as loss of employment or professional licensure.

Similar to P18, P12 sought out a testing site away from his town but for somewhat different reasons. A clergy member not yet out as gay, P12 did not want members of his church or local area to know he was seeking an HIV test as this would indicate he had probably broken
the vow of celibacy or even intimated that he was gay; consequently, he drove to another locale within the state for anonymous testing.

Participant 9 had a different reason for getting tested. He said he got tested “because among [his] circle of friends, [he] really didn’t know that many people that were positive and for some reason in [his] paranoia, it was like [he would] be the one person that everybody else knows.”

In addition to various levels of anonymity in their testing, another variation occurred in how participants were notified of their results. Several participants, including P13, recalled having to report to the testing site for results. He said “When you go there, they’re very careful, you know? They wouldn’t tell you your results; you had to come in and be sitting with the person. You know, they were being very cautious about that kind of stuff.” This caution was due to the high levels of discrimination those testing positive were facing.

Participant 1’s experience was different. He was supposed to receive his results by telephone; however, his healthcare provider failed to call. This caused heightened levels of stress as noted below:

I could hardly sleep at night, and it takes a week or so before you get the results! And I called the doctor, you know a few times after, and he said ‘Oh yeah, I forgot about it.’ I was furious he didn’t get back to me, but he said ‘Oh no, you’re fine.’ But geez, you know, I basically didn’t sleep for two weeks!

Participant 5’s results were the same as P1, yet their experiences receiving results drastically varied. The experience of P5 was joyful; his catalyst for getting tested was having multiple sexual partners at the height of the epidemic. His testing was anonymous. The day he reported for his results, he recalled:
I went back knowing I was going to be positive, and when [the tester] said “You’re HIV-negative” and then “we need to talk about how to keep you that way.” I got up and went around the desk and picked her up and started dancing around the room! She sat back down, and I did it again!

Participants 5 and 20 both feared their testing results. Participant 20 was in his 30s when he decided to have his first HIV test. It took fear of infection for him to finally get tested as described below:

I was probably in my early 30s and my soon-to-be partner had stepped out of a monogamous environment, so there was a risk of exposure. So, I went and got tested, it was unnerving, don’t get me wrong. For some reason I had an internal sense that maybe I hadn’t been that exposed, so it wasn’t something to be overly worried about. But still, you play it in your mind very heavily. [Waiting to hear your results] affects your mood, your ability to sleep. It is something in the back of your mind, in your waking hours.

Participant 16 lived in the Southeastern region of the United States. He was a pioneer in the early outreach initiative to provide services to those infected with the virus in his area. Part of the role led him to be one of the first persons in his community to receive the ELISA (enzyme-linked immunosorbent assay) test. According to P16, having an HIV test done was a definite way for people to out themselves. That being said, when asked why he did it he said:

I did it basically to set an example. We wanted everyone to take this test and so we said, “Well, you know, you gotta ask people to [get tested], so you have to be able to say ‘well, I already have.’”

Although some participants chose to go by themselves for testing/result notification or were told they could not have anyone else in the room (P12), P19 took his brother with him.
I remember going in and my brother went with me and the minute the guy started talking, for some reason it pops into my head “he’s going to tell [me] it’s negative.” Of course he did and as soon as me and my brother left, I went and called my folks, because they knew I was getting tested. I broke down in tears on the payphone and my parents misunderstood when I said the results were negative. I immediately had to correct them like “no, negative is good!” so they had a small heart attack. I remember that very vividly. I felt like I could get on with my life, so I decided to go to law school.

With the loss of friends and testing HIV-negative, participants often made some form of behavioral change. The next section highlights these changes.

**Behavioral changes implemented.** Experiencing such loss early in the pandemic contributed to some participants adopting behavioral changes. These changes ranged from pledging to practice safer sex to refraining from sexual intercourse altogether. Participants 1 and 6 both increased their safer sex practices because of losing friends, while P7 refrained from having sex of any kind for nine years because he “didn’t dare venture out into something [he] wasn’t comfortable to encounter.”

Impacted not only by the deaths of his friends, P5’s work in HIV/AIDS prevention in the 1980s influenced him. He preached safer sex, prevention, and was conducting HIV-testing all day and said that he was “horrified to have sex.” Similarly, P17 decided to “cut out unprotected sex and anal sex altogether because it scared [him].” He, along with P14, expressed a desire to be in monogamous relationships. Having covered life prior to HIV and their responses to various aspects of the virus, participants were asked to reflect on their current behaviors and relationships.
Current State of Participants’ Relationships

This section focuses on why individuals thought they were negative, dating and sexual relations after 50, and risk factors including communication within intimate and non-intimate relationships. In general, these issues concerned participants regardless of whether they were single or currently in a relationship.

Why I am negative. During interviews, participants were asked “Why do you think you have been able to remain HIV-negative?” Responses varied from “luck” to behavioral changes such as using condoms during sex. Participant 1 said “It was always something I kept in the back of my head, so I would always be safe.” According to P12, “After five years in my monogamous relationship and us both having HIV testing done, I am confident I don’t have it.” Participant 16 simply said unprotected sex was a “death wish” that he wanted to avoid.

In addition to several other participants, P2 and P5 both mentioned luck, and their stories speak to their rationalization of safer sex. Participant 2 said:

There was no such thing as safe sex when I was 20 or 24 even. So, it was more like, “how did I dodge that bullet?” I wasn’t the most promiscuous person on God’s earth, but I wasn’t sitting at home twiddling my thumbs, either. So, you know it was one of those, “hey, how did so and so get it and I didn’t?” And, there was this amazement that I was one of the lucky ones, if you want to say that.

Participant 5 worked at a local organization offering HIV-testing and said “over the years, I had a lot of sex partners, and I was surrounded by it so much. Everybody was testing positive. ‘Why wouldn’t it be me?’ And it’s by the grace of God and luck that I wasn’t!”

Similar to P5, P3 witnessed individuals dying from AIDS as a volunteer with an HIV/AIDS service organization. Here is a description of his experience and its ramification on
his decision making: “I would pick up people needing to go to the hospital, doctor's or a lawyer’s office, and I really got to know them personally—as a face of someone dealing with [HIV/AIDS].” He continued, “one can read about things or see movies, but until you actually meet someone whose talking to you who’s giving you information about what they’re going through, you’ll not completely understand.”

Participant 3 had been in a closed-relationship with P4 for nearly 30 years. In a separate interview, P4 offered his philosophy for why he was negative and gave credit to his commitment to a monogamous relationship. He said “[HIV] makes you look at your relationship and go ‘gee, I’m glad I met [my partner].’” He continued by saying, “I have this relationship and I want to make it work; I don’t want to put myself at risk of infection or infecting my partner. It isn’t worth the risk.” Participant 17 expressed a similar viewpoint: “If anything it probably pushed me toward thinking a more intimate monogamous relationship with one individual [is what I want].”

Participant 12 voiced concerns with the notion that opting for monogamous relationships was a successful means to reducing HIV-transmission. He knew people who decided to stay in their long term relationships because of their fear of HIV and raised the question, “Why is monogamy safer? It may be safer as it relates to disease, but I think, gosh, is that why people are in relationships?” The participant questions if people stay in relationships because of fears. He equated the situation to couples that stay together for the sake of their children.

Participants also mentioned other behavioral changes besides monogamy that they believed influenced their current HIV-seronegative status. As with many men, P19 reported being adamant about using condoms when sexually active with other men. In one situation in
which a sexual partner wanted him to remove his condom and he responded with an ultimatum to continue using a condom or refraining for having sex:

We stopped what we were doing, he got up and walked into the other room, and I was like “well, we’ve only been together a couple of months. This is for your benefit as well as mine. I had a test and this was 15 years ago, how do you know the accuracy of it?” I then told him wearing a condom was mandatory. This relationship did not last long after this conversation.

Other participants reported similar sexual behavioral changes. Participant 6 only took part in mutual masturbation with other men, while P5 only engaged in oral sex with “special” men, special being defined as those he feels a special connection with and sees as potential dating material. He also expressed that he does not consider oral sex to be a risk factor. Participant 11’s behavior change is a combination of those of P5 and P6. He reports only taking part in frottage, kissing, and masturbating. Perhaps the most drastic role reversal came from Participant 8. Using messages from acquaintances and national media, he decided that receptive anal sex was riskier than insertive; therefore, he “decided to stop being a bottom and only be a top in sex.” As shown, individuals had various explanations for why they were still HIV-negative. The next section covers dating and current sexual relations.

**Dating and sexual relations.** Of the 22 gay males that took part in this study, 7 identified as single, 11 were in closed-relationships, and 4 were in open-relationships. While nature of relationship status influenced the level of sex or intimacy, more importantly this differed with each person. For example, P11 is single and “refrains from having sex.” When asked if he was celibate, he replied “No, I do not like that word.” In an open-relationship, participant 22 reported that he and his partner “enjoy each other’s company and love each other,”
and “fooling around with somebody else doesn’t seem to threaten that.” Participant 9 was single and said sex had “become less and less a focus in [his] life.” In a closed-relationship for 16 years, P17 reported being “highly sexual and that three times a day [was] not enough to satisfy him.” He continued by saying his partner was not as sexual and that he masturbates to satisfy himself and “would never cheat on [his] partner…there is too much to lose.”

As with many men over 50, some participants reported erectile dysfunction or lowered libido as problems in their relationships (P1, P5, P9, P13, & P20). Participant 13, 69 years old, reported his prostate medication “kills the drive,” but he was fine with that, because at “[his] age [he] has had a fulfilling sex life.” Participant 14, a diabetic, reported his drive had gotten “less and less” as he aged and struggled to keep his diabetes under control.

Participant 5, a widower, proclaimed that there were alternative sexual behaviors in spite of erectile dysfunction. He said, “There are a lot of neat really wonderful fulfilling things you can do if it doesn’t get erect.” On a similar note, P12 said:

But when you get older, sex is a part of it—it’s a great part of it—but there are so many other pieces that support you and carry you through the day, it isn’t “I can’t wait to get home and get in the sac with him.” I mean those things happen, but that is not always the be all, end all. So, if something doesn’t happen in bed or something doesn’t function the way you think it is going to function, it is ok.

With gay men over 50 being sexually active, participants were asked where and how men in their cohort found men to date and/or with whom to have sexual intercourse. The vast majority reported the internet as the main method. According to P5, “The internet has changed everything. If you wanted to pick someone up in my day, you went to a bar, and now you go online.” He identified sites such as Craigslist or Men4Now, as common hook-up sites frequented
by men in his mid-Atlantic city. Participant 7 claimed that his experiences with online dating have been successful:

I’ve tried the bars and clubs, but it just doesn’t work. But, online, for some reason, I’m no different, but it seems to work. I used to post ads, but got no responses. So, now I respond to ads, and it works. I’m not saying it’s 100%, because it’s not. It’s more of a miss than a hit. But, those times I do encounter a connection and I meet someone turns out to be nice.

The internet not only assisted P7 and others with finding dates and intimate partners, it also helped shape self-identifying behaviors. Participant 20 said online sites “support self-identifying up front. It has made it easier and more acceptable to ask what someone’s status is.” While this is great for the individual, P20 reports that this can be a deterrent because people appear to be “too trusting of what they are told” by those they interact with online. When talking about sexual behaviors it is important to discuss risk factors.

Risk factors. A variety of risk factors for HIV infection were mentioned during interviews. The most common themes were not using protection (condoms), risk factors such as not knowing the virus’s transmission route, and a lack of communication with intimate partners. These were common among all subgroups and will be a part of the upcoming prevention section. The purpose of this section is to raise attention to several risk factors that were alarming or specific for the 50 and older gay male.

Participant 7, who previously mentioned having success with online dating had been in a closed-relationship for 17 years; however, over the last six years, he had been having sexual relationships outside of his relationship that his partner does not know about. He said:
I’ve feel out of [the relationship], I wasn’t sexually attracted to my partner anymore. He’s a much older gentleman and just the intimacy wasn’t what it once was. I just got tired of it, and pretty much shut down on him and it was kind of mutual and we don’t talk about it, but yes, I look outside the relationship.

During the interview, P7 revealed that he had multiple married men he had sex with when they were in his city on business. He explained the structure of these relationships and how they led to unprotected sex:

It’s just their personality, their sincerity that they show to me… they’re good guys. They want to enjoy natural sex without the protection, and just feel that the person they are encountering through conversations, because it’s not just a quick hook up. We do not have unprotected sex until after a few conversations, getting to know one another, our lives, makes them feel more comfortable in having unprotected sex and vice versa.

Participant 7 acknowledged taking a “large leap” when trusting these men, but reiterated that his relationship at home was “dead.”

Alcohol use was another risk factor concerning participants. Several report that alcohol abuse inhibits decision making, which can result in a decrease in practicing safer sex. When sober, P20 reported that he always used condoms during sex; however, while drinking alcohol his decision making was affected resulting in riskier behaviors. Participant 1 declared that everyone “gets drunk and loses inhibitions” causing a possible increase in risky behavior and HIV infections.

Participants 3 and 4 had been together for 30 years, almost the entire duration of the HIV pandemic. Interviewed separately, both reflected on their experiences prior to HIV and during the initial outbreak they witnessed in their Illinois town. Neither of them had been tested for
HIV, even though P3 had spent over a decade volunteering with AIDS service organizations. He said his likelihood of contracting HIV was slim, “because [of] my sex life prior to meeting my partner and my faith in our relationship.” Participant 4 said “I’m sure somewhere along the line when I was in the hospital or something they tested me, and I just never heard anything.” Further questioning revealed that he had never asked a provider to conduct a test. Neither indicated an interest in being tested at the time of their interviews.

Participant 6 raised the point that in the early days of HIV “you could look at someone and know they had it.” Being that there was no longer a “face” to the virus, P6 felt that the lack of visibility had led to adults, including older adults, taking greater chances with unsafe sexual behaviors. Another concern related to this is the decrease in the number of newly infected individuals. While this is what society should strive for, P6, along with others, feel the decrease in infection rates could lead to a false sense of security causing rates to ultimately increase.

Another example of bareback (unprotected) sex comes from P5 who recalled a recent situation in which he found out his friend was having unprotected sex and thought he had “converted.” In other words, the friend thought that he had contracted HIV. The participant responded with “I just wanted to choke the shit out of him. This man works in HIV and should know better! He’s 50, he’s got a 30 year old partner who has AIDS, and they have unprotected sex.”

Participant 14 also brought up bareback sex in the context of the porn industry. He feels that “there’s so much more barebacking… in the 90s and early 2000s.” According to the participant, more recently there are porn companies such as Titan that require condom use, yet others such as Corbin Fisher and Shawn Cody allow individuals to have sex without protection,
which also concerned P14. Several participants were upset with the display of condomless sex citing these films as a means of education for many given we learn from what we watch.

Communication. Communication is an essential component of any behavioral change initiative and can be a key factor to reducing risk. When effective communication is not taking place, individuals may decide to ignore or refrain from taking on a particular behavior. Open, well-informed communication with intimate partners, health care providers, and friends is important to help reduce HIV infection in all at-risk groups including older MSM. Participants in this study shared examples of effective and non-effective communication among these different groups. The purpose of this section is to provide examples of different ways communication impacted the various relationships of participants. Three primary routes of communication are with the intimate partner, friends, and healthcare providers.

Intimate partner. Participant 1 had a deep conviction to remain HIV-negative and to always have protected sex. He said “I decided, if I am going to be seeing men, having sex with them, I would ask ‘are you HIV-positive,’ because I [couldn’t] have a relationship if you’re positive.” In other words, P1 would not engage in sexual intercourse with someone if they were HIV-positive.

Similar to P1, P6 had a conversation with his intimate partners. From the beginning of the virus, P6 was “very conscious about whom [he] was with sexually.” His philosophy was if people were willing to talk about STDs, “obviously they [were] people who are aware and concerned themselves.” During the interview he stated that he no longer felt this way and acknowledged that the amount of HIV knowledge a person has does not dictate their status; therefore, he realized that there is more to prevention than just knowing about the various STDs.
As noted earlier, P13’s partner found out he was HIV-positive after they started dating and died while in the relationship. Participant 13 recalled times when his partner attempted to end their relationship. When asked why, P13 said that his partner did not want him to have to witness his death. The two never separated and P13 felt that their “open communication” and “love for each other” is what keep them together. In addition to intimate partners, communication with friends is important when supporting risk reduction.

**Friends.** When asked about the level of communication with his peers, P20 said “my friends say I have no filters.” By this, he meant that his friends know he will talk about anything and that he will provide feedback—positive or negative—to them based on their behaviors, especially as it relates to their sexual decisions. For example, P20 had a younger friend that he regularly talks with about HIV and safer sex. Their conversations tended to focus on the younger male’s perception of HIV and how it varies from that of his peers. According to the participant, his friend was appreciative of their relationship because he (the friend) was able to talk opening about HIV, safer sex, and being a young gay male.

Similar to P20, P1 talked to his friends openly about their sexual relationships. He said, “I think sometimes they keep their sexcapades from me because they know how I feel about being unsafe.” However, he felt that his friends considered him supportive and that his motto is “if you’re going to do it, do it safe.”

Not all friends have discussions about safer sex. Several men expressed a lack of needing to talk about risky sex, because their assumption was their friends always are sexually safe (P7 & P12). Participant 2 said “We are all members of the ‘sex is great, but you need to use protection’ group.” Participants 13, 17, and 18 all reported having little to no conversations with their friends focusing on safer sex or their sex lives. According to P13, “when you’re at this stage and
you’re with gay people, it’s a mix bag. If they’re talking about sex, they’re talking about it in light terms not in serious conversation, while others are talking about everything but sex.”

While attempting to assist the researcher with recruitment, P5 informed his 50 and older friends about the study. During the interview, he had an “aha” moment and reflected on how he simply assumed his friends were HIV-negative and that they had never talked about their HIV-status. It is unknown if he asked someone to participant that is HIV-positive. Participant 5 said “[My friend] is healthy and I thought ‘I’ve got to be careful with this, because I don’t want to hurt one of my friends’ feelings or acquaintances who hasn’t shared.’ Honestly, I never really thought about [asking my friends their status]”. To this point, focus has been on communication with friends and intimate partners, another relationship of importance is the healthcare provider.

**Healthcare providers.** Unfortunately, the vast majority of participants reported not having conversations with their healthcare providers about safer sex. Some participants reported having conversations with their providers about erectile dysfunction or requesting ED medications, but safer sex was not addressed by the providers.

Participants 9 and 20 had openly gay medical providers. While P20 had open dialogues with his provider discussing his sex life and safer sex decision making, P9 reported more limited conversations. According to P9, his physician seemed uncomfortable talking to him about his sex life or possible risk factors. “When I am [at his office] for my yearly physical, [my doctor] will say ‘let’s do an HIV to cover all bases’.” A week later, P9 will receive a phone call from his doctor office and is told “everything is fine.” All participants felt that providers should feel comfortable talking about safer sex with their patients and were disappointed that this was not their experience. After covering their current sexual behaviors and various risk factors,
participants were asked to provide insight into prevention and discuss effective ways to reach older gay males.

**Insight into Future Prevention**

Thus far, attention has been on participants’ experiences with HIV and prevention, the time period they first heard about the virus, their first testing experience, and the current state of their relationships. The purpose of this section is to gain insight into their current knowledge level regarding HIV, the types of HIV messages they have encountered, and how they define prevention and its components.

As previously mentioned, HIV rates within the 50 and older MSM group are increasing (CDC, 2008a; CDC, 2008b; CDC 2011a; & Zablotski & Kennedy, 2004). A quote from P10 summarized the current state of HIV in the older MSM community and implied that prevention will be a difficult task:

> You have to do the math and realize that half the people who experienced this and could provide some guidance are dead. The other half is not particularly interested in talking about it, because it brings up stuff that is very, very painful. Stuff people don’t have to think about anymore. At least they think they don’t have to.

While it is difficult to calculate the number of lives impacted, the message is clear; HIV has significantly influenced the older MSM, specifically those who have experienced loss.

In addition to P10, others expressed similar thoughts. For example, P4 raised the question, “Are [men 50 and older] getting to a point, where they are like ‘OK, I’ve not had or I’m not in a relationship, I’m getting 50 or older?’ And its last call at the singles bar, type thing.” In other words, are older MSM becoming haphazard in their relationship and sexual behavior decision making and letting their guard down? Participant 9 thought so: “They are
throwing caution to the wind. It’s like alright, well, let’s start smoking and drinking, and driving recklessly.” His thoughts on the matter were, “I’ve come this far, I don’t want to be infected!” Participant 20’s response echoed that of P9 and elaborated on the message by advocating for mentorship. He said, “Be proud of who you are and you might establish a positive role example for younger people.”

Not everyone felt that prevention of HIV warranted as much attention. According to P2 some older gay men have the mentality that getting HIV at their age would not hinder their quality of life, because they will ultimately die of something else first such as prostate cancer. While not accepting it as their personal belief, P6 and P22 said they could understand where these men were coming from. Participant 18 agreed and said, “I think it’s understandable, because people have become complacent. Primarily, because there are not regular commercials on TV nor do you hear statistics being reported like you did 20 years ago.”

Participant 14, who has had prostate cancer, got angry by P2’s statement and said:

If there was something that I had known, some type of regimen that would have prevented me from getting cancer, I would have done it. It was no fucking fun and for [them] to go out there and think ‘well this is just another disease,’ they’re stupid. [They] do not love [themselves].

Others interviewed (P15, 17, & 19) described HIV as a contractible disease; therefore, in their opinion, contracting or spreading it impacts others more directly unlike illnesses such as cancer, and felt it was not appropriate to compare the two diseases. Now with an understanding of the men’s experiences with prevention, the next section provides their definition of prevention.

**Definition.** Overwhelmingly, participants defined prevention simply as education. One needs to “understand the disease” (P6), “have a discussion with their partners before engaging in
sex” (P7), and “be aware of their partner’s histories and know that they have to use protection while having sex” (P4). Participant 20 offered a complementary viewpoint that expanded on the aforementioned definition, adding, “prevention is multi-dimensional and it is about education. Learning is the first thing. HIV prevention means practicing safer sex when you are sexually active. The second part is encouraging those around you to practice safer sex.” In other words, educating oneself and others. One part of prevention is educating people using messages.

**HIV/AIDS Prevention Messages.** As previously mentioned, HIV/AIDS messages were routinely found in various forms of media (newspapers, magazines, or television) and from within the gay community by means of verbal communication. To some degree, participants expressed this still being the situation. For example, P6 still accesses HIV prevention brochures at his healthcare provider’s office and P14 continues to read gay magazines and watch local and national broadcast news. Participant 7 emphasized the importance of “really educating yourself in any new progress in drug therapies and meeting individuals in the health field who are also gay, so can keep in tune with gay society and what’s going on as far as health.” Another method of obtaining HIV messages that still exists, but less frequently, is the use of flyers or posters in bars and restaurants (P12).

A final area where education remained important, yet inadequate, was with healthcare professionals such as physicians, nurses, pharmacist and providers of social services. As a physician, P17 reported that, while not a state requirement, he attended annual continuing education courses regarding “medical and ethical treatment of those with HIV/AIDS.” He said he “encourages [his] colleagues to attend,” but they “don’t always go.” Participant 13 is a pharmacist and he too attended continuing education programs. His goal was to “better understand the pharmacological make up of medications” individuals are prescribed. Together
they both aimed to improve the quality of care for medical patients and pharmaceutical consumers.

As previously eluded to, participants felt that prevention messages were scarce compared to those in decades past. Participant 4 noted, “We have commercials on TV for erectile dysfunction and all kinds of women’s issues, and I still see a closing off of HIV/AIDS in the media.” He felt the media could greatly improve the state of HIV/AIDS because of the media’s ability to put messages “in your face.”

In addition to the route of the message, participants shared various viewpoints about the content of the message. Participant 19 felt that messages should have a component that speaks specifically to the older gay male that targets immunity. He suggested “something with the idea ‘just because you lived so long and haven’t become HIV-positive, doesn’t mean you are immune to it.’” Along the same lines, P1 advocated for a quality prevention message that asks men 50 and older the question “How do you really want to spend the last 20 years of your life? Being uncomfortable and sick all the time or living a healthy lifestyle, and practicing healthy and safe sex?” Both of these questions advocate bringing prevention messages to the forefront and imply that some older males are sexually active with more than one partner.

Participant 6 stressed the need for messages to cover multiple ways to prevent the spread of the virus. One campaign that influenced his decision making was a pamphlet obtained from his healthcare provider titled “Come on me, not in me!” He said that this pamphlet spoke to him as a gay male and validated his safe sex practices of using condoms, being careful not to come into contact with body fluids while sexually engaged. Another message that spoke to the public health aspects of HIV was provided by P17. He suggested messages that specifically mention “We’re not talking about just you, we’re talking about individuals you might infect and we’re
talking about the overall society.” Messages such as this foster the awareness that older adults, including gay males are sexually active and that their decisions affect not only their health, but that of others and the community at large. This is a message that P19 believed was needed, because “people have not only grown complacent, they have lost interest. [Prevention] is not a key topic.”

Not all HIV-prevention messages have been received well by participants. Participant 18 said “I haven’t seen anything effective, because we are so puritanical and we are afraid to talk about [sex].”

A statement echoed by many is that current HIV messages allude to the fact that the disease is “something you can live with” or is “treatable” (P1, P5-P7, P12-P14, P17, P19, & P20) and it is no longer a “death sentence” (P1, P5, P12, & P16). Participant 1 summed his thoughts on this by saying:

I think the biggest thing is [older adults] don’t see it as such a huge sickness or a death sentence anymore. Also, if you’re already over 50 you say “Oh, what the hell, I only have 10 to 20 years left anyway.”

Many variables are at play in order for older gay males to have this philosophy. According to P9 and P18, one such variable is the availability of medications to treat the virus. Having so many drugs available leads to individuals saying “heck, I don’t mind getting infected” (P9) and “just take enough meds, you’ll be fine” (P18). Regarding available medications, P7 felt they are “generating too many drugs and they are giving the public a false sense of ‘we are going to conquer this.’” P2 expanded on the previous individualistic perceptions of HIV (P7, P9, & P18) and relate to how the virus has been downplayed as a social concern. He stated “there aren’t the pictures of people with Karposi’s sarcoma or laying in bed wasting away.” One area needing to
be covered in messaging is stigmatization because older gay men who are HIV-positive often experience some form of discrimination in their communities.

**Stigma.** Stigmatization is the phenomenon in which individuals are judged based on a visible and/or invisible difference they have and these differences are judged as inferior, or culpable and deserving of punishment (Goffman, 1963). Often this occurs as a comparison of the stigmatized group with the larger or more powerful group. Several examples of stigmatization and discrimination were mentioned during interviews. Participant 12 offered the story of Robert, one of the first individuals living with HIV that he met in the early 1980s. Robert was “shunned and people did not talk to him.” Members of the community, including the gay community, said that Robert “should not be living in their neighborhood.” Participant 12 was a newly ordained priest and he experienced parishioners asking him to “do something about the new guy in their neighborhood” who was living with HIV, Robert.

Similarly, P10 recalled the mistreatment he and his partner experienced in their community because of his partner’s HIV-positive status. He said, “The way people would look at us, look at him, would be so hurtful some days.” These experiences led to P10 and P12 becoming well-known advocates for the gay and HIV/AIDS communities in their respective cities.

Participant 12 also felt that stigmatization and discrimination were strong in the southern church. It was his belief that “we would be miles ahead” in regards to prevention and treatment, if the churches, particularly African-American churches, were supportive of parishioners infected or impacted by HIV/AIDS.
Participant 7’s experience with stigma related to the coming out experience. As a closeted gay male, P7 dealt with his friends conflating homosexuality with HIV/AIDS. This made his coming out process a “troubling experience.” He said:

Hearing what they were saying made me feel bad, but I kept quiet. I just didn’t want to bring any attention to myself. There was stigma that it was a gay disease. I felt bad for myself—that I had to keep my comments to myself.

Another example of discrimination reported by P12 involved a friend who encountered discrimination while attending a doctor’s appointment with a new provider. The patient shared his medical background and when he mentioned that he was gay, the doctor said “guess we need to test you for HIV, huh?” The patient said, “I guess I’m leaving, because if that is the first thing you think about, I’m not staying here,” and he left the office. Both P7’s personal account and P12’s friend’s account provide examples of how discrimination and stigmatization affected gay men’s behavior when confronting with bias.

However, not all discrimination and stigmatization came from the heterosexual community. Participant 14, an open gay male, offered an experience in which he acted irrationally based on casual—not sexual—encounters he had with an individual with HIV/AIDS. In each case, P14 attended functions at a friend’s house with individuals who were HIV-positive. The only contact he would have was a handshake or kiss on the cheek as a salutation, yet P14 felt the overwhelming need to be tested for HIV. In hindsight, P14 “feels horrible about his reaction.” In this example, P14’s lack of knowledge and fear of the unknown led him to discriminate against those with HIV by simply getting a test because of lack of knowledge about the disease transmission route.
A final example of stigmatization found within the context of the interviews is ageism. Participant 7 addressed the need for older men to fit in and be accepted. He said:

It just seems to be running rampant that in our gay culture - youth is everything. So, the older gentlemen do their best to try to stay youthful and try to blend in with the younger generation, so that they are not seen as old trolls.

Troll, within the gay community, is a term used to describe older men. Addressing and eliminating each of these forms of stigma is critical if we are to improve the quality of prevention and treatment offered to older adults, including MSMs.

**Prevention after 50.** Although there was agreement on a definition of prevention, perspectives about its effectiveness varied greatly, with most participants feeling negatively about the potential of prevention. Participant 1 said “If you’re 50 and still don’t know how to be safe you’re sort of screwed. It’s too late for it!” The same sentiments were shared by P2:

It still amazes me that there are people out there that don’t seem to care. I don’t know whether they just don’t think it’s something they have to worry about anymore or think that it’s a manageable disease. Either way they have a “so what” attitude.

The idea that things are manageable ties in with what participants previously mentioned regarding the impact HIV medications have on the risk factors of those 50 and older. Participant 12 echoed the comments of P1 and P2 when he said, “If someone doesn’t think they should be preventing something bad from happening to them, things like pamphlets are not going to work.” He suggested educating HIV and its transmission routes in addition to a focus on self-esteem and self-image issues needs to occur before the behavioral change is promoted. Another comment relating to the structure of prevention initiatives was from P13. He expressed
dissatisfaction with using a group format when attempting to promote behavior changes, feeling that groups were more about “following the leader” instead of truly changing one’s behaviors.

While the tone of the above comments was negative, some participants noted the importance of prevention. For example, P13 acknowledged that behavioral changes are “hard,” but “worth it.” Participant 18 praised HIV prevention as a worthwhile public health campaign stating “assisting someone with acknowledging their negative behaviors is difficult and complicated. Yet, worth it and I support that!”

**Content and Dissemination.** Effective prevention initiatives need to have meaningful, clear and relevant message(s) and realistic strategies for dissemination. Through the interview process, participants were asked to provide feedback on what content should be included in HIV-prevention messages and how best to disseminate this content to gay men 50 and older. See Table 2 for a breakdown of these findings.

Prevention messages for this cohort should have components that speak to individual traits and behaviors as well as HIV specific material. As it related to the self, participants suggested that messages have a component advocating for improvement of an individual’s self-love, self-image, and self-awareness (P12, P16). According to P16, individuals need to love themselves before they can adequately make changes. Another component related to the self is pride. Participants suggested that programs have to deal with one’s experiences with and pride in being gay (P15) and growing older (P3). A final segment of this category is communication. Overwhelmingly, participants stressed the importance of communication with intimate partners (P4-P7, P11, P15, & P17), friends (P13 & P17), and health care providers (P20 & P22).

Additional content necessary to promote risk reduction includes HIV-specific messages such as individuals knowing their own HIV status and that of potential sexual partners.
Participants felt this was important because it is one of the “key factors to eliminating this public health crisis” (P2). Other areas mentioned by participants related to HIV knowledge.

Participants expressed concerns that the 50 and older age group have limited or faulty knowledge of safer sex practices and basic HIV knowledge (e.g. wearing condoms appropriately) and recommended that prevention initiatives include such materials. Participants called for up-to-date statistics to bolster the case that older adults are becoming infected and the need for prevention (P18). A final HIV specific component for newer initiatives should be the increase in condom distribution, which can assist with alleviating stigmas that older adults are not sexually active (P4-6, P13, P17, & P21).

Finally, participants provided insight into methods for reaching the older adult gay male for HIV-prevention. As expected, participants mentioned usefulness of one on one, group, and on-line formats. Several recommended posting prevention material on websites and phone applications that are often used for dating or finding others to hook-up with (e.g. Craigslist, Silverdaddies, and Scruff) (P7 & P14) and within porn movies and websites (P14 & P18). Advertisements and articles about HIV-prevention should be on television and in newspapers and magazines whose audiences are older adults and/or gay males (P4, P6, P7, P16, P17, & P21). Messages should also be disseminated through workshops/in-services and health fairs to reach both the layperson and healthcare providers (P3 & P4). In addition to these media related strategies, taking materials and programs to gay or aging community centers, bars, and restaurants might be an effective way to reach at-risk groups (P5, P17, & P22).
### Table 2: Content and Dissemination Methods for Older Gay Male Prevention Initiatives

<table>
<thead>
<tr>
<th>CONTENT</th>
<th>METHODS</th>
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<tbody>
<tr>
<td><strong>THE SELF</strong></td>
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<tr>
<td>Self-love</td>
<td>One-on-one between participant &amp; professional</td>
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<tr>
<td>Self-image</td>
<td>Group settings</td>
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<tr>
<td>Self-awareness</td>
<td>Online</td>
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<tr>
<td>Gay Pride</td>
<td>Posters/banners</td>
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<tr>
<td>Pride in being Older</td>
<td>Dating/hook-up sites (e.g. Craigslist)</td>
</tr>
<tr>
<td>Communication (partner, friends, &amp; health care providers)</td>
<td>Media- Television, Newspapers, &amp; Magazines</td>
</tr>
<tr>
<td>HIV SPECIFIC</td>
<td></td>
</tr>
<tr>
<td>Knowledge of status (self and partners)</td>
<td>Community centers- Gay&amp; Senior</td>
</tr>
<tr>
<td>Safer sex</td>
<td>Workshops, in-services, and/or health fairs</td>
</tr>
<tr>
<td>HIV education/knowledge (including how to use condoms)</td>
<td>Bars/restaurants</td>
</tr>
<tr>
<td>Up-to-date HIV/AIDS statistics</td>
<td>Pornography (movies &amp; sites)</td>
</tr>
<tr>
<td>Condom distribution</td>
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**Patterns in the Categories**

Several interesting patterns emerged when comparing participant groups or study categories. Those who said that they were “lucky” to not have contracted HIV and those in closed-relationships are less likely to promote prevention initiatives for gay men 50 and older. They said prevention did not work or it was a waste of time. Men in long term relationships
were also least likely to have been exposed to HIV-preventions messages than men who identified as single or in open-relationships.

Another interesting pattern is that early volunteer work or exposure to deaths due to HIV/AIDS resulted in behavioral changes such as using condoms. However, over time participants showed a decrease in safer sex practices or risk reduction behaviors. This was consistent across relationship statuses. When it comes to open dialogue with their friends about sexual behaviors and sexual partners, single men were more prone than were men in closed relationships to have these conversations. Men in closed relationships regularly mentioned that they talked with their friends about many topics, but sex was rarely on the list.

**Conceptual Model**

Figure 1 is a visual representation of the aforementioned findings and is one viewpoint to express the interconnectedness of the four categories that emerged from participants. The first category spoke to participants’ lives prior to the onset of the HIV virus in the early 1980s. During this period, participants reported being in sexual relationships, taking part in what would later be identified as ‘risky’ behaviors (e.g. visiting bathhouses and having unprotected sex), being exposed to stigma (e.g. homophobia), and living in rural or urban locations. All of these factors were influential to the second category “Initial Reaction to HIV.” From this category three significant sub-categories emerged, the first being “knowledge.”

The sub-category spoke to the level of knowledge individuals had regarding HIV/AIDS including how it was transmitted and its risk factors. Depending on the previously mentioned factors, an individual’s level of knowledge varied resulting in a spectrum. At the high end of the continuum were those with significant levels of knowledge while those with little to no knowledge ranked as low level.
When testing became available in 1985, participants reported being proactive and wanted to know their statuses. Within this sample, 20 of the 22 interviewed received an HIV test during the first five years of the virus. The catalyst behind the decision was simply to know. With knowledge of the virus and having been diagnosed HIV-negative, participants often opted to take on behavioral changes to remain HIV-negative. Similar to “Knowledge,” “Behavioral Changes” fell on a high to low continuum as shown in the conceptual model. This category has a direct relationship with “Relationship over Time” and indirect with “Prevention.”

“Relationship over Time” covered the three decades following the onset of HIV/AIDS. Similar to “Initial Reaction,” the category has an indirect relationship with prevention. It represented a period of change for participants such as relationship status (single or in open/closed relationships), sexual identity and health. Because of these changes, the category had direct implications for “Current State of Relationships.”

At this point, participants have lived through 30 years of the HIV pandemic. They are 50 and older, HIV-negative, and for some, unable to articulate why they have been able to stay HIV-negative. Participants’ knowledge of HIV has decreased or is outdated and when compounded with changes in relationship status and increased sexual risk taking, their risk for contracting the virus increases.

While this three decade period of time has a direct connection to the final category “Current Prevention Initiatives,” further exploration is warranted to adequately understand its implications on older gay males. A better understanding of their HIV-knowledge, communication skills, and how they define their intimate relationship status are necessary to better articulate the current state of prevention for this unique cohort. Future research with this topic is discussed in the next in chapter five.
Conclusion

This chapter presented the overall theme and related categories that emerged from the analysis of the stories told by 22 gay men as it related to their experiences with HIV/AIDS over the last three decades. Each category was discussed in-depth with participant examples imbedded to strengthen the depiction of their experience. The next chapter will discuss the implications of these findings.
Figure 1: Conceptual Map
Chapter 5

Discussion and Implications

Discussion of Findings

This study explored the following three research questions: (a) How have older HIV-negative MSMs experienced the first 30 years of the HIV/AIDS pandemic? (b) What are older HIV-negative MSMs’ experiences with HIV-prevention? and (c) What factors (if any) influenced older HIV-negative MSMs from contracting HIV? After a comprehensive literature review, four theories were chosen to inform this study: (1) Health Belief Model (HBM) (Champion & Skinner, 2008; Coleman & Ball, 2009; Harrison, Mullen, & Green, 1992), (2) Ajzen’s Theory of Planned Behavior (TPB) (Ajzen, 1991; Ajzen & Madden, 1986; Montano & Kasprzyk, 2008; Sheeran & Taylor, 1999), (3) Prochaska and DiClemente’s Transtheoretical Model/Stages of Change (TMC) (Prochaska, DiClemente, & Norcross, 1992; Prochaska, Redding, & Evers, 2008), and (4) the Empowerment Approach (McWhirter, 1991; Lee, 1996; Robbins, Chatterjee, & Canda, 1998).

Individually, 22 gay males completed a demographic form and took part in semi-structured interviews lasting approximately 60 minutes. Participants selected the form of their interview from the following options: face-to-face (16), phone (5), or Skype (1). All but one participant authorized the use of audio recording during the interviews. Recordings were transcribed and uploaded to Atlas.ti, a qualitative data management system, for storage. Once all interviews were complete, data analysis took place using Corbin and Strauss’s (2008) methodology of open and axial coding. This process yielded four categories with sub-categories that are represented within this document in narrative and pictorial formats. These findings have not been previously described in the literature and thus provide a foundation for further research,
development of assessment instruments, and most importantly, formulation of prevention
initiatives.

Life Prior to HIV

In the late 1970s and early 1980s, several marginalized groups were dealing with a virus
that was causing the deaths of thousands. One such group was men who were having sex with
men (MSM). At the time, there was no known cause of the illness, not even a consistent name.
In this study, participants were asked to reflect on their experiences as gay men/MSM during this
troubling time by responding to the following open-ended questions: tell me about the first time
you heard about HIV/AIDS, how old were you, where were you living at the time, and how did
the experience make you feel?

To help capture their experiences at the onset of the virus, participants described their
lives before HIV/AIDS. “Liberating” was one word used to describe this time period.
Participants spoke about the history of the gay community and the not so distant victories that
had occurred in cities around the country such as the riots at the Stonewall Inn in New York’s
Greenwich Village, along with others which served as a catalyst for the gay liberation movement
of the late 1960 and early 1970s (Duberman, 1993). The camaraderie created during these years
of protest served as a support network for those who lost family or friends during the coming out
process. In the late 1970s and 1980s, this camaraderie once again served as a lifeline to those
living with the unknown virus and to those whose loved ones were dying.

The environment prior to the virus was characterized by frequent episodes of casual sex
according to participants. Gay men were able to find male sexual partners in bars, restaurants,
community parks, bathhouses, libraries, porn shops, and “cruising” any number of locations.
These options were available in all towns and cities; however, the frequency and availability
depended on the size of the community, especially the gay community. There were no theoretical applications for this section, because HIV was not present warranting concerns.

Initial Reaction to HIV

After explaining their experiences and grounding them in a time and place, participants were able to reflect and move forward with the posed questions. Participants’ experiences varied. Some were active in their careers; others were still in school. Some identified as gay while others were questioning their orientation or in relationships with females. Some resided in large metropolitan communities with identified gay communities while others were in rural communities where they felt isolated by their sexuality. One similarity emerged among the 22 men in this study: fear of an unknown sexually transmitted disease.

As their knowledge of and exposure to those with the virus increased, participants began to evaluate their own sexual practices. The decisions made by participants varied based on the sexual act(s), the person(s) with whom they were intimate and, at times, their level of intoxication. For example, P7 refrained from sexual intercourse for over a decade, P8 refrained only from receptive anal intercourse, and P6 discontinued performing oral sex to climax. Hence, safer sex was not only about refraining or discontinuing engagement in sexual relationships. Other participants adopted safer sex practices such as using condoms with all partners or just while engaging in what they deemed to be “riskier” sexual acts. Participants also spoke to the difficulty of practicing safer sex when under the influence of drugs or alcohol.

Unfortunately, loss was and has been a major event in the lives of the majority of participants, more so in the beginning of the HIV epidemic. Two participants shared heart wrenching accounts of their personal experiences with death that vividly described the impact the virus had on the gay community. Participant 10 lost his partner and fellow parishioner to the
virus, and P5 was able to drive through his mid-size city, pointing out many houses where his deceased friends or acquaintances once lived. The loss experienced by these men and others in the study impacted their personal and social lives leading some to volunteer or work in the HIV/AIDS or LGBTQ advocacy fields.

HIV testing became available in 1985 and gave a person at risk the ability to know his/her status. For some, the testing experience was stressful for a variety of reasons. For one (P17) it meant being “outed” as gay and for another, it meant being safe from a disease that was killing his partner. Others reported encountering unfriendly staff, problems getting results, and experiencing social biases when they sought testing.

These experiences usually led to various behavioral changes such as wearing condoms, talking to sexual partners about their status, and decreasing the number of sexual partners. Not all were safe or supported in risk reduction, such as P6 being told by a healthcare professional that applying diluted alcohol on his genitals would indicate if he had any cuts. A stinging sensation indicated a cut and increased the risk of contracting HIV/AIDS.

**Theoretical applications to findings.** During the initial reaction to the virus, individuals were embarking on different stages of the previously mentioned theories. Reflecting the “perceived susceptibility” and “seriousness of the disease” constructs of the HBM and the “behavioral beliefs” construct of the TPB, individuals questioned if they were at risk of contracting the virus and the behaviors they could change. In other words, they were weighing the risk factors of the disease to determine the ultimate threat the virus had on their health. In the language of TTC, participants appeared to be in the pre-contemplation and contemplation stages. They knew that risk existed and questioned what could be done, but had not yet made changes to
prevent contracting the virus. Findings affirm that the TTC has relevance for HIV prevention given its focus on assessing a person’s readiness for change.

With an increase in deaths and people testing positive as well as better scientific explanations of the virus’s transmission routes, individuals became more vigilant about practicing safer sex. The Health Belief Model (HBM) speaks to participants’ comments about consciously evaluating the threat of the virus and measuring their level of susceptibility to risk. As described in the overview of the HBM in chapter 2, numerous factors play a role in the likelihood that an individual will make behavioral changes. Some of these factors are age, sex, personality, knowledge, and symptoms of the virus. Based on interviews, the latter two were paramount for many men taking on safer sex practices because the more knowledgeable they were about the virus, the more likely they were to take precautions against becoming infected (an example of primary prevention). Also, seeing people with HIV/AIDS put a face to the epidemic and served as a consistent reminder of the need for safer sex practices. Several participants commented on the number of men they knew who had Karposi’s sarcoma lesions, which served as a visual reminder of HIV.

The Theory of Planned Behavior (TPB) can also be used to describe the behavior changes exhibited by participants during the early years of the HIV virus. In addition to what has already been said about the virus and the theory, at this stage participants began noticing the societal response to the virus, i.e., safer sex practices, society’s view of those infected and/or affected by the virus, and the government’s lack of response to HIV. Collectively, these influenced their understanding of how society felt about the virus, which TPB refers to as “subjective norms.”
Within the Transtheoretical Model of Change (TMC), participants remained in the pre-contemplation and contemplation stages in addition to the preparation and action stages. Those in the preparation stage had the knowledge regarding prevention and were weighing the consequences of taking on the behaviors, while individuals in the action phase had decided on a behavioral change and implemented it when necessary.

**Current State of Participants’ Relationships**

The purpose of this study was to learn from a group of older gay males, who had remained HIV-negative some 30 years after the onset of the virus. The question, “As an older HIV-negative gay male or MSM, what has influenced you to remain HIV-negative” solicited their understanding of this experience. Responses ranged from “luck” to strategic plans or behavioral changes that reduced exposure to the virus. It is important to note that two participants had never been tested for HIV, and therefore, their status is unknown. These men have been in a closed relationship with each other since the start of the virus and feel confident that they are both HIV-negative.

The age of participants ranged from 50 to 77 (M=58.5). Although four reported not being sexually active because of personal choice or health complications, the remaining 18 reported still being sexually active in some capacity. Seven were single, four were in open-relationships, and the remaining eleven were in closed relationships. The majority of participants felt satisfied with their current sex lives. Concerns were expressed regarding decreased libido and/or erectile dysfunction which are commonly related to the aging process for older adult males. Despite this, most felt comfortable enough to discuss sex with partners and to initiate a change in sexual practices (replacing one sexual act with another).
With the assumption that older males are sexual beings, participants were asked about friend’s sex lives as well as their own aiming to gain insight into risk factors for the cohort. Similar to other demographic groups, men take risks such as unprotected sex, sex while under the influence of substance(s), and sex with multiple partners. Participants also spoke about issues unique to older males such as risk relating to erectile dysfunction (ED) and the use of medications to treat this health condition. Some disclosed that the effects of ED cause men to lose erections, which leads to condom slippage and possible frustration that can result in the decision to not wear one. Finally, the increasing rate of older men having sexual relationships with younger men may increase their chances of contracting HIV because of the possible decrease in their inhibitions to practice safer sex. This is often because of the desire to fit in or be accepted by younger men. These are examples of an aging effect. In other words, these complex issues often influence the lives of the older male, not exclusively older gay males.

Another risk factor discussed by participants is that older gay males appear to be less attentive to the need for prevention than in the early years of the pandemic. Losing countless number of friends, being HIV negative, and knowing the risk factors has lost its significance with some men within this cohort; therefore, a cohort effect is present. According to participants, some men in this age group no longer practice safer sex. Also, they are seeking out sexual environments that were once avoided, and use drugs while having sex. Although not every participant had these concerns or personal knowledge of such activities, their comments do speak to reasons for the rise in the infection rate for this cohort of gay men.

Findings also speak to what researchers refer to as fatalistic beliefs (Hoyt, Nemeroff, & Huebner, 2006; Yi, Sandfort, & Shidlo, 2010). According to Niederdeppe and Levy (2007) this phenomenon is “an outlook that events are controlled by external forces and humans are
powerless to influence them” (p. 998). Fatalism has been studied in cancer prevention (Niederdeppe & Levy), driving behaviors (Elias & Shiftan, 2012) and various areas relating to HIV prevention (Hoyt, Nemeroff, & Huebner, 2006; Kalichman, Kelly, Morgan, & Rompa, 1997; Yi, Sandfort, & Shidlo, 2010). Similar to the findings in this study, researchers have found connections between an individual’s decisions to implement necessary preventative task or behavioral changes are influenced by societal influences.

The need for effective communication with intimate partners, friends, and healthcare providers frequently appeared as a sub-category. To aid in the reduction of HIV transmission, participants felt that all sexually active men need to have open and honest communication with their sexual partners prior to having sex. As P5 suggested, the conversation needs to occur before the start of any sexual contact to allow all parties to be “level headed.”

Recommendations for communication with friends and healthcare providers were similar. Participants expressed the need for support networks that are non-judgmental and open to honest dialogue. Findings from this study suggest that not all social networks are supportive or foster an open environment. Healthcare providers often appear to lack interest and possibly skill in discussing sexual issues and appear too busy for communication.

**Theoretical applications to findings.** The category “current state of participant’s relationships” yielded three sub-categories: “why I am negative,” “dating and sexual relations,” and “risk factors.”

Many of the participants have made successful personal changes or decisions that led to risk reduction. As it relates to the HBM, this cohort measured the threat of the virus, weighed the benefits of the behavioral change(s), and demonstrated self-efficacy to foster effective personal change. These are important constructs of the HBM, supporting the theory’s relevance
for promoting individual behavioral change. The TPB’s influence on behavior construct is reflected in the data. This construct is influenced by individual and societal attitudes toward the behavior and individuals’ perceptions that they will be able to take on the behavior. Participants also spoke to various forms of personal empowerment and support from their social networks.

Men who identified “luck” as the reason for their HIV-negative status or those who reported higher levels of risk taking fell into the following constructs. HBM’s perceived susceptibility, seriousness of the virus, and perceived threat along with TPB’s attitudes and perceived behavioral control because of the lack of motivation or interest in taking on necessary behavioral changes within the individual, such as condom use.

**Participant Insight into Future Prevention**

After the participants reflected upon their lives during the onset of HIV/AIDS and the last three decades, their opinions about effective HIV-prevention were solicited. Questions that helped shape this conversation were: What about HIV-prevention do you think is beneficial? What about HIV-prevention do you think is not beneficial? Do you have any suggestions for HIV-prevention strategies/initiatives that could benefit other gay or MSM males who are 50 and older?

Collectively participants perceived effective programs to be those that acknowledged the virus still exists and addresses the importance of prevention, while non-effective programs are those in which the message is unclear or glamorizes HIV/AIDS in instances like HIV medication advertisements. However, when asked what qualities should remain or be removed from prevention initiatives, responses sometimes contradicted each other. What some mentioned as being effective, others labeled as problematic. Three sub-categories emerged during this phase...
of the interview process: stigmatization, HIV/AIDS prevention messages, and prevention after 50.

**Stigma.** As previously mentioned in chapters two and four, stigmatization comes in various forms such as ageism, homophobia, and heterosexism. The men in this study reported stigmatizing experiences during their coming out process, while volunteering with HIV/AIDS organizations, when seeking medical care, and more currently, while dating. Therefore, stigma could be experienced from outside and within their gay community.

**HIV/AIDS prevention messages.** Participants reported mixed reviews on the quality of HIV messages over the past three decades. In years past, safer sex messages were visible in print and television media and from within the gay community. Participants expressed dissatisfaction with the current state of prevention messaging, because it does not seem to be adequately reaching and/or educating the target audience. Suggested ways to achieve this goal are to understand the demographic or community the message targets and use an appropriate medium for the message and population including how, when, and where to present the message.

During the interviews, participants provided examples of more and less effective educational efforts. For example, P6 felt that the campaign “Come on me, not in me!” was effective in getting gay men to consider safer sexual practices. Another effective approach echoed by several was the distribution of condoms and lubrication at bars and venues associated with sex. That being said, P17 expressed his dissatisfaction with messages that imply the virus is something someone can simply live with. These messages minimize the severity of the disease and possibly impact safer sex decision making.

**Prevention after 50.** In addition to the feedback on general HIV prevention messages, participants were asked to comment specifically about prevention initiatives for the older gay
male. Responses varied. In agreement with others, P1 felt that it was too late to attempt to educate older gay males about HIV/AIDS. Others referenced the changes that older adults, especially gay males, experience. For example, they discussed that over time, sexual interest varies, partners change due to death or separation, and bodies change as they age.

Participants provided suggestions for effective prevention initiatives in two categories: individual feelings about themselves (the self) and knowledge about HIV (See Table 2). The self consisted of self-love, image, awareness, gay pride, pride in being older, and communication with partners, friends, and healthcare providers. The HIV specific content was knowledge of status, safer sex, HIV education and knowledge, up-to-date HIV statistics, and condom distribution. The suggested interventions included one-on-one with a professional (testing counselor, therapist, and/or physician), group settings (psycho-educational or support), online, poster/banners, dating/hook-up sites, media, community centers, bars/restaurants, and pornography.

Together these topics and presentation methods, according to participants, will serve as effective means of reaching the older gay male and aid in reducing the rates of HIV-infections in this vulnerable cohort.

**Theoretical applications to findings.** Three categories were discovered in this section: “stigma,” “HIV/AIDS prevention messages,” and “prevention after 50.” One common thread among them is education, which is an important part of each of the aforementioned theories. As it relates to HBM, participant education is one of several “cues to action” that informs the participant’s “perceived threat of the disease.” In other words, the level of HIV/AIDS knowledge an individual has informs his/her perception that the virus is a threat to his/her wellbeing. This concept is similar to the “behavioral beliefs” and “normative beliefs” found in
TPB. While not specifically related to education, these concepts imply that a level of knowledge is required to make decisions. Therefore, in order for an individual to have the intention to make a behavioral change there needs to be a level of knowledge.

In addition to HBM and TPB, TMC has an education component. When individuals are in the “precontemplation” or “contemplation” stages his/her level of knowledge about HIV/AIDS can vary from little to high. The theory implies that the more an individual knows about his/her negative behavior and its consequences, the more likely he/she is to consider change. This potentially would move him/her to the “preparation” or “action” stages. As individuals move through the cyclical process, “relapse” is possible. A possible solution or resolution for relapse is continual education on the disease.

Similar to these models, the Empowerment Approach speaks to the importance of educating individuals on micro and macro levels to improve their quality of life. As it relates to HIV-prevention and older HIV-negative men, their quality of life is to remain HIV-negative.

**Implications**

**Implications for Micro Social Work Practice**

Based on the findings of this study and using the social work process, the researcher can make several clinical practice suggestions in various areas of the social work process, education, and prevention.

**Social work process.** The social work process consists of five stages: assessment, planning, intervention, termination, and evaluation with each stage requiring the social worker to have different skill sets (Johnson & Yanca, 2010). This section covers two areas that are relevant segments of the model: assessment and intervention.
Assessment. As social workers start the generalist practice process, they begin with an assessment (Johnson & Yanca, 2010). During this stage, “the social worker collects and analyses information about people with the aim to understand their situation and determine recommendations for any further professional intervention” (Crisp, 2003, p.3). The assessment phase can be a formidable one if the social worker presents biases such as stigmatization toward the client unit. As it relates to client satisfaction, the need for the reduction of stigma and its related messaging is paramount. As was mentioned in chapter two, older adults and members of the LGBTQ communities have experienced various forms of stigmatization such as homophobia, heterosexism, and/or ageism from family, friends, and/or healthcare providers.

These experiences could influence a participant’s decision to practice safer sex or take part in HIV-testing. For example, P12 reported having a friend whose physician suggested that the friend needed to have an HIV test because he was gay. As stated in chapter two, the CDC has created testing recommendations for high risk groups, and gay males are one. Those same recommendations state that the individual’s behaviors and risk factors should be taken into consideration when suggesting testing. While this negative experience was with a physician, the message could have come from many professionals including social workers. It is for that reason that professionals need to implement precautionary measures in an attempt to eliminate or reduce the level of stigma projected onto clients.

Open dialogue among healthcare providers is essential, yet potentially problematic. The aforementioned case of P12 along with that of P8 are examples of such problems. While P8 could not talk openly with his healthcare provider because of fear of judgment, P20 could and feels adamant his decision to practice safer sex is partly due to his supportive communication with his doctor.
An open and supportive dialogue with providers allows consumers the opportunity to learn more about the virus and strategies to reduce the chance of infection. These relationships also foster a testing environment that is caring and non-judgmental, which leads to more consistent testing patterns. Findings reinforce the importance of conducting a thorough assessment in which patients feel accepted and therefore safe to raise questions and honestly discuss their risk-taking behaviors. All of this underscores the importance of effective communication within the assessment and intervention phases of the social work process.

**Intervention.** In addition to assessment, social workers in HIV/AIDS settings will be called on to design and implement quality interventions with clients. An example of a client needing assistance is P7 who was not able to talk openly with his friends, because his friends were homophobic and called HIV/AIDS the “gay disease.” In such situations, clinical social workers can facilitate the bolstering of self-esteem and self-image within the individual. Participants stated, and research suggests, that individuals with increased levels of self-esteem and satisfactory self-image are least likely to engage in risky sexual behaviors (Kalichman, Cherry, & Brown-Sperling, 1999). Techniques help foster self-esteem and develop a positive self-image could take the form of individual psychotherapy or support groups.

Psychotherapy has been an important component in several participants’ lives. Participant 6 shared that he was in therapy during his 20s and 30s, primarily focusing on personal and family acceptance of him being gay. He reported that the support and kindness received by his therapist made “those days” easier. As previously stated, P20 heard about the HIV virus during a therapy session, and credited his commitment to keeping up-to-date with HIV and its risk factors to his therapist.
Participant 3 provided an example of an effective support group environment. He identified an HIV-prevention program for young gay males (MPowerment Project) that he thought was “extremely successful” because the group allowed youth to be themselves while building necessary support systems. The CDC has aided in the creation and promotion of programs, including MPowerment Project, because of the program’s ability to identify concerns and offer appropriate solutions for the targeted population. Findings from this study suggest that older gay males would benefit from similar programs that encourage communication and risk reduction education, which are often a part of group interventions.

**Education.** Along with the social work process, education is an essential component of micro practice implications. The importance of education is to create knowledgeable social workers and communities with decreased levels of bias and increased knowledge of HIV/AIDS. This section begins with a description of social work education regulations and then a discussion of the importance of HIV/AIDS prevention in social work education.

Two professional supports that can help ensure both beginning and experienced social workers are better prepared with knowledge and skills to address the issue of HIV/AIDS across the lifespan are the National Association of Social Workers’ (NASW) *Code of Ethics* and the Council on Social Work Education’s (CSWE) *Educational Policy and Accreditation Standards* (EPAS).

The 2008 NASW *Code of Ethics* provides social workers with guidelines to perform their required task. The code has six core values and ethical standards that serve to create a professional that is prepared to interact with client units in various settings and one who is able to serve his/her client with full attention in a non-judgemental and supportive manner (NASW, 2008).
In 2008, CSWE revealed a new approach to measuring accredited social work programs. As part of the evaluation process, the new EPAS looks at student achieved practice competencies (Holloway, 2013). In other words, a part of the program’s evaluation is based on the level of knowledge, skills, and values the students receive during their coursework and field experience, while in an accredited social work program (CSWE, 2008).

Together, the Code of Ethics and EPAS help produce educated and ethical social work practitioners. In order to complete a quality assessment of a client unit, the social worker requires an understanding of the client’s background to know the presented need, be competent, and be confident in his/her assessment skills. These skills help promote an environment and experience that is more relevant and empowering for the client, whether the client is an individual, family, group, or community.

Well educated social workers are better able to serve client systems. There are several skill sets necessary when working with older gay males. An understanding of social justice is paramount and is a core value of the social work profession. Simply put, social justice is the viewpoint that everyone deserves equality (Morris, 2002). In addition to knowing what the term means, workers need to know its implication on marginalized groups and society as a whole. As it relates to older gay males, workers need to understand that several forms of stigmatization can be experienced by this cohort such as ageism and homophobia. This includes stigma coming from professionals because this can impact the client/worker relationship.

In partnership with social justice, providers of services to older gay males need to be cognizant of the aging process, sexuality, and sexual health. Having a clear understanding of the biological and psychological concepts of aging allows workers to better understand problems presented by clients. For example, a social worker who recognized the embarrassment
experienced by a client seeking therapeutic services due to depression resulting from erectile dysfunction would be better able to meet the client’s needs than a worker with insufficient training. A social worker with a clear understanding of the biological male and the emotions connected to ED is better able to address the client’s concerns and assist with the appropriate response. The same applies to sexuality and sexual health. In addition to knowing these concepts, participants suggested that providers raise attention and initiate dialogue to reduce stress on the patient.

A final skill required of an effective social worker is an understanding of communication. In addition to sufficiently speaking with and on behalf of clients, social workers should possess the ability to educate clients on improving their own communication skills. Examples can be communication with intimate partners or healthcare providers regarding sexual health concerns; open dialogue with partners about sexual preferences and safer sex; and communication with family, friends, and healthcare providers about aging-related issues.

Social work students and professionals have the opportunity and obligation to serve all clients effectively to reflect the NASW’s Code of Ethics and the various skills learned in their CSWE accredited social work program. This is especially important when working with a marginalized group such as older adults, members of the LGBTQ communities, and minorities.

**Implications for Macro Social Work Practice**

Thus far, prevention has been discussed as it relates to education of practitioners on a micro level. Practice implications exist relating to macro areas of social work practice as well. One such area is prevention policy.

Nationally, policies exist to protect the lives of those infected, affected, and at risk of contracting HIV/AIDS. The largest policy maker is the CDC. In its *HIV Prevention Strategic
Plan, the CDC recommends that testing be offered to at-risk individuals up to age 65 and that services are available to those infected (CDC, 2007). While an official policy, it is difficult to mandate or require such procedural implementation in testing programs. Unfortunately, testing is often not offered to adults 50 and over because they are not deemed at risk or providers are uncomfortable inquiring. These practices lead to a false sense of security in older adults.

An effective policy would be one that incorporates components mentioned by participants during interviews. Participant 2 stated that there needs to be a public health campaign specifically targeting older adults. He went on to state “[society] needs to be reminded of what this virus has done.” In other words, America needs a campaign that speaks to individuals of different ages and reminds citizens that the virus still exists and prevention is necessary.

HIV/AIDS is a global pandemic. Three participants compared the current state of prevention in the US with other countries that they have either lived in or spent extensive amount of time visiting. Born in South Africa, P1 recalled free HIV testing being offered at bars. Individuals were allowed free entry into bars if they opted to get tested. This is a more common practice in the US today, but P1 remembered thinking it was “weird” not seeing it when he moved to the US in the 1990s, because it had been occurring in South Africa for many years.

Participant 18 lived in Australia for roughly six months in 1988. He talked at length about the country’s openness to sexuality and HIV testing. He recalled billboards and television commercials were common and that officials would distribute condoms on local beaches because it was known that people frequently had sex there. He elaborated with “I think in the States [HIV] was sort of a taboo subject. You would never hear it on the news; never hear a politician
say anything about AIDS prevention.” As noted in chapter two, President Reagan took five years to publically mention “HIV/AIDS.”

Similar to P1 and P18, P21 compared the US with countries he has visited. He said he has never been impressed with the prevention messages in the US. From parades, print media, to the news, he said the US was behind various European countries for example “Spain.” He expressed similar views as P18, by saying “Europe seems very aware, but here I think [we] are always afraid that somebody is going to be insulted” if they see advertisements promoting safer sex.

The participants expressed a call for a national prevention initiative to reduce the increasing rates of HIV/AIDS in older gay males. Programs focusing on aging adults, gay males, or both can serve as the foundation or housing for such programs. For example, AARP already focuses on aging issues and has, as of recent, begun providing sexual health messages relating to HIV to its members through its bi-monthly magazine.

A second platform would be through Services and Advocacy for GLBT Elders (SAGE), a non-profit organization whose mission is to provide services to the older LGBT communities (SAGE, 2013). Similar to other LGBT organizations, SAGE has begun to dedicate resources to aging and HIV issues, more specifically LGBT individuals already living with the virus. Together, AARP and SAGE can be leaders in HIV-prevention with older adults.

**Implications for Research**

Research regarding older MSM and HIV/AIDS is scarce. This qualitative study using Grounded Theory adds to existing HIV literature by introducing the experiences of older gay men and HIV/AIDS prevention. One theme and four categories were identified during the data analysis phase. The theme was experiences of gay men during the onset of HIV and their
relationships during the period since onset of the virus and how these experiences have
influenced their current prevention practices. The categories were the following: Life Prior to
HIV, Initial Reaction to HIV, Current Status of Participant’s Relationships, and Insight into
Future Prevention. The purpose of this section is to explore alternative approaches or responses
to the research process and to present future research opportunities.

**Research Limitations.** Despite the significant time dedicated to the design of this
dissertation study, there were challenges with recruitment. The following alternative techniques
relevant to recruitment and analysis have been identified.

In recruiting participants, the goal was to use maximum variation to ensure the sample
was diverse. In an attempt to reach individuals of diverse racial/ethnic backgrounds, as well as
variation in relationship status and exposure to HIV/AIDS, the recruitment strategy was to reach
out to individuals, organizations, and websites targeting older MSM. Participants varied
regarding relationship status (single, open/closed) and exposure to the virus (no experience,
volunteered, and worked in HIV field). Unfortunately, the end sample represented little
racial/ethnic diversity with only two participants identifying as Hispanic.

Several factors may have led to this outcome. First, there was an influx of potential
participants within the first two weeks post IRB approval and recruitment materials being made
public. Second, interviews were completed in less than five weeks, which was much sooner than
anticipated. Third, various fears may have deterred men of color from participating in the study.
For example, fear of research and its processes due to historical accounts of inappropriate
research with persons of color. Fourth, men of color may not have received or accessed the
different forms of recruitment used in the study. Together, these factors may have implications
for the lack of participants who were men of color. The researcher attempted to recruit participants up until data analysis was started; however, this attempt was unsuccessful.

Several alternatives exist that may have yielded different results. First, more time could have been given during the recruitment period to allow for the inclusion of men of color. Second, reaching men of color proved to be difficult using the recruitment outlets mentioned in chapter three; therefore, other sources more appropriate for reaching this population could have made improvements in recruitment such as communicating with more faith based representatives. Another concern with recruitment was the use of couples as participants. Two sets of couples (four participants) were among those interviewed. While each provided their own lived experience with the virus, it was noted that their level of HV-knowledge and responses to questions about their communication with their partners were similar; therefore, resulted in some findings being tentative. A simplistic resolution would be to not interview individuals in relationships.

As described in the sampling technique section of chapter three, analysis of this study included field notes and the use of the data management software Atlas.ti. Due to data collection occurring in such a short time period, the upkeep of field notes was difficult. In the future, more time or study personnel could be provided in the data collection phase to allow for a smoother process.

While a good source for some, Atlas.ti was not useful for the researcher. The researcher was the sole interviewer, typed or reviewed each transcription, and analyzed all data. That said, the researcher was immersed in the data and preferred to remain close to the data then the software allowed for. It was helpful for the purposes of storing transcriptions and during the
initial coding process. However, after the first wave, coding was done using more traditional paper and stacking techniques.

**Future Research.** The purpose of this research was to develop a deeper understanding of older MSM’s experiences with HIV/AIDS and prevention. While being successful at presenting the participant’s stories, this study serves as a foundation for future qualitative and quantitative studies with similar interest. The researcher recommends that future studies take the limitations and difficulties discussed within this chapter into consideration when designing or implementing a study.

This study has sparked the following research questions and ideas. If funding was obtained by sources such as the CDC or NIH, this study could be replicated on a larger scale. Funding could be used for incentives and hiring of research assistants, which could aid with the recruitment dilemmas previously mentioned.

As mentioned in Conceptual Map section of Chapter four, one area needing to be addressed is a better understanding of how the past 30 years have influenced the lives of older gay males who are HIV-negative. With the use of mixed method approaches, participants can be interviewed and asked to complete instruments that speak to the following: relationship dynamics, communication, HIV-knowledge, safer sex practices, personal views of mortality, and experiences with various forms of stigma including internal and external homophobia.

Another area that could be addressed is self reported HIV-status. As designed, participants self-reported their HIV-status during the screening process. When asked “are you HIV-negative,” participants had the option to say “yes” or “no and those who responded “yes” met criteria for the study. Based on the number of men who had never been tested and those
who have not received testing in over a decade, offering “don’t know” as an option may offer another layer of complexity in understanding the participants.

A final option would be to create a new study that used a multidisciplinary approach with gerontology and health psychology to answer questions that stemmed from this study. The following are some potential research questions and the types of research designs in which those questions could be explored.

**Possible Qualitative or Mixed Method Studies**

- How do gay males in open-relationships discuss HIV with their intimate partners?
- How do gay males in open-relationships negotiate that status with their primary partner?
- How do older gay males with significant experience(s) with HIV (e.g. volunteer or work history) view end-of-life decisions?
- How do older gay males who are single differ from their heterosexual counterparts when it comes to HIV knowledge and prevention practices?

**Possible Quantitative or Mixed Method Studies**

- Do HIV-positive gay males view HIV-prevention for older gay males differently than HIV-negative males?
- What forms of HIV-intervention would work best with older gay males?
- How receptive to prevention messages are MSM who are men of color?
- Which populations are more likely to practice safer sex, older gay males who are HIV-positive or those who are HIV-negative?

In summary, this study is not the final voice for older gay males to express their experiences relating to HIV/AIDS. It serves as a stepping stone to future studies allowing the voices of this population to continue to inform science and the social work profession.
Conclusion

In conclusion, the findings and implications presented here reflect the experiences of the 22 participants that took part in interviews. The primary theme and categories speak to the lived experiences of these men during the HIV/AIDS pandemic. As social workers, we need to strive to help raise their voices to ensure they are protected and offered opportunities to be healthy personally and as a community.
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DATE: March 29, 2013

TO: Pamela J. Kovacs, PhD, MSW
Social Work
Box 842027

FROM: Lisa M. Abrams, PhD
Chairperson, VCU IRB Panel B
Box 980568

RE: VCU IRB #: HM15080
Title: Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention

On March 23, 2013, the following research study was approved by expedited review according to 45 CFR 46.110 Category 7. The approval reflects the revisions received in the Office of Research Subjects Protection on March 23, 2013. This approval includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: None

- VCU IRB Study Personnel Roster, received 2/25/13, version date 12/1/12
- Participant Demographic, received 2/25/13, version 1.0, dated 10/1/12
- Interview Script, received 2/25/13, version 1.0, dated 10/1/12
- Recruitment Screening Tool, received 2/25/13, version 1, dated 10/1/12

CONSENT/ASSENT (attached):
- Research Subject Information and Consent Form, received 2/25/13, version 1.0, dated 10/1/12, 3 pages
- Waiver of Documentation of Consent for Interviews: One of the conditions set forth in 45 CFR 46 117(c) (1), for waiver of documentation of consent has been met and the IRB Panel has waived documentation of consent.

ADDITIONAL DOCUMENTS (attached):
- Third Party Permission to Contact Script, received 2/25/13, version 1, dated 2/27/13
- Permission to Release Information Form, received 2/25/13, version 1, dated 2/27/13
- Gatekeeper Letter, received 2/25/13, version 1, dated 2/27/13
- Banner Advertisement, received 2/25/13, version 1, dated 2/27/13
- Tear-Off Flyer: Research Participants Needed, received 2/25/13, version 1.0, dated 10/1/12

This approval expires on February 28, 2014. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

(Continued...)
The Primary Reviewer assigned to your research study is Mary Katherine O’Connor, PhD. If you have any questions, please contact Dr. O’Connor at mkoconnor@vcu.edu and 828-0688; or you may contact Jennifer Rice, IRB Coordinator, VCU Office of Research Subjects Protection, at irbpanelb@vcu.edu and 828-3992.

**Conditions of Approval:**

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must *(as applicable)*:

1. Conduct the research as described in and required by the Protocol.

2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).

3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent is specifically approved).

4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.

5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).

6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.

7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in *VCU IRB WPP VII-7*:

8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.

9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.

10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on [http://www.research.vcu.edu/irb/guidance.htm](http://www.research.vcu.edu/irb/guidance.htm).

11. The VCU IRBs operate under the regulatory authorities as described within:
   a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
   b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
   c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).
RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention

VCU IRB NO.: HM15080

If any information contained in this consent form is not clear, please ask the study staff to explain any information that you do not fully understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY
The purpose of this research study is to learn from how men who have sex with men (MSM) over the age of 50 who are HIV-negative have managed to remain so, including their experiences with HIV/AIDS and HIV-prevention over the last 30 years.

You are being asked to participate in this study because you are MSM, 50 or older, are HIV-negative, and have limited experience working or volunteering in HIV-prevention or treatment.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT
If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what your participation involves.

In this study 20-25 men will be asked to take part in a one-on-one interview session. As a participant, you will be asked to complete a demographic form and then take part in a 60-90 minute interview. You will be asked questions about when you first heard about HIV, how HIV has affected you over the last 30 years, your experience with HIV-prevention, and about what has helped you remain HIV-negative. With your permission, the session will be tape recorded to help assure accuracy of your responses, but no names will be recorded on the tape.

RISKS AND DISCOMFORTS
Sometimes talking about these subjects cause people to become upset or emotional. Several questions will ask about things that have happened in life that may have been unpleasant. You do not have to talk about any subjects you do not want to talk about, and you may end the interview at anytime. If you become upset, the study staff will give you names of agencies to contact so you can get help in dealing with these issues.

BENEFITS TO YOU AND OTHERS
You may not get any direct benefit from this study; however, the study findings may help in the design of more effective HIV-prevention programs for older MSM.
COSTS
There are no costs for participating in this study other than the time you will spend traveling to the interview and participating in the interview and filling out the questionnaire.

ALTERNATIVES
The alternative to participating in this study is not participating.

CONFIDENTIALITY
Potentially identifiable information about you will consist of your interview notes and recordings. Data is being collected only for research purposes. Your data will be identified by an ID number and pseudonym, not your actual name, and stored in a locked research area. All personal identifying information will be kept in password protected files or in locked cabinets and these files will be deleted once the study ends. Interview transcriptions will be kept indefinitely. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

We will not tell anyone the answers you give us. But, if you tell us that someone is hurting you, or that you might hurt yourself or someone else, the law says that we have to let people in authority know so they can protect you.

With your permission, the interview will be audio taped, but only your pseudonym name will be recorded. The tapes and the notes will be stored in a locked cabinet. After the information from the tape is typed up, the tapes will be destroyed.

VOLUNTARY PARTICIPATION AND WITHDRAWAL
You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

QUESTIONS
If you have any questions, complaints, or concerns about your participation in this research, contact:

Pamela J. Kovacs
Associate Professor
Virginia Commonwealth University
School of Social Work
pjkovacs@vcu.edu
804-828-2607

[Version 1.0; 10.1.12]
Johnnie O’Neal  
Doctoral Candidate  
Virginia Commonwealth University  
School of Social Work  
onealj@vcu.edu  
843-509-8887

The researcher/study staff named above is the best person(s) to call for questions about your participation in this study.

If you have any general questions about your rights as a participant in this or any other research, you may contact:

Office of Research  
Virginia Commonwealth University  
800 East Leigh Street, Suite 3000  
P.O. Box 980568  
Richmond, VA  23298  
Telephone: (804) 827-2157

Contact this number for general questions, concerns or complaints about research. You may also call this number if you cannot reach the research team or if you wish to talk with someone else. General information about participation in research studies can also be found at http://www.research.vcu.edu/irb/volunteers.htm.

CONSENT
I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study. I will receive a copy of the consent form once I have agreed to participate.

Participant name printed  Participant signature  Date

I authorize the recording of my interview: ______________________________ (signature)

Name of Person Conducting Informed Consent Discussion / Witness (Printed)

Signature of Person Conducting Informed Consent Discussion / Witness  Date

Principal Investigator Signature (if different from above)  Date

[Version 1.0; 10.1.12]  
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APPROVED
Appendix B: Recruitment Materials

THIRD PARTY PERMISSION TO CONTACT SCRIPT

Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention

I would like to let you know about a research study that is being conducted by Virginia Commonwealth University (VCU) that involves men who have sex with men. The purpose of the study is to help them better understand how MSM have remained HIV-negative over the last 30 years of the AIDS pandemic. It will take about 5 minutes to hear about it. If you qualify, you will receive no payment for participating in the study. Your decision about whether to be in the study or not will not affect your involvement with agency/business in any way. If you would like to hear more about the project, please sign the Release of Information Form and I will give the information to Johnnie O'Neal who will contact you.
Appendix B: Recruitment Materials

VCU IRB Permission to Release Information Form

Study: Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention

I, ________________________________, give permission to ________________________________ to release my name and contact information to the research staff of VCU IRB protocol # ______, Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention.

Signed ________________________________ Date __________
Appendix B: Recruitment Materials

Gatekeeper Letter

Gatekeeper/business owner's Name
Street Address
City, State, Zip

Date:

Dear [Gatekeeper/business owner name]:

My name is Johnnie O'Neal and I am a doctoral candidate in the School of Social Work at Virginia Commonwealth University. I am contacting you because I need your help to recruit participants for my dissertation study, "Older MSM and HIV/AIDS: A Grounded Theory Study to Inform Prevention." I am seeking 20-25 men who have sex with men (MSM) and are 50 or older, HIV-negative, have limited experience working or volunteering with HIV-prevention, and are willing to take part in a 60-90 minute interview with me. Interviews will be conducted face-to-face, but if that is not possible, phone interviews will be considered. The purpose of the study is to understand three things about these men. First, I would like to understand how they have experienced the first 30 years of the AIDS pandemic. Secondly, I want to know about their experiences with HIV-prevention. Finally, I want to learn from them how they have remained HIV-negative over the past 30 years.

As an openly gay male in my mid-thirties, the future of my community is important to me. I have spent many years working and volunteering with those infected and affected by HIV/AIDS. I feel that this study is another way that I can help improve prevention efforts and help the greater LGBTQ communities. I am contacting you, hoping you can help me reach men in Virginia/Richmond area, etc., who might be willing to speak with me to help me address these research questions. I would appreciate it if you would tell individuals who meet the above criteria about this study and provide them with my contact information. I have attached a study flyer for you to display or provide to those that may be interested. Feel free to forward this to anyone else in the community that may be able to help me reach this often forgotten group of men.

Thanks for your time and energy with this important study.

Sincerely,

Johnnie O'Neal, MSW

Version: #1; 2/27/2013

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APPROVED
Banner Advertisement

Note: The number of words allowed will vary based on website.

Study seeks men who have sex with men (MSM) who are 50 or older and HIV-negative who would like to help their community and researchers better understand how they have remained HIV-negative over the last 30 years of the AIDS pandemic. With your help, this study hopes to improve HIV-prevention efforts and help our aging MSM communities. If you are interested in taking part in a 60-90 minute on-line interview, please contact the researcher, Johnnie O'Neal, MSW at onealj@vcu.edu. To learn more about the study, visit www.johnnie.oneal.info. This study has been approved by the Virginia Commonwealth University’s Institutional Review Board.
Research Participants Needed!!

Study seeks men who have sex with men (MSM) who are 50 or older and HIV-negative who would like to help their community and researchers better understand how they have remained HIV-negative over the last 30 years of the AIDS pandemic.

With your help, this study hopes to improve HIV-prevention efforts and help our aging MSM communities!

This study uses face-to-face and technology (e.g. Skype or phone) interviews that will last 60-90 minutes.

To learn more about this study go to www.johnnie.oneal.info or contact the researcher below!

**Researcher**
Johnnie O’Neal, MSW
Doctoral Candidate
Email: onealj@vcu.edu