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Health Service Utilization and Stigma among
HIV-Positive Men-Who-Have-Sex-With Men (MSM) in Rural Appalachia

A dissertation

presented to

the faculty of the Department of Public Health

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Doctor of Public Health with a concentration in Community and Behavioral Health

by

Roger Lee Blackwell, Jr.

December 2013

Dr. Maryann Littleton, Chair

Dr. Robert Pack

Dr. Kathleen Rayman

Keywords: MSM, Stigma, HIV/AIDS, Health Usage, Qualitative

ABSTRACT

Health Service Utilization and Stigma among HIV-Positive Men-Who-Have-Sex-With-Men (MSM) in Rural Appalachia

by

Roger Lee Blackwell

The world has now entered the third decade of the AIDS epidemic. Men-who-have-sex-with-men continue to be disproportionately affected by HIV/AIDS. The United States still struggles in its response to this ongoing crisis in many areas: disease prevention, treatment, and HIV related stigma, prejudice, and discrimination. Much of the information reported on MSM living with HIV has come from urban population centers, but only a few studies have focused on HIV positive MSM living in rural areas.

Therefore, the overall aim of this dissertation was to explore the lived experiences of MSM living with HIV/AIDS, in particular the intersection of HIV related stigma with social, behavioral, and health outcomes in rural, South Central Appalachia.

For this dissertation, data were collected via semistructured, face-to-face interviews with 23 HIV-positive MSM living in South Central Appalachia. Using a descriptive narrative approach, the researcher sought to address the influence of HIV/AIDS related stigma in the lives of these men and provide a forum for their voices. Qualitative data were sorted into various categories from which emergent themes and topics were generated using Nvivo software for data management and manipulation. In addition to qualitative interviews, demographic data were gathered and analyzed to produce basic, descriptive statistics.

Results indicated that MSM participating in this study accessed health services through various agencies. MSM also experienced stigma in multiple and overlapping ways; MSM described stigmatizing experiences stemming from religious sources, communities, family and friends, and from the medical establishment. Moreover, it was revealed that homophobia and HIV-related stigma were related; participants did not differentiate between the two. Homophobia and HIV related stigma were specifically contextualized in relation to rurality and religiosity. The use of health related services was not mediated by stigma.

The results within this dissertation are intended to inform health professionals in the planning and implementation of interventions and treatments for this hidden population in Appalachia. This exploratory dissertation provides insight and contextual information for a highly stigmatized population. Lastly, this project provided rural MSM with a voice.

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DEDICATION

In memory of J. Kevin Hall, William A. Kroener, and John W. Morace. Your friendships have had a profound effect on me both personally and professionally. This project was written with you in mind.

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ACRONYMS AND ABBREVIATIONS

ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immune Deficiency Syndrome
ARC	Appalachian Regional Commission
ART	Antiretroviral Therapy
ARV	Antiretroviral Drug
ASO	AIDS Service Organization
AZT	Zidovudine
CAM	Complementary Alternative Medicines
CBO	Community Based Organization
CD4	Cluster of Differentiation of 4: T Cells
CDC	Centers for Disease Control and Prevention
HAART	Highly Active Antiretroviral Therapy
HC	Health Care
HIV	Human Immunodeficiency Virus
IRB	Institutional Review Board
LGB	Lesbians, Gays and Bisexuals
LGBT	Lesbian, Gay, Bisexual, and Transgender
MCC	Metropolitan Community Church
MSM	Men Who Have Sex with Men
PLWA	People Living with AIDS
PLWHA	People Living with HIV/AIDS
STI	Sexually Transmitted Infection

CHAPTER 1

INTRODUCTION

Statement of the Problem

The world is now in its third decade of the AIDS pandemic. A little over 29 years have passed since the first confirmed HIV-related deaths in the United States. On June 5, 1981, the Centers for Disease Control and Prevention (CDC) published their first report of Acquired Immune Deficiency Syndrome (AIDS), referring to five cases of *Pneumocystis carinii* pneumonia (PCP) among homosexual men as possibly indicating a “cellular-immune dysfunction related to a common exposure” and a “disease acquired through sexual contact.”(Fenton & Valdeserri, 2006). Hence AIDS was reified and given life, even though the pathogen Human Immuno-deficiency Virus (HIV) that causes AIDS was not discovered for another year (Barré-Sinoussi et al., 1983). Scientists have made progress in treating the disease with a multitude of medications; however, they have not yet found a cure for AIDS or developed a successful vaccine for HIV. The one caveat at the time of the writing of this dissertation is the case of Timothy Brown, also known as (AKA) the “Berlin patient.” Mr. Brown was HIV positive and was later diagnosed with leukemia. In the course of his cancer treatment, he underwent total body irradiation and multiple bone marrow transplants. These bone marrow transplants came from a donor who had a mutation in the chemokine receptor type 5 (CCR5) gene. Persons with this rare mutation seem to have a natural immunity to the HIV virus, as the virus uses this main coreceptor to enter host CD4 cells. Subsequently, Mr. Brown, having received these bone marrow transplants, continues to test negative for the virus (Hutter et al., 2009).

Worldwide as of 2010 it is estimated that 30 million people have died from AIDS and approximately 34 million people are now living with HIV/AIDS. (Joint United Nations Programmes for HIV/AIDS, 2011). Here in the United States 2010 estimates tell us that there are about 1.1 million people living with HIV/AIDS, and over 650,000 have died of AIDS since the beginning of the epidemic. The CDC estimates that over 50,000 new infections occur yearly and that one in five Americans who are infected with the HIV virus do not know it. (Kaiser Family Foundation, 2013). The states of Tennessee and North Carolina cumulatively (2010) reported 15,881 and 24,476 cases of persons living with HIV respectively (Centers for Disease Control, n.d.a). Moreover, there were 8,026 (TN) and 9,824 (NC) cases of persons living with AIDS (Centers for Disease Control, n.d.b) as of the same time period. Tennessee ranked 18th highest among the 50 states in cumulative reported AIDS cases (Centers for Disease Control, n.d.c); North Carolina's ranking was 12th highest (Centers for Disease Control, n.d.d). Additionally, for 2010 there were 874 (TN) and 1,521 (NC) newly diagnosed cases of HIV (Centers for Disease Control, n.d.e). Of those new cases, 526 (TN) and 891 (NC) were attributed to male-to-male sexual contact.(Centers for Disease Control, n.d.f).

HIV/AIDS infection rates among men-who-have-sex-with-men (MSM) continue to persist and are a major health concern. According to the CDC point estimates show that overall male-to-male sexual contact remains the most prevalent mode of transmission of HIV/AIDS in the United States (Center for Disease Control and Prevention, 2012). Although MSM represent only approximately 4% of the male population in the United States, they account for more than 78% of all new HIV infections among men, and nearly 63% of all new infections for the year 2010. The CDC further reports that

although HIV diagnoses for MSM did decrease in the 1980s and 1990s, this trend has reversed; increases within this demographic are now being reported.

The United States continues in its struggle to respond to its HIV/AIDS epidemic. In doing so, it not only faces the disease and related disease processes but additionally issues of stigma, prejudice, and discrimination. Parker and Aggleton (2003) posit that there are three distinct phases associated with the AIDS epidemic. Phase one was the initial epidemic of HIV infections in the early 1970s. It was unnoticed and unknown and it quietly spread from host to host. People began dying of AIDS in the early 1980s, when the disease had progressed to the point of opportunistic infections. The AIDS epidemic of the 1980s ushered us into phase two. We have now entered the final phase of the epidemic, one where social, cultural, economic, and political arenas have often responded in negative ways to the epidemic as to produce and perpetuate stigma, prejudice, and discrimination.

The purpose of this study is to examine the lived experiences of MSM living with HIV/AIDS, in particular the intersection of HIV related stigma with social, behavioral, and health outcomes in rural, South Central Appalachia. It is important to understand and measure HIV/AIDS-related stigma in Appalachia for several different reasons. First, the distinctive culture of Appalachia may exacerbate or attenuate feelings of stigma among HIV positive individuals. For example, Hansen and Resick (1990) identified a “cultural lag” in Appalachia that stems from “geographic isolation, lower-than-average educational levels, and limited availability or underuse of health care resources” (p. 2). These cultural artifacts might be related to stigma among HIV-positive adults living in the region. Likewise, Southern Appalachia is characterized by a fundamental Christian

religious tradition (e.g., see De Jong & Ford, 1965; Sutton, 1977) that has typically been unsupportive and unresponsive to issues related to those infected with HIV/AIDS. Alternatively, Appalachia is also known for a strong family tradition, which might actually attenuate feelings of stigma if the family provides social support rather than consternation for the HIV-positive family member. It is important to determine whether individuals experiencing HIV-related stigma report any cultural influences (i.e., family, religion, economic) on the level of their stigma and its effect on health outcomes and access to care. Likewise, by knowing how cultural or social forces influence HIV-related stigma, perhaps this information can be used to inform antistigma campaigns to increase the quality of life of HIV-positive folks.

Another important reason to look at stigma associated with HIV-positive individuals in Appalachia is to be able to make comparisons between stigma in Appalachia with the phenomenon in other parts of the world. For example, Surlis and Hyde (2001) looked at stigma among HIV-positive patients in Ireland, Castro, Orozco, Aggleton, Eroza, and Hernandez, (1998) studied responses to HIV-positive family members in Mexico, and Duffy (2005) examined HIV/AIDS related stigma in Africa. The study adds to a growing body of literature that examines HIV-related stigma among various cultural and geographic groups. Specifically, my research explores four important and interconnected themes: HIV-interrelated stigma, homophobia, culture (i.e., Appalachia, religion and spirituality, etc.), and health services usage.

Intersection of HIV Stigma and Homonegativity

Populations at risk for HIV/AIDS infection experience stigma. This is especially true for MSM, who are often blamed for the epidemic itself because of traditional attitudes toward homosexuality (U.S. Department of Health and Human Services, 2004) and corresponding views of promiscuity, moral degeneracy, and being “diseased.” HIV/AIDS related stigma has implications for the health of yet uninfected MSM at risk for HIV infection and for incidence and prevalence of the disease itself. For example, HIV/AIDS related stigma makes it difficult for MSM to initiate safer sex practices because doing so implies that your partner is “unclean.” Conversely, requesting the use of a condom can also as easily imply that the one making the request is “unclean.” (Hall & Nokes, 1999; Madru, 2003). Additionally, HIV/AIDS related stigma and discrimination may deter individuals from seeking information and assistance for risk reduction practices and supplies. (Herek, 1999). For example, MSM in small, rural enclaves realize that anonymity is hard to come by in their communities. For example, the mere *threat* of being noticed (and identified) buying condoms is more than enough in a small town to dissuade many from purchasing prophylactics. This is reinforced by traditional views that negatively associate condoms with infidelity and promiscuity. Stigma is so associated with condom use that sexuality curriculum for middle school youth specifically address this stigma. For example, when addressing concerns that youth do not use condoms, discussion prompts include “Are you suggesting I might have a disease or something?” or “it’s embarrassing to purchase condoms.” (Goldfarb & Caspian, n.d.) Similarly, a session entitled “Carrying Condoms Carries Stigma” can be found in a HIV Stigma Toolkit (Change Toolkit, 2003) developed for addressing HIV

stigma in Ethiopia, Tanzania, and Zambia. The objectives of this particular module were to uncover how carrying condoms imparts stigma and to encourage participants to think of ways to challenge this form of stigma when talking about HIV/AIDS. Specifically participants were asked how to change things so that condoms would be linked to responsible behavior.

In short, HIV/AIDS related stigma makes it difficult for MSM to talk about HIV and to even disclose their HIV status. This fear can lead to silence around the entire issue. To initiate discussion is to invite suspicion of your status. Some MSM might be so reluctant to disclose their status that they would rather risk possibly transmitting their infection rather than arousing suspicion that they might be infected. (U.S. Department of Health and Human Services, 2004). Stigma fuels misinformation and contributes to MSM denial of their risk status perception. Foster (2007) suggested that rural areas are known to deny that HIV exists in their communities. This denial explains why rural MSM may risk unprotected sex in the erroneous belief that they are not in the same high risk category as urban MSM. Assumptions might be made about the HIV status of their sexual partners based on beliefs of how someone with HIV should look.

The area in question for this project has its own stigmatized history with the emergence of HIV/AIDS in the local community. At a time when HIV/AIDS was still considered an urban problem, at a time when there was such open hostility towards those living with HIV/AIDS, Verghese was an exemplar of compassion and professional integrity to a growing number of HIV patients in the Northeast Tennessee area (Verghese, 1994). He did not react in fear or judgment to his patients; he sought to treat them with dignity. He sought to understand. This cannot be said of many in the local

medical community at the time. His experiences have been read by many from his published memoir and also learned of him through a made for TV movie (Nair, 1998).

Also consider the following more recent occurrence in Northeast Tennessee. Area police conducted a 2-week long investigation into two popular city parks. This resulted in the arrest and prosecution of 40 local men for indecent behavior. The men were accused of engaging in lewd acts (e.g., homosexual sex acts). Not only were these men arrested, their names, addresses, and photos were laid out in the local newspaper for all to see (Swing, 2007). While it may be said that these men were engaging in illegal activities on public spaces, the extent of information revealed by the local media (i.e., names, addresses, photos) was perceived by many as severe and an extension of the homophobic views of the region. Similar occurrences such as area men seeking out the services of commercial sex workers (i.e., heterosexual sex) did not receive similar coverage in the area media. Many of those accused reported that they had been sought out for entrapment. As a result, these men now had a criminal record, many lost their jobs, were threatened by others, and there was at least one suicide linked to this undercover sting operation. Being identified as a MSM in rural Appalachia has consequences, sometimes fatal ones.

Appalachia

This study takes place in a region of the United States known as Appalachia. Appalachia in the simplest of terms refers to the land areas around the Appalachian Mountains. This mountain chain extends from Quebec down through the eastern United States ending in Alabama, covering some 205,000 square miles. (Pollard, 2003).

Appalachia as a geographic region has been defined in many different ways. The most widely accepted definition of this region comes from the Appalachian Regional Commission (ARC). This organization founded in 1965 was the result of President Lyndon B Johnson's War on Poverty and was the product of the landmark 1964 Presidential Appalachian Regional Commission report. The ARC has redefined the boundaries of Appalachia many times. Currently Appalachia as defined by the ARC includes 410 counties in 13 states extending from southern New York down to northeastern Mississippi. Furthermore, Appalachia has been divided into different subregions: North, Central, and Southern Appalachia. (Pollard, 2005). Lastly, for purposes of this study, the geographic area of NE Tennessee and W North Carolina, where the participants of this study come from, is currently classified as South Central Appalachia. (Appalachian Regional Commission, n.d.).

In the Commissions' 1964 report, Appalachia in its entirety was described as a single entity and being distinctly different from the rest of the United States. However, Appalachia is not a homogenous region. Appalachia contains large swaths of sparsely populated rural areas and also growing metropolitan sites. There are also differing socioeconomic characteristics between the various subregions. For example, rural areas of Central Appalachia (e.g., West Virginia) have noticeably different socioeconomic status indicators that are less favorable than the rest of the United States and even other regions in Appalachia. Southern Appalachia fares better when compared with the rest of the U.S. in household income and residents falling below the federally established poverty line (Pollard, 2003).

Religious Faith

Religious faith is an important part of life for many living in rural Appalachia. In fact, there is a large diversity of religious expression to be found in South Central Appalachia. Many church traditions and cultures are represented in the region. Mainline denominational representations compete with a rich religious heritage that operates outside of traditional denominational organization. That is, many community churches are congregational in church organizing structure, self-determining, and not beholden to a larger ecclesiastical body. (Dorgan, 2006).

Much has been written about life in Appalachia, including commentary on religious life, but most of the offerings have come from regional outsiders, and most of their assessment of religion in the mountains was negative (e.g., see Carter, 1984; DeJong & Ford, 1965; Goshen, 1970; Photiadis, 1978; Shapiro, 1986; Sutton, 1977; Weller, 1966). Many authors depicted rural religious life as a rationalization of poverty or at best an outgrowth of ignorance. Mainline denominations sent many missionaries into Appalachia at the turn of the century because mountain folk were in need of mainstream religion, and it was up to these missionaries to bring mountain folk proper religious instruction and a good education. This trend probably had more to do with cultural and social class differences than actual spiritual deficit. What many of these “do gooders” failed to recognize was the richness of life and spirituality found in the many rural communities that they descended upon (Coyne, Demian, Randolph, & Friend, 2006; Poage, 1993).

Two great religious traditions were and still are today vibrant in the region. Calvinists (many Baptist groups) and Arminian (Wesleyan, Methodist, Pentecostal Holiness) congregations can be found throughout the area. These two influences have helped to shape religious life for many living in the area. Calvinism encourages independence in practice and thought and tolerates other views while simultaneously contributing to the feelings of helplessness and anxiety in their views on the human condition. For example, humankind cannot be improved here on earth, and therefore tackling social problems in church is not a priority. Arminianism advocates living above fleshly desires and being transformed into a new creature in Christ. Separation and sanctification are terms used to describe the Christian life. This carries over into involvement with the world; that is, if individuals can be made new and improved, then a better world can be remade through the social gospel. Proselytization efforts emphasize the inadequacy of people in their current situation. Failure to transform or “rise above” it all breeds disillusionment and guilt among adherents, as this view glorifies perfectionism (Jones, 1999).

Religious life in Appalachia often presents a Christian fundamentalist tone in congregations and in the individual lives of believers (Jones, 1999; Photiadis, 1978). Fundamentalist beliefs are varied but those most common involve biblical inerrancy coupled with a literalist interpretation, cathartic conversion experience, evangelicalism, and apocalypticism as a road map to interpreting eschatology (Davis, 2006). These views can contribute to an absolutist view of the world. For example, everything is categorized as good or evil, black or white, of God or of the world, natural man vs. the spiritual man, etc. There is great concern to determine those things that proceed from God and those

things that come from the world. Preachers tend to classify things as being directly caused by sin instead of social problems, psychoses, family dysfunction, disease, and economic hardship. Bad occurrences are the result of secret sin in one's life (Jones, 1999). Groups or individuals who find themselves not in compliance with prescribed social mores are seen as being in league with ungodly satanic forces. Outlier group views and motives are distorted and viewed as being harmful to the survival of the community.

For those to ascribe to absolutist views, any difference to those views are seen as threatening and must be eradicated. (Armstrong, 2000). For example, several Old Testament passages are often directed towards MSM in particular to prove that MSM (i.e., sodomites) are, by their actions, abominations not to be tolerated: Genesis chapters 18, 19, and Leviticus 18:22 and 20:13. Similarly in the New Testament several passages are quoted by believers as evidence that MSM are against the natural order of God's creation and will not partake in a heavenly afterlife: Romans 1:26-27, 1 Corinthians 6:9-11, and 1 Timothy 1:8-10. In these instances MSM are described in terms of being immoral, sinners, reprobate, and given up to their "shameful lusts." Following this line of biblical reasoning, MSM are often viewed as cursed or punished by God, deserving of death by HIV/AIDS, and the cause of HIV infections but because they are the believed to be the source carriers (Change Project, 2003).

As such, many MSM live their lives under considerable stress, that is feeling the disapproval of religious instituted societal norms and the weight of implicit and explicit homonegativity. Having to deny or hide one's sexual orientation when seeking any sort of medical care can have tremendous consequences for MSM. HIV/AIDS and

homophobic stigma may influence how or even when MSM seek health care services. Barriers that MSM experience include the following: fear of bias from health care providers, past negative experiences, pathologizing of their identity, concerns about confidentiality, and even the refusal to treat or refer once the client has “outed” themselves to their medical provider (Kaiser Permanente National Diversity Council and the Kaiser Permanente National Diversity Department, 2000).

Use of Health Care Services

Those living with HIV/AIDS need effective and reliable health care services. Early diagnosis of infection can initiate prompt medical care and highly active antiretroviral therapy (HAART) medicine therapy. Early treatment can result in better short- and long-term health outcomes for those infected. Early diagnosis and treatment also have direct implications for reduced risk of transmission of the virus from one person to another. In fact, knowing one’s HIV status is one of the primary health promotion campaigns now being marketed by government and health care agencies. It is hoped that with more testing, more people who are unknowingly infected with HIV will come to know their status and as a result seek earlier medical care for this now chronic medical condition. Particularly for MSM, delaying HIV diagnosis is troublesome for this at risk population. MSM often report several reasons for this delay; fear of diagnosis, not recognizing that they were at risk for HIV infection, lack of responsibility to themselves and others in disclosure, social stigma associated with HIV and also homophobia. MSM who delay testing often cite sickness as the main reason to seek diagnosis. (Krawczyk, Funkhouser, Kilby, & Vermund, 2006; Nelson et al., 2010; Young & Bendavid, 2010). Also, MSM may experience multiple layers of stigma that may impact testing and

diagnosis. In addition to behavior (homosexual sex, injecting drug user), identification with various racial or ethnic groups (e.g., African American, Latino), and social class may increase vulnerability to stigmatization. Lastly, many MSM may be living with additional stigmatized health issues such as tuberculosis or hepatitis C (Mill et al., 2009).

Accessing quality and consistent availability of health care services may be problematic in rural Central Appalachia. (Napravnik et al., 2006; Reif, Geonnotti, & Whetten, 2006; Reif, Golin, & Smith, 2005). Living in rural areas poses a special challenge to those infected with HIV/AIDS. For example, health care services might be limited; more specifically, HIV related care may be nonexistent for patients. Patients may be viewed by medical professionals who are not trained in current best practices for HIV management. Patients often have long commute times in order to receive care for infectious diseases (Krawczyk et al., 2006; Napravnik et al., 2006; Reif et al., 2005). In fact, transportation is often an issue that compounds efforts to seek care. Long distance commuting and lack of reliable transportation make it difficult for patients to receive consistent care.

Medication adherence is yet another challenge that those living with HIV face. HAART has revolutionized HIV care as these finely tuned drug cocktails can significantly reduce viral loads, increase CD4 counts, and increase long-term health outcomes. Failure to adhere to prescribed treatment plans can result in negative health outcomes (e.g., recurrent opportunistic infections) and the possibility of producing drug resistant strains of the HIV virus.

HIV patients do not follow medical treatment plans for a variety of reasons. Belief may play a role in how HIV disease progression is viewed, and it is linked with self-regulation of the illness and how one proceeds with treatment. In a study conducted by Kempainen, Kim-Godwin, Reynolds, and Spencer (2008) participants who believed that their HIV disease progression depended on chance were also more likely than other study participants to believe that HIV/AIDS was caused by God's will. Researchers noted that it is important to gauge spiritual belief systems as these beliefs may affect treatment adherence and planning.

HIV related social stigma is also a factor in medical adherence. Although HIV patients generally understand the importance of taking their ART medicines in order to have good health, many patients have offered up various reasons for not following best practices in their daily lives. Many living with HIV/AIDS fear that taking their HIV medicines will somehow expose their HIV status to others. For example, a patient may not take his prescribed dosage at lunch when directed because it may rouse the curiosity of family, friends, or coworkers, and he may find himself answering unwanted questions. Given this scenario, many find it easier not to take the meds in public, opting to take them at home or in a secure, private area.

Patients may not adhere to HIV medicine plans if they do not keep up with prescription refills where they are seen entering a local health center known for serving HIV/AIDS clientele. They may also fail to pick up a prescription at their local pharmacy due to concerns over privacy and confidentiality. Patients may experience embarrassment when seeking out their meds as it is a reminder of their disease status.

These issues are often cited as reasons for noncompliance (Golin, Isasi, Bentempi, & Eng, 2002; Rintamaki, Davis, Skripauskas, Bennett, & Wolf, 2006).

Conceptual Model Guiding the Study

The conceptual model for exploring the stigma related experiences of rural HIV positive MSM is presented in Figure 1.

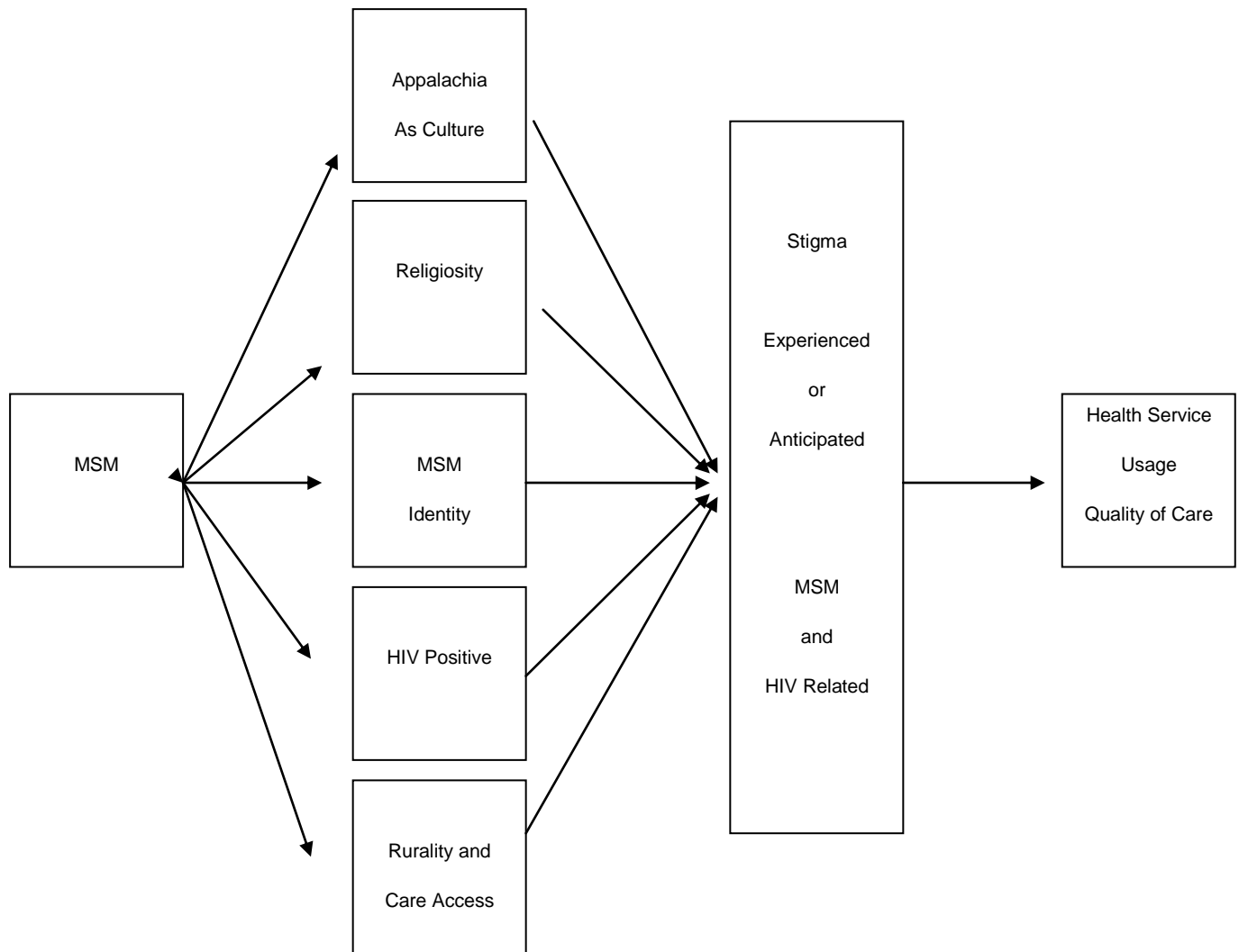


Figure 1. Conceptual Model of HIV Positive MSM Experiences Through Various Life Domains

This conceptual model focused on documenting the various life domains that rural HIV positive MSM navigate and the impact that stigma has in these various aspects of their lives. Specifically, as the model illustrates in Figure 1, MSM operate within these domains (i.e., Appalachian culture, religiosity, identification as MSM, HIV positive status, and accessing health service) and are influenced by them. It is hypothesized that their experiences are adversely affected by stigma and that stigma determines the level of health care usage and the quality of care that they receive.

Method

The present study employs a qualitative research design. In the simplest of terms, qualitative research may be defined as research designed around data that are nonnumerical in nature (i.e., words, visual imagery). Quantitative research involves the use of numerical data. There are a number of characteristics that delineate qualitative research from traditional positivistic approaches. Qualitative approaches take place in a natural setting. The researcher is the primary instrument, and this thus requires self-reflection of assumptions, worldviews, and values and how these might add to or influence research. Research is emergent, rather than prefigured, and is interpretive in nature. Qualitative research embraces a more holistic view of phenomena and uses both inductive and deductive reasoning and analysis. More than one strategy of inquiry can be employed. There are also differences between these two modes of inquiry when regarding such things as: the nature of reality, how one "knows" what one knows and the relationship between the knower and the known, generalization, causal linkages, and the role of values as related to scientific inquiry. (Denzin & Lincoln, 2005; Glesne & Peshkin, 1992; Lincoln & Guba, 1985).

There are a number of ways that qualitatively minded researchers can approach their research. Examples include grounded theory, phenomenology, and descriptive narrative. For example, a grounded theory approach would attempt to devise a theoretical construct from the views of participants (Charmaz, 2005). Another approach available to researchers is through phenomenology. Its purpose is to describe the essence of the lived human experience. Here the researcher is encouraged to lay aside all previous interpretations of a particular phenomenon and to see the "things themselves" with eyes wide open (Groenewald, 2004; Penner & McClement, 2008). Another approach to research can be defined as descriptive narrative. This entails describing individual and group depictions of particular life events. For purposes of this project what the researcher seeks to describe are the lived experiences of HIV positive MSM living in rural Appalachia. The researcher seeks to understand how they navigate through available health care services and how they experience life in a largely heteronormative society.

Descriptive narrative inquiry seeks to understand how those participating explain their current situations and how they construct meaning from life events. This approach also requires that the researcher recognizes first and foremost that what has been shared is someone's life story. It is that person's story first of all, not just information to be described, transformed, and analyzed. These narratives speak from very specific historical and culturally situated standpoints. The researcher is in close contact with the data, and it is to be expected that the data influence the point of view of the researcher and simultaneously, that the data are interpreted and transformed by the investigator. However, the descriptions themselves must always truthfully convey events and

perspectives as they are told. In other words, this type of research acknowledges the futility of trying to speak from a “god’s eye point of view” in regards to an outsider looking in omniscient or objective stance. The primary researcher will be researching from a very particular race, gender, and sexual orientation identity location (Foley & Valenzuela, 2005).

Most qualitative researchers benefit from having an insider status role from the populations that they are researching. If they are not a part of the particular community of study, they will need a credible informant to legitimize their study. The researcher does claim insider status with this particular study group: HIV-positive MSM who live in rural Appalachia. In fact, the researcher feels a special sense of responsibility to this group that he self-identifies with (i.e., MSM from rural Appalachia). It is the researcher’s belief that this community lacks voice, social status, and representation in society at large and in particular in Appalachia. Like many of these MSM the researcher grew up in rural Appalachia having similar life experience contexts regarding to rural social mores, religiosity, and heteronormativity. The researcher can identify with these HIV-positive MSM through his own personal experiences with HIV. The primary researcher has personally known and lost many friends and paramours from HIV/AIDS, where the virus or disease was either directly or indirectly associated with their deaths. There have been many times he has had to personally reflect on his HIV status and confront the stigma associated with seeking testing or medical care from local health care providers. These MSM carry multiple stigmas with them on a daily basis. There is the social stigma of being identified as a homophile in an overwhelming intolerant and hostile climate. The researcher shares this stigmatized identity, still having to navigate

through it on a daily basis. Even in a college town, Appalachia is still a dangerous place for a gay man. The men in this research also carry the social stigma associated with HIV/AIDS. And for many, they carry yet another stigma if they are HIV-positive MSM of color. This racism not only comes from without the gay community, but is easily found within the LGBT community at large.

Sandelowski (2000) described descriptive studies as those sorts of inquiries that address questions of specific relevance to questions such as:

- What are the concerns that people have about a particular life event?
- What are their feelings or attitudes towards these events?
- What are the reasons that people have for using or not using a particular service (e.g., health services)
- Who uses a particular service and how do they access it?

Descriptive research Sandelowski (1991) further indicates that investigators may use this form of inquiry as they seek to describe: lived experiences nested within a particular life event, the conditions in which individual stories may be similar or dissimilar with one another in relations to similar life episodes, how these descriptions relate to what is already known culturally, and how these life events might serve in how the individual constructs meaning in the telling of their lives.

It is important to note that this qualitative study will not be working from a hypothesis testing paradigm. That is, the research project is not being conducted to examine a phenomenon by statistically testing a relationship between dependent and independent variables that are measured numerically. The aim of this project is not to

statistically show whether there is a relationship between dependent and independent variables. The working ideas on this topic are more in line with hypothesis generating than hypothesis testing for a number of reasons. Although the researcher does identify with MSM as a sexual minority, his own experiences with HIV/AIDS do not mirror their own life experiences, and so he would not be able to meaningfully identify a working hypothesis of his own. This is in line with a naturalistic inquiry (i.e., researcher as learner). For example, this project is not based upon inductive logic, where the data are gathered to test a hypothesis; rather my research is based upon deductive reasoning where my observations inform my working ideas.

More importantly, the primary investigator is interested in understanding the subjective experiences of HIV-positive MSM living in South Central Appalachia. Subjective experiences cannot be defined numerically as is common with hypothesis - testing research. The researcher wants to understand what is meaningful to these men as they respond to questions that explores their own personal journeys. In other words, he is seeking a way that will allow him to study their subjective experience directly.

Assumptions

The working ideas of this project generally involve HIV-related stigma, homophobia, culture (i.e., place, religion and spirituality), and health services usage. In particular, these concepts are not independent of one another. The researcher's first working idea posits that HIV-related stigma and homophobia are related; the former is most likely a consequence of the latter. Secondly, both HIV-related stigma and homophobia are most likely contextualized within one's culture; place and religion or

spirituality most likely reproduce stigma and homophobia among individuals. Lastly, the use of health services by HIV-positive men who have sex with men (MSM) is mediated by the three aforementioned concepts; that is, the use of health and medical services depends on internal mechanisms such as HIV-related stigma and internalized homophobia as well as social and cultural forces like homophobia, place, and religion or spirituality. Again, it is felt that by exploring these themes, we can come to a better understanding of the experiences of MSM in rural Appalachia who are living with HIV/AIDS at this time.

CHAPTER 2

LITERATURE REVIEW

Stigma

People living with HIV/AIDS experience stigma. The word itself literally means “to mark, brand, or tattoo.”(Merriman-Webster’s Online Dictionary, n.d.). Ancient Greeks invented the word to describe the deliberate marking of slaves, criminals, and traitors to the State with a physical mark (e.g., cuts, burns) to designate them as being “different” and “Other.” These marks set them apart from the general public and social mores of the day required these “Others” to be avoided. (Madru, 2003). It is easy to recall Hawthorne’s literary figure, Hester Prynne and her scarlet letter, or the Star of David and pink triangles that were sewn onto the clothing of Nazi concentration camp victims to envision more modern symbols of this barbaric practice. In all of these instances, individuals marked were considered discounted, less than human, having deviated from some social norm, or possessing something within themselves that was undesirable and to be feared.

Stigma may also be defined as “a discrediting social label” (Wright, Naar-King, Lam, Templin, & Frey, 2007) also as behavior characteristics of individuals that run contrary to the norms of social units, that is, they behave in ways that do not support shared beliefs of others (Ahern, Stuber, & Galea, 2006). Stigma can be negative reactions to socially unacceptable characteristics (Chenard, 2007). Goffman (1963) in his now classic book defined stigma as an undesirable and discrediting attribute that reduced a person from being viewed as a whole person to a tainted or discounted one. Similarly, stigma may also be considered a social identity within some social category

that questions that person's humanity in such a way that they are considered damaged, flawed, or devalued in the eyes of others (Foster, 2007).

Stigma is socially constructed and contingent on relationships and context. It occurs interpersonally, between people through words, gestures, meanings, and feelings and via this subjective process results in such things as labeling, stereotyping, and strong emotional reactions. For example, during an interpersonal exchange those who stigmatize place individuals into distinct categories they then use to base stereotypical belief systems (Yang et al., 2006). In attempting to classify some general characterizations of stigma it is helpful to consider the following terms to help the conceptualization process: discrimination, labeling, loss of status, discounting, discrediting, stigma on an individual and group basis, institutional, cultural, internalized, and whether the person stigmatized is a primary or secondary target (Foster, 2007). Parker and Aggleton (2003) citing Foucault's work present the view that the process of stigmatization requires marking of differences between types of people and then placing them into hierarchal systems or structures of power. This structuring promotes the interests and views of the dominant group. Dominant groups legitimize their standing rank wise through hegemonic processes, whereby they "convince" those in the minority to accept their reduced status. Unfortunately, stigmatized individuals or groups often accept this reduced status, which ultimately reinforces their stigmatized condition. On an organizational or institutional level stigma can produce structural discrimination.

HIV/AIDS Related Stigma

Likewise, several research articles have recently looked at the lived experiences of HIV-related stigma among men and women who are affected by this illness. For

example, Duffy (2004) conducted an ethnographic study in rural Zimbabwe where she uncovered themes of silence, secrecy, and denial in HIV-related stigmatization. Carr and Grambling (2004) talked to women with HIV/AIDS and noted social rejection caused by stigma by family members, friends, health care providers, employers, and church members. Lastly, Castro et al. (1998) examined family responses to HIV/AIDS in Mexico. They found that social support was key in mitigating HIV-related stigma. On the other hand, fear, pre-existing familial conflict, and prejudice were all related to HIV-related stigma.

A variety of sources examine HIV-related stigma from a quantitative perspective (Green, 1995; Herek, 1999; USAID, 2006). For example, according to Herek (1999), “a variety of social, psychological and demographic variables have been found to correlate with AIDS-related attitudes” (p. 1108). He went on to identify age, education, personal contact with people with AIDS (PWA’s), knowledge about HIV transmission, and attitudes toward homosexuality to be associated with HIV-related stigma. Green (1995) also developed a short inventory that is supposed to measure HIV-related stigma; it is important to consider aspects from both Herek’s and Green’s work with HIV-related as part of this research project dealing with perceived community attitudes regarding HIV/AIDS.

Stigma is real and affects the lives of individuals living with HIV/AIDS. HIV-positive adults have reported being victimized by their partners or loved ones with the HIV infection documented as the cause of the violence (Seals, 1996, Zierler et al., 2000). Those living with HIV/AIDS often experience social isolation and rejection from family, friends, employers, and religious institutions (Carr & Gramling, 2004; Duffy,

2005). For example, a woman fears telling her child's teacher that she is HIV-positive, a local man keeps his HIV status a secret from his family, and stigma caused a faith based homeless shelter to evict a homeless man from its facilities after his HIV medications were discovered (Western North Carolina AIDS Project, 2009). These examples illustrate the frustrations of many people living with HIV/AIDS (PLWHA), that is, not only are they dealing with the effects of the disease diagnosis and process, they also contend with the negative aspects of enacted (i.e., sanctions applied to those with HIV/AIDS from others) and felt (i.e., the internalization of enacted stigma) stigma (Green, 1995).

HIV/AIDS related stigma has implications for the health of HIV positive individuals and for prevalence of the disease itself. PLWHA often do not easily disclose their status to others and consequentially this affects seeking behaviors for physical, psychological, and social needs (Herek, 1999). Stigma is a barrier to accessing care in a timely manner. Individuals may delay or not seek diagnostic testing and treatment to bring viral loads under control. In fact, fear of HIV/AIDS stigma can keep individuals from ever being tested for the virus (Fortenberry et al., 2002). Knowing one's status is the first step in any HIV/AIDS prevention initiative. The CDC estimates that that one in five Americans who are infected with the HIV virus do not know it (Kaiser Family Foundation, 2013). Not knowing your status means you don't take the necessary steps to care for yourself and additionally you may unknowingly pass the virus along to someone else. PLWHA suffer from chronic stress hiding their illness, their medications, and reasons for doctor visits, etc. from others (Ahern et al., 2006; Carr & Gramling,

2004). As mentioned previously, PLWHA are often subjected to physical abuse (Seals, 1996; Zierler et al., 2000).

PLWHA encounter HIV/AIDS related stigma when accessing health care. Fear of stigma may inhibit discussion of risk factors (e.g., drug use, high risk sexual behavior) with health care providers. This is a barrier to care resulting in inaccurate reporting of health issues, treatment plans, and overall quality of care. PLWHA often experience stigma directly from those in the health care arena. Patients report that physicians, dentists, and nurses have reacted to their HIV status with disgust and disapproval, refused treatment, and have overtly blamed them for their illness. PLWHA report that the confidentiality of their health status have oftentimes been breached either intentionally or unintentionally resulting in stigmatization from health care workers and other patients (Carr & Gramling, 2004; Surlis & Hyde, 2001).

Social issues that surround the HIV/AIDS epidemic may be vastly different in the rural South and present unique challenges in HIV prevention and in the delivery of HIV related services. For example, those living in rural settings may often deny that HIV exists in their communities (K. Hightower, personal communication WNCAP, January 2009). Similarly, stigma surrounding HIV/AIDS appears to be more prevalent in these areas and creates a formidable barrier to HIV/STI prevention, testing, and treatment. Traditional value orientation may contribute to negative views on homosexuality, drug use, and HIV/STI. Rural populations tend to have a more conservative mindset and be more supportive of conservative values and less tolerant of diversity in populations. Religious belief or ideology has a more prominent role in shaping the social norms of rural communities. For example, Rosser and Horvath (2008) noted that the proportion of

evangelical Protestants within a state was inversely associated with more successful HIV prevention efforts. That is, in terms of HIV prevention efforts, states were successful if they had less religious and evangelical Protestant adherents. Cultural and social oppression influence many MSM to hide their sexual orientation and may contribute to nondisclosure of health concerns related to sexuality with health providers. Health resources available to rural MSM may be limited or nonexistent.

For example, Zukoski and Thorburn (2009) documented the experiences of HIV-positive individuals living in a predominantly rural area with low HIV prevalence. Specifically, researchers wanted to identify HIV related stigma through the lives of those living with the disease in their respective rural communities. Sixteen participants were recruited through physician referrals and flyers distributed through physician offices. Interviews consisted of open-ended questions and probes. The guide went through several revisions with the final instrument addressing topics such as stigma, issues of trust relating to health care providers, discriminatory practices in accessing healthcare, and health information literacy. Researchers gleaned three main themes relating to stigma and discrimination from interview data. Participants experienced social rejection from family, friends, and others due to their HIV serostatus. They further described rules of social contact where interactions were limited due to fears of HIV transmission and infection. Individuals also described instances where they were treated differently because of their HIV.

Similarly, in healthcare settings participants reported that many providers behaved as though they were afraid of touching the participants. Many providers used added barrier protection in the examination of these individuals. Healthcare providers

were also described as discouraging treatment or outright refusal in treatment of participants. Patients also reported that providers were often rude in their dealings with them, or that they were treated differentially by healthcare personnel. Individuals responded to these stigmatizing experiences in a variety of ways: anger, discouragement, shame, and nondisclosure of their HIV status to others. Some respondents coped by rationalizing the attitudes and behaviors of those perpetuating these negative attitudes, others by physically isolating themselves from others, and lastly some responded by seeking out positive emotional support.

Internalized Homophobia or Gay Related Stigma

Populations at risk for HIV/AIDS infection experience stigma. This is especially true for MSM, who are often blamed for the epidemic itself because of traditional views on homosexuality and corresponding views of promiscuity, moral degeneracy, and being “diseased.” Homophobia, that is, negative attitudes toward MSM, can be viewed as part of a larger construct that encompasses a more general belief in traditional gender roles. Davies (2004) set out to show that men’s attitudes towards MSM are more negative than women’s views in the area of homosexual behavior and homosexual persons. Attitudes towards homosexual persons was conceptualized as same sex attraction being a threat to the respondent, to those close to them, to strangers, and to any social restrictions used to manage homosexual persons. She devised a scale to measure these attitudes. Additionally, the author explored the relationships between these components and other attitudinal measures: male toughness, male sexuality, and hostile sexism towards women. Data were obtained from questionnaires received from 170 male and 302 female undergraduate students in

NW England. Multiple regression revealed three predictors of affective reaction in men towards MSM: male toughness, hostile sexism, and male sexuality. These findings support previous research that homophobic attitudes towards MSM are but part of a larger construct involving traditional gender roles. She further posits that these negative attitudes are related to the constructs of conservative authoritarianism (e.g., traditional values, belittling of out groups) and social dominance orientation (i.e., respondent group membership viewed as superior to other groups).

Stokes and Peterson (1998) interviewed African American MSM (AA MSM) to gauge perceptions of negative attitudes of homosexuality from individuals and communities. They wanted to know to what extent these MSM internalized those negative attitudes and how these attitudes might impact their self-worth and psychological adjustments. Did homophobia play a part in behaviors that would put these MSM at risk for HIV? Individual interviews were conducted with AA MSM (n=76) between the ages of 18-29 years of age. Questions were designed to be open ended with optional probes. These questions were designed to probe several areas such as perceptions of homophobia, the role of the Black church, internalization of homophobic attitudes, sense of community support, and homophobia, self esteem, and risk for HIV infection.

Respondents perceived their communities as having negative attitudes towards homosexuals. They felt as though the AA community was less accepting of homosexual behavior than the white community. They further informed researchers that negative attitudes towards homosexuality were stressful and damaging to AA men. Many of the participants in this study had internalized the community's attitudes on homosexuality

and were distressed by their same sex attractions. Participants were able to inform researchers on ways that homophobia and internalized homophobia might influence behaviors that put AA MSM for HIV infection.

Two hundred twenty participants recruited by Igartua, Gill, and Montoro (2003) answered a series of questions to clarify whether internalized homophobia was a factor in depression, anxiety, suicide, and substance abuse in gay and lesbian populations. Researchers were also interested in identifying those risky periods of gay identity development such as suicidal attempts and ideation. Participants were recruited through a psychiatric out-patient clinic that caters to the LGBT population as well as through snowball recruitment strategies. Internalized homophobia was measured through the use of the standardized Nungesser Homosexual Attitudes Inventory (NHA). The NHA measured according to three subscales: attitudes towards one's own homosexual orientation, attitudes towards other homosexuals, and attitudes concerning self disclosure.

Researchers showed linkages between internalized homophobia and psychological distress, especially depressive and anxious symptoms. Negative attitudes concerning one's own homosexuality was most predictive of psychological distress. This study failed to show an association between internalized homophobia and substance abuse. Neither did internalized homophobia independently predict suicide apart from depressive episodes. The age group where suicide and suicidal ideation were most prevalent for this group of respondents was identified as their mid-20s.

In a similar vein, Allen and Oleson (1999) also used the NHA1 to examine the relationship between internalized homophobia and shame in MSM. Researchers wanted to explore relationships that might exist between high degrees of internalized homophobia and higher levels of shame in MSM. They also wanted to ascertain whether there were certain aspects of homophobia that caused shame and also any inverse relationships between internalized homophobia and self-esteem issues in gay men. Research subjects were between the ages of 22 and 65 years and were recruited through various gay venues. Results provided evidence of a significant positive relationship between internalized homophobia and shame in gay men and a significant inverse relationship between self-esteem and internalized homophobia. Several variables related to self-consciousness were shown to be correlated to shame perverted, effeminate, weak, sick or defective, passive, and engage in anal sex. Descriptors used to describe stereotypes of gay men that were significantly correlated to shame were lacking masculinity and sexually perverse. The authors concluded that shame may be the primary pathogenic factor in internalized homophobia. Consistent identification with internalized shame can lead to a shame-based identity. Consequences of this shame-based identity include overwhelming sense of worthlessness, poor ego integration, and rigid defensive processes.

MSM and men who are attracted to other men in the Minneapolis / St. Paul area were surveyed by researchers to develop a scale to measure internalized homophobia and its relationship to sexual attraction, length of relationship, satisfaction with relationships, social interactions with other gay people, and self-disclosure (Ross & Rosser, 1996). Eligibility requirements for this study included being male by birth, 18

years or older, willingness to be exposed to sexually explicit materials, and a willingness to be identified as MSM or admit to being attracted to other men. Dimensions of internalized homophobia were identified as publicly identifying as being gay, perception of stigma associated with being gay, social comfort with other gay men, and moral and religious acceptability of being gay. These dimensions were significantly associated with duration of and satisfaction with relationships, attraction to men and women, membership in gay and bisexual identified groups, extent of social time with other gay identified people, HIV status, and disclosure of their sexual orientation. Researchers noted data confirmed that stigma is a component of internalized homophobia. This stigma is unrelated to any *actual* level of societal discrimination but rather is associated with *anticipated* discrimination. In other words, perception of anticipatory negative responses was enough for MSM to downplay or hide their orientation from others.

Diaz, Ayala, Bein, Henne, and Marin (2001) set out to examine the relationship between experiences of social discrimination (homophobia, racism, poverty) and mental health outcomes (anxiety, depressive episodes, and suicidal ideation) among urban Latino MSM. Data were obtained from 912 Latino MSM recruited from various gay venue sites. The quantitative arm of this research was informed by a qualitative study where researchers through the use of interviews and focus groups sought to develop survey instruments that reflected the lived subjective experiences of MSM. The final survey instrument contained scales to measure symptoms of psychological stress, participant experiences of homophobia, racism, and financial hardship, social isolation, low self-worth, and resiliency.

MSM in this study reported having to pretend to be heterosexual at various points in their adult lives. Many reported having to move away from family and friends in order to live an authentic life, and many also reported gay related police harassment. Commonly reported homophobic experiences during childhood were hearing that being gay was not normal, that gays grow up being all alone, and that being gay reflects badly on the family. Researchers commented that these experiences were consistent with known Latino family value orientation, immigration patterns, and adverse encounters with the US criminal justice system.

Stigma related to homophobia is often manifested through verbal harassment, discriminatory practices (e.g., housing, employment), and even physical violence. Self-identified young MSM were recruited by peers through various gay related venues by Huebner, Rebchook, and Kegeles (2004) to document experiences of harassment, discrimination, and physical violence related to their sexual orientation. Researchers additionally were interested in associations between these aforementioned experiences and mental health manifestations (that is, low self-esteem and suicidal thoughts). Participants (n=1,248) between the ages of 18 – 27 years self-reported the following during the preceding 6 months: verbal harassment (37%), discrimination (11.2%), and physical violence (4.8%). Lower self-esteem and a two-fold increase in odds of suicidal ideation were associated with these events. MSM between the ages of 18-21, those opting to be more open about self-disclosure, and HIV-positive most often reported these events. The authors concluded that HIV-positive men were more likely at increased risk of these mistreatments due to the additional stigma associated with HIV. One conclusion researchers noted was that perhaps qualitative studies might further

clarify the contexts in which these experiences occur and offer additional insight into these phenomena.

Children devise various attachment styles (secure, avoidant, and anxious-ambivalent) to their caregivers during the course of childhood. Jellison and McConnell (2003) assessed whether attitudes towards one's homosexuality and other related self-relevant views among MSM were influenced by the attachment style that these MSM developed during childhood. They hypothesized that MSM who evidenced a greater secure attachment style would be more self-disclosing, more self-confident, and have higher self-esteem and would have a more positive view towards their own homophile orientation. Additionally, they surmised that the positive relationships between endorsed secure attachment style, greater levels of sexual orientation self-disclosure, and higher self-esteem would be mediated by favorable attitudes one's own homosexuality. MSM (n=40), mostly Caucasian between the ages of 19-63 completed a series of questionnaires addressing attachment styles, attitudes towards homosexuality, self-disclosure, and self-esteem. Participant's responses revealed that as secure attachment style increased MSM reported more positive attitudes towards their homosexual orientation, and greater levels of self-disclosure and self-esteem. As overall positive attitudes on homosexuality increased, so did self-esteem and self-disclosure. Additionally, as self-disclosure increased so did self-esteem. However, the relationship between self-esteem and self-disclosure became nonsignificant when self-attitudes towards homosexuality were added to the regression equation. That being said, homosexual attitudes remained significant a significant predictor of self-disclosure, even with the addition of self-esteem and secure attachment style included in the equation.

Researchers concluded that attachment styles might have special significance for MSM, notably in the acquisition of positive attitudes toward their own homosexual orientation.

MSM negotiate their sexual orientation due to the stigma of homosexuality. These negative attitudes are experienced in differing ways by individuals and so are the strategies that MSM devise to deal with these “effects of the majority on an oppressed minority.” Dooley (2009) set out to identify how MSM recognized stigma related to their homosexuality and the ways in which they coped with it. Participants (n=15) were recruited through networking colleagues and ranged in ages from 27-58. The majority of these men were Caucasian. Seven of the 15 MSM were not open about their sexual orientation with at least one significant person in their life. One of these seven men was open to everyone in his life except those who were in his minority group.

Qualitative interviews were conducted with individuals and the following themes emerged from their narratives: recognition of stigma (of being different), strategies for validating gay identity, strategies for maintain close relationships, and strategies for negotiating gay identity in the workplace. Participants reported linking being different and being gay and the stigma attached to it. The majority of men initially felt shame and isolation due to this association. MSM in this study recognized at some point in their lives that they would have to leave their home environments and physically move in order to construct a new identity that was more authentic and affirming of their sexual orientation. Mentors were mentioned as an important coping mechanism against the effects of stigma. These role models often acted as cultural brokers who operated in both the dominant culture and subculture helping these MSM to access a shared meaning system that helped to reinforce a more positive definition of themselves. In

workplace environments many men felt that nondisclosure was a more successful strategy.

The effects of internalized heterosexism have been linked to more than just psychological distress. In a study conducted by Johnson, Carrico, Chesney, and Morin, (2008), researchers examined suspected interrelationships among HIV-positive gay identified men in regards to high levels of internalized homophobia and negative affect (that is, mood or mental state such as stress, anxiety, depressive episodes), greater use of stimulants (e.g., meth), nonadherence to antiretroviral therapy (ART), and increased risk of transmitting HIV to others through high risk behavior. Medically documented HIV-positive gay men in the San Francisco area (n=465) completed interviews via Audio Computer Assisted Self-Interviewing (ACASI) and Computer Assisted Personal Interviewing (CAPI).

Researchers framed this study within a social action theory construct. Here they hoped to detect and manipulate environmental factors (internalized homonegativity) and those self regulating mechanisms (negative mental states and substance use) that either promote or hinder health outcomes. Measures included demographic, internalized heterosexism, substance use, negative affect, ART medication adherence, and HIV transmission risk. Data supported their hypothesis that higher levels of internalized homophobia may increase risk of transmitting HIV and in greater nonadherence to HIV medications via increased negative affects and higher usage of stimulants. The authors reported that they had identified one particular stimulant (i.e., meth) that emerged as an indirect mechanism through negative affect can influence HIV risk transmission (e.g., risky behavior). They posit that gay men may use stimulants to

mitigate negative feelings about their orientation. In other words, gay men may deliberately engage in cognitive escape through drug use because of internalized heterosexism. The authors concluded various therapy strategies might be used by therapists to combat heteronormative beliefs: gay affirmative therapy, affirmative cognitive-behavioral therapy, and acceptance therapies.

In addressing the issue of stigma in relation to homophobia it is important to remember that identifying oneself as an MSM is not all about counteracting societal negativity towards being a sexual minority member. It is just as important to recognize and remember that there are positive aspects to being a gay man (MSM). Riggle, Whitman, Olson, Rotosky, and Strong (2008) sought to inform themselves as to the positive psychological aspects of being a gay man or lesbian. Researchers conducted an online survey of 553 gay men and lesbians in order to describe and delineate domains and related themes positively associated with being a gay man or lesbian.

Disclosure as a gay man to oneself and to others is an important step for having a positive identity. Participants reported that belonging to the GLBT community was a positive aspect. Support from others of your “own tribe” was important and the commonality of experience (i.e., being gay) was a powerful coping mechanism. Many MSM experience rejection from their families of origin due to their sexual orientation. In response, many MSM create families of choice and viewed this as a positive strategy. MSM also reported that they were able to have strong connections with others due to part to being a sexual minority. MSM often noted that being out in the workplace facilitated a positive aspect of being a role model to coworkers and to those questioning their own sexual orientation.

Another domain identified was that of personal insight and empathy for self for others. Participants reported living an authentic life and being honest about who they were was a positive aspect of being gay. MSM enjoyed a deepening of insight and stronger sense of self. This skill was seen as critical and that this personal insight informed other areas of their lives. Another positive association for gay men is that they reported feeling a greater sense of empathy and compassion towards those groups of people who were marginalized and oppressed. Gay men and lesbians also reported a greater desire for social justice issues and being active for GLBT and broader social issues.

Lastly, respondents in this study reported that being homosexually oriented was a freeing experience in areas of societal expectations related to gender roles. For gay men, this freedom from gender specific roles included the freedom to express themselves emotionally. That is, they did not feel the need to self-monitor their emotions or behaviors to traditionally rigid roles of what a “real man” should be. MSM also reported that freedom from gender role expectations carried over into exploration of their sexuality and different configurations of how they might construct intimate relationships. That is, because MSM relationships are considered “unconventional” to begin with, many MSM felt increasing freedom in how to work on those relationships from an unfettered point of view.

Spirituality and Religiosity

Those oriented to same sex relationships and behaviors have always had a problematic relationship with traditional religious faiths and their corresponding social

institutions. In fact, most organized Westernized religious institutions have not only been unsupportive of same sex coupling, their codified beliefs label homophile orientation and activities as sinful and outside the faith's accepted code of behavior. These religious prescriptives endorse and support a solely heterosexist worldview (Barret & Barzan, 1996; Fulton, Gorusch, & Maynard, 1999; Greene, 2009; Lynch, 1996; Mark, 2008; Rodriguez & Ouellette, 2000; Schuck & Liddle, 2001; Yarhouse & Burkett, 2002; Yarhouse & Tan, 2005). Many MSM growing up in the church hear messages that constantly reinforce this negative view. They are subjected to messages such as gays go to hell, will burn in hell for being gay, that they are bringing this country down, and that they might even have a demon inside of them (Kubicek et al., 2009). The more they hear these homophobic messages the more likely MSM will "start believing that it's true." (Kubicek et al., 2009, p. 612). Religion can be hijacked and can often be used to subvert and divide socially marginalized groups. Sacred texts can be presented in such a way to support a system that is organized around patriarchal domination. This male-dominated system requires a clear delineation between what constitutes maleness and femaleness. Same sex relationships violate this socially constructed boundary and therefore threaten the stability of the system (Greene, 2009).

Traditional value orientations may contribute to negative views on homosexuality, drug use, and HIV/STI. Rural populations tend to have a more conservative mindset, and be more supportive of conservative values and less tolerant of diversity in populations. Religious belief-ideology has a more prominent role in shaping the social norms of rural communities. For example, Rosser and Horvath (2008) noted that the proportion of Evangelical Protestants within a state was inversely

associated with more successful HIV prevention efforts. That is, in terms of HIV prevention efforts, states were successful if they had less religious and Evangelical Protestant adherents. Cultural and social oppression influence many MSM to hide their sexual orientation and may contribute to nondisclosure of health concerns related to sexuality with health providers. Health resources available to rural MSM may be limited or nonexistent.

Most if not all MSM grow up in the context of their identity formation being birthed in the context of a culture that has extremely harsh views towards homosexuals and same sex behaviors. An important thing to remember is that unlike other members of marginalized groups (e.g., ethnic minorities) MSM as children do not grow up with parents who share this stigmatized identity. That is, the majority of MSM grow up in heterosexually oriented households. Consequently, there is no parental buffering from a dominant heterosexist orientation, nor do they have visible and appropriate role models. Furthermore, even before they themselves are aware of their same sex orientation or attractions, these children have already begun to learn and internalize all the popular myths and stereotypes that society promulgates about homosexuality (Huebner, Davis, Nemreoff, & Aiken, 2002).

Fulton et al. (1999) set out to explore the relationship among religious orientation, homophobic sentiment, and fundamentalism among Christians. They hypothesized that negative attitudes towards homosexuals was a function of fundamentalist beliefs, low intrinsic and high extrinsic social motivation, and a lack of open-mindedness in the search for truth. Approximately 250 university students from a conservative oriented Christian college participated in this study. Scale items addressed intrinsic and extrinsic

motivation, questing (i.e., open-mindedness in the search for truth), fundamentalism, antihomosexual attitudes, and social distancing. Those who scored higher on the fundamentalist scale were more rejecting of homosexuals than those who scored lower on fundamentalism. Some of this antipathy is understood to correspond to fundamentalist ideology (i.e., literal interpretation of biblical passages concerning same sex behaviors). However, researchers concluded that much of the antihomosexual sentiments espoused by fundamentalists were in excess of what was *required* by their religious ideology.

Subsequently, many MSM have religious conflicts with their sexual identity and orientation (Bartoli & Gillem, 2008; Borgman, 2009; Foster, Arnold, Rebchook, & Kegeles, 2011; Garcia, Gray-Stanley, & Ramirez-Valles, 2008; Harris, Cook, & Kashubeck-West, 2008; Kubicek et al., 2009; Lynch, 1996; Rosik, Griffith, & Cruz, 2007; Schuck & Liddle, 2001; Wagner, Sarafini, Rabkin, Remien, & Williams, 1994; Yarhouse & Tan, 2005). Yarhouse and Tan (2005) addressed conflicts that adolescents were experiencing in their emerging sexual and religious identities. They posit that both of these developmental identities often emerge during adolescence. Their aims were to elucidate the religious and sexual identity development contexts that some homophile oriented adolescents experience, identify the religious conflicts that might present themselves, and offer suggestion to address these conflicts. They also wanted to be respectful of both religion and sexual orientation in their assessment and suggestions for resolution.

The authors listed several suggestions that psychologists could consider in seeking to address religious and sexual identity conflicts. Practical solutions include

assess the explanatory framework (i.e., religious orienting system) of clients. Additionally, psychologists can help youth identify coping resources that religion provides. LGB-centered religious communities and LGB-centered ministries may be a valuable coping resource as they support and LGB identity within a religious context. Youth and families who conform to conservative religious beliefs and values would not benefit from these ministries. However, it would be beneficial to give clients permission to explore and express negative emotions towards God. Help the client to explore intentional attributes that God might express toward them. Assist the client in addressing family ideological conflicts surrounding LGB identities. Help by trying to understand the conflict from individual family members and identifying those dissonant tensions that exist. Finally, researchers admonished mental health professionals to be cautious about disputing religious beliefs and values that clients and their families might have.

In 1986 then Cardinal Ratzinger (later Pope Emeritus Benedict XVI) issued a “Letter to the Bishops of the Catholic Church on the Pastoral Care of Homosexual Persons” where he proclaimed that “homosexuals are disordered in their nature, and evil in their love.” In a later letter regarding the legal recognition of same sex unions, he reminded Catholic politicians that it was one thing to tolerate evil (i.e., homosexual acts) but clearly another thing altogether to legitimize evil (e.g., rights for cohabitating homosexuals). It is no wonder that gays and lesbians in this particular institution feel as though they must live lives in an unauthentic way, many seek out other religious or spiritual practices to replace their faith or origin, and some come to the conclusion that

religion and spirituality are meaningless and have no place or meaning in their lives. (Lynch, 1996; Ratzinger, 1986)

For example, Barret and Barzan (1996) cited from their clinical work the experience of “Mike” a young man in the latter stages of AIDS who returned to his church of origin to attempt reconciliation with his childhood faith. He was nearing death and was seeking spiritual and emotional support. After approaching his minister, he was told that he would be welcomed into the church only after renouncing his homosexuality. Furthermore, he must cut off all contact from the “homosexual world.” Only after acquiescing to these demands would the minister and the church “consider helping” him. Having been rejected by the very institution that could have nurtured him during his final days, he succumbed to guilt and feelings of rejection, fearing that he no longer had any hope of eternal life.

It is important to note that not all religious organizations hold LGBT populations at an arm’s length. In response partly to heteronormative and unwelcoming faith organizations, GLBT affirming nontraditional faiths groups have developed and as a result, many gay men may more readily integrate their sexual orientation with their spiritual or religious beliefs. Straight allies in these groups are helpful in this process as well (Borgman, 2009). Examples of these organizations include Dignity (LGB Catholics), Lutherans Concerned, Integrity (LGB Episcopalians), and Metropolitan Community Church (MCC). Additionally, there are several more traditionally based churches that are inclusive with LGBT populations: United Churches of Christ, Unitarian Universalist, and Quaker (Friends) congregations. (Lease, Horn, & Noffsinger-Frazier, 2005;

Rodriguez & Ouellette, 2000; Wagner et al., 1994). Reformed congregations with Judaism also are listed as being more welcoming (Blando, 2009).

For example, Rodriguez and Ouellette (2000) explored the influence of a gay-positive church (MCC/NY) on the integration of homosexual and religious identities of their members. They noted that gay-friendly and gay-positive church are not synonymous. Gay-friendly congregations welcome LGBT but do not typically address the religious and spiritual needs inherently found in these communities. Many of these churches are rooted in denominational structures that view homosexual behavior as sin. Gay-positive churches are formal institutions that preach positive messages surrounding homosexuality and minister specifically to LGBT communities. Data collected revealed that a majority of participants self-reported that they had successfully integrated their homosexual and religious orientations. This integration was related to higher commitments in involvement as members, attending more services, participation in more church activities and ministries, and more years of church attendance.

Some non-Judeo-Christian-Islamic faiths are also more affirming of sexual minorities than their Westernized counterparts (Blando, 2009; Smith & Horne, 2007). Smith and Horne (2007) sought to determine experiences of LGBT persons in the coming out process; that is, comparing those LGBT Earth-spirited persons who had come out initially in a Judeo-Christian context with those who came out in an Earth-spirited environment. Researchers also wanted to assess how initial membership in a LGBT affirming non-traditional faith compared to that of a more traditionally oriented faith. Finally, the study was interested in documenting whether these Earth based faiths

were actually LGBT affirming by noting the presence of LGBT affirming behaviors in these faith communities.

The authors concluded that Earth–spirited faiths appeared to offer an affirming environment to LGBT members. Many of these faiths actively welcomed and supported LGBT peoples. Participants who had initially come out in a traditionally oriented Judeo-Christian faith self-reported statistically significantly more internal conflict in this process than those who had done so in an Earth-spirited faith. Researchers noted that because these nontraditional communities offer a viable option to the LGBT population, it would be helpful to understand the process that initiates go through in order to become members of these communities. They further noted that not all religious denominations are disaffirming of LGBT issues. In fact, they surmised that as LGBT individuals open up about their spiritual lives and become more visible, many denominations will develop strategies to become more welcoming and inclusive.

Stigma and Access to Medical Care and Health Services

Wilkerson (1994) takes on issues related to gay related stigma and the ways in which medical science expresses, perpetuates, and legitimizes homophobic values. The author presents several aspects that illustrate the moral authority of medicine that can serve to oppress MSM and those living with HIV/AIDS. For example, health care providers (e.g., dentists) have been reluctant or have even refused to treat those living with HIV/AIDS for either fear of infection or because they believed HIV-positive patients did not deserve to access their services. Also, she documents the struggles that nontraditional families have had in the area of visitation rights and decision-making powers in regards to health care.

Secondly, she posits that moralistic assumptions are often presented as medical fact. The use of language to convey moralistic and fear-based pronouncements further polarize both clients and communities as this can lead to placing “sin, shame, and blame” on those infected with HIV. It is not specific behavioral practices but specific groups of people that are emphasized when discussing HIV transmissions. This conceptualization can then carry over into media representation and medical theory and conceptualization of HIV/AIDS. As an example, she reminds us that in the early years of the AIDS epidemic risk and transmission were discussed in terms of specific risk groups or identities instead of behavioral practices. This set up an Us (i.e., not at risk) versus Them (i.e., Others at risk) mentality that is still prevalent today.

Lastly, medicine has an exalted status in society because it is equated with science. The perception is that this “science” is unbiased, detached, and objective in its practice and thus often unchallenged. Wilkerson states that scientific proclamations often serve the interests of those powerful in our society. For example, medical language has been used to argue that gays and lesbians should not be allowed to serve in the military and to censor sexuality curriculum that is sensitive to the needs of gay and lesbian youth. She concludes that in order to overcome medical homophobia, the mistreatment of people with HIV/AIDS by health care personnel must be exposed, the use of medical language to vilify same sex practices must be opposed, and medical institutions should be held to principles of social justice.

People living with chronic illnesses experience stigma in association with their illnesses. Earnshaw and Quinn (2011) posited that internalized and experienced stigma would predict increased anticipated stigma in health care settings. They also

hypothesized that these stigmas synergistically would result in decreased care access and also decreased quality of life. This online study, Body-Mind Connection, explored the impact of health related stigma for 187 participants living with various chronic illnesses.

Their findings strongly suggest that participants who perceived that they had experienced stigma in a health-related setting also internalized stigmatizing attitudes more. Greater anticipated stigma was also related to experienced and internalized stigmas. Those who internalized stigmatizing attitudes more accessed health care services less often and had a lower quality of life. That is, not only was physical health affected by stigma but also their overall satisfaction with life. The authors suggested that health care professionals would benefit from interventions designed to reduce stereotyping and prejudiced and discriminating attitudes and behaviors that were multi-approach oriented. They further suggested that assisting patients in ways to reduce internalized stigma and increasing access to care would be the best way to address internalized and anticipated stigma, which in turn would improve their quality of life and increase their access of care.

A lack of trust in health care providers and the government can act as a barrier to health services for HIV-positive individuals. Whetten et al. (2008) interviewed a cohort of 611 HIV-positive individuals from five states in the Deep South to examine trust with both health care providers and the government. Researchers were interested in both health service usage and subsequent health outcomes. They additionally explored racial differences associated with levels of trust.

Nearly 23% of minority respondents and 11% of nonminorities indicated that they believed that the government created HIV to kill off minorities. Additionally, more than half of minority participants and one third of nonminorities indicated that information about HIV/AIDS was being held back from the public. The following were statistically significant ($P < .001$): minority participants were more likely to believe that HIV/AIDS was a punishment from God, minority respondents also were more likely to believe the HIV was created by the government, and HIV information was being withheld. Ten percent of minority respondents did not trust their health care providers to give them adequate care. Researchers were surprised to learn that nonminority groups were distrustful of healthcare providers and the government. That is, for both minority and nonminorities, being distrustful of health care providers and their government they were less likely to use clinics, more apt to use emergency room services, less likely to use antiretroviral therapies, and more likely to report both poor physical and mental health.

Rahmati-Najarkolaei et al. (2010) wanted to better understand the perceptions and experiences of HIV patients in regards to their healthcare providers. Specifically, they were interested in the stigmatizing attitudes (perceived and enacted) and behaviors of health professionals charged with patient care. Semistructured interviews were held with 69 HIV patients purposely selected for this qualitative study. Participants reported experiencing stigma and discrimination from their providers. Participants perceived that the stigma they experienced was a result of health care professional's fear of being infected and additionally that provider views on the causes of HIV infection (e.g., sexual orientation, sex work, drug use) influenced how they as patients were treated. Provider religiosity related to sin was mentioned by patients as being an indicator or stigma or

discrimination. Stigma was experienced in a variety of ways: denied treatment, differential care, excessive precautionary measures, and through humiliation and verbal abuse. Health seeking behaviors of these patients were impacted by perceived HIV stigma in a variety of ways: delay or avoidance of care, nondisclosure of their HIV status, and seeking out alternative healing therapies (i.e., spiritual healing). Participants also reported the following psychological responses to stigma: low motivation to staying healthy, low self-esteem, anger directed towards their providers, and emotional distress.

Researchers did note that participants experienced higher quality of care from providers who had been accessed because of a direct referral from an HIV clinic. These providers were viewed as being better informed and educated about HIV and HIV care. Participants consistently reported that they received poor care from dentists. Here it was surmised that dentists have a higher fear of contracting HIV through occupational related risk factors than other medical personnel. Researchers suggested that through enacting universal precautions measures should reduce stigma. They also recommended that agencies strengthen training programs by including stigma-reduction modules as part of overall programming for health care professionals.

In a similar vein, Sayles, Ryan, Silver, Sarkisin, and Cunningham (2007) explored the impact of stigma in healthcare related settings from the perspective of 48 HIV positive participants in the Los Angeles, CA area. Their qualitative designed study used focus groups to generate ideas and real life examples related to HIV stigma and how this might influence the health and the health care services used by these participants. Their data analysis revealed four key domains of HIV stigma from their

sample: blame and stereotypes of HIV, fears of being contaminated, negotiating disclosure of their HIV status, and renegotiation of social contracts.

All focus groups reported stigmatized experiences related to the health care communities they accessed. Only in HIV specialty care did some of these participants feel free to be open about their HIV status. Participants reported that they did not always disclose their HIV status to medical personnel because they anticipated stigma in these instances. As a result of nondisclosure, their medical care could be compromised.

Participants also reported that at times they perceived that the care they received was suboptimal because they were HIV positive. However, those health service providers who specialized in HIV care were reported favorably. Participants reported fewer instances of refusal of care, inappropriate comments, and provision of lower quality service.

Participants reported that they often perceived that the medical professionals responsible for their care feared being contaminated by their illness. Medical personnel should already be informed and educated as to HIV and transmission risk. Many reported excessive precautionary measures used for routine medical testing and examinations. Study participants became adept at noticing subtle indications of behaviors they perceived as being stigma related.

Researchers also noted that participants reported that physical changes, those resulting from HIV infection or from HIV related medicines, contributed to stigma. For example, the visual evidence of physical wasting, Kaposi's Sarcoma, lypodystrophy, and

lipoatrophy were listed. In these instances participants did not feel that had any choice in whether or not they wanted to disclose or not. These were things they could not hide. These changes in fat distribution (i.e., lypodystrophy and lipoatrophy) were cited as influencing patient decisions on whether to begin or even stop taking antiretroviral drug therapy.

Efforts have been made to increase access to free HIV testing and to antiretroviral therapies in China. In 2003 Chinese governmental officials launched a national policy entitled “Four Free and One Care.” This policy increased HIV testing and brought large numbers of people into HIV related care. Researchers (Li et al., 2013) conducted a randomized controlled trial whose aim was to reduce health care providers’ stigmatizing behaviors towards people living with HIV. The intervention, White Coat, Warm Heart, used the diffusion of innovation theory as its behavioral-level component. Institutional level barriers were addressed by the provision of universal precaution supplies to all participating hospitals. The intervention was conducted in 40 county level hospitals in two provinces. Hospitals were randomized into either intervention or control groups. In those locations selected for intervention, providers were asked to nominate coworkers who were considered to be influential. These popular opinion leaders attended training sessions that covered universal precaution techniques, providing better patient – provider communication, stigma reduction, action and efforts in the care of patients, overcoming challenges, and building a better medical environment. Both intervention and control arms of this study received information related to medical procedure safety and universal precaution supplies.

The intervention group showed significant positive change in the reduction of prejudicial attitudes towards those living with HIV, reduced avoidance behaviors, and increased perceived structural support towards providers at both 6 months and 12 months. Researchers reported that this success was dependent upon the development of the intervention message, focusing on occupational safety and personal protection, identification of popular opinion leaders, and improving skills related to communication.

Chesney and Smith (1999) discussed the impact that HIV/AIDS stigma has on HIV testing and care. They posit that those engaged in high risk behaviors cited the stigma associated with HIV/AIDS as a factor that caused them to delay HIV testing or to forgo it all together. As an example, MSM feared that test results would be used against them in some way or that a HIV positive test result would affect relationships. MSM feared the discrimination that people living with HIV experience. HIV/AIDS stigma also influenced the type of HIV testing used. Those at risk for HIV are more likely to submit to testing when it is offered anonymously rather than confidentially. In fact, mandatory reporting of positive test results has resulted in a decline of those at risk seeking testing. They cited a survey of MSM conducted to ascertain reasons why they did not want to be tested. A commonly held reason was that MSM did not want the state health department to know if they have tested positive. MSM who are more apt to decline testing are more likely to be HIV positive. Early testing is important as this often leads to early treatment and changes in behavior that will reduce the risk of exposing others to infection. Simply put, knowing one's own HIV status is the first step to better health outcomes and it is also the first step in preventing others from being infected.

Rao, Kekwaletswe, Hosek, Martinez, and Rodriquez, (2007) explored barriers to HAART medication adherence that urban youth faced. Twenty-five youth (ages between 17-25) predominately ethnic and racial minorities participated in a series of focus groups that explored their attitudes and experiences with medication adherence. Topics explored were: invulnerability, medication side effects, patient-provider relationship, lifestyle factors, substance use, stigma, HIV status disclosure, and psychological factors. Almost half (48%) responded that they did not readily admit to their providers when they skipped doses of their medications. Similarly, participants admitted skipping doses for fear that someone (family, friends) might discover their HIV status. For example, several youth described having to use separate eating utensils at home; one youth describing having his grandmother write his name on his dishes and utensils as not to mix these with others. Another participant revealed he was kicked out of the house after his mother discovered his HIV-positive status. Participants, overall, preferred to keep their HIV status a secret. As such, many described their efforts to hide their medications from others. This often resulted in elaborate concealment and lifestyle adjustments in order to keep their status and medications under wraps. Lastly, participants described depressive episodes as a barrier to medical compliance.

Qualitative Research in Public Health

The dominant research design in public health is usually quantitative in nature. However, qualitative approaches offer insight and understanding as well. Why is qualitative research important to the discipline of public health? There are many ways in which to answer this question. The following thoughts are offered for consideration. Popay and Williams (1996) look back in history to remind us that public health and

epidemiology emerged as disciplines that were linked to early 19th century social reforms. These complementary disciplines developed out of necessity as urbanization and industrialization grew and from health problems associated with a new and rapidly changing society. Public health initiatives advocated social reform. Public health soon became medicalized as epidemiology and medical science came to dominate the scene using bio-scientific methodology. Researchers noted that public health focused so acutely on what was “downstream” in such a way as to lose sight of what was taking place “up in the river.” In short, public health research took on a largely quantitative stance that seemed to be better suited to the types of research questions developed at that time in a medicalized model of illness.

Quantitative and qualitative research approaches are often thought to be diametrically opposed to one another, quantitative research is often characterized as being objective, “hard” science, and measurable while qualitative research is cast as being subjective, “soft” science (i.e., fuzzy) and largely interpretive in nature. In fact these two approaches are deemed antithetical to one another. Nothing could be further from the truth. Each approach can actually complement the other. For example, Pope and Mays (1995) propose several ways in which qualitative techniques can complement quantitative research approaches.

First of all, qualitative descriptive research is a vital first step in the development of quantitative research. This is especially true in areas of research where there is a lack in general information. In this case, qualitative techniques can provide rich descriptive accounts that give a broader sense of understanding or informational context of a particular situation, behavior, or population of interest.

Qualitative research may also be used to supplement quantitative work. Most often, this can be done by a triangulation process, that is, where multiple (at least three different methods) are used to provide corroborating evidence. Here researchers will be attuned to the different types of answers given from the differing methods as they access different levels of knowledge. Qualitative research used in this setting can help paint a wider picture of the topic of interest. Qualitative research can help “flesh out” a bare bones statistical quantitative foundation.

Lastly, qualitative research complements quantitative work “by exploring complex phenomena not amenable to quantitative research” (Pope & Mays, 1995, p.44). They posit that this approach may be especially useful when looking at health services in times of change (i.e., policy) or when assessing change from the point of view from patients and health professionals affected. For example, patients might be assessed to discover how their health care experience changed when health care providers initiated new patient best practice guidelines in a clinical setting. Researchers may be interested in the positive and negative aspects of this change in interaction from a professional change in influence.

Qualitative research can increase our understanding of the interplay between individuals and their social environment (Popay & Williams, 1996). No longer are individuals viewed as passively reactive to their environments, many now subscribe to a more transactional model relationship. A constantly adaptive person lives in a constantly changing environment. Individuals construct meaning in their lives according to the various lifeworlds that they inhabit (Asp & Fagerberg, 2005). Qualitative research can help us understand these particular lifeworlds that individuals operate from and the

importance that context, history, and coping strategies play in the lives of these individuals (Faltermaier, 1997; Kearney, 2001; Popay & Williams, 1996). Understanding these specific cultural products may be key to the development of more effective public health promotional activities.

Community health promotions and research are moving toward a more participatory action research (PAR) stance. For example, there is shared ownership of research projects between researchers and the community of interest, community analysis of community problems, and the research orients itself to community action and change (Kemmis & McTaggart, 2005; Meadows, Lagendyk, Thurston, & Eisner, 2003). PAR can initiate communicative spaces that marginalized populations desperately need. Community's disproportionately affected by specific health issues can become actively involved in identification, formulation, and course of action related to health issues. PAR will assist communities in studying, reframing, and reconstructing various socially constructed health practices. Qualitative research approaches are useful in PAR, for example quantitative research will tell you how many MSM in rural Appalachia participate in unsafe sexual practices. Qualitative research will help to illuminate the thought processes that MSM operate from when negotiating from safe to unsafe sexual practices, even though they know they are potentially putting their health and the health of their sexual partners at risk. Quantitative research will tell you how many MSM in rural Appalachia live with HIV/AIDS; qualitative inquiry will tell you what it means to live with HIV/AIDS in a rural setting and the many ways that this disease affects their daily lives (Faltermaier, 1997). Qualitative methods will tell you how many MSM access health services in their communities, qualitative inquiry will tell you the

challenges and concerns that they face in accessing care in this setting. (Popay & Williams, 1996).

Qualitative Methods in Community Health

The decision to choose a qualitative research design over a quantitative design is both philosophically and methodologically based. The researcher's particular beliefs and assumptions about the world do not fit a post positivist worldview. Traditional research (i.e., positivist/post positivist) operates from working assumption that the nature of reality is singular and tangible. This paradigm is deterministic, and causality is key to understanding how things operate on a system level. In other words, action causes or produces reaction or effects and outcomes, and these outcomes predict yet future events and conditions. Generalization of findings are broadly applied and considered to be time and context free. Knowledge is considered objective, that is, the knower and the known are independent of one another. Lastly, research is considered value free. These are the assumptions of quantitative methodology.

This approach is contrasted with the researcher's worldview. The researcher's approach assumes that there are multiple realities that are socially constructed and holistic in nature. In this paradigm, not all behaviors or health events are necessarily bound to one singular and knowable cause. That is, viewing all things as being in constant motion or shaping, it is often impossible to separate causes from effects. Generalization of research findings are time and context bound, no broad generalizations are possible. Knowledge is ultimately subjective in nature, being that the knower and known interact with one another in such a way to be inseparable. Scientific

inquiry is laden with values (Glesne & Peshkin, 1992; Lincoln & Guba, 1985). This is qualitative paradigm on which this research is based.

The researcher felt it is important to note these philosophical underpinnings as he embarked on this research project. These assumptions influence research practice and also give voice as to why the researcher chose to go in this particular direction. It is in line with qualitative methodology. That is, because inquiry is value laden, the researcher has an obligation to acknowledge that his interpretations come from a specific historical and culturally situated standpoint. To not do so would be dishonest. The researcher's operational paradigm is influenced by social constructivist and advocacy or participatory elements. Borrowing from social constructivism, the researcher assumes that meaning is subjectively constructed by all as we interact with the world around us, we interpret our world through the culture(s) that we were born into (historical and social contexts), and that meaning is always socially constructed through our interactions with others. Advocacy and participatory approaches towards research insist that research should be politically oriented. This can be accomplished by focusing on issues and needs experienced by populations that are marginalized or disenfranchised. Research can illuminate challenges and suggest an action agenda. Advocacy gives voice to groups that are often constrained by dominant culture values, language, and inequities in political power. Participatory inquiry works with others rather than for others in collaborative endeavors. (Creswell, 2003)

Types of Qualitative Research

There are a number of ways that qualitatively minded researchers can approach their research. Examples include grounded theory, ethnography, and narrative description. A grounded theory approach would attempt to devise a theoretical construct from the views of participants. According to Charmaz (2005) crucial points for this approach are:

- (a) theorizing is an activity;
- (b) grounded theory methods provide a way to proceed with this activity ;
- (c) the research problem and the researcher's unfolding interest shape the *content* of this activity, not the method; and
- (d) the products of theorizing reflect how researchers acted on these points (p. 511).

Another approach to research can be defined as ethnography. Ethnography entails describing and interpreting a cultural or social group. Here the researcher examines a cultural group's behaviors, customs, and ways of life. Group beliefs, values, and attitudes are uncovered in the process. It takes on many forms: critical, performance, public, auto, reflexive, native, literary, or personal narratives. (Dieser, 2006).

Another approach to research can be defined as narrative description. This entails describing individual and group depictions of particular life events. For our purposes what I sought to describe were the lived experiences of HIV positive MSM

living in rural Appalachia. I sought to understand how they navigate through available health care services and how they experience life in a largely heteronormative society.

Descriptive narrative inquiry seeks to understand how those participating explain their current situations and how they construct meaning from life events. This approach also requires that the researcher recognizes first and foremost that what has been shared is someone's life story. It is their story first of all, not just information to be described, transformed, and analyzed. These narratives speak from very specific historical and culturally situated standpoints. The researcher is in close contact with the data and it is to be expected that the data influence the point of view of the researcher and, simultaneously, that the data are interpreted and transformed by the investigator. However, the descriptions themselves must always truthfully convey events and perspectives as they are told. In other words, this type of research acknowledges the futility of trying to speak from a "god's eye point of view" in regards to an outsider looking in omniscient or objective stance. I will be researching from a very particular race, gender, and sexual orientation identity location (Foley & Valenzuela, 2005).

Most qualitative researchers benefit from having an insider status role from the populations they are researching. If they are not a part of the particular community of study, they will need a credible informant to legitimize their study. The researcher does claim insider status with this particular study group: HIV-positive MSM who live in rural Appalachia. In fact, as a researcher, he feels a special sense of responsibility to this group that he self-identifies with (i.e., MSM from rural Appalachia). It is his position that this community lacks voice, social status, and representation in society at large, in particular in Appalachia. Like many of these MSM the researcher grew up in rural

Appalachia having similar life experience contexts regarding to rural social mores, religiosity, and heteronormativity. The researcher can identify with HIV-positive MSM through his own personal experiences with HIV. The researcher has personally known and lost many friends and paramours from HIV/AIDS, where the virus or disease was either directly or indirectly associated with their deaths. There have been times that the researcher had to reflect on his own HIV status and confront the stigma associated with seeking testing or medical care from local health care providers. These MSM carry multiple stigmas with them on a daily basis. There is the social stigma of being identified as a homophile in an overwhelming intolerant and hostile climate. The researcher shares this stigmatized identity, still having to navigate through it on a daily basis. Even in a college town, he still finds Appalachia to be a dangerous place for a gay man. The men in this research also carry the social stigma associated with HIV/AIDS. And for many, they carry yet another stigma if they are HIV-positive MSM of color. This racism not only comes from without the gay community but is easily found within the LGBT community at large.

Sandelowski (2000) described descriptive studies as those sorts of inquiries that address questions of specific relevance to questions such as:

- What are the concerns that people have about a particular life event?
- What are their feelings or attitudes towards these events?
- What are the reasons that people have for using or not using a particular service (e.g., health services)
- Who uses a particular service and how do they access it?

Descriptive research Sandelowski (1991) further indicates that investigators may use this form of inquiry as they seek to describe lived experiences nested within a particular life event, the conditions in which individual stories may be similar or dissimilar with one another in relations to similar life episodes, how these descriptions relate to what is already known culturally, and how these life events might serve in how the individual constructs meaning in the telling of their lives.

Examples of Studies with Qualitative Methods

For example, Zukoski and Thorburn (2009) documented the experiences of HIV-positive individuals living in a predominantly rural area with low HIV prevalence. Specifically, researchers wanted to identify HIV related stigma through the lives of those living with the disease in their respective rural communities. Sixteen participants were recruited through physician referrals and flyers distributed through physician offices. Interviews consisted of open-ended questions and probes. The guide went through several revisions with the final instrument addressing topics such as stigma, issues of trust relating to health care providers, discriminatory practices in accessing healthcare, and health information literacy. Researchers gleaned three main themes relating to stigma and discrimination from interview data. Participants experienced social rejection from family, friends, and others due to their HIV serostatus. They further described rules of social contact where interactions were limited due to fears of HIV transmission and infection. Individuals also described instances where they were treated differently because of their HIV.

Similarly in healthcare settings, participants reported that many providers behaved as though they were afraid of touching the participants. Many providers used added barrier protection in the examination of these individuals. Healthcare providers were also described as discouraging treatment or outright refusal in treatment of participants. Patients also reported that providers were often rude in their dealings with them or that they were treated differentially by healthcare personnel. Individuals responded to these stigmatizing experiences in a variety of ways: anger, discouragement, shame, and nondisclosure of their HIV status to others. Some respondents coped by rationalizing the attitudes and behaviors of those perpetuating these negative attitudes, some by physically isolating themselves from others, and lastly some responded by seeking out positive emotional support.

Internalized homophobia as experienced by MSM has consequences in the way that MSM relate to one another in a social setting. Whittier (1997) recounts through observation and interviews the disunity and social conflict among MSM in a small southern town. This descriptive qualitative study relied on observations and casual conversations that the author had with approximately 170 men over a 2-year period. Local networking and snowballing were the means by which participants provided entrance into the social environment in this rural southern town. Respondents characterized the local gay community in terms of “distrust” and general characterizations of MSM as being “mean and nasty.” The author determined that one of the more prevailing attitudes that might contribute to untrustworthiness and the nastiness described above was the animosity between those MSM who were “out” and those who were “closeted.” Those MSM who were closeted felt that those who were out drew unneeded attention to

sexual identity and activity. That is, they upset the status quo of hiding sexuality. Conversely, the “out” MSM felt that being secretive and having sex in semipublic spaces and cruising areas frequented by closeted MSM reflected badly on the gay community. This animosity is fueled by internalized heterosexism and norms. Internalizing these anti-homosexual attitudes creates a gendered hierarchy of status based upon oppressive masculinity. For example, MSM in this study often were divided along the lines of either being considered “butch” or “nelly”. Butch MSM followed a more heterosexist view on masculinity in appearance and mannerisms. Nelly MSM are described as being overtly effeminate in appearance and behavior. These men are also described as “screaming queens” and “sissies.” The researcher noted that MSM reported that family and religious beliefs were the source of many of the homophobic attitudes they experience.

CHAPTER 3

METHODS

Introduction

Data for this project were collected via semistructured, face-to-face interviews with 23 HIV-positive MSM in northeastern Tennessee (n=9), western North Carolina (n=13), and northwestern South Carolina (n=1). The objectives of the project were to describe holistically the lived experiences of HIV-positive men living in rural Appalachia. More specifically, the researcher wanted to understand and describe aspects of their culture (i.e., folkways, mores, values, etc.) in the contexts in which they live their everyday lives. Using descriptive narrative the researcher sought to address the influence of HIV/AIDS related stigma in the lives of these men and provide a forum for these men's voices. Specifically, the influence of stigma on delivery and access to health services was explored along with documenting their lived experiences in work and social arenas in the context of being MSM and HIV positive.

Study Setting

The study settings for this study were in South Central Appalachia (Appalachian Regional Commission, n.d; Pollard, 2003, 2005). Within this region, two support groups serve HIV-positive men and women. Entree' to these two groups provided the participants for the current research project. Not only did the researcher observe the group processes for over 2 years before initiating the present study, the researcher also participated in group discussions and other related activities within these groups.

Site One: POZ HIV Support Group, Northeastern Tennessee

Site number one was located in northeastern, Tennessee. The city has developed and grown into a city of nearly 63,182 (U.S. Census Bureau, n.d.a) and is home to a regional University and College of Medicine. Straddling a three-county area, this city is the largest city in the Tri-Cities metropolitan area and the fourth largest metropolitan area in Tennessee (MSA projections 500,538) (Johnson City Chamber of Commerce, n.d.). The HIV specialty clinic that the majority of participants used serves approximately 436 HIV/AIDS clients from northeast Tennessee, southwest Virginia, and western North Carolina (L. Bynum, personal communication, October 4, 2013).

Site Two: Western North Carolina

The second site was located in western North Carolina,boasts a population of approximately 72,789 (U.S. Census Bureau, n.d.b.), and is home to several historic sites. Site two for this research project included clients from a local ASO who received HIV case management services. The ASO serves approximately 460 HIV/AIDS clients in a 17-county region (J.Smith, personal communication September 23, 2013).

Participant Recruitment

A flyer, approved by the ETSU Institutional Review Board (IRB), was distributed by liaisons at these two organizations. The flyer asked for MSM volunteers to discuss their experiences about using health care services and what it is like to live in rural Appalachia. Those considering participating were given two ways to contact the researcher, via phone number or by email. The flyer also stressed the confidentiality of their information and that a small token of appreciation (e.g., \$5.00 gift card from Wal-

Mart) would be given to study participants at the end of the interview. Please see Appendix A to view a copy of this flyer.

In addition to the flyer, the researcher approached the facilitator of the HIV support group in northeastern Tennessee and asked him to email all the members, past and present, as a means to generate interest and volunteers for this project. The facilitator sent out a mass email to the entire list-serve of members asking for volunteers. The email provided some general information about the researcher and then listed the same content as the IRB approved flyer.

At the western North Carolina site, participants were recruited through the ASO staff about the study and were asked for their assistance in recruiting participants. The director gave his employees permission to contact clients they felt might have an interest in participating and tell them about the project. If at that time, clients indicated they were interested in participating, then with their permission, the principal investigator was given their contact information. No one's health information status was revealed without their verbal consent, and the researcher was able to contact individuals for possible inclusion in the study.

Snowball sampling was also a technique used to recruit interested participants. At both research sites those who participated in the study recommended friends, stating that they would be interested in speaking to the researcher as well. This informal social networking extended the reach of participants to include MSM who did not associate with either the HIV support group, or the ASO.

Interview Procedures

Interview appointments were set up in a variety of ways. Most of the participants in the Tennessee area contacted the researcher through email to set up an appointment. Additionally, the researcher was contacted via phone calls, and some approached directly at meetings. Most of the appointments in the North Carolina area were set up by the staff of the ASO. That is, when they identified a client who was interested, they set up appointments for the researcher. When presenting the project to the staff, the researcher had given them days of the week that he was available to come to North Carolina or the surrounding areas. This was coordinated through their administrative assistant and individual case managers. Here too, emails and phone calls from interested MSM were the case as well. Standard IRB consent procedures were adhered to during this process.

The interviews were conducted from December 2010 through March 2011. In the NE Tennessee area, the interviews were conducted for the most part on the campus of a regional university. This was centrally located for most of those participating and the researcher had access to empty classrooms where conversation could take place uninterrupted. It was important that the men felt at ease in discussing some rather sensitive topics and so the researcher wanted the place of conversation to be quiet and one where there was no foot traffic. IRB requirements related to privacy and confidentiality were followed. For example, the researcher and the participant were alone in classrooms and the doors were locked from the inside. A notice was placed on the outside of the door stating that interviews were being conducted and that there were to be no interruptions. The researcher did venture out to the private home of one

volunteer in the Tennessee area. The interviewee felt more comfortable talking to the researcher in his home. At his residence the researcher and participant were isolated from other family members and had ample opportunity to conduct the interview without interruption or privacy or confidentiality concerns.

The majority of the interviews in North Carolina occurred in the offices of the ASO. The staff always provided a private office where the researcher could conduct the interviews without interruption. As in Tennessee, the researcher did venture out into the surrounding counties and conducted interviews in the homes of participants. The interview from South Carolina took place in his private residence.

Each participant met with the interviewer at a predetermined time, and the interview process began with a brief information introduction. After getting situated in the room and some brief informal conversation, the researcher introduced himself and presented each participant with a written copy of the consent form. They reviewed this item together, discussing the purpose of the interview, how the interview process would work, and possible benefits of this type of research project. Special attention was spent on discussing issues related to confidentiality, and the researcher asked for any questions or concerns related to confidentiality and if there were any, the researcher addressed these. Standard IRB privacy and confidentiality procedures were followed. The researcher assured participants that this project would use minimal identifying information only. They were free to not answer any questions. They were informed that there were no right or wrong answers to these questions; the researcher was seeking their input on these topical matters. Their feedback will be used to better understand the lived experiences of MSM living in rural Appalachia within the context of also being HIV

positive. All interviews would be audio taped with their permission and if at any time an interviewee wanted the researcher to turn off the recorder, the researcher would do so. Anything said “off record” would remain as such.

A waiver of consent was approved by the IRB due to the sensitive nature of the topic and related stigmas associated with being MSM and HIV positive. The researcher had privacy and confidentiality concerns with the research site being located in such a rural area. The overall climate in this area is intolerant towards MSM, and for those who are HIV positive, the researcher wanted to insure that their identities could not be compromised in any way. ETSU’s IRB committee approved oral consent being required for inclusion in this study. All participants received a copy of the consent form for their records. A copy of the informed consent document can be found in Appendix B. Each participant was asked if he wanted to be part of the study.

Demographic Information

Besides qualitative interviews, participants were also asked demographic information prior to the beginning of the interview process. Demographic information obtained included age, race, relationship status, year tested positive for HIV, latest CD4 count, health insurance, and HIV related medications. A copy of this form can be found in Appendix C. A two-page form was administered to participants to gather general demographic information. Demographic data were entered into SPSS statistical software.

Instrument Development

The interview instrument was developed from topics via the literature review process and from the researcher's goal to explore the lived experience of life as lived by MSM in this particular geographic location. Semistructured questions were developed to explore various salient issues and topics discovered and documented in the literature review process.

The following objectives were derived from the literature review related to HIV and MSM stigma in HIV positive men and included in the interview script:

- To explore and describe HIV/AIDS related stigma as experienced by those living with HIV in Appalachia,
- To explore and describe homophobia as experienced by men who have sex with men (MSM) in Appalachia,
- To further understand how stigma may influence health-related outcomes for HIV-positive MSM,
- To provide those HIV-positive MSM in Appalachia a voice, to tell their stories.

It is through these objectives that a descriptive narrative approach was employed. These participants had stories to tell. The sharing of those lived experiences was made meaningful through the interaction between the interviewer and the interviewee. Although it was important to elicit new information for purposes of this research project, the narrative itself was recognized to be important. That is, their words, not just those health-related events described, were paramount. They were the

focus of this project, and their willingness to share helps us to better “make sense” of their lives and to understand them in a greater social context. These descriptive summaries should then be used to produce concepts and theories that could be used to better serve this hidden population. (Hollway & Jefferson, 2000; Sandelowski, 1991, 2000)The questionnaire (see Appendix D) consisted of 74 questions and transition statements from section to section. It also included 38 prompting subquestions that were frequently used to clarify and to specify specific areas the researcher wanted to further explore. Questions and discussions did deviate from this specified process at times, largely depending on statements that participants shared in the course of the interview that sparked new conversation both the researcher and participant pursued. The questionnaire was the outline used to keep this guided conversation on track.

Devised in this manner, these questions allowed participants to express themselves freely and in such a manner as they choose. These questions were used to assess the participant’s subjective experiences (Sandelowski, 2000) in a number of areas;

- Religion,
- Appalachia as culture,
- Social aspects of being MSM and HIV positive,
- Health care access and services, and
- Medical adherence.

Interview Process

The interviews themselves ranged anywhere from 55 minutes to a maximum of 2.5 hours in length. Questions were asked in such a way as to maximize the conversation. That is, the researcher at times adapted the wording of the questions to reflect the language and educational skills of the participant. The participants were not homogenous in educational, linguistic, or social skills. For example, sometimes a question did not resonate with the participant and he would ask for clarification (e.g., what do you mean?), while others would remain silent. Active listening skills dictated that the question or statement be rephrased or expanded in such a way that would elicit a response from the participant. Special attention was taken by the researcher as not to lead volunteers to answer in a particular way.

Sometimes, respondents did not follow the discussion guide prompts. If the conversation deviated from the guide, the investigator allowed this to gain further understanding and to add richness and depth to the topic at hand. Often, as is the case in everyday conversation, the sidetrack discussion came around full circle, back to the original query asked. It was here that the narrative approach to this project allowed participants to share their stories in their own way, allowing them to express themselves according to their life stories. This was consistent for qualitative research methods as it was never to be assumed that all interview participants would follow the same kind of reasoning modality to discuss anything at hand. For example, some individuals would answer a direct question in a way that might not seem logical to the interviewer. Some could not express themselves in a direct way, and thus, the narrative story they shared

gave them a way to process and construct meaning as they understood it. The researcher welcomed this diversity in thought and expression.

Data Collection and Transcription

A two-page pen and paper anonymous selfadministered form was used to gather general demographic information before the interview.

Interview Data

Digitally recorded interviews were transcribed using Dragon Naturally Speaking Software 10 and Sony Digital Voice Editor 3.3. Audio files were transcribed word for word and data were transferred to Word documents. All audio files were transferred from the audio recorder and erased from the recording devices. These mp3 files were stored on a password protected laptop computer.

Interview material such as transcriptions produced did not include the participant's name. Rather all data transcripts and demographic data were assigned a unique date number attached to it. For days where more than one interview was conducted, the date number also included a numerical identifier (e.g., A, B, or C). In the event that in the course of the interview that identifying information was revealed (e.g., when telling about an experience the participants would sometimes use their own names and/or the names of their partners or family members), the researcher masked this revelation by substituting other names not associated with the participant. This was done to further protect a participant's privacy and confidentiality. The researcher generated a separate word processing document for each interview. A cover sheet for each interview documented: interviewer name (i.e., Roger Blackwell), pseudonym

identifying interviewee, date(s) of the interview, interview location, and total number of pages for the interview.

Data Analysis

Demographic Data

Demographic data were analyzed by SPSS (SPSS, 2007) to produce various descriptive statistics, that is, sample size, measures of central tendency, measures of variability, and percentages that were then developed into tabular form. Data were displayed in a variety of ways. For example, demographic information were summarized and displayed in tabular form. Items such as age, race, relationship status, state of residence, etc. were listed in this manner. Additionally, demographic information such as age and years on viral medication were further stratified to tease out additional information.

Qualitative Interview Data

QSR NVivo 9 qualitative data analysis software (NVivo, 2012) was used to organize the data for this project. In particular, the researcher sought a software platform that could assist him in analyzing text, identifying themes, code and categorize information, and sort and locate data segments with relative ease (Creswell & Marietta, 2002).

Coding Process

Group data were sorted into various categories and classifications, in order to discover emergent themes and similarities and/or differences in participants' responses.

A line-by-line analysis of the data was conducted before the data were sorted. First, theme nodes based upon the discussion guide used in the interview were created. The first pass helped condense the data. After this first pass, a further reorganization of the data occurred into five categories; religion, Appalachia, social experiences of being MSM and HIV positive, health care services, medicines and adherence and were developed into nodes that responded to answers from the respondents. Also, at this time, a main node, Other, was created to include newly emerging themes not specifically addressed within the interview script. Examples of this “Other” coding included advocacy, HIV criminal prosecution, illicit drug use, serosorting, and transgender.

An iterative process was used (i.e., labeling, coding) several times, each time looking for ways to further refine the coding process (i.e., subcoding). Also dichotomized codes were created when a yes or no response was possible (e.g., have you ever been refused [medical] treatment because of your HIV status?). Based upon how participants answered these items (i.e., yes or no) the researcher was able to further sort according to their responses and further develop the node tree by use of this subcoding. That is, the text was sorted in a way that explained the participant’s responses. The coding process was completed once it was apparent that the data were sorted into appropriate categories that could be displayed.

Saturation

Saturation of the data set was important to the credibility of this study. The sample size for this research reflected data saturation and also the availability of

participants. All those who were interested and contacted the researcher were interviewed for the study. In fact, the researcher exhausted interested contacts from the Tennessee research site area. That is, no new contacts were available from the site. Additional participants could have been procured from the North Carolina research site; however, after 24 interviews this was not necessary as the researcher began to hear similar stories and patterns. There was redundancy in the information shared. Data collection ceased when replication of information was documented (Bowen, 2008). The researcher concluded that to continue to seek additional participants would have diminishing returns for the study, that is, little would have been added to the data already collected and analyzed.

Node Tree

The resulting node tree was topical in nature and reflected the unfolding conversation and themes identified during the transcription process. Only those nodes used in the current study are listed below. A more complete node hierarchy can be found in Appendix E.

Religion

- Religious Affiliation Past and Present
 - Religious Affiliations Past
 - Current Religious Affiliations
- Current Beliefs
 - Frequency of Prayer Public or Private
 - Frequency of Involvement
- Sexual Identity and Practice
 - Support of Identity
 - No Support of Identity
 - Guilt
 - No Guilt

Appalachia as Culture

- Enculturation
 - Time Frame In Appalachia
 - Always Lived in Appalachia
 - Self-Identification
 - Do Not Identify as Appalachian
 - Define Appalachia
 - How Would They Describe Appalachia to Others
 - Features of Appalachia that Affect Daily Life

Health Care Services

- Health Care Services Used for HIV/AIDS Management
 - Where for Treatment
- Location of Health Care Services
 - Easily Accessible HC Services
 - Not Easily Accessed
 - Concerns at Being Identified at Treatment Establishment
 - No Concerns Being Identified
 - Community Knowledge of HIV Services Offered
 - No Community Knowledge of HIV Related Services
 - Signage and Advertisement of Services
- Distance and Time to Access Health Care Services
 - Distance to HC Service
 - Means of Transportation
 - Transportation Other Than Own Vehicle
 - Transportation Difficulties
 - No Transportation Difficulties
- Experiences with Health Care Professionals
 - Positive Experiences with HC Professionals
 - Tennessee Locations
 - North and South Carolina Locations
 - Negative Past Experiences Because of MSM of HIV/AIDS Status
 - Treated Differently or Badly
 - Not Treated Differently or Badly
 - Refused Treatment
 - Not Refused Treatment
 - Refused Referral
 - No Negative Past Experiences
 - Privacy and Confidentiality in HC Settings
 - No Concerns about Privacy or Confidentiality
 - MSM or HIV/AIDS Status Revealed Without Consent
 - Inaccurate Information or Treatment Guidelines
 - No Inaccurate Information/ Treatment Guidelines
 - HC Provider Confronted
 - Adverse Reactions

No Adverse Reactions

HIV/AIDS Related Medicines

- Importance of Antivirals
- Circumstances Related to Beginning to Take ARVs
Initial Reaction When Informed to Begin Taking ARVs
- Alternative Therapies
- Medical Adherence
Missed Dosages
Full Disclosure to Physicians
Not Fully Disclosing
Influence of Others on Adherence
No Influence from Others
Avoidance of Taking Meds around Others

For example, many of the responses were dichotomized into either yes or no categories. These were grouped into their own node responses. Once separated into these groups, it was easy to summarize group findings. Due to dichotomized responses, summaries using dichotomized percentages were presented and then in some instances, those responses were highlighted by use of germane quotes. When quotes were displayed, a numerical identifier was included to differentiate participants from one another.

Data were displayed in a variety of ways. The interview data were summarized according to theme, and quotes were used to highlight salient examples. The preferred method of display was through the use of quotes. Due to the narrative approach participants own words were important to illustrate as much as possible. By using the actual words of the participants, individual voices were allowed to be heard, replete with symbolic meaning, contextual factors, coded language, and emotion. This was life as they have experienced it.

Themes were identified in a variety of ways. First, the interview document specifically raised questions about the types of health care services that participants used. The researcher wanted to document how participants accessed health services and to know more about their experiences with their health care systems. Similarly, questions related to MSM and HIV related stigma were asked and generated rich data for the purpose of this study. Participants freely discussed these themes at length and provided insightful perspectives germane to this project. Lastly, in keeping with a narrative approach, case studies were chosen to illustrate in part the journey that the men had undertaken; that is, to provide a snapshot into the lives of MSM and to give a more cohesive and personalized view of their life in rural Appalachia.

Two interviews were selected for showcasing and for a more in-depth review. The researcher chose these two individuals after reviewing all of the interview transcripts. These two individuals were not chosen as exemplars per se but were selected because they had lived in Appalachia for most of their lives and also because of the richness of information that they shared during the course of the interview. The researcher wanted to present a brief glimpse into their lives and as much as possible the comparison of similarities and differences in their experiences. This study was focused on describing the experiences of HIV positive MSM and by including these case studies. The researcher intentionally wanted to further personalize the topic and give a more detailed context in which all of these men could be considered.

Themes

Three major themes emerged from the interview data. Results data were grouped according to the following themes: seeking health services, stigma, and

personal journey. By organizing the data in this manner, a clearer picture was developed that can assist health professionals in understanding the experiences that MSM and MSM who are HIV positive may influence accessing health care services or might affect quality of care that many of these men receive.

CHAPTER 4

RESULTS

Introduction

Twenty-four men, (age ranging from 26 to 71, mean age 46 yrs \pm 11.6) consented to the interview process. One MSM identified as being in transition male to female (MTF). One interview was unable to be transcribed due to excessive background noise interference; therefore, interview data are presented on 23 men.

Demographic Information

Table 1 describes demographic information gathered about the participants. A little over half of participants were from the western North Carolina area (58%) with most others residing in northeastern Tennessee (37.5%) and one from northwestern South Carolina. MSM were overwhelmingly White (87%), the remainder being of African American decent. The majority of MSM had attended or graduated from college with at least an undergraduate degree (79%), half (50%) identified as being single at the time of the interview, and 29 % reported as being in a same sex relationship. Please refer to Table 1.

Table 1.

Descriptive Characteristics of Study Participants, *N*=24

Variable	Categories	N	%
Age	Under 30	3	12.50
	30 to 39	3	12.50
	40 to 49	8	33.33
	50 to 59	8	33.33
	Over 60	2	8.34
Race	Black	3	12.50
	White	21	87.50
State of Residence	North Carolina	14	58.30
	South Carolina	1	4.20
	Tennessee	9	37.50
Relationship Status	Single, No Relationship	12	50.00
	Divorced, Opposite-Sex Partner	4	16.70
	Widowed, Opposite-Sex Partner	1	4.20
	Same-Sex Partner Relationship	7	29.10
Education Level	High School	2	8.33
	College (Undergraduate)	19	79.17
	Graduate or Professional	3	12.50
HIV Status	HIV+ Asymptomatic	12	50.00
	AIDS	12	50.00
Type of Health Insurance	No Health Insurance	9	37.50
	Medicaid	2	8.33
	Medicare	5	20.84
	Veteran's Affairs (VA) Benefits	2	8.33
	Private Insurance	6	25.00
Years on Antiviral Medication	Less than 5 years	8	33.33
	5 to 10 years	7	29.17
	10 to 20 years	5	20.83
	Over 20 years	4	16.67

Geographic Place and Cultural Identification

This project occurred in south central Appalachia with all men currently living in the area. For some (13%, *n*=3), Appalachia is all they have known, they have lived in

the area for all of their lives. For others (52%, n=12), although this is home for them, they did leave at some point, only to return at a later time. And still yet for others (35%, n=8), the area is fairly new experience for them. They shared freely about what this area means to them and how they perceive Appalachia in regards to being a geographical area, its people, and also to their own cultural self-identifications.

When asked “what does Appalachia mean to you?” their first responses referred to nature or geographic landmarks. They described in great detail the mountains, seasonal changes, scenic vistas they had seen, and marveled at the beauty of the area. They expressed their love and appreciation for the natural beauty of living in “God’s country” and enjoying the peacefulness of their surroundings.

Participants referred to the area as underdeveloped, devoid of social life, not diverse ideologically and racially, heavily steeped in religion, run down, and full of poverty. Appalachia as place associated with poverty was described this way by one participant:

What I think about and this is the honest truth, my mother was raised by her mother, 12 children, 4 of whom died before adulthood. Her father died when she was 8 years old in a tar paper shack...and my granny raised all 12 children. And the story I think of when I think of Appalachia and the way it was in my childhood...my grandmother buying a jar of peanut butter for those 12 kids and dropping it and breaking it and crying...because she didn’t have the money to buy any more. That’s what I think of. (14)

Appalachia was also defined by its inhabitants. For some, the images of people in the area represented the gamut of descriptives that were used by previous researchers who journeyed to the area in the 1960s such as self-sufficient, hardworking, strong family units, Scotch Irish, traditional, and conservative. Individuals were also

described as Southern, welcoming, able to tell wonderful stories, having manners, easy going, proud, private, more giving of themselves, and more spiritually based. One man summed it up by stating:

People that are from here are wonderful people. They're the salt of the earth. But they are what they are. (14)

Area residents were also described in ways that were not positive. Folks were frequently identified as rednecks, hillbillies, close-minded, ignorant, stubborn, threatened by anything outside of what they're used to, Bible thumpers, "back hills", wary of outsiders, slow, homophobic, very White Anglo-Saxon Protestant, and very "Southern Baptist to the bone."

Questions were asked to gauge whether respondents felt as though they were "Appalachian" in the sense of self-identifying culturally with the area, its people, and in some cases the values found in the region. Having lived here all their lives or most of their lives (58%) was a deciding key in identifying with being Appalachian. They reported:

I grew up here; I've been here my entire life, so I'm obviously Appalachian. (2)

Born and raised. I'm proud of my Appalachian heritage. It's very hard to make the two mesh up but I'm incredibly proud of the people I come from. (19)

Well Jeff Foxworthy he talks about being a redneck and I are one. My lifestyle is what I learned in this area. (11)

Conversely, there were those who did not identify as Appalachian. These eight men moved to the area during their adult lives and the fact that they had not been born here was the primary reason they did not self-identify as such. They also cited

differences in language (i.e., accent) and not sharing the dominant religious beliefs of the area as reasons not to consider themselves natives.

Religious Orientation

Participants indicated being involved at least nominally in Christian churches throughout their childhood and early youth. The majority of these churches (91%) are considered evangelical in nature. The majority of these early affiliations were amongst the various denominational sects from a Baptist orientation (61%) with the rest from other denominations such as Methodists, Lutherans, Presbyterians, Adventists, and Pentecostal affiliated congregations. There was a marked difference noted when asked about current beliefs and identifications. Only 1 (4%) out of the 23 had remained with his church of origin (i.e., Methodist), the remaining (96%) (N=22) either switched denominational affiliations (68%), changed religions completely (18%), or indicated that they no longer believed in a deity (14%). Whereas Baptist churches were a large part of their early child and youth formative experiences, not one of these men currently attended or was affiliated with a Baptist church. Many participants (39%) were not connected or involved in any faith community organizations. For those attending churches (30%), the majority (57%) now attended Methodist congregations, with the rest being involved in Roman Catholic, Church of God, and Latter Day Saint (i.e., Mormon) assemblies. Those identifying outside of the Christian perspective (32%) now identified themselves as being; agnostic or atheist (43%) with the remaining decidedly self-identifying as Buddhist (28.5%) or as a practicing Wiccan/Pagan (28.5%).

A little over half (57 %) of participants indicated that they believed that their religious beliefs assisted them in managing HIV/AIDS. Many directly attributed God as the reason for their continued success in living with HIV/AIDS. One respondent declared that:

My mother taught me years ago that a man can go so far...but God can go all the way. (13)

He believed that God had prolonged his life and continually sent people into his life to help him, and also for him to help as well.

Another believed that contracting HIV was “the hand that God dealt me...I’ve been playing it ever since then and I haven’t lost yet.” He was at peace that he had HIV and believed that because God had dealt him this particular circumstance, this was something he could live with.

Personalities other than God (i.e., Judeo Christian Islamic references) were mentioned by MSM as being influential in coping with HIV and their disease progression. One respondent declared that the ministry of angels was important in his life:

I let the angels take care of things. There’s more angels around us than we know and if we just let them go do what they need to do, things will work out. (18)

The personification of a “higher power” was also mentioned:

I have a connection that I feel to that higher power, that energy I’ve never wavered from (19)

I manage my HIV very well. I feel that I should take care of myself as best as I can. I do that on the principle that there is a power greater than myself (22)

What follows is a presentation of the most prevalent themes that emerged from the narratives. These descriptive narratives provided a source of rich data that are displayed via summarization and salient quotes.

Theme: Seeking Health Services

Where for Treatment

Respondents were asked where they received HIV-related care in order to learn about the availability of HIV related health services in the study site area. In the northeast Tennessee region, research participants received treatment for HIV related care at:

- Specialist Clinic for HIV/AIDs in NE Tennessee (n=7)
- Regional Military Medical Center (n=2)

In the Western North Carolina area, participants received services at the following treatment sites:

- Community Health Center in WNC (n=9)
- Specialist Clinic for HIV/AIDS Care (n=3)
- Regional Medical Care Center (n=1)

Lastly, one participant received HIV related care at a Community Health Center. It should be noted that these locations were primarily for HIV related care. Some participants received primary and ancillary care at these locations, while others had a separate general care physician.

Rurality and Health Access to HIV Related Services

The majority of participants reported that their HIV related health care services were located in an easily accessible area. Comments endorsing this view include:

Yes. I live very close to where their offices are located (11)

Very centrally located. If I need to get in, they will get me in. If I need to get in, I could go straight into the emergency room and there's never a wait [speaking of VA facility] (16)

It's all under one roof...dental, health, mental, [and] pharmacy (24)

Some indicated that their health care services were not located in an easily accessible area for them. For many, it was the long drive needed to come from their place of residence to where they received treatment. For others, not having their own means of transportation, the difficulty was navigating area bus lines to get to and from their treatment areas. At times, the bus routes and operating times did not coincide with their work schedules. For some, catching a bus meant having to walk distances to reach a bus stop or sometimes having to walk on foot because of limited service time and areas covered by bus lines.

Rurality

For these participants living in rural Appalachia means having to always drive. Living in rural areas means that they must drive long distances to work, home, school, church, food, and even for medical care. In regards to distance traveled to access HIV services, participants were evenly divided in their responses. Many reported that they traveled considerable distances to receive care. Their responses include:

It's a 45 minute drive over. Twice every 4 months, you know blood work, then back for a doctor's visit to get the results and have prescriptions refilled (1)

100 miles [one way]. The trip hurt me physically. And then I get there and it's 5 minutes with the doctor...It's a money racket you know. I honestly believe he makes me come out there so that he can get to bill for that visit. (13)

One hour [one way] (12)

The majority of participants had their own vehicles to travel to treatments sites. However, a few commented that transportation was not always consistent. Other means to get to health related appointments included walking, taking the bus, having others take them, and using social service related transportation programs.

The overwhelming majority of interviewees reported that they did not experience any times where they were not able to keep an appointment due to transportation issues. For those few the primary challenge was using local bus line services. Either they were unable to catch the bus at appointed times or bus line service hours were not operational at the times that respondents needed in order to make appointments. For example, certain bus lines discontinued service in some areas of Western North Carolina at 5pm. Therefore, respondents had no way to make a late doctor's appointment or they found themselves without a means to get home after visiting their treatment center.

Challenges in Obtaining Medications

HIV related medications are necessary for many living with HIV/AIDS. HIV medications are also expensive. The majority (57%),n=13 reported that they did not face any hardships in obtaining their medications. However, others (43%) n=10 reported that they did face challenges in receiving their medications. Many reported problems

and issues stemming from medication service providers. For example, insurance providers changed service providers for clients in order to minimize cost expenses. For some, this change in providers resulted in procedural differences in which the new providers would not or could not complete the necessary paperwork for reimbursement. This resulted in delays in processing and mail delivery of medications to patients.

Formulary changes were cited as reason for substitutions made in some medication disbursements. In most cases, substitutions were made, but in other instances medicines were discontinued. Decreased funding in state ADAP programs also resulted in changes to formularies and in some instances patients were dropped from these programs when programs restricted and restructured their requirements for assistance.

Monetary cost was reported as the number one challenge men experienced to obtaining and maintaining their medicines. For some the cost of maintaining insurance itself was a struggle. Coupled with deductibles and copays, one respondent reported that:

Like this past month I had to go 12 days without any of my medications. Cause I could not afford to get them (17)

Another remarked that:

There was a time since I changed jobs...the copays on my meds were \$50 apiece...that was something I couldn't afford. So I stopped taking my meds probably for about a year. (15)

Another cited challenges relating to the Medicare Part D coverage gap (i.e., Medicare doughnut hole) as the reason he could not afford to purchase his HIV medications. At the time of his interview, he was currently 2 days out from being out of

his medications. He could not afford to pay into the program in order to receive his medications. Because he was also receiving social security benefits, he could not access programs such as Ryan White for drug assistance relief.

Quality of Services

Related to accessing quality services the men interviewed 87% (n=20) reported favorably in regards to the quality of care that they were receiving. These men indicated that although the quality of their HIV related care wasn't always the best, it was consistently good and they viewed their care and their corresponding health care professionals in a positive manner. In other words, the care that they received was not the "latest" or not always best practiced based. Many noted the differences in care that they received from larger metropolitan areas, but even then, the care that they received in Appalachia was never described as bad or substandard. Others complained about the amount of "red tape" needed to accomplish things related to care and the delays that this caused. Lack of insurance was cited as a reason that care might not be better, that is, if someone did not have health insurance, then those delivering care could not order the needed medical tests to diagnose certain opportunistic infections common to those PLWA. Those without insurance were perceived to not have as high as a priority in care related issues.

Additionally, it was reported that doctors did not specialize in HIV related care only. That is, HIV care was just a part of their practice and not their specialty. As such, quality of care was not optimal as it was perceived that their physicians did not know the latest best practices in HIV care. Financial constraints placed upon these treatment

centers was reported as a reason why physicians could not specialize in HIV related care only.

Lastly, it was reported that the level of HIV care was a component related to the quality of care received. Participants did not perceive their care as being comprehensive in scope. Specifically, it was reported that:

When I start talking about things just beyond taking my pills everyday and just showing up at the doctors every 3 months, I get a blank stare. (2)

This respondent did not feel that providers were making proper connections in how to better his care. For example, when sent to a nutritionist, the nutritionist asked if he was on food stamps but stopped there. According to the respondent, the nutritionist did not want to talk about the quality of food that he should be eating; only that he had food to eat. The participant believed that a more comprehensive approach was warranted.

Accuracy in Treatment Issues

When asked to recall the quality of HIV related care that MSM were receiving with their local health care providers, respondents were queried as to whether they could recall any instances where they were given incomplete or inaccurate information or treatment guidelines related to managing HIV/AIDS. Over a third (35%) n=8 replied and several comments related to this issue are listed below:

I'm sure I was back in the beginning. But I think everybody was. (18)

Last June when I was in the hospital, they brought me the entire days medication administration in, and I said 'I can't take that [all at once]' [they said] 'well this is what the doctor ordered.' I said 'no, it's not'... so I actually had to do what I call

some informing...education with them...I said 'well write this down, patient refuses, and you call my doctor and you tell her go ahead and clarify for you and that damn pharmacy what I need to take and when.' (11)

I mean it inevitably happens, because you have a whole bunch of people telling you different stuff (5)

I wouldn't call it inaccurate, like at the time I was diagnosed was when they were deciding on the new treatment levels, like when you should get treatment (2)

It would follow that if there are inaccurate treatment guidelines given there might be adverse reactions as a result of following these guidelines. When asked about any remembrance of adverse reactions a few (26%) n=6 responded in these ways:

HIV the virus causes a hell of a lot of reactions in your body...the high blood pressure medication and it started adversely affecting me. My blood pressure went down it was something like 70/40. I thought I was dying...I called over there [clinic]...talked with a nurse and said this is the situation. [She said] 'let me touch base with the doctor and I'll give you a call back. The doctor says if this happens again call, call back' ... I called over to Dr. X's office, talked with the nurse...she didn't say 'I'll check with Dr. X' she said 'can you get here?'...I did. They immediately whacked one of the medications in half, kept me there and did some observing...I know what those kind of situations leads to, has led to people dying (11)

I got some real shitty medicine...he put me on AZT, he had me on Zaret, and it was killing me. I was running into walls, I'd be writing and my arm would just go dead numb. So I got some really bad medical advice from him. (24)

They were doing the different cocktails on me. Didn't realize I was on sulfa drugs. I was allergic to sulfa drugs...I'm not faulting my doctor over this...she was throwing whatever she could at me just to save my life...I'm certainly not blaming anybody, but that may have been bad fiscal policy at the time (21)

I was given a drug called Zaret in 1995 [and] after about three years of horrible numbness, burning and sharp pains in my lower extremities... at the time they just didn't realize it...it was determined that Zaret was the cause of my peripheral neuropathy. (22)

Positive Experiences with Health Care Professionals

Over half (57%) n=13 of respondents reported positive experiences with their providers. Overall, they reported:

All I can say is from what I've seen here in [city of residence]... is remarkable as far as helping people manage you know...I've had the same doctor the whole time. And she's, she's right on it. (8)

My doctor has a lot to do with it. I didn't know anybody other than Joe who had AIDS or HIV. I was still under the impression which is embarrassing that it was a fatal disease...as a gay man I should be more educated...and my doctor was like 'you know what, it's a chronic disease'...it's manageable. (4)

The nurses treated me like gold they all love me. Like I said prisons not all that bad. It could be worse [commenting on his HIV treatment while incarcerated] (7)

Here it's like when I go to the doctor or the therapist; it's like going to see my sister. It is that comfortable. I can't wait to go to the doctor. (17)

Negative experiences with health care professionals were discussed at length by participants as well. These findings are presented under the theme of stigma.

HIV and General Care Issues

While exploring issues related to HIV related care, many participants also shared comments related to general care issues and the communicative process between HIV related health professionals and those of a more primary or general care nature.

Respondents (17%) n=4 were generally positive about the coordination of care between their HIV specialists and their general or primary physicians. They were aware that their providers communicated with one another and there was an effort to deliver better comprehensive care to their clients. They also responded positively to incident where general care physicians would refer them to more specialized HIV related care when they believed that they had offered all they could from their own practice. These general

care physicians recognized that sometimes it was necessary to defer to other physicians who had advanced training in the latest HIV best practices.

However, there was also dissent. Just where does general care end and HIV related care begin? How are patients to really know when to seek care through their HIV related services or to seek assistance through their primary care providers? One participant discussed a recent dilemma:

Well they told me because I'm privately insured that my general care is still handled by my general care. That they [HIV doctors] only handle the HIV stuff. I'm finding well that line is so blurry...when I have a cold do I go to my regular doctor because it's a cold or do I need to go to my infectious disease doctor because it could be something insane like thrush...or is it up to my regular doctor to figure out with labs a week later 'Oh this isn't something that I should handle, you need to call them' and I'm like 'O I am a week worse now. What am I supposed to do there?'...I haven't quite figured it out. (2)

Accessing Health Care Services: Testing Positive for HIV

The researcher's aims were to document how MSM living with HIV accessed health related services regarding their HIV care and the role stigma played in these activities. However, in the course of coding data, **how** these individuals learned that they were HIV positive surfaced. For those who discussed this issue (this was not a question on the discussion guide) they reported the following ways that they discovered that they were HIV positive:

- Serious illness prompting doctor care or hospitalization (n=5)
- Routine screenings (n=7)
- Specifically seeking HIV testing (n=11).

For those who sought out HIV testing, 2 of the 11 did so in response to their partners testing HIV positive. The other nine indicated that HIV testing was something they regularly did. Routine screenings fell under a number of reasons: annual physicals, military, donating blood, changing of insurance carriers, and medical errors.

HIV/AIDS Related Medicines

Study participants and HIV medications spanned a wide gamut of usage, from zero use (n=1) (i.e., not currently on HIV meds) to those who had taken antiviral medications for well over 20 years (n= 4). Please refer to Table 1 for more information related to the breakdown of years on HIV medications. Interview transcriptions revealed themes related to importance of meds, circumstances related to beginning regimen, use of alternative therapies, and challenges related to obtaining medications.

When disclosing the circumstances under which they began taking medications, 43% (n=10) reported that they began taking ARV's from the moment they were first diagnosed as having HIV. These men began immediate ARV treatment because of their low CD4 count at the time of diagnosis. For the rest, these medications came later in the course of their treatment plans.

Men responded in a variety of ways when advised to begin drug related treatment. Some wanted to exert control over their lives and resisted until their T cells dropped to certain low levels (e.g., 350-550 range) to begin treatment. Others did not begin ARV until they were diagnosed with AIDS. Still, many accepted the advice of their health providers. One respondent disclosed his feelings on the matter in this way:

I debated on even starting them or just letting nature take its course. In part because they are so expensive. (1)

Another, debating the value of beginning this course of treatment, considered the advice from his spiritual adviser:

My pastor said that if I wanted to save the world that I would have to be alive to do that. So I was like okay, I guess so [starting med] (2)

One of the interviewees was not currently on antiviral medications. When asked to what he would think if his physician recommended that he start on antivirals he replied:

Actually I can answer that very well... so she [doctor] actually asked me if I wanted to go ahead and start medicines out now or wait for another round. I said let's wait another round. Because if she has hope, I have hope. And she also knows that I leave everything in her hands. She's the one with the knowledge and experience and the training on this (9)

Alternative Therapies

Nearly half 48% (n=11) of the study population have used or experimented with various complementary alternative medicines (CAM) and practices. Seven items were listed by participants: vitamin supplements, medical use of marijuana, herbal supplements, food items, acupuncture, massage therapy, and chiropractic services. Of these items, vitamins and acupuncture were the most popular, followed by medical use of marijuana and herbal supplements.

Varying degrees of success were reported concerning the effectiveness of these items. Medical use of marijuana use was identified as helpful in increasing the appetite, helping with gastrointestinal issues, and for relief of peripheral neuropathy. Massive amounts of vitamins and herbal supplements were perceived to help ward off immune system degradation and fatigue. Furthermore, those taking these items felt these items

were better for them because they were natural. When asked to describe the benefits of massage therapy, one respondent replied:

Acupuncture and massage...if I could afford it I would still see her once a month...the last part of the massage...you start relaxing ...all of a sudden tears just started coming down my temples. What the hell is happening? I'm not sad enough to cry or anything. [She said] 'Your body is releasing a lot of pent up frustration and all that. I can tell when I start massaging anybody through here, sometimes these muscles you can break bricks on.' (11)

He felt that this sort of therapy was beneficial to him. He also reported that at first he was hesitant to try acupuncture because he identified himself as a "child of Western medicine." However, he found benefit in this practice. He reported that acupuncture helped to reduce the stress that was trapped deep inside his body. He claimed it was effective but not as intense as his massage therapy sessions.

About half (52%) n=12 did not incorporate alternative therapies into their treatment plans. Many had not considered this option or were only willing to submit to accepted, proven, and standardized medical products or practices. Most did not see any value to these therapies and in fact, when discussed, responses such as the following were common in this regard:

I kind of like to make fun of those things...I have seen the yoga and the hoop de do (19)

No, I am an MD and I don't believe in hoodoo (6)

Ancillary Care and Support

Participants also accessed local cultural resources that served to support their health seeking behaviors. In fact, MSM turned to various spiritual support systems where they received emotional and spiritual support in coping with their HIV related

illness. Pastoral care was most often reported as being supportive in dealing with HIV and other health related issues:

Any time I need him all I have to do is call him...he comes he brings me the sacrament and [we] have a little chitchat...yes he definitely plays an important part in my life. (11)

There's an open door policy that I can come to speak to her on anything. She's the one person in the church who knows my status... (3)

So I went to him and said so this is where I'm at. He was supportive. He prayed with me and we talked about it...he and I talked several times about my struggles with deciding on medication...he's been very supportive. (2)

Christian-based programs were cited as important for spiritual and emotional support. Specifically programs such as Strength for the Journey, Alcoholics Anonymous, and Narcotics Anonymous were structured programs accessed by study participants. Five area churches were identified as being supportive to same sex orientation and those living with HIV. Three were identified in NE Tennessee and two were mentioned in the W North Carolina areas.

Additionally, respondents accessed chaplains and their services through local hospital systems. Non-Christian based programs such as Gay Spirit Vision (i.e., Native American spirituality) were reported as being very HIV supportive.

Specific Spiritual Practices

Specific spiritual based practices were mentioned by respondents perceived as being beneficial in coping with HIV and other health conditions. They were: meditation, prayer, attending church services, associating with their faith community, positive thoughts, breathing techniques, use of devotional materials, cultivating acceptance, and

use of creative visualizations. Of these, prayer was most often cited, followed by mediation and creative visualizations.

Side Effects

All but two of the respondents reported experiences with medication side effects. One MSM reported not experiencing any adverse side effects related to his meds. The other participant was not currently on antiviral medications and so could not answer to this issue. Everyone had stories to share about their experiences with these various medications. When asked to describe their experiences in taking their medications, it was common to hear reports such as:

Just read the back of any bottle [laughs] (18)

One day you feel pretty good, the next day you feel like you've been run over by a herd of rabid elephants. (11)

Or,

None really that would make me want to stop taking them (15)

MSM reported experiencing a wide variety of side effects they attributed to their medications. Side effects included itching, skin rash, explosive diarrhea, vivid dreams, jaundice, enlarged liver, pain in the liver, change in sleep habits, tunnel vision, changes in their sense of taste and smell, changes in appetite, extreme fatigue, nausea, vomiting, loss of hair, peripheral neuropathy, facial wasting, lipodystrophy, headaches, painful joints, elevated cholesterol, blurred vision, and dryness in the eyes. Many reported that most of these side effects subsided as the body became more adjusted to the medicines, but they also reported that many of these side effects they experienced on a daily basis (e.g., diarrhea, vomiting, neuropathy, changes in lipid profiles). Kaletra,

Zaret, and AZT were the most common ARV's to be discontinued because of the severity of the side effects.

Disclosure to Health Care Professionals on Adherence Issues

The majority of respondents (78%) n=18 reported that they did not withhold any information from their providers in regard to adhering to their drug regimens;

No, she knows. Even if I don't tell her (8)

No, because that's the only way (5)

For those who responded that they sometimes withheld adherence information from their providers the reasons commonly cited were:

I sometimes fudge telling him how many times I haven't taken it...I know I need to take them...I know it upsets him (10)

Because sometimes my body just needs a 48-hour break...I just need to give my body a day or two and by the end of that second day I feel like a million dollars...I just need to be able to feel "me" again, just for a minute (24)

Missed Dosages

Related to full disclosure is the topic of noncompliance in regards to medical usage. Only 13% (n=3) of participants indicated that they had never missed taking their daily HIV medicines. The remaining 87% (n=20) reported a variety of reasons for not consistently taking their medications;

I tend to be out there away from home for long periods of time. With it being a spur of the moment deal, I don't think to take them with me. (8)

Sometimes it's just even though they're my little friends sometimes you just say 'look I'm tired of taking these pills' cause it's almost like eating a meal. (15)

Back in the day when I was having two T cells, I was mentally thinking refusal. I didn't want to take them. Made me nauseous, made me sick. Reminded me of being sick every time I took them. I didn't like it. (19)

Well I do miss at least one a week probably on the average. It's because I don't get to eat right away in the morning. [He sometimes does not have food to eat] (6)

Sometimes when I've just had a mental block, like I'm just tired of it. There's a combination, If I don't take my HIV meds which I know I need to take, that means I don't take my antidepressants. And it didn't take but 2 days...for it to my psyche to sink (10)

Information on how families and friends helped to attenuate feelings of stigma related to HIV was uncovered. It was reported by 26% n=6, that others did not play a part in staying on track with their various medicines. The remaining 74% (n=17) indicated that others did play a part in medication adherence;

If he knows I'm not taking them, either there is a reason why, whether I'm aware of it or not. That might tip him off to me, that I'm about ready to relapse, or I might be depressed or something like that. (8)

Oh I have friends who guilt me (5)

I've got a couple of friends who will remind me I've got to take them...you know the consequences. He appeals to my sense of self responsibility. (10)

My partner if I miss, Tends to tell me that I better not do that again...and then I get the wrath (19)

Theme: Stigma

The participants in this study shared experiences that were stigmatizing in nature. Germane to this project, reports of either experienced or anticipated stigma were collected and classified under the following headings: religion, Appalachia as place or culture, MSM identification, HIV positive status, and health care. The

researcher also included reports of stigma stemming from family members. These were separated into those related to MSM status and HIV positive status.

Religious Stigma Related to Homosexuality

Religious institutions and their corresponding ideologies account for the majority of reports regarding stigmatizing and negative attitudes and behaviors towards the men in this study. These men who had for the most part grown up in the Christian church heard messages from the pulpit that;

I was going to hell; there was just no saving me whatsoever (18)

You were told that you were going to hell if you had homosexual thoughts or you had homosexual activity (3)

I just always heard that you'd go to hell by being gay...it was in the Bible and it wasn't the right thing to do (20)

These messages had a negative impact on their lives. Men struggled with not conforming to these societal standards of heteronormalcy in a variety of ways;

It gave me a good sense of guilt...for being a sinful individual (6)

I was told that I should be stoned to death in this life and burn in hell...I became an alcoholic from believing they were right...took me 20 years of drinking and 10 years of therapy to get over what I believed religiously (14)

The whole religious aspects of my mother's form of Christianity, was kind of imposed on me, really did a number on me psychologically...it was very confusing because the messages that I was receiving from my mother and her religion were basically saying that what I felt was bad (21)

[It made me feel] worthless, it degraded me even more than how I was feeling...I was just more than that. But I couldn't see it at the time. (18)

Appalachia as Culture and Place Stigma Related

MSM described various incidents where their experiences led them to view the area itself (people, beliefs, rurality) to be discrediting towards them. That is, their social identity was reported to be devalued in a variety of ways:

I have to live my life more closeted I think than I would if I was anywhere else. Again, the people who refuse to accept anything different than what they're used to. And to refuse to open their mind to maybe it's something different than what they were taught. (19)

They're afraid of the stigmatism [sic]. They're afraid of being true to who they are. They're afraid what people are gonna say. They're afraid of what consequences may come from their boss, their church... (18)

You know it's heavily, heavily steeped in religion which just affects every aspect of everything...I think the South is always the last to get anything...I still think there is a lot of repression and stigmatization here (12)

Let's see a lady called me last week who was fired from her job because she is a lesbian. A lesbian called me last month because there was a child in her apartment complex who had been sidewalk chalking "queers live here" in front of her apartment. (2)

Participants additionally reported incidences that involved violence. In these cases, individuals and groups were purposely targeting MSM in physically violent ways:

I've had beer bottles thrown at my head while I was walking down the street because I looked too gay walking down the street at night. I've been yelled at. (5)

I think a lot what you might call rednecks come into the city and sometimes if they have absolutely nothing to do, they will haunt areas frequented by gay people just to you know act out their latent homosexuality aggressiveness. (21)

One participant was subjected to public humiliation and ridicule as a result of being implicated in a police sting operation in 2007. In the closet to his family and coworkers, he was concerned of being outed. He reported that the arresting officer said that the incident would not be reported in the paper. However,

It was in the paper, it was in all of the news stations...I had family as far as Florida and North Carolina that saw or heard the news...it was devastating to say the least...my privacy was gone...I saw a therapist for almost 3 years over this...I was just emotionally destroyed and as a result I had several obscene phone calls [made to me] because of that. (1)

MSM Related Stigma

Participants reported a variety of experiences where they had been discredited because they identified as MSM or it was assumed that they were MSM. This was often manifested in the form of verbal assaults such as:

People screaming inappropriate things across the parking lot. People screaming things across the Walmart store that are probably inappropriate, people screaming things at me while I'm walking down the side of the street...and I'm too close to a gay bar so they obviously assume that I'm gay.(2)

Or from another participant:

I got called nigger fag by women younger than my mother holding small children, yelling at me and telling me I was going to hell...teaching that hate to their kids in the street (5)

In another case, verbal slurs turned violent for one participant. He describes the incident this way:

I could see him looking at me, I can hear him mumbling gay slurs at me, calling me a faggot and all that stuff...I confronted him...he gets up in my face thinking he knew something, thinking he could run over the faggot you know? And again I defended myself and I put him down on the ground. (9)

For one participant, admitting that he was gay resulted in his being fired from his job.

This incident occurred over the phone where:

He asked me straight out and I wasn't going to lie...over the phone he says 'I don't think we have a place for you in the company anymore.' (15)

Participants relayed these experiences to the researcher in the context of their adult lives. That is, these negative experiences occurred as adults. However, this was not the case for all those interviewed. One participant recalled his experiences in high school. He reported that he was singled out and bullied by kids on the school bus because he was perceived to be gay. He remembers it this way:

I had a terrible time...I didn't want my parents to know what a hard time I was having so the bus would come, and I would walk to school or catch a ride with one of the teachers...they tormented me on the bus so badly that I couldn't even ride the bus to school. (13)

MSM Family Based Stigma

Participants were stigmatized by their families in various ways. Often it took the form of verbal abuse where one participant received:

A lot of Bible banging, a lot of telling me going to hell, it's an abomination...all the standard lines. You know the result of having an overprotective mother or not being a good Christian. I've heard all the rhetoric. (21)

In other incidents, avoidance was the means where one participant remarked:

Well my oldest brother hasn't talked [to me] since my mom died in 89 (18)

Another participant reported that:

I went to see my aunt in South Carolina and she knows I'm gay. Her husband left the house when I came...he left the house, he didn't want to see me. (4)

Anticipated stigma was reported by one participant where he revealed the reason why he could not be open about his affectional orientation with his family. He feared losing his job. He reported:

I cannot come out to my family...if I were to come out now to my family, then I am stuck here in XX County until I can get out. And my boss is my step dad...he would definitely fire me. (9)

Physical violence, whether as an actual occurrence or threats made, was documented by participants. One participant described an incident that occurred between him and his father:

The most humiliation came from my father as I was sitting on a judge's panel for some contest [gay venue]. My father is as country as cabbage and in his overalls and backwards cap [he] came into the bar and dragged me out of the bar. This huge fight ensued in the parking lot. (24)

Another participant was threatened with physical violence; the threat was directed at another member of his family simply because he had come out to his parents. He reported:

When I first came out to my parents...I thought my mother would accept me...She couldn't take it and my father came in with a shotgun ...and my mother told me to get everything in the house that belonged to me, get it out of the house. They disowned me. My father came in ... and I thought 'Oh shit he's fixing to kill me for being gay.' But he didn't, he said 'I'm going to go in there and kill your mother if you don't go in there and make her believe you're going straight.' So I go in there and I sit down and talk with my mother. I tell her I got mixed up with the wrong people... (17)

HIV Related Stigma General Community

Two events stand out amongst the feedback given by participants related to HIV related stigma from non- health care professional sources. In the first incident, one participant explained that for a short time he was married to a woman. They both lived in a small rural township where she worked for the state in social services. It was rumored that he was gay and HIV positive in this close knit community. According to him, she was fired from her government job when it was discovered that he was her husband, because of his serostatus. Upon

learning this, the participant confronted his wife's coworkers and threatened to sue.

In the second incident, another participant reported going to a local pool with some friends. In the course of their conversations they discussed the fate of a friend of theirs who had just recently died of AIDS. He reported the following:

We were talking about him [deceased friend] in this pool, and this guy went and got a gun and said 'get out of the pool' and held a gun at us...because we were talking about a guy who had died of AIDS...we were talking quietly but he overheard and he went and got a gun...and he was a redneck...he held a gun to our backs...we called the cops and we went to court. He got out of it because he had connections with the law.
(19)

HIV Related Stigma Gay Community

Three of the participants reported that a source of their HIV related stigmatizing experiences originated from the gay community. It was reported that:

The only prejudice and discrimination I've experienced [was] within the gay community and within the group of people that claim to be supportive of the HIV community. (3)

Or,

I think [sound of exasperation]... I think some people ASSUME that, you know they find out you've got pneumonia, that you're in the hospital they assume 'oh God she's sick!' and the word gets out and gets out and out... we kind of eat our own... we do, we do. Get a bottle of steak sauce and a queer and you've got a meal. You know? People are always trying to knock you down. It's a cutthroat business [performs as a gender illusionist]. And they'll always... they'll throw out 'oh God she canceled her book[ing] and she's sick, she's dying, she's almost over' That's just how it works. (24)

And similarly:

Some [gays] will avoid me because they know that I am an openly gay man who has HIV...because then you know people are going to say 'oh look who he's

talking to, I wonder what's going on there.' That type of situation. Which leaves me isolated once again. So my big thing is the isolation... [It's] unbearable. (13)

Lastly, one participant reported he was harassed online by another MSM member on a social media website. The participant's online profile indicated that he was HIV positive. He had this to say about the experience:

They're very mean because I had somebody email me and in my profile I say I'm poz. Because I don't want to beat around the bush. If you want to talk to me, you can. And this one little snotty nosed kid said 'Oooohhh you're nasty. You need to get off line. You need to go somewhere else.' (15)

HIV Family Based Stigma

In the context of being treated differently by family members because of their HIV status, two participants shared experiences worth noting here. For one, when visiting his ex wife and his children, he reported that:

I have my own separate towel to wipe my hands on and stuff like that. (6)

For another, the extent of how his family treated him because of his HIV positive status was extreme, even cruel. The only family this participant has is his brother, sister-in-law, and their children. The participant tearfully told the researcher that:

They took their children away from me when they were little kids, they couldn't be around me...because I had HIV...so it's only within the last 2 years now which now those children are grown and they're strangers to me...But I go anyway [to Thanksgiving and Christmas dinners] and I feel badly because they still eat before I get there and they leave me what's left...they've allowed me to come into their life. I'm still treated in such a way that it's not worth it. It's really not...they make me feel dirty and second rate citizen kind of thing. (13)

Participants (47%) reported that there were family members who they would purposely avoid something as simple as taking their medicines in front of them. These

individuals reinforced negative attitudes about HIV and served as consternation to those living with HIV. These men reported;

My mom for example, she still believes that this is something that God will lift off of me... [It's belittling, naïve ...it's hard for me to understand why she would take something she really doesn't know nothing about [and] actually say it can be lifted up (8)

I feel so self-conscious about that, taking my pills...I just hate that people looking at it like 'Ohhhhh you're dying, and that's proof that you're dying.' (2)

No not in front of my son or my brother...it reinforces their fear (10)

Health Care Related Stigma

Regarding negative past experiences in a health care setting in regards to either MSM or HIV status identification, many participants reported accounts that were subtle in nature. Whether enacted or perceived, MSM continually reported past experiences such as:

I think sometimes I sense it's a practice thing...sometimes they're not real sure...they are different ethnicities and backgrounds...they don't have any bedside manner...they're afraid. (18)

She just kind of looked at me...I felt she was a little rougher than she needed to be...and she just looked at me and just dirty...and I think it's just how she kind of looked at me (4)

I can remember a nurse or two... just sort of a negative attitude towards I don't know if it was necessarily towards John, but the fact that I was there as his partner and that was well known...I remember having to talk to the nurse manager...I think it was the attitude she used toward him [same sex married partner discussing his husband] (20)

There is always someone in the group that has a little fear and you get to where you can really detect that in a person...you know, very quiet and standoffish. They watch your every move...we have learned to pick up on those signs...and then we become uncomfortable as a result of that (13)

When I got referred out to get a stomach screening done, the technician was a bit weird when I told her I had AIDS...her facial expression changed and her manner got a little more formalized (21)

One participant had an especially overtly adverse interaction with a health care professional. He had been referred by his primary care physician to an area specialist. When he went to meet this doctor the following ensued:

She [physician] said 'what medications are you on?' I said 'they told me to bring these.'... She picked one up...'what's this for AZT?'...and I told her 'it's for HIV.' [She replied] 'Well you can take your things and go now.'...Well it floored me at first. And then I started getting mad. Thinking how many people go through this situation being insulted. (11).

Most men reported no negative experiences with HC providers due to MSM status or HIV status. Many seemed surprised at the overall positive interactions with HC providers, that is, they anticipated being treated differently or badly because of their MSM/HIV status.

Three men reported that they been refused treatment, all because of HIV. One participant has already been discussed previously in regards to this negative encounter. He further commented on being refused:

As far as being refused I lay it out. I like a physician who knows about HIV and AIDS...I'll ask them [now] on the first meeting 'have you treated people with HIV/AIDS?'...I like to have a discussion with them. Because I don't want to go through 'get out of my office' cause I will bend over and kick your ass. You have the right to choose or not! Do it in a professional matter! We still have blood in our system and we still have feelings...good God if they did that to us what to do with people with cancer or something? (11)

Two other men reported that:

Just one. It was a dentist who used to be in [other township]...I needed a tooth pulled. He says 'I'm not able to do that.'...He knew that I was HIV positive and he didn't want to take the risk. He wouldn't even clean my teeth. (15)

I feel like my treatment options are limited within [city] because I'm HIV positive...I think it's limited unlike normal people...some doctors will not touch me. I've been in the hospital three times (19)

Physicians will routinely make appropriate patient referrals to area social service agencies. Participants were unanimous in replying that they had never been knowingly refused a referral to other agencies because they identified as MSM/HIV. Some reported that:

Actually just the opposite. It was like pulling teeth to get referred to different places. I've got some neuropathy in my legs...it was like pulling teeth you know before I was diagnosed HIV positive...but now that I'm HIV positive...[my doctor] he gets me to the eye doctor and refers me to the physical therapy place and refers me to oral surgeons and stuff like that (4)

No surprisingly I think...I've had surgery several times...the doctors always they got their gloves and I guess they would rather know that I do have it than not. Right? (7)

Health Care Insurance Related Anticipated Stigma

Using health care insurance was associated with anticipated HIV stigma for at least one of the participants. He was a full-time employee with great job benefits and health insurance coverage. However he reported that:

They [HIV medicines] cost an arm and a leg. [I pay for them] out of pocket. It's expensive that's why I'm living with my sister. It's \$2,800 a month. (4)

He further disclosed that he did not use his health insurance coverage for fear that his employer would discover he was HIV positive and gay. He believed that if this were known, he would be fired from his job.

Privacy and Confidentiality Stigma Concerns

Some men perceived that their health information was not as private or confidential as it appeared to be:

I think it's a joke. So I don't think everything is as private as everybody says it is...being in the field we all talk around the water cooler (18)

The line gets grey because this is a small place and I run into a lot of people from [various health care settings] around town. (5)

Concerns revealed that health information was shared in health care settings in a seemingly casual way. Information was processed in such a way to be of concern to participants, that is, who had access, or the ability to learn about their protected health information:

I did have my first hospital visit it was on my record that I was HIV. And so the Catholic minister came to pray and do rites and ...I had to explain, almost defend and it felt really annoying. (19)

When he got sick many years ago and when you were HIV positive, you had an orange dot on the door...I didn't like it. I didn't like it for him and I really wouldn't like it for me. I'd probably take it off. (10)

Okay, you go to have your blood work done. Picture this, and the person says ... 'I need it for a CD4 count and' out loud. So if anyone knows I mean, you would have to know what that is, but I don't think they should be broadcasting...I've been very embarrassed by that. (13)

I had one prescription filled just a couple blocks away because I needed it immediately. So they called it in to the local CVS and the pharmacist says 'this is one of AIDS or HIV' [drugs]...out loud...and everyone's there getting their own prescriptions, and I felt my entire being just dropped to my feet (20)

I do... I mean I know that credit card companies used to reveal to insurance companies who then dropped clients because of their purchase history and knowing, well we can guess, you know that sort of thing. So it concerns me here because people do judge you... (2)

Others reported (30%) that their MSM/HIV status had been revealed to others without their consent originating in a health care setting. These occurrences overtly violated their patient rights to confidentiality and privacy. It was reported that:

There was that guy you know in the Centers of Excellence, he was a big talker, he was going around telling everybody 'he's gay, he's HIV positive' talks between friends and stuff (15)

My doctor came with my mother to my house...because he thought my mother should be there...brought her over to tell me...she already knew, my brother knew and my aunt knew...my status before I did, before I was told...he told her and she called all of them in her anguish (5)

My last CNA told my neighbor that I was HIV...my neighbor was like 'he has what?' [CNA replied] 'You know, HIV.' So that neighbor's never spoken to me again (13)

People gossiping and thinking they knew. My ex wife works at a hospital...and some of the people that she worked with...would say that I was gay and HIV positive, they were sure they were absolutely sure... I didn't confirm it (10)

When I went in for surgery my aunt had came up to watch me...my pulmonologist...was going through the chart and 'so are you taking your HIV medication every day?' and my aunt was sitting right beside me...the stigma it's just so it's never going to go away...just those three little letters...'Dr. Z I am so mad at you right now if you weren't giving me all this morphine I'd fire you.' We had a long talk about it...he apologized profusely. (24)

In one instance, the fear of health information being revealed specifically in a public health clinical setting was so great that one participant deliberately chose not to reveal important information to an attending physician. He feared that relatives working in the local public health clinic would be able to access his information. His reacted in the following way:

Now like I said when I was getting these stitches of course being where I was, being that local I chose not to disclose that [HIV status] not for fear of being turned away, but for fear of being found out and for the word spreading. (9)

Others did not express any concerns regarding privacy and confidentiality.

Referencing HIPAA legislation, these men reported that the fear of being sued or being noncompliant in regards to protecting health information was so great, that health care

facilities were proactive in protecting their information. For them, the perception was that bureaucratic processes worked.

Privacy issues also surfaced surrounding the treatment sites themselves. Many (48%) (n=11) felt there was enough local knowledge about where HIV related services were offered to stigmatize these areas. These MSM had internalized these feeling and subsequently had concerns about being recognized at these treatment locations. They reported:

I'd be lying if I said no, but at the same time it's like a "tell." It's like going to an adult bookstore and coming out of the booth, and realizing that the person on the other side is someone you know. It's like that... (5)

Well sure absolutely. You know you never know who you're going to see...the question after you're seen going in 'Well why are you going into [treatment facility]?' I mean what do I tell them? (4)

I am now because right next to them is this auto [shop]...that's where I take my car...I'm sitting there waiting for my car to get done and they're telling a story about this new low skid row clinic that's opening next door. I'm sitting in here listening to this...so ever day even today, I always look always shift my eyes and kinda hope they don't see me coming in and out. (19)

Well I'm embarrassed as far as the people who's with me you know, they're like 'well what's wrong with him? Why would he be going in there?' And then of course they have questions when you come out you know like 'well was the diagnosis good?' [Uses bus line to get to treatment. Bus drops off and picks him up right in front of the clinic area] (13)

Every time I pull into the parking lot...Well it makes me feel like I'm just lowlife. (20)

My private life is very private. I don't want to have to explain why I am somewhere. I think anybody would have the same feeling...I've seen people in the building and covertly made my way to a different side of the building...it's a very personal thing with me...I don't really want to confront it (24)

However, the majority (52%) (n=12) did not internalize these feelings. They reported that they did not have any concerns of being recognized at their treatment centers. These men reported that these locations served various medical needs, not just those that were HIV related. At these establishments they could blend in. Additionally, the lack of HIV related signage and advertisement were cited as reasons for not being concerned about being identified in these areas.

Theme: Personal Journey

One of the purposes of this study was to provide HIV positive MSM living in Appalachia a voice. In order to better highlight and understand the personal journeys that these men have undertaken, two brief case studies have been provided to illustrate some of their lived experiences.

Case Study One: John Doe TN

John is a white male in his mid-20s who lives in northeast Tennessee. He has lived in the South Central Appalachian region for most of his life. He works full time and also takes college classes through a local community college. He is active in his local church congregation and is highly involved in several community groups. He is in a relationship with another male.

As a self-identified MSM, John is now out to most of his family and friends. His personal coming-out experience was a complicated one because of the influence of his religious background. He reported that his religious faith made him feel “shamed and full of self hate,” so much so that he was hospitalized once for trying to harm himself. He considered pursuing “ex gay therapy” (i.e., Exodus International) at one point. He

explained that he took considerable time to sort through the religious perspectives related to being MSM. He was outed by a family member in whom he had confided. This same family member told the rest of his family. His church of origin shunned him after it was known he was a homosexual.

He has experienced verbal harassment in public, yelled and taunted by strangers who assumed that he was gay. He reported being shunned by a member of his own extended family who also has threatened him with physical violence.

John tested positive for the HIV virus in 2009. He did not seek HIV testing on his own. He reported being ill and asked to be tested as part of his physician's assessment of his illness. The results of his HIV test were given to him over the phone, not by vis a vis interaction with his health care provider. He is currently asymptomatic and at the time of our interview his CD4 count was approximately 809 and his viral load was undetectable. He is currently on antiviral medication therapy (Truvada, Isentress) and has been taking these medications for less than 1 year. He reports going to stringent measures to make sure that he has medicines available for all circumstances and also in keeping with medicine adherence guidelines. He has private insurance provided through his employer and therefore has a general care provider for his non- HIV related primary care needs. He also receives health services specifically related to HIV management through another health service provider. He has received social services support via a local ASO.

As for the quality of the HIV related care that he receives, he feels that it is mediocre at best. He believes that medical information and treatment guidelines coming

from the State of Tennessee are often compromised, often due to funding issues. He has concerns about the lack of comprehensive care surrounding HIV, that is, he feels that providers are too focused on HIV medicine management to the neglect other issues such as nutrition and health.

John confided that he returned to church after being diagnosed with HIV. He reported that he has received support (e.g., emotional, spiritual) through his local congregation and from his pastor. His pastor has advocated from the pulpit in support for sexual minorities. His pastor is aware of his HIV status and has offered spiritual support. His family is aware of his HIV status and although they love and need him, he reported that he does not receive much familial and emotional support from them.

John identifies as being a native son of Appalachia. He has given much thought to what it is like to live in the area, what it is to be different, and how many folks negatively view homosexual men, and those living with HIV. What it is like for him personally can be best illustrated by the following:

I make a lot of accommodations for people. I make accommodations for bigots; I make accommodations for Christians, for Muslims, for poor people.

And,

A lot of the work that I do I mean I talk about advocacy and equality but the truth is like it's a lot of PR [leans into the microphone playfully] its public relations. It's a lot of putting forth an image and it's an image that contradicts the regional assumptions about my life and the way I should be. And so I am constantly having to prove to them that I'm different ... that even if I am not.... even if their assumption is true about me? The fact is the assumption isn't true about everyone. So when they see me, they need to see something else.

Case Study Two: John Doe NC

John is a white male in his mid-40s who lives in western North Carolina. He has lived in the South Central Appalachian region for all of his life. He works part time and is on disability. He has pursued college level coursework. He identifies himself as spiritual with leanings towards Buddhism, but he does not associate with any local religious or spiritual group. His religious experiences involve being out in nature. He works closely with a local CBO in his spare time. He is in a sero-discordant relationship with another male.

As a self-identified MSM, John is out to most of his friends. His personal coming-out experience was facilitated by his friendships with coworkers who also identified as same sex oriented. He grew up in a household where he heard disparaging remarks about gay men, even hate speech that advocated violence against gay men. It is for this reason that he is not out to his family.

He has been verbally harassed by a family member who suspected he was gay. This relative unsuccessfully tried to out and shame him in front of other family members. In this instance, he denied the accusations and refused to further engage with this individual. He reported that to confirm this truth would hurt his family. He also reported that a complete stranger threatened him and his friends with a handgun due to overhearing a conversation that they were having that was MSM/HIV related. The police intervened and charges were filed.

John tested positive for the HIV virus in 1995. In 1998 he was diagnosed with AIDS. He did not seek HIV testing on his own. His diagnosis was the result of a routine

physical assessment for work. He had been previously contacted via partner notification from the local health department that a former sexual partner had tested positive for HIV. John did not follow up with this notification. The results of his HIV test were revealed to him over the phone, not by vis a vis interaction with a health care provider. Luckily for him, his partner at the time immediately took him to seek HIV related care at a local health center. His partner helped him in navigating the health services that he needed. At the time of our interview his CD4 count was 366 and his viral load was undetectable. He is currently on antiviral medication therapy (i.e., Kaletra, Viramune, Epzicom) and has been taking various HIV related medications for 16 years. He has struggled in the past with medicine adherence, but after a close call which landed him in the hospital, he now takes them on a more consistent basis. He receives Medicare benefits and receives health related services for both HIV and primary care through a federally qualified health center. He also accesses social support services through his local ASO.

As for the quality of HIV related services that he receives, he reported that he has a great doctor. However, he reported that he felt the quality of his health services decreased when his doctor began to take on primary care patients and did not continue to work primarily with HIV patients. As such, he felt that his physician was not current with the latest HIV medical developments. He additionally stated that his treatment options are limited because of HIV. In fact, his physician found it challenging to find specialized health services that would accept a referral for an HIV patient.

John finds emotional support through his friends, through the staff at the health center, and through the staff and services offered through the local ASO. He feels a

spiritual connection from a higher power. He has received emotional and spiritual support from a Metropolitan Community Church pastor.

Living in Appalachia as MSM and HIV positive is challenging in its own right, living in the closet adds to those challenges. For example, the participant shared an experience where a family member came across his HIV medications while cleaning his house.

She questioned me [about the medicines]. I denied because the pain in her face was just more than I could confirm. So the pain eased when I denied it...she knows but we can't, we can't talk.

Here he shares his perspective on what the cultural climate is like in his area:

I have to live my life more closeted I think than if I would if I was anywhere else. Again, the people who refuse to accept anything different than what they're used to. And refuse to open their mind to maybe it's something different than what they were taught. I think Appalachia is the worst to let go of that.

Conceptual Model Revisited

The conceptual model created to guide this dissertation project has been revised to reflect the findings presented in this section. Originally, homophobia and HIV related stigma were conceived to be related but separate in definition and function. Similarly, Appalachia as culture and religiosity were defined as separate domains. Lastly, the use of health services was hypothesized to be moderated by stigma. Figure 2 illustrates changes to the conceptual model presented as Figure 1.

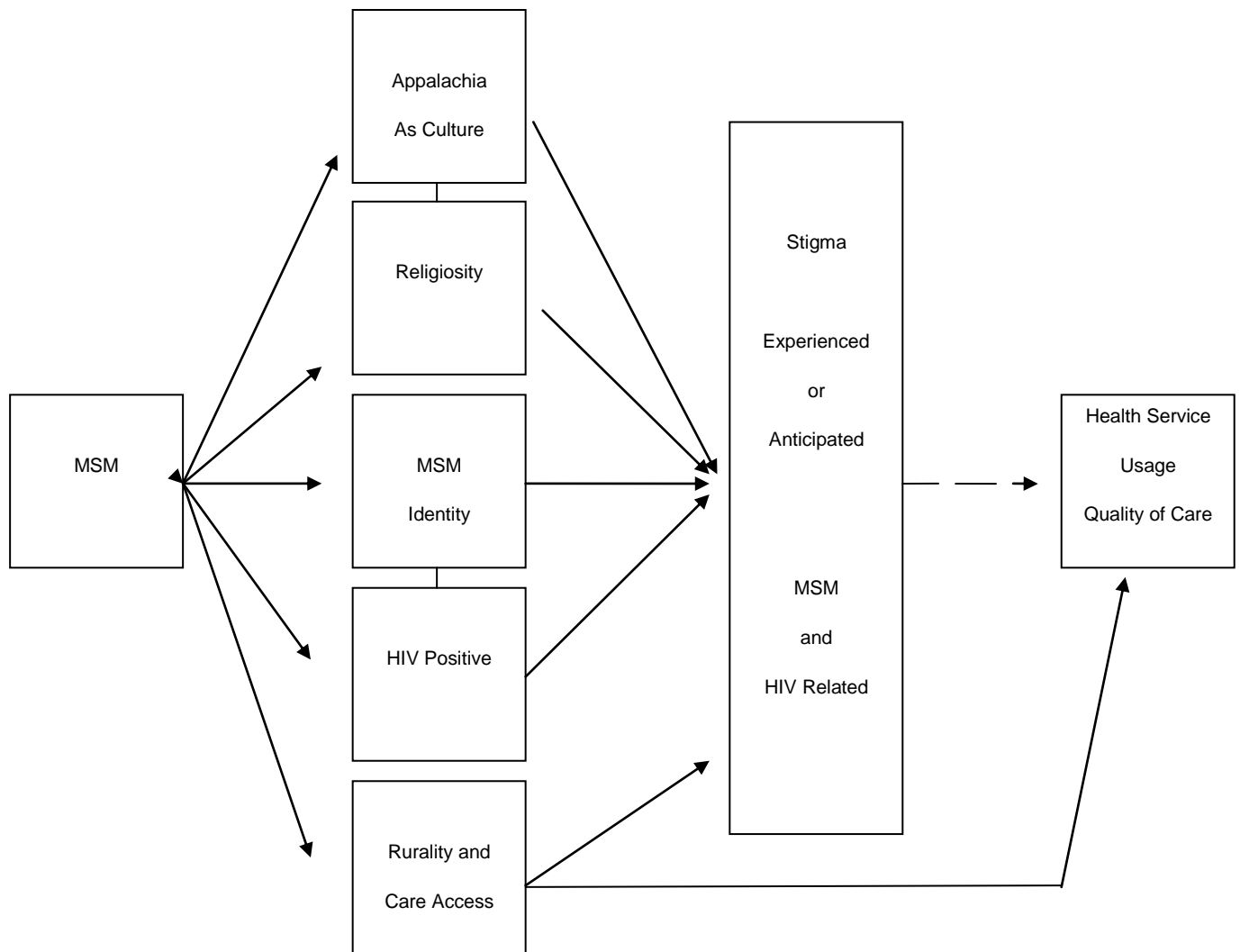


Figure 2. Conceptual Model of HIV Positive MSM Experiences Through Various Life Domains Revisited

Homophobia and HIV related stigma were related and could not be easily separated in feedback from participants. MSM as a population are at risk for HIV/AIDS and thus experience stigma from the general population. That is, by identifying as MSM, they are blamed for the spread of HIV. The general community might wrongly assume that to be MSM was to be HIV positive, and to be HIV positive was to be MSM. This bias could then be internalized by the study participants. Regardless of the reason, participants considered these labels and corresponding stigma to be the same. Appalachia as culture and religiosity were better conceptualized as being highly interdependent of one another, instead of being considered as exclusive domains. The geographic area and culture were characterized and defined by their religious traditions. Participants described the geographic region as being heavily steeped in religion and home to conservative ideology. MSM who didn't identify with being Appalachian cited not sharing the religious views of the area as a reason.

Although stigma was discovered to be present in all topical areas, it did not negate the pursuit usage of health care services. All participants were receiving health services. However, the impact of HIV stigma was documented in areas including refusal of care, privacy and confidentiality, interactions with health care professionals, disclosure, and use of health insurance benefits. Moreover, stigma was identified as a probable influence in the HIV testing behaviors of participants.

Lastly, rurality and health care access were minimally impacted by stigma. Although MSM may have had limited choices regarding HIV related care, they did have access to services in the region. They used the services that were available in their local communities. Those services were not always regarded as being best practice

Lastly, rurality and health care access were minimally impacted by stigma. Although MSM may have had limited choices regarding HIV related care, they did have access to services in the region. They used the services that were available in their local communities. Those services were not always regarded as being best practice oriented, but the services were consistent and were viewed favorably by the majority of participants. Transportation and distance challenges were reported but did prevent the majority of MSM from accessing treatment. Difficulties were reported by some in regards to the manner of transportation they used to make appointments, and the distance and cost required to access HIV care.

CHAPTER 5

DISCUSSION

Introduction

The purpose of this study was to examine the lived experiences of MSM living with HIV/AIDS, in particular the intersection of HIV related stigma with social, behavioral, and health outcomes in rural South Central Appalachia. The researcher posits that HIV related stigma and homophobia are related, that homophobia and HIV related stigma are a product of one's culture, and that access to health related services and medicines is mediated by these mechanisms. Three main themes emerged from the analysis of these 23 interviews: seeking health services, stigma, and personal journey.

Seeking Health Services

Research indicates that accessing health care services may be problematic in rural Appalachia. Specifically, that access might be especially challenging for those living with HIV/AIDS (Napravnik et al., 2006; Reif et al., 2005; Reif et al., 2006), that is, HIV related care might be limited or nonexistent. The men interviewed for this study did not experience this. Participants were receiving HIV related care at the time of this study. This may not give a clear indication of what the lives of others in the same geographical area may experience. The men for this study were all recruited through a local ASO and a local support agency. In other words, these men were already connected to various health and social service resources.

Rurality

Living in a rural area might serve as a barrier to accessing health related services. Services might not be available in a given area and thus not easily accessible. Respondents were asked a series of questions related to the location of their HIV related health care services in relation to accessibility. Where accessibility was an issue for some, it centered around transportation and the distance to their providers. Men experienced long commute times to receive treatment. This was consistent with the literature (Krawczyk et al., 2006; Napravnik et al., 2006; Reif et al., 2005,) that those living in rural areas had considerable distances to travel to connect with their health care providers. The majority of these men had their own means of transportation, and for those who didn't, they relied on friends, social service providers, and public transportation. Those who indicated using public transportation experienced difficulty more often than others. Accessibility was limited to those times when bus lines were operational. For example, one participant reported that when he was scheduled to have labs run every 3 months or so, that he was not given times to choose from in order to make his appointments. Instead of being asked when he could make an appointment, he was told *when* his next appointment was scheduled. If labs were going to be taken early in the morning, he frequently did not make these appointments as the bus line that he depended on did not begin service until after his scheduled appointment, or he did not have enough time to make it to his appointment because of the route the bus lines ran. This compounded issues for him as missing lab appointments did result in being labeled noncompliant and being dropped as a patient. This participant also reported that

at times he had no way home from his doctor's visits because the bus lines discontinued at a certain time in his city.

Quality of Services Provided

Those living with HIV/AIDS require ongoing medical treatment and care in order to better manage their lives and to have better health outcomes. This requires consistent interaction with their health care providers. Participants discussed their experiences with the various health care professionals that they interacted with in the course of their treatment plans related to HIV/AIDS care. Overall, those participating in this project viewed their quality of HIV related care and providers in a positive manner (87%) n=20. For those men who had for a time lived outside of the geographical area, there was a constant comparison between the services that they received in more urban population areas (i.e., California, Florida, and Philadelphia) and those that they now received in NE Tennessee and W North Carolina. These men accessed HIV services provided by physicians who specialized in HIV care only and their health centers were connected to abundant social support services. They indicated how seamless their continuum of care was through these larger ASOs. Health related services in Appalachia did not meet those "gold standard" expectations, but these men did not feel that their care was substandard.

MSM perceived that the quality of their care was affected by the inability of their physician to concentrate only on HIV care. In other words, MSM felt their health care providers were pulled in too many directions, and as a result, they were not up to date on the latest and best practices associated with HIV care. MSM were well educated in

their own care and knew how to best advocate for themselves in this regard. They were often aware of breakthroughs and best practices and subsequently brought this information to the attention of their providers.

Related to quality of care issues were a series of questions asked to ascertain whether during the course of treatment for HIV/AIDS they had been given inaccurate or incomplete treatment guidelines. Here, these MSM were largely forgiving. This was true especially for those who had been living with HIV/AIDS for a considerable long time. There was an understanding here that health professionals in the early 1980s and 1990s were subject to a huge learning curve where HIV was concerned. The epidemic decimated the gay community with such a virulence that caught health professionals off guard. Clinics were full of patients who were not just HIV positive, but in the latter stages of AIDS. It was not until the late 1980s that the first HIV medications were developed, and even then, it was a trial by fire to observe which drugs were effective in treating HIV. In hindsight, these men had a better contextual understanding of what they had experienced in their early days of treatment. Knowing *when* to begin treatment for HIV was something that one of the younger respondents struggled with. He had been newly diagnosed and during that time frame the CDC changed the benchmark levels of where CD4 counts should be before beginning a drug regimen. Such things do happen as advances are made in medical knowledge.

One respondent did report an overt occurrence of inaccurate treatment guidelines that he experienced while being hospitalized. In his case medication administration brought his entire day's worth of HIV meds to him at once. He refused to comply with their instructions and proceeded to "educate them" about their medical

error. While in the hospital he was not under the care of his regular physician. This is an example of a patient receiving care from professionals who were not aware of proper HIV treatment practices. As previously mentioned, those living with HIV are often more well informed and knowledgeable about their own health issues than those who treat them. The patient responded accordingly.

Positive Experiences with Health Care Professionals

The discussion guide prompts were aimed towards learning more about the negative experiences that MSM had with health care providers. They were not asked to provide positive feedback; however, in the course of the interviews this topic (i.e., positive experiences) came up frequently and without prompting from the investigator. Over half (57%) n=13 of respondents reported positive experiences with their providers. These favorable responses serve to remind that there are many health professionals who treat their HIV positive clients with dignity and respect. This is in sharp contrast to those reports that document stigma related occurrences within some health care settings (Earnshaw & Quinn, 2011; Sayles et al., 2007; Wilkerson, 1994).

One participant offered the following as an explanatory reason for his affirming experiences with his provider. Universal precaution best practices were mentioned as perhaps one reason behind these nonnegative interactions. That is, because health care personnel are required to practice these standardized procedures with all patients, that this praxis has lessened the need for concern in interacting and treating HIV positive patients. In other words, using the same precautions for everyone helps those with HIV/AIDS not to be stigmatized because of their particular medical condition.

Testing Positive for HIV

The current project focused on how MSM accessed their HIV health care services and to uncover any role that HIV stigma might have had in those behaviors. MSM are disproportionately affected by HIV/AIDS. Research (Fortenberry et al., 2002; Krawczyk et al., 2006; Nelson et al., 2010; Young & Bendavid, 2010) indicates various reasons why MSM do not seek out HIV testing and treatment, and among them HIV social stigma is listed. While the current study did not specifically address this question, that is, whether MSM sought out HIV antibody testing as a part of their personal health practices, these men did discuss this in the interviews. It cannot be directly inferred that stigma prevented these men from being tested; however, their responses indicated that out of 23 men, only 11 specifically sought out HIV testing on their own (Nelson et al., 2010). Of those 11, two reported that they sought testing because their partners had tested positive. Public health programming must continue to seek inroads into HIV testing. That is, how do we increase HIV testing for those in high risk behavior categories? Is it by continued educational efforts? Increased testing opportunities in culturally accessible locations? Better marketing? Is stigma being addressed in these efforts?

Increased screening does have a positive effect. The experiences detailed here evidence that adding HIV testing as a regular part of check-ups and screenings is beneficial. Thirty percent of participants learned that they were HIV positive as a result of annual physicals, blood donation screenings, and preliminary exams for employment. Allow patients the choice of opting out of testing instead of opting in. This is the directions that should be taken. Reduce the stigma of testing by testing everyone,

everywhere, and in all appropriate circumstances (Young & Bendavid, 2010; Young, Monin, & Owens, 2010). However, it's a passive approach. The challenge for public health professionals is to assist and prompt individuals and communities to take responsibility for their own health and then provide the means and programs to assist them in doing this.

HIV Medicines

The advent of HIV medications was a definitive game changing event in the battle to save lives for those infected with the HIV virus. These participants have a love and hate relationship with their antiviral medications. They felt that taking these medications were vitally important in their overall health. Many attributed the drugs to saving their lives. They believed that they would not be living today without the medications. They weren't getting any sicker by taking them and the general consensus was that HIV medications are good.

However, it was widely reported that many HIV related medicines had deleterious side effects. They reported that taking medications was an uncomfortable process, that the side effects experienced affected the quality of their lives. Taking these various medications sometimes influenced the way they felt about themselves. They described times when they discontinued their regimen because of the way they felt, that is, they were tired of the constant use of medications and so discontinued ARV therapy. One participant reported that he felt as though he had been sentenced to taking these pills for the rest of his life. He thought this was a weird way to feel about his medications.

Complementary Alternative Therapies

Not everyone pursued the same path in regards to medical treatment for HIV/AIDS. In addition to taking physician prescribed FDA approved medications, many living with HIV seek out complementary and alternative medicines and practices (CAM) (Hoogbruin, 2011; McDonald & Slavin, 2010). These nonstandardized products and practices may include acupuncture, chiropractic services, and herbal and/or vitamin supplements. This was true for the participants of this project, that is, many of these men currently used or had used these items and practices at one time or another. Some studies caution the use of CAM as a means to enhance the management of HIV disease progression (Hoogbruin, 2011). Additionally, other reports suggest that the use of CAM could lower adherence to ARV medications as CAM was perceived as being just as effective as ARV therapy (Ekwunife, Oreh, & Ubaka, 2012; McDonald & Slavin, 2010). However, this was not the case for the men in this study. For those who took this approach 48% (n=11), these products and practices were used in conjunction with HAART. They used CAM to relieve stress, prevent weight loss, and to treat side effects associated with their ARV medicines (e.g., nausea, peripheral neuropathy). This is consistent with the literature (Kremer, Ironson, & Porr, 2009; Nicholas et al., 2010; Shedlin et al., 2012) where patients seek to further support their immune system health through various supplements and self-care behaviors.

Spiritual Support and Practice

It has been suggested that religious belief and spirituality are associated with better psychological adjustment and effective coping skills for persons living with

HIV/AIDS (Foster et al., 2011; Kremer et al., 2009). Conversely, MSM face unique challenges interacting with most Western traditional religious groups. Their sexual orientation is often viewed as abhorrent and sinful, and they are either directly or indirectly given the message that they are not welcome and cannot participate in religious activities (Barrett & Barzan, 1996; Fulton et al., 1999; Lynch, 1996; Ratzinger, 1986).

Those participants who endorsed CAM products and practices also embraced spiritual support systems and practices. Various faith-based organizations (FBOs) and specific spiritual practices were perceived as being beneficial in their daily lives. As with previously mentioned CAM, these participants used these resources in conjunction with their prescribed health directives. None of the men interviewed used these practices as a substitute for medical care. Participants identified several FBOs that were accepting and inclusive. While the general tone of Appalachian religious orientation remains fundamentalist (DeJong, 1965; Jones, 1999; Photiadis, 1978), it is nonetheless a positive indicator to note that there are religious organizations that are either gay friendly or gay affirming in the area. These congregations do not view HIV as a challenge to their value system and outreach efforts (Werber, Derose, Dominguez, & Mata, 2012). These groups serve to support and nurture MSM by helping to meet their emotional, spiritual, and physical needs. Future public health initiatives would benefit by teaming up with area FBOs in reaching out to those living with HIV/AIDS. Working with these affirming religious communities is a step to ameliorating MSM and HIV related stigma, stigma that often originates from conservative religious belief systems and structures. Additionally, public health programs and providers gain valuable entry into

local communities and FBOs contribute to the health of their communities (Coleman, Lindley, Annang, Saunders, & Gaddist, 2012).

Adherence

Research is clear that success in lowering viral loads and increased CD4 counts comes with consistent use of ARV's (Ickovics & Meade, 2002; Kremer et al., 2009; Rao et al., 2007). Health care personnel make it a point to routinely ask about adherence during the course of a medical visit. Study participants taking HAART (95% n=22) know the importance of complying with the rigorous demands of daily drug therapy use. Occasional nonadherence can diminish the effectiveness of these medicines. A large majority of participants (87% n=20) admitted to missing dosages. The various reasons given mirror those reported in the literature; adverse side effects, medication fatigue, extra planning, poverty, and depression (Ickovics et al., 2002; Konkle-Parker, Erlen, & Dubbert, 2008; Rao et al., 2007). From a clinical standpoint training health care staff to recognize and document these sorts of barriers to adherence during intake and treatment may be key to addressing nonadherence issues. Follow up that explicitly addresses these barriers should be considered.

Social support systems and relationships play a part in helping these men stay on track in keeping to their medication usage and schedules. Whether via family, friends, or significant others, the processes involved in reminding, checking in, and being accountable to supportive friends, family, and colleagues is consistent with factors known to facilitate better adherence. Positive social relationships are paramount. Relationships that allow for honesty and openness (e.g., being MSM, being HIV

positive) allow for this sort of interaction. That is, in circumstances where men have been able to share about themselves, there is the opportunity for them to receive emotional and social support from others. Conversely, a loss or lack of social relationships due in part to stigma associated with being identified as MSM or HIV positive is associated with nonadherence. Nondisclosure of HIV status or affectional orientation for fear of rejection or harm may in turn reinforce nonadherence factors that lessen the effectiveness of HAART and ultimately the health of the participant (Gonzalez et al., 2004; Ickovics et al., 2002; Konkle-Parker et al., 2007).

Public health initiatives that help foster and support positive social relationships should be considered when devising interventions and community programming. Advocating for those who experience discrimination and stigmatization (i.e., MSM, PLWHA) is a larger systems approach in addressing health challenges. For example, supporting marriage equality initiatives can help fight HIV. The recent Supreme Court decision on Defense of Marriage Act (DOMA) and Proposition 8 (PROP 8) will have a positive effect on the lives of same-sex couples. Marriage recognition confers legitimacy and a degree of social standing. There are many federal benefits that same-sex married couples will now be able to access that were not previously afforded to them. Recognizing marriage equality will reduce stigma that may have prevented couples and individuals from seeking out health promoting services and behaviors. These equality actions add value and respect to their lives and as such, they may be more inclined to take better care of themselves, get tested regularly, have more open and honest conversations with their partners, friends, and family, and seek out health related information and resources (Giuliano, 2013).

Stigma

One of the primary reasons for conducting this study was to identify and document ways the experiences of MSM who are HIV positive are stigmatized. Participants indicated that their lives had been affected by stigma, often in multiple and overlapping ways. These reported incidents were present throughout all interviews and permeated all topics and perspectives of these participants. Not everyone experienced stigma in the same way; however, not one of the participants was able to report that he had escaped this “spoiling” of his identity. MSM described stigmatizing experiences stemming from religious individuals and organizations, various communities, family and friends, and the medical community.

In the course of interviewing participants, a pattern of response developed that was quite unexpected. For example, when asked questions related to homophobia, many participants responded with feedback and perspectives related to their HIV related stigma. The same happened when queried about HIV stigma, that is, participants replied with reports related to homophobia. Time and time again this occurred. The researcher found it difficult to sometimes separate MSM and HIV stigma related responses; participants did not often readily differentiate between the two without further probing. As a result many of the responses were not “pure” but were instead best described as being intermixed and intertwined with elements relating to both homophobia and HIV related stigma.

To the researcher’s knowledge, this has not been documented before. This discovery was not identified during the course of the interviews. In fact, it was only

recognized afterwards while transcribing, and therefore, the researcher did not query as to why participants answered in the way they did. Perhaps they simply did not perceive a difference between stigma experienced as MSM and that due to HIV. Had they experienced both for so long that recollection of past events had amalgamated into a broader more generalized classification of events? Did these responses indicate a multilayering of stigma and if so, which of these (i.e., homophobia, HIV related) was the more dominant and prevalent of the two in regards to negatively affecting the psychological well being of these men? Is it naturally assumed that accompanies the other? Had these men internalized societal assumptions of bias directed at MSM? That bias goes something like this: if you are gay and male, it is assumed that you are HIV positive. Conversely, if you're HIV positive and male, it is assumed that you are gay.

This distinction should be noted for future research and outreach initiatives, to better inform how we ask questions and how we frame assumptions about responses. This would be helpful in addressing multilayered issues and to better assist researchers and health professionals in assessing the health of sexual minority populations.

Homophobia

Homophobia from Religious Sources

All of the participants grew up under the influence of the Christian church. Many were involved in church youth groups and choir. Others attended parochial school and private Christian schools. One participant grew up overseas as his parents were missionaries. For some, their parents were pastors, deacons, choir directors, and Sunday school teachers, and others worked in church administration services. While the

range of involvement varied between participants (e.g., three or more times a week, on Sundays, if the church bus ran), all participants reported hearing negative messages and attitudes expressed towards homosexual orientation and behavior. This is consistent with reports that some faith communities endorse a perspective that is hostile to same sex oriented peoples, labeling them as sinners, outside the religious fold, and not in line with a solely heterosexist worldview (Barrett & Barzan, 1996; Fulton et al., 1999, Green, 2009; Kubicek et al., 2009). The message was clear, that is, same-sex inclination and behavior were morally wrong and subject to disapproval and punishment from God. The psychological health of these men suffered as they internalized these negative attitudes coming from their religious institutions. Their own sense of personhood and self-worth were diminished as a result of these messages; messages that were explicitly shared from the pulpit and from select scriptural references where both sources were condemning, punitive, and vindictive towards homosexuals. Alcoholism and attempted suicide were reported as means of coping with this devaluation of self. These participant's responses are added to those already found in the literature documenting stigmatizing sentiments towards sexual minorities from traditional religious groups (Barret & Barzan, 1996; Fulton et al., 1999; Ratzinger, 1986; Stokes & Peterson, 1998). In fact, this is also consistent with current suggestions in the literature that fundamentalist belief (i.e., biblical inerrancy, literalist interpretation, cathartic conversion experience, evangelicalism) predicted negative attitudes towards homosexual orientation and behaviors (Davis, 2006; Fulton et al., 1999; Hunsberger, 1996; Jonathan, 2008; Schwartz & Lindley, 2005). The majority of MSM previous church

experiences had taken place in Baptist congregations (61%) n=14, which are classified as fundamentalist (i.e., Bible believing) churches.

As such, the vast majority of those interviewed had an uneasy relationship with their churches of origin. All but one of these men switched church affiliations and others went further and changed religious faiths altogether. The majority of these former religious associations were with those of the Baptist faith. Not one of these men remained connected to a Baptist organization as an adult. To stay within a fundamentalist oriented congregation was to deny any chance of resolving their sexual identity or orientation with their spiritual beliefs (Brent, 1994; Schuck & Liddle., 2001). For those that stayed within the realm of Christianity, the majority migrated to Christian groups that were more accepting and affirming of their same-sex orientation. This too, was consistent with the literature in that not all religious organizations are hostile towards sexual minorities. The majority of these men gravitated towards United Methodist congregations; these congregations are more widely known for inclusiveness with LGBT populations (Borgman, 2009, Lease et al., 2005; Wagner et al., 1994).

Some were not able to reconcile their childhood faith to their adult lives and for varying reasons no longer self-identified as Christian in their religious orientation. The majority of these participants decided upon an atheist or agnostic conclusion in matters of spirituality. Their life experiences convinced them that belief in an external deity was inconsistent with their lives and with rational and scientific thought. Those remaining tied to a religious faith embraced non- Judeo-Christian-Islamic perspectives. As Blando (2009) and Smith and Horne, (2007) noted, there are Earth-spirited perspectives that

are LGBT affirming. It was within these belief systems that these men found a spiritual home.

Heterosexism Stemming from Geographic Location

Much of the research on the determinants of homophobia has been conducted in urban settings. While this literature is a valuable resource, helping us to better understand the processes involved in homophobic beliefs and feelings, it does not specifically speak to those who experience homophobia in more rural settings. Anti-homosexual sentiments may vary along urban and rural lines. This project adds to our understanding of how homophobia operates in rural areas.

Being gay and living in a rural area is difficult (Boulden, 2001; Yarbrough, 2003). Same-sex attraction and behavior violates traditional gender roles and subverts the heteronormative assumptions that are perpetuated and reinforced by predominately conservative political and religious ideologies found in more rural areas (Eldridge, Mack, & Swank, 2006; Herek, 2002a; Oswald, 2002). The men participating in this study echoed these sentiments with feedback of their own lived experiences. Rural Appalachia is still at times a hostile and inhospitable place for sexual minorities. Their own experiences with homophobia whether described as prejudice, mistreatment, or discrimination were documented. Participants perceived the area to be heavily influenced by conservative religiosity and as such they felt this resulted in conflicts with people who were close-minded, Bible thumpers, and “Southern Baptist to the bone.” Conservative religious orientation was perceived to be synonymous with their

geographic location. The resulting negative attitudes whether real (i.e., enacted) or perceived affected their lives in considerable ways.

MSM experienced minority stress, that is, they experienced conditions that required them to change the ways in which they presented themselves to others and interacted in their social environments in order to protect themselves in hostile and nonaffirming situations (Boulden 2002; Swank, Frost, & Fahs, 2012). For example, MSM reported concealing their stigmatized identity (i.e., MSM) from others, not allowing themselves to present in a more authentic manner for fear of reprisal (e.g., loss of social status, family disapproval, violence, loss of job). They described being hyper-vigilant and on guard in fear that someone would discover that they were homosexual. This constant monitoring and adaptation of behaviors impacts well being and mental health resilience (Igartua et al., 2002; Preston, D'Augelli, Kassab, & Starks, 2007; Swank et al., 2012) especially in the areas of self-esteem and internalized homophobia.

Men responded in various ways to minority stress. For example, men reported keeping a low visibility in regards to presenting as gay or being identified as such. In other words, these men consciously crafted personas that publicly denied the existence of anything that might clue others in to their gay behavior, identity, relationships or community. They felt the need to do this in order to survive in their rural communities. But this came at a cost as this limited personal, social, and interpersonal growth. That is, because important aspects of their lives could not be shared openly, they either severely edited or distorted themselves in efforts to make their identity as nonstigmatizing as possible (McCarthy, 2000; Oswald, 2002). For these individuals, subjugation to heterosexual hegemony was their way of fitting in to social surroundings.

For others, the solution, at least for a time, was to leave their home communities and to move to more urban areas (Diaz et al., 2001; Dooley, 2009, Yarbrough, 2003). Over half of the participants (52%) left the Appalachian area and moved to more urbanized areas for work, school, military service, and to just “get the hell out of here.” These men found the social climate in Appalachia to be stifling, lacking in tolerance and diversity, and isolating. Beginning the process of coming out to oneself or others is a difficult process for many in rural areas. The researcher posits that these men left the area to be in more accepting environments. The effort was too difficult for many who have grown up in the rural South. Family kinship, obligations, social conformity, and privacy constraints were overwhelming for many. Participants grew up in rural communities where everyone knows everyone else’s business. Self-discovery and growth often can only happen by undertaking a journey to places where there is freedom to explore and where there are supportive opportunity structures. Large cities and urban areas provide space to undertake that evolutionary process (i.e., discover oneself, define oneself, seek out similar folks). Cities have larger populations and greater cultural diversity. In these spaces individuals are exposed to a variety of diverse, new, and competing belief systems and ways of being. This is vastly different from the culture that those who grow up in rural areas are familiar with; that is, they come from communities that value cultural and racial homogeneity, high religiosity, and traditional family values.

Harassment, Discrimination, and Violence. Institutional (e.g., religious groups) and cultural (e.g., rural geography) homophobic disgust of MSM and same-sex orientation devalued the lives of the men participating in this study. Stigmatization often

took on the guise of harassment, employment discrimination, and violence.

Homophobia was manifested through these means by strangers, employers, and family members.

Verbal harassment was reported more often than other prejudicial acts. These incidents often took place in public spaces and in front of others. Perpetuators of hate speech are often emboldened in their harassment of sexual minorities by their own perspectives of morality and the prevailing social mores of their communities. In other words, they are acting out because they have been socialized from an early age that it's acceptable to despise gays. Gay men deserve the ridicule and shaming that comes their way. In fact, they by virtue of their deviant orientation are asking to be harassed (Hart, 2001). When harassed by strangers, participants responded by leaving the immediate area to avoid further conflict, often because they feared that violence might follow. As reported by one of the participants, at times groups of people will purposely seek out areas (e.g., gay venues, parks, bars) that MSM and other sexual minorities frequent **solely** to harass, bully, and to commit acts of violence. Again, in the minds of these individuals, this sort of harassment and violence is culturally justified.

In other instances, harassment came from family members. Being told that they didn't measure up, that they were morally or spiritually weak were ways that these men reported being addressed. It's a delicate situation where family is concerned. Many of the participants could not remove themselves from these situations at the time (i.e., underage, living with family) and so in these instances, they had to endure shaming and ridicule from their family. That is, they were unable to negotiate an acceptance of their differentness with their families of origin. Families in rural areas that are influenced by

community norms and approval can place intense pressure on their homophile children to conform to prevailing societal norms (Oswald, 2002). Others reported that they were shunned by various family members. In many rural areas, including the South, differences are sometimes dealt with in a “don’t ask, don’t tell” strategy. That is, if you are gay, don’t draw attention to that fact or, never directly share information that would confirm that suspicion (Boulden, 2001; Whittier, 1997). To admit this, especially in some family situations, is a social taboo. If you transgress social norms, then family members are forced to acknowledge what they already may know in a private sense, in a public manner. Heterosexism must be enforced (Oswald, 2002). Faced with this knowledge, family tensions may be such that ostracizing the individual is the only way that families know how to respond. While this may be a way for families to “save face”, for MSM and other sexual minorities, this inability to acknowledge, discuss, and celebrate their differentness is demeaning and has a negative psychological impact on their well being (Diaz, et al., 2001; Meyer, 1995; Swank et al., 2012).

Antigay sentiments like other attitudes are internal. That is, these negative attitudes cannot be directly observed but can be inferred by corresponding behaviors (Herek, 2004). Sometimes there are costs to being truthful and authentic. In fact, there are often negative consequences to coming out of the closet (Corrigan & Matthews, 2003). Employers can discriminate by denying employment to MSM or can terminate their employees without legal repercussions. This unfortunate outcome has been documented in literature (Hatzenbeuhler, Phelan, & Link, 2013; Huebner et. al., 2004). A participant of this study was fired for being truthful. He lost his job for no other reason than for who he was. Currently, there is no federal legislation that protects employees

from discrimination based upon their sexual orientation or gender identity. Passage of the Employment Non-Discrimination Act (ENDA) would ensure some protections for sexual minority groups. In simplest terms, discrimination based upon sex and gender are already illegal, in part because it is irrational to do so. Is it any more rational to deny or discriminate in the employment arena based upon sexual orientation? This legislation has been introduced to Congress multiple times over the years but has yet failed to gain momentum and gain passage. (Eskridge,1999). Such legislation, if passed, benefits individuals in areas of employment and in addressing health inequalities. That is, because the majority of health insurance is purchased through employers, protection against loss of employment due to sexual orientation or gender identity serves to ameliorate the effects of homophobia, which in turn, serves to address health inequalities for stigmatized groups (e.g., MSM) (Hatzenbuehler et al., 2013).

Sexual orientation ranks as the second highest motivator for hate crime incidents (20.8 %) reported to the Federal Bureau of Investigation in 2011. Of the reported 1,508 hate crimes reported in 2011 based upon sexual orientation, 57.8% were classified as antimale homosexual bias (Federal Bureau of Investigation, U.S. Department of Justice, 2011). Of those antimale homosexual incidents, the top three types of crimes perpetrated against MSM were simple assault (n=291), intimidation (n=218), and aggravated assault (n=162) (Federal Bureau of Investigation, U.S. Department of Justice, 2011a). The most frequent known locations for sexual orientation motivated hate crimes were: in residence and home, highway and road and street and alley or sidewalk, and bar and club. (Federal Bureau of Investigation, U.S. Department of Justice, 2011b).

Participants reported all three types of crimes committed against them. Not one of these hate crimes was reported to the police. MSM worry about being attacked because of their sexual orientation (Hart, 2001). Why aren't more of these crimes reported to the authorities? Internalized homophobia could help to explain some of the reasons these go unreported. MSM who internalized negative sentiments about their orientation would not be as forthcoming to others about what had happened. That is, if there is any shame about their sexual orientation or if there is a need for secrecy (i.e., not out to others), then reporting what happened places the individual in an uncomfortable situation where others may then be privy to their information. And for some, this would not be acceptable under any circumstance.

MSM might also be reticent to report attacks to police due to distrust of law enforcement. Attitudes towards the police have been shaped by historical events where law enforcement dealt a heavy handed approach to the LGBT community. For example, consider the Stonewall riots, acknowledged now as a seminal event for gay equality rights, pitted armed police units against patrons of the Stonewall Inn. Police came to arrest those inside the bar and were met with resistance and subsequently violence and rioting ensued for days (Carter, 2004). Similarly, in recent past, police acted as agents of the state and arrested consenting same sex couples for committing sodomy. For example, the *Lawrence v. Texas* case brought before the Supreme Court exposed the discriminatory and oppressive function of the law that criminalized homosexual sodomy but ironically not that of heterosexuals. In this case police entered a private residence and arrested two men for engaging in anal sex (Pedriana, 2009). Given this strained history between LGBT populations and law enforcement, it is easier to understand why

there is a lingering distrust of the police. MSM doubt as to whether they will be given fair treatment and protection under the law. This fear and distrust might result in underreporting of hate crimes (Marzullo & Libman, 2009). However, this is not always the case. Gillespie (2008) hypothesized that LGBT attendees at a Pride festival would have negative attitudes towards police. However, the majority of respondents reported high satisfaction with community policing efforts. In fact, those interviewed were highly supportive of police presence.

The Matthew Shepard and James Byrd Jr. Hate Crime Prevention Act of 2009 was passed and now offers funding and assistance to state and local officials in their efforts to investigate and prosecute hate crimes (U.S. Department of Justice, 2013). However, this legislation will not have any “teeth” unless law enforcement officials assist in changing the cultural climate of their organizations. Marzullo and Libman (2009) suggest that diversity training, external monitoring, and improving criminal justice curriculum emphasizing LGBT populations are positive steps towards effecting change within law enforcement. The authors also suggest that health professionals would benefit from training that would assist them in identifying hate crime victims who seek help in emergency rooms, clinics, and community outreach programs. Not only can health professionals treat these patients, but they can also assist in reporting hate crimes and make the appropriate referrals to ancillary support systems.

HIV

HIV Related Stigma

There are a number of processes that occur to produce stigma. First, human differences are identified and labeled; second labeled persons are compared to dominant cultural beliefs and assessed to be not possessing desirable traits and thus linked to negative stereotypes; next, those undesirables are categorized as not belonging to the dominant “in” group and thus viewed as “others”; they then experience discrimination and a loss of social status; and lastly they are subjected to disapproval, rejection, exclusion and discrimination from the dominant societal group (Sayles et al., 2007). This process is crucial to the creation and enforcement of the dominant social order. That is, in groups (dominant, normalized) use stigmatization to marginalize out groups (minority, stigmatized) to build and maintain their “droit de seigneur” positions in power and culture (Parker & Aggleton, 2003). In many cases, these differences must be identified through observation (e.g., race, behavior, illness).

What if there is nothing to observe? Homosexual orientation is internal; it's not something that can be readily identified unless the individual presents as such. What about being HIV positive? There is no definable observable behavior associated with being HIV positive. In fact, being HIV positive is largely a hidden issue. This is evidenced in the general public's inability to successfully serosort when it comes to determining whether someone is HIV positive or not. It is one of the reasons that HIV infection rates remain high. We cannot assess ourselves or others by appearance alone to confirm HIV infection.

So, if the presence of HIV is largely invisible, why then is HIV stigma experienced? How is it known that someone is HIV positive? The men in this study experienced HIV-related stigma in a variety of ways. However, not one of them was subjected to stigma due to his own physical appearance or presentation (i.e., behavior). What follows is related to disclosure, inference, and association.

Disclosure. PLWHA don't readily disclose their HIV status to others. They are acutely aware that to do so is to invite judgment, disapproval, and a discrediting of their lives. Herek (2002) suggests that HIV/AIDS is stigmatized because it is an undesirable condition that is *seemingly* brought on by the bearers own responsibility, is a lethal and incurable condition, and is perceived to pose a risk to others.

The men in this study were selective in who knew about their HIV status. Participants' responses ranged from almost no one knowing about their HIV infection to those who disclosed openly to close friends and family. They were guarded about who knew what. This is in part a way to manage any HIV stigma they might experience. Knowing about their serostatus depended largely on the types of social relationships that others had with them (Bairan et al., 2007). For example, health care providers knew in the context of treatment and health services. In personal relationships an individual's degree of involvement in his life was a salient issue. For example, long-term friends, supportive family members, and long-term sexual partners knew their HIV status more so than employers, strangers, acquaintances, and casual or anonymous sexual partners. Moreover, MSM sought out individuals who would be supportive and accepting of their HIV status. Men described various experiences in disclosing their

potentially stigmatizing role to select individuals and in the process reintroduced and renegotiated themselves and their social relationships to others (Sayles et al., 2007).

HIV Related Stigma General Community

Participants lived in rural Appalachia where privacy and confidentiality concerns would be greater than those in a more metropolitan area. Individuals are more likely to know their neighbors, making them more identifiable and knowing more about them in general. Participants might be fearful of community members learning of their HIV status. They feared a breaching of confidentiality and being unable to blend in once their stigmatized condition was exposed. They might be fearful of rejection from their community, of personal threats, potential loss of income, and being able to maintain any sense of privacy. Harm might also come to those closely associated with them. For example, one participant reported that his wife lost her job in their local community because he was rumored to be gay and HIV positive. He suspected his health information had been leaked from the county-level health department. Those working at the health department also lived in the same rural community and he perceived his HIV status had been passed along to others from this source. Foster (2007) similarly stated that confidential lists of HIV clients were distributed to others and clinic staff members broke confidentiality agreements in divulging the names of their HIV patients in the rural townships she used in her study. In other words, confidential information did not remain private in these rural areas.

In the second example the man who pulled a gun on a group of MSM discussing a friend who had died of HIV acted in a highly irrational manner. Rural residents who

are uncomfortable around MSM are also fearful of contracting HIV (Eldridge et al., 2006). So fearful in fact that casual contact was perceived to put his life at risk for contracting HIV. This man was manifesting a fear of contagion (Sayles et al., 2007). His exaggerated response is what Phelan, Link, and Dovidio (2008) determined to be one of the functions of stigma and prejudice, that is, avoidance of disease. Casual contact is not a health threat. This sort of prejudice only serves to further exploit an already vulnerable population. The situation described also informs norm enforcement, that is, these MSM were a disruption of the natural social order, and his extreme prejudicial response speaks to his feelings toward homosexuals.

Anticipated stigma for one participant influenced the manner in which he organized his life. Anticipated stigma prompted him to censor and modify his behavior in a way in order to avoid disclosure of his MSM identity and HIV status. He had full-time employment and insurance coverage but did not access his employee benefits. Instead he used HIV related care but paid the full cost of his care and medication out of pocket. He feared that if he used his health insurance to offset his medication costs, his employer would be notified that he was HIV positive and MSM. He reported that his boss would fire him if this were known. As a result, his own personal resources (i.e., salary) were diminished and in order to make ends meet, he lived with family members (Chesney & Smith, 1999; Hatzenbeuhler et al., 2013).

HIV Related Stigma Gay Community

HIV has always been associated with MSM. In the early days of the epidemic, before scientists knew what caused AIDS, the condition was initially classified as gay

related immune deficiency (GRID). This association set the stage for prejudicial attitudes towards MSM. MSM have struggled throughout the years in establishing a thriving and cohesive community due to the politics of the closet. The emergence of HIV/AIDS further complicated unity and identity processes by dividing the community itself. That is, after testing was devised in identifying exposure to HIV antibodies, the gay community became divided into two separate communities, those who tested HIV positive and those whose status was unknown (Courtenay-Quirk, Wolitski, Parsons, Gomez, & SUMS, 2006). In many cases these separate communities and identities are hostile towards one another. Participants reported experiences of HIV stigma stemming from their local gay communities. Their feedback indicated enacted (actual) stigma as contrasted with perceived stigma. These occurrences hint at broader issues that rural gay communities face. Rural MSM communities often exist without much unity and cohesion that is further exasperated by oppression and disapproval from the larger general community. MSM stay in the closet and suffer from internalized homophobia. Self-hatred is transferred to those in their community who are HIV positive. The gay community's fear of HIV is amplified by those negative attitudes from the larger community's view of HIV and its association with homosexuality. It becomes a pecking order hierarchy where a loss of status is experienced by those who are known or suspected to be HIV positive (Galindo, 2013; Sayles et al., 2007). Gay men are fearful of HIV infection and as Swendeman, Rotherman-Buros, Comulada, Weiss, and Ramos (2006) suggest, these MSM may be more sensitized to signs or symptoms of HIV infection that in turn results in negative reactions to other MSM living with HIV. In other words, they don't want to be identified as being sick.

MSM who disclose their HIV status are subjected to ridicule and harassment from their peers. For example, one of the participants disclosed his HIV status on Adam4adam.com, an online dating site for men who want to meet men. He did so to be honest and as a means of predisclosure to potential sexual partners. Comments made to him came unsolicited. Being told “you’re nasty”, “you need to get offline” and “you need to go somewhere else” told him that he was considered “less than” and should be socially excluded. It’s bully behavior. The lack of anonymity, rural geography, population density, and social opportunity structures make these online sites a boon to men looking to meet other men. It is a highly competitive arena for dates and hook ups (i.e., sexual encounters). Unscrupulous MSM have been known to initiate rumors in the online chat rooms that someone is infected in attempts to better their own chances for an encounter. Perhaps men such as these think that these men who proactively share their HIV status with others in this context are making other gays look bad, that they are sharing something that should be kept on the down low (Whittier, 1997). Again, this indicates internalized homophobia from the naysayer. It also illustrates the difficulties that MSM have in discussing HIV status and testing with one another (Bairan et al., 2007). It’s a discussion that everyone should have but one that often goes unsaid and unchallenged.

HIV Related Stigma Family

Families can be part of a strong support system for MSM living with HIV. They can be a source of emotional, physical, monetary, and social support. However, in order for care and support to happen, MSM must disclose their HIV status to their families. Given the stigma associated with HIV, many men choose not to disclose. For example,

one of the participants was unable to share his status with a family member due to the psychological harm that he felt this would cause her. So when asked, he denied. He participated in a self-stigmatizing manner (Salter et al., 2010), sparing her feelings, but in doing so denying an opportunity of care and support from a family member.

For those who have disclosed to their families, the responses received were not always favorable. The examples given illustrate social rejection, differential treatment, and rules for engaging in social contact. Family fears of infection are made evident in forcing MSM to use separate towels when visiting or not allowing individuals to eat with the rest of the family during family functions. Family difficulties with HIV/AIDS are often compounded with family tensions regarding homosexuality. Cultural and religious values may also contribute to HIV stigma. One participant shared that his mother repeatedly told him that God was the answer to his illness. That given the right circumstances (i.e., repentance, prayer) that God would remove this from him. Her religious beliefs are the source of her stigmatizing statements, that is, a lack of morality is the cause of this disease. Her solution (i.e., prayer) is in direct conflict with providing appropriate HIV care (Brown, BeLue, & Airhihenbuwa, 2010).

Family fears of infection may be related to lack of knowledge about the mechanics of HIV and transmission and also due to fear of contagion (Bogart et al., 2008; Eldridge et al., 2006; Sayles et al., 2007). Families might also be fearful of secondary stigma. In other words, there might be concerns about stigma directed at family members because of their close association to someone with HIV (Brown et al., 2010; Change Project, 2003a; Herek, 2002; Salter et al., 2010). Family members might experience a loss of social standing in their communities if their family member's HIV

status were known. Stigmatizing behaviors and words towards MSM may be strategies that family members employ in order to avoid being stigmatized themselves.

Research suggests that families are important in the fight to eliminate HIV/AIDS related stigma. Family religious values can be starting point for developing solutions aimed at reducing stigma (Brown et al., 2010). Acceptance of MSM homosexuality can positively influence family responses to HIV/AIDS. This involves re-education processes that lead families from discriminatory attitudes and beliefs to those that are more accepting in nature. Health organizations and LGBT social networks were cited as being instrumental in facilitating change (Castro et al., 1998).

HIV Related Stigma Health Care

Participants were invited to discuss any negative encounters with health care professionals that they experienced in the course of their treatment for HIV/AIDS. They were asked specifically in regards to describe any negative past experiences they had with providers in relation to either being identified as MSM or HIV positive. The aim was to ascertain if they felt they had ever been treated differently or badly for either their MSM or HIV positive status. This line of inquiry led to further probing in asking about instances of being refused treatment or referral other agencies based upon MSM or HIV positive status, concerns about privacy and confidentiality, and possible stigmatization of treatment sites.

Anticipated Stigma . Occurrences of stigma in health care settings were divided into three categories: anticipated, perceived, and enacted. Reports of anticipated stigma were the most numerous overall, that is, participants expected to be treated differently

because of their stigmatized identities. However, many were surprised when this did not occur. This is welcome news and shows improvements in the ways that providers interact with their HIV clientele. However, there is cause for concern. Those who anticipate stigma often will censor themselves in an effort to avoid a negative experience (Salter et al., 2010). In doing so, MSM may alter the information that they share with their providers. This could result in incomplete information needed to devise treatment plans. Earnshaw and Quinn (2011) reported that patients who anticipated more stigma in healthcare settings were less likely to access health care services. Anticipated stigma impacted their quality of life. Interventions aimed at reducing stigma should also target increasing access to care. Specifically, encouraging patients living with HIV to access care despite their fears of stigma may improve their quality of life.

Perceived and Enacted Stigma. Stigma was sometimes experienced in subtle ways. Men perceived stigma originating from ambiguous nonverbal cues (e.g., looks, body language, distance maintained from patient). Experiences such as this blurred the line between perceived and enacted stigma. Regardless, MSM were sensitized to these nonverbal cues. They perceived these actions as proof of disapproval and fear from those who treat them and so they responded accordingly. In other words, it became a part of their experience.

Men reported that interns and HC trainees from different ethnic and cultural backgrounds seemed to exhibit a greater discomfort in interacting with HIV patients. This could be related to an intern's inexperience with patients in general and perhaps differences from cultural aspects of communication. There might also be cultural discomfort associated with the stigmatization of homosexuality and as a consequence

HIV. If true, interns could be experiencing anxiety and fear in caring for these patients (Zukoski & Thorburn, 2009). Cultural competency training is recommended; health care professionals should be encouraged to explore their own values and biases and discover those that would conflict with their professional duties (Vance & Denham, 2008).

The married couple in the study reported experiences that were perceived to be related to homophobia. They reported incidents where the nursing staff responded negatively towards them. They perceived this to be due to their same-sex partnership. Moreover, they reported that when the participant was admitted to the hospital that his partner was required to produce legal documentation specifying his legal standing to make medical decisions for his partner. Even when producing these documents, they experienced challenges to visitation rights and consultations from health care staff. These challenges were met vis a vis by his partner. These challenges were experienced numerous times.

Refused Treatment

Project participants were queried as to whether their MSM or HIV positive status being made known in a health care setting had ever resulted in being refused treatment or a referral to another health or social service related agency. No one had ever been refused treatment because of being identified MSM. However, there were reports of refused treatment because of the patients HIV status. One example was especially overt in nature.

The participant was referred by his primary care physician to a specialist. As is procedural with all new intakes, the participant brought his current medications for the initial visit, so that the specialist would be aware of what he was currently taking for other health related conditions. She responded in an unprofessional and disrespectful manner. She refused treatment. Examples such as this are well documented in the literature (Rahmati-Najarkolaei et al., 2010; Yanessa, Reece, & Basta, 2008; Zukoski & Thorburn, 2009) and serves to remind that although advances in HIV care and patient advocacy have been made, there is still the need for continued efforts in the reduction of service providers stigmatizing attitudes and behaviors towards their patients.

The researcher included this participant's response to this discrediting experience in order to allow him his voice. He had been humiliated and embarrassed by this interaction with a health professional, someone who should have had the personal and professional courtesy to act and respond in a very different way. Even at the time of our interview, he was still visibly angry. He reported being treated in a dehumanizing way. He appealed that HIV patients should be treated in a professional manner because "we still have feelings." This is a stern reminder that words matter. How patients are spoken to, how they are treated, it all matters.

Dental care is essential to the overall health of HIV patients; however, persons living with HIV have long been denied services by dentists (Carr & Gramling, 2004; Rhamati-Najarkolaei et al., 2010). Best practice guidelines related to universal precaution measures make this refusal unnecessary. That is, precaution measures used consistently for all patients prevent accidental transmission of the HIV virus. Perhaps dentists erroneously believe that by refusing care to HIV patients they are

lessening their chance of exposure to HIV. This assumption erroneously rests on the premise that everyone discloses truthfully during intake. Gloves and masks should be used for all patients. Autoclaving of dental instruments should be the standard practice for sterilization.

The experiences noted here support previous findings that some health care providers are uncomfortable in associating and treating people living with HIV. Various solutions have been recommended by researchers. Brown, Macintyre, and Trujillo (2003) posited that interventions pairing information AND skill building exercises would improve attitudes towards HIV patients and also increase a willingness to treat these patients. Similarly, Li et al. (2013) suggested that factual information alone was insufficient to change attitudes with providers. Their intervention focused on self-protective measures and occupational safety. Popular opinion leaders within the study were also taught skills and techniques for better communication.

Privacy and Confidentiality Concerns

MSM experience certain barriers when accessing health care services. In rural areas MSM are concerned with issues related to privacy. They cannot risk having their sexual orientation known in their localities. This is further compounded when considering additional privacy and confidentiality issues related to their HIV status. MSM perceived that their medical information was not as confidential as it appeared. Concerns about privacy and confidentiality were presented in the interviews. These experiences were classified under institutional policies, unintentional disclosure, or intentional disclosure.

MSM reported that their chart information was coded in such a way that their HIV status was known. They considered this a breach of confidentiality. One participant complained that his medical record was displayed in such a way that a hospital chaplain learned he was HIV positive. He felt as though he had to explain and defend himself against this intrusive interaction with the priest. In other words, he didn't want to be identified and known as an HIV patient to this priest. This participant's record was handled carelessly; his information was not protected.

Similarly, another participant recalled that his partner's hospital door had clearly been marked with an orange dot, indicating that he was HIV positive. In this case hospital personnel might have been trying to maintain patient confidentiality by using codes. However, although the intent may have been to protect patients, in effect, this action branded his doorway with a scarlet letter. Anyone who spent any considerable time in this hospital ward (e.g., patients, visitors, other HC personnel) could have deciphered this code (Moyer, Igonya, Both, Cherutich, & Haron, 2013) and made the connection. Health care professionals may not have had any choice in this matter, that is, this type of policy could have been the result of institutional policies (Surlis & Hyde, 2001).

At other times MSM confidentiality and privacy were breached in unintentional indirect ways. In these cases confidentiality was breached through careless talk. However, MSM perceived these as damaging and a breach of trust. Assurances of confidentiality are particularly important in rural areas. For example, careless broadcasting in a public pharmacy for "one of those AIDS drugs" puts MSM at risk of being outed in their rural communities. This sort of chatter is inappropriate. It doesn't

take long for the word to get out and once this has transpired, these MSM, having been discredited, are forced to find new ways of interacting within their community. Public knowledge of their health condition may have adverse effects on their employment, housing, health insurance, and social standing within their communities.

HIV related stigma intersected with confidentiality, accessing health services, transportation, and distance times to providers for some men associated with this project (Chesney & Smith, 1999). Privacy concerns were so great for three of the participants they refused to seek treatment in their own communities. Their fear of being recognized at local health centers coupled with fears related to confidentiality and privacy resulted in their seeking treatment and services *outside* their local area. In all instances these men sought health related care across county lines. HIV stigma did not inhibit these men from seeking care, but it did alter the way and means in which they sought out health related services. Two of these men had transportation but still drove considerable distances to access care. The remaining participant relied on public transportation, and when that wasn't available, he paid friends or his CNA to transport him to and from his appointments. His case was extreme, that is, he routinely traveled approximately 200 miles to and from his health care providers. Furthermore, his situation often resulted in financial hardships resulting from paying bus fares or for gas and time to those who transported him. This extra travel, time, and expense had a very real potential to diminishing their personal resources. (Whetten-Goldstein, Nguyen, & Sugarman, 2001).

The most troubling experiences were those related to an intentional breach of confidentiality. Participants' HIV status was revealed to others without their consent.

HIV patients have the right to control private information about themselves. Health care professionals have a responsibility to protect the privacy of their patients. In discussing the intentional breach of patient confidentiality, research largely refers to those disclosures that *seem* to be obligatory for the protection of caregivers and sexual partners (Bayer, 2008; Chan, 2013; Moyer et al., 2013; Odunsi, 2007; Warburton, 2005). A specific type of patient is addressed here, that is, one who is recalcitrant. This manner of patient is one who has contracted an infectious disease (e.g., HIV) and has no intention of notifying his sexual partner(s), has no intention of disclosing to future sexual partners of his HIV status, and does not intend to practice safer sex techniques. The literature is in support of a doctor's obligation to protect others who might be at risk for HIV infection.

This does not represent the men in this study. MSM did not want to put others at risk for HIV infection. They disclosed their HIV status to their wives, their same sex partners, and their sexual partners. They reported practicing safe sex (i.e., condoms) and disclosing to potential sexual partners (e.g., disclosed on dating websites), and some went even further as to no longer seek out partners, fearful of transmitting their infection. But, MSM reported experiences where their status was intentionally shared without their consent. These men were the victims of gossip and paternalism. Malicious gossip was especially potent. Health care professionals violated their employer's privacy and confidentiality policies in order to spread gossip and rumors about patients, knowing that the information would be damaging to those involved. These employees acted in an unethical manner. This sort of behavior should not be tolerated by any health care organization. A reputation of this sort can damage the institution's credibility

in the community, become a legal liability, and ultimately decrease shareholder value for financial stakeholders.

One participant stated that his physician, upon receiving his HIV test results, did not call to give him the results of his HIV antibody test. The doctor instead contacted the patient's mother and disclosed his HIV status to her. The doctor felt she had a right to know. Moreover, his mother contacted other members of the family and shared this information with them. So, before he was aware that he was HIV positive, his mother and extended family were aware of his infection. The doctor acted out of a sense of paternalism. That is, he believed that it was his duty to disclose to others regardless of HIPAA guidelines. He acted as though he was operating in his patients' best interest (Moyer et al., 2013). The results for the patient were devastating. Not only did he have to initially process that he was HIV positive, he also had to act upon the fact that his family knew. His doctor exposed his patient to stigmatization and discrimination from his own family. Newly diagnosed patients need time to process the implications of their health condition; they need time to initially come to terms with this new reality. Various protective and coping mechanisms are adapted in these early months as the patient tries to make sense of everything and find solid ground to stand upon. This participant never had the opportunity to do this.

Medical personnel should be held to strict standards of ethical conduct, and be trained about HIPAA guidelines and the importance of maintaining patient privacy and confidentiality. Those personnel who violate those policies should be accountable and punished (Whetten-Goldstein et al., 2001).

Anticipated stigma associated with a loss of confidentiality was perceived to be so great for one MSM that he did not disclose his HIV status to the attending physician who treated him for a work related injury. His injury involved considerable bleeding and required several stitches. He feared that if he had confessed to the physician that he was positive, this information would have been noted in his medical file. Family members worked for a local health clinic and he believed that his medical information would not be confidential. His strategy was to manage his devalued identity to attempt to control his privacy. It would be easy to characterize his behavior as selfish and perhaps criminal, but it doesn't address the barriers that people living with HIV have when it comes to disclosure. As long as those living with HIV continue to face stigma and discrimination from loved ones, from healthcare professionals, and from society, it's not going to be easy for them to disclose. Their fears concerning privacy and confidentiality must be taken seriously, and appropriate measures should be taken to ensure that their protected health information is handled appropriately. Until then, some patients will continue to respond accordingly. Universal precaution measures should be strictly adhered to by medical personnel in all appropriate incidents.

Treatment Site Stigmatization. A series of questions referred to the treatment sites that these men used for health services. Specifically, questions were asked to discover if they perceived that the general community knew that these locations were sites where HIV related services were offered. Were there any local advertisements for HIV/AIDS related services in the local media? Was there any outside signage designating these locations as servicing HIV/AIDS related care? Did they have any concerns about being seen entering or leaving these treatment sites? A sizeable

number of men reported concerns of being recognized at the locations where they received care. They believed that there was adequate information available to make connections to their care and HIV/AIDS (Doshi, Malebranche, Bowleg, & Sangaramoorthy, 2013). Participants don't want to be readily recognized and labeled "AIDS patients." Living in smaller areas implies having less anonymity. While they at times experienced shame and discomfort when accessing these locations, none reported that it would cause them to miss or delay an appointment. But it did cause them psychological distress, especially when recognized by others or when they recognized others. They did not want to be devalued in the eyes of others. They wanted to be able to pass, to not be labeled, and to not lose social status.

There were no media advertisements (e.g., newspaper, tv ads, billboards) for HIV related care at either of the study sites. Feedback indicated some internal advertisement (e.g., informational pamphlets) in several health related locations (e.g., clinics, ASO) but this information was not readily accessible to the general public. That is, the general public would have to be present at one of these health and support service areas to access these items. Response concerning outside signage were a varied. A few of the sites included words (i.e., infectious) in their clinic names. However most of these locations did not advertise their HIV services. Service providers made a point of intentionally avoiding and removing any identifiers that would associate them with HIV/AIDS. For example, an ASO used by many of the men in WNC has no outside signage denoting anything at all. The organization feels that to place identifiers on their exterior is a breach of confidentiality and privacy. The ASO is located in a residential neighborhood and on the city's bus line stop. Additionally, mail sent from this ASO to

clients has nothing but a P.O. Box listed on the return address. The envelope contains no identifying information that someone (e.g., family, friend, neighbor) might be able to trace back to the ASO and thus, “out” the patient to others. These are real concerns for men living in rural areas.

While these adjustments are currently necessary to easing client and patient concerns, a question arises: are they inhibiting or actually reinforcing HIV stigma in their localities? In other words, what are health and service agencies doing to actively tackle HIV stigma in their respective communities? It could be debated that the “invisibility” that agencies employ as part of their strategy to lessen stigma, actually reinforces shame because it *is* shameful and should be hidden from view. That is, HIV/AIDS is a shameful condition and not one that should be acknowledged in public. This can also reinforce the anecdotal misperception that HIV is not a rural issue. Furthermore, this invisibility could be a barrier to those who are outside the system. In one site area accessing information about HIV related services was a challenge. There were no direct links, no information easily available for those who were not familiar with the system. It was hidden. Someone newly diagnosed, new to the area, or someone who was concerned about his sero status would find it challenging to access information about health and service organizations in the area.

These are difficult challenges. The researcher posits that as long as HIV continues to be “closeted” that stigma will be difficult to challenge and harder to eradicate. HIV is an illness; it says nothing about the value or the values of that person. Those who speak out and share about their infection often do so at a great cost to themselves, and yet they find it to be empowering and transformative. Sharing with

trusted family and friends takes courage. Disclosure can assist PLWHA out of social isolation and into supportive care from those they disclose to. Simply put, people cannot assist others when they don't know. It can also be life changing for those who discover that they know someone who is HIV positive. That knowledge has the potential to change the way they view HIV and those who live with the condition. It dismisses misperceptions, challenges stereotypes, and becomes a real bonafide issue.

The researcher acknowledges that he is not HIV positive and therefore cannot fully understand what it is to live in rural Appalachia as HIV positive. He by no means is attempting to simplify or lessen what others have shared from their perspectives. He is reflecting upon his own experiences with homophobia and the processes of coming out. Both identities are highly stigmatized by rural populations. Both identities are highly misunderstood and feared. Both identities are branded by conservative religious ideology in morally negative terms. However, neither homosexuality nor HIV infection is discrediting in itself. Identifying with either of these labels does not devalue a person. There is no shame in being homosexual or HIV positive. There was a time when many homosexuals lived in fear of coming out of the closet. But there is life outside of the closet, there is authenticity and pride to be gained by acknowledging who you are. There is also life outside the closet of HIV. The researcher suggests that if those who are living with HIV can find ways of being more open about their status, that this will have positive effects. This is not to be addressed by those living with HIV alone, that is, other persons and agencies must also be involved in confronting stigma. Stigma must be challenged and confronted in the medical community. Training and education efforts geared toward health professionals can help to confront resistance to providing care for

HIV patients (Brown et al., 2003). Community education is warranted to combat the perception that HIV doesn't exist within rural communities. Local health fairs, World AIDS awareness events, and community public service announcements can give communities a new perspective. For example, the "i need U2 know" campaign, debuted in Western North Carolina beginning in 2009. The local ASO developed this program to directly address HIV stigma within their service area. The campaign used multimedia approaches to get out their antistigma message. Print advertising (e.g., billboards, posters) along with four televised public service announcements were produced. These items showcased local residents who were concerned about ending HIV related stigma in their area. This was a uniquely localized approach and it garnered the attention of the surrounding community (Western North Carolina AIDS Project, 2009a).

As long as HIV remains stigmatized by family, friends, and society, especially in rural areas, treatment site locations for HIV related care will continue to be stigmatized. One approach to addressing stigma is to integrate HIV care with other primary care services (Doshi et al., 2013; Nguyen & Whitten, 2003; Odeny et al., 2013; Topp et al., 2012). This approach was reported by more than one participant, that is, they did not perceive any stigma associated with their being seen at their service location because other patients were there for a variety of health related illnesses. In other words, they could have easily been seen at these locations because they were diabetic, seeking reproductive services, or accessing general care. Integrated services take a bite out of perceived stigma. Other advantages to this approach include increased resource and allocation efficiency, enhanced care coordination, provider skills, increased patient access, retention, quality of care, and patient satisfaction. Other studies suggest that

privacy and confidentiality issues must be adequately addressed, even in these integrated approaches, as rural health services are still perceived to be more stigmatizing for some patients (Mill et al., 2009).

Personal Journey

Case information from John TN and John NC were selected in order to provide a more in-depth and personalized context in which to consider their lives and experiences. The researcher wanted to present their information in a format that helped to flesh out their lives in greater detail. Two stories were offered allowing for comparison to identify similarities and differences in their experiences. We come to know what has happened in their lives only in terms as what they have chosen to reveal as their experience.

Participants were encouraged to share their experiences and to tell their stories. The researcher wanted to better understand the issues that HIV positive men face in rural Appalachia. To better understand the health experience, to know what it is like for these men to live with their illness can be beneficial to health care professionals (Kearney, 2001). It can be used to frame an illness in a different way and provide insight of how to offer better support to patients in their care. Professionals with a broader understanding will recognize cues from the patient and be able to respond in a more culturally competent way than before.

It was important to the researcher that the data provided not be reduced in such a way that the individuality of these men was lost. In other words, there was a purposeful process of not presenting the data as succinctly as possible. Each response

had a unique flavor to it. Individual voices matter. The third theme presented was intentional. It was an extension of the data already presented, that is, not only did their individual voices matter, but their journeys mattered as well. Lives come from somewhere and are going somewhere (Frank, 2002). These are the things that matter most. Data were displayed in a case study format to give greater contextual detail, to allow readers a greater sense of being there. It's a way to further "connect the dots." (VanWynsberghe & Khan, 2007).

Sharing these stories is important for several reasons. Qualitative research can be a tool for the advancement of social justice. Change can happen when lives are understood in a broader context. This research project has "given voice" to a highly stigmatized and marginalized population. Their voices had been silent, their perspectives not considered. This research was a platform to allow them to say what they had to say. The act of sharing significant life experiences can lead to personal emancipation for the storytellers resulting in positive changes. Moreover, for others, there is a need for others to hear their stories and the desire to be recognized and heard (Chase, 2005).

Moreover, we, the readers, need to consider their stories. This project was more than just an academic process; this opportunity was presented as a means to better ourselves as an audience. What can be learned from considering their perspectives? What do we learn about ourselves as we reflect upon what we know about their journeys? That is, do we recognize the similarities from our own experiences or do we only acknowledge what is different? What does *that* say to us? Does this knowledge

move the reader to empathy and understanding or does it produce resistance and hostility?

Appalachia

Both men are sons of Appalachia. Both reported that living here all of their lives made them Appalachian in the broadest sense. Appalachia was described as being a difficult place to live because of their sexual orientation (Yarbrough, 2003). People were harsh; they were intrusive and disrespectful. Neither of these men identified with this Appalachian mentality. They rejected it. However, they did not leave the area as others had (Diaz, 2001; Dooley, 2009) to 'come into their own' but instead chose to remain in the area.

Religion

Their childhood experiences with religion were nominal at best. That is, neither reported strict adherence to organizational religiosity (e.g., church attendance, membership) for themselves or their families. Both reported complicated relationships with their childhood religious faiths; both were exposed to negative messages from their congregations about the nature of homosexuals and the lives they were living (Kubicek et al., 2009; Yarhouse & Tan, 2005). However, both men found a way to reconcile their lives and their spirituality. John TN's spiritual path led him back to a gay affirming traditional church congregation (Lease et al., 2005) while John NC found his spiritual identity in a more non-Judeo-Christian-Islamic perspective (Smith & Horne, 2007). Both receive spiritual and emotional strength from these belief systems.

Coming Out

Each man acknowledged that he knew since childhood that he was different and that he was attracted to other men. Both believe that they were born with this orientation and that it was a natural process for them.

Both men were out to others in varying degrees. This openness with others had a positive psychological impact on their lives (Riggle et al., 2008). Whereas John TN confronts and challenges stereotypes by actively disclosing his sexual orientation, John NC struggles with internalized homophobia and has been unable to negotiate his identity in an authentic manner around his family (Dooley, 2009; Johnson et al., 2008)

HIV Diagnosis

John TN was diagnosed with HIV in 2009 and has been living with HIV for approximately 4 years. John NC was diagnosed in 1995 and has been living with HIV for approximately 18 years. Both learned of their serostatus as the secondary result of seeking other health assessments. HIV was regarded as an urban problem, not one that existed in Appalachia (Foster, 2007). Each of them struggled with the implications of being HIV positive. In the beginning, they thought they were going to die.

Reflecting on that time period John TN reported that his seroconversion was a wakeup call. That is, this was God's way of telling him that if he wanted to continue doing good works, then he must make some difficult choices that he (at the time) had not been willing to make. He turned to spiritual support and belief to better cope with his HIV diagnosis (Foster et al., 2011, Kremer et al., 2009).

John NC took another route during those initial days. His emotional support came from a close relationship (Bairan et al., 2007). His partner made the necessary introductions and contacts to connect him to the appropriate health and mental health care services that he needed.

Disclosing HIV

Both participants were selective when disclosing their HIV status. The types of relationships that they had with others were the determining factor of whether they shared their status at all (Bairan et al., 2007). Each had struggled in deciding to disclose to others, in part because of their fears of how people would respond. People might use disclosure information against them (Chenard, 2007; Foster, 2007). They might become the targets of gossip and anticipated rejection from family and friends (Change Project, 2003b; Galindo, 2013).

Discussing HIV serostatus was difficult in the context of disclosure to potential sexual partners (Courtenay-Quirk et al., 2006; Grov, Agyemang, Ventuneac, & Breslow, 2013). Both men believed it was important to disclose to their sexual partners, but the process was challenging and cause for anxiety and fear. Fears of rejection and privacy were given as reasons for the difficult nature of initiating these conversations. John NC questioned the directive placed upon HIV positive men to disclose their status in every sexual encounter; the criminalization of potential HIV exposure (Cameron, 2009; Swendeman, Ingram, & Rotheram-Borus, 2009). What if a condom was used? Was there still the need to disclose? What if the sexual activity had negligible risk associated with it? Should he still have to disclose? At what point in dating or hooking up should

disclosure take place? What if he disclosed and at a later time his sexual partner claimed that he didn't? These were the questions that he wrestled with. He felt that responsibility should be equally shared. Consenting adults engaged in sexual activity must take responsibility for their own health.

Health Care Providers

These men accessed health care services differently. John TN had private insurance offered through his employer. He also received HIV related care services through another health service provider. Having health insurance offered him various choices in how to access services and who to choose from. He has been challenged by the lack of communication between his providers. This lack of communication has resulted in duplication and redundancy in his care. He feared that absolute contraindicative episodes might occur if his physicians continued not to consult one another for treatment.

Things operated differently for John NC. As a Medicare recipient, he has restricted income that resulted in him accessing care in a different way. His primary care and HIV care are handled through a federally qualified health center. He has personally been challenged in obtaining referrals to specialty care because of his low T cell count. He believed this limited him health wise. He has also accessed services through a local ASO for supportive services. For example, he qualified and accessed assistance through Housing Opportunities for Persons with AIDS (HOPWA) and the Shelter Plus Care Programs.

HIV Medicines

These men struggled in their decisions to take HIV medications. After being diagnosed, John TN did not want to begin ARV. He initiated a period of social withdrawal after his diagnosis. His struggle to begin treatment was in conflict with his personal beliefs regarding the millions of people living with HIV who did not have access to medication. It felt wrong to have something that others did not have just because of where they were born or whom they worked for. This is consistent to other reports of those newly diagnosed with HIV (Kemppainen et al., 2008; Mill et al., 2009). His incongruity was resolved after seeking counsel from his spiritual advisor (Kremer et al., 2009). His self-care behaviors reflect a commitment to maintaining balance and purpose in his life (Chenard, 2007).

Although John NC began taking medications immediately after being diagnosed, he wrestled with maintaining consistency in adhering to his regimen. AZT was prescribed for treatment and he reported that this was a horrendous experience. Side effects he experienced contributed to periods of time where he did not take his medications. He felt the medicines were intrusive, that they affected the way he felt about himself and made his working life more difficult (Kemppainen et al., 2008). It took a near death experience in the hospital to convince him to be more consistent. As with John TN, he too strived for normalcy and equilibrium in his life. Adhering to his medication schedule was a means to accomplishing this (Chenard, 2007). He also attributed his adherence success to the emerging new class of HIV medications and experiencing fewer side effects.

A more personal approach was taken in order to describe a more detailed accounting of the lives of these two men. We are able to understand the experiences of their lives in greater context. They reported their experiences of growing up gay in rural Appalachia. Their backgrounds influenced the ways that they experienced, perceived, and processed the various events that they encountered along their way. Their lives were heavily impacted after testing positive for HIV. This was a major life change, one that required personal reflection, reevaluation, and redirection. They experienced stigma on multiple levels as MSM and being HIV positive. They educated themselves concerning their illness and learned how to navigate an often fragmented and confusing health care system. Each experience informed and prepared them for the next one, moving them along their way.

Study Limitations

Sample Size

Limitations to this study include those related to qualitative data; that is, the sample is a relatively small number of participants. Moreover the sampling method was not random; nonprobability sampling techniques such as snowball sampling were used to recruit participants to the study. The geographic area in which this study drew from is small when compared to other areas of the United States. Generalizations about other HIV positive MSM should not be derived from review of this particular study. The study reflects only those experiences described by these men living in NE Tennessee, W North Carolina, and NW South Carolina.

Health Care Usage

The participants interviewed were HIV positive MSM already connected and 'plugged in' to local health services. Responses may have been quite different if MSM who were not already connected to health care services had been included in the study. HIV positive MSM not connected to care should be considered in future studies.

Researcher Bias

Researcher bias may be present in this study. For example, qualitative data analysis is an interpretive process, and it is possible that other coding themes were present in the data that the researcher overlooked. Data were filtered through the views of the researcher; this is a potential source of bias. The researcher is also an instrument of data collection and analysis; therefore, it is difficult to separate all biases from the interpretive process. Through self-reflectivity it is possible to know biases but not to account for all of them.

Social Desirability Bias

The researcher's presence may have been a source of social desirability response bias in this study. The investigator was accepted as a cultural insider by the men in this study, which proved to be beneficial in establishing rapport and good rapport during data collection. However, there were times during the interviews where some participants appeared to craft their responses in such a way in order to gain social approval from the researcher. Some of the participants may have felt they knew the researcher in a personal manner. The investigator repeatedly reminded participants that

he was seeking honest and accurate feedback, reiterating that there were no right or wrong ways to respond to any of the questions asked.

Discussion Guide Language

The language of the interview script may have been too difficult for some of those interviewed. Therefore, questions were modified to better suit each participant's social and educational status. Also there was a lack of uniformity in methods used and this would be hard to replicate due to the nature of the study. This could create issues in validity when attempting to compare information across individual responses from the interview data.

Contributions to Public Health

This study adds to a growing body of literature documenting the lives and experiences of MSM living with HIV in rural America. This exploratory dissertation provides the public health community with insight and contextual information for a highly stigmatized population. The insight gained can be used to inform health care professionals about how to better serve their patients. Public health programming for MSM populations will also be better equipped to meet the needs of this population of interest and respond in a more culturally competent manner.

Conclusion

The purpose of this study was to examine and document the lives of HIV positive MSM living in Central Appalachia. Of particular interest to the researcher was the intersection of homophobia and HIV related stigma with various aspects of culture

(i.e., place and spirituality) and health care usage. Participants were connected to local health services. Although participants reported experiencing stigma in multiple and overlapping ways, stigmatization did not mediate their health care usage. The researcher gathered and preserved many life stories in the course of this project. Documenting and describing these experiences will lead to a greater understanding of how MSM navigate their lives in rural Appalachia.

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APPENDICES

APPENDIX A: Recruitment Flyer

Participate in a Research Study East Tennessee State University

As a MSM (men who have sex with men) what sort of interactions have you experienced related to health care usage and living in rural Appalachia?

Roger Blackwell, from East Tennessee State University is conducting interviews with MSM about their experiences with health care services and living in rural Appalachia. If you would like more information about this study, please email Roger Blackwell at blackwer@etsu.edu or call him at (423) 302-0812. Your contact information will be kept confidential.

A small token of appreciation (e.g., \$5 Walmart gift card) will be offered to study participants at the conclusion of the interview.

APPENDIX B: Informed Consent Document

EAST TENNESSEE STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

ORAL EXPLANATION OF INFORMED CONSENT

“Health Service Utilization among
HIV-Positive Men-Who-Have-Sex-With-Men (MSM) in Appalachia”

Roger Lee Blackwell, MPH, DrPH ABD

Department of Community Health

College of Public Health

East Tennessee State University

This Informed Consent will explain about being a participant in a research study. It is important that you read this material carefully and then decide if you wish to be a volunteer.

PURPOSE

The purposes of this research study are as follows:

- To explore and describe HIV/AIDS related stigma as experienced by those living with HIV in Appalachia;
- To explore and describe homophobia as experienced by men who have sex with men (MSM) in Appalachia;
- To further understand how stigma may influence health related outcomes for HIV-positive MSM;
- To provide those HIV-positive MSM in Appalachia a voice; and,
- To provide information from the perspective of HIV-positive MSM that will inform a dissertation project.

DURATION

As a research volunteer, you are being asked to participate to a conversational, but guided, interview and short survey that will take no more than 90 minutes to complete.

PROCEDURES

The procedures, which will involve you as a research subject, include:

- A qualitative research technique known as a guided interview
The interview consists of you responding to a set of pre-determined questions that I, the researcher, have written. This type of research is non-experimental. It is non-invasive. It is not numeric, and no statistical analysis will be conducted. Qualitative research generally looks for patterns in the words and phrases of research volunteers to arrive at a deeper meaning of the phenomenon under investigation.
- The interview will be audio-recorded with a digital audio-recorder, but no names or identifiers will be used during this process. Furthermore, the audio-recording will be erased once the interview is transcribed (or written).
- A quantitative research instrument known as a demographic survey questionnaire.

This short survey consists of you responding to a set of pre-determined questions that I, the researcher, have written. This type of research is non-experimental. It is non-invasive. Your answers will be translated numerically and statistical analysis will be conducted.

ALTERNATIVE PROCEDURES/TREATMENTS

There are no alternative procedures to collect this information.

POSSIBLE RISKS/DISCOMFORTS

You may experience some discomfort due to the sensitive nature of the topic.

POSSIBLE BENEFITS

To the researcher's knowledge there has been little research done in describing HIV/AIDS stigma as experienced by MSM living with HIV in Central Appalachia. By participating in this research project, you may gain satisfaction of knowing that you are assisting with the development of research that gives a snapshot of rural Appalachia

from the perspective of those living with HIV. Otherwise, there are no direct benefits to you as a study volunteer.

FINANCIAL COSTS

There are no financial costs to participants from participation in this study.

COMPENSATION IN THE FORM OF PAYMENTS TO RESEARCH PARTICIPANTS

A \$5 gift card from Walmart will be offered to study participants at the conclusion of the interview.

VOLUNTARY PARTICIPATION

Participation in this research experiment is voluntary. You may refuse to participate. You can quit at any time. If you quit or refuse to participate, the benefits or treatment to which you are otherwise entitled will not be affected. You may quit by calling Roger Lee Blackwell, whose phone number is 423-302-3539. You will be told immediately if any of the results of the study should reasonably be expected to make you change your mind about staying in the study.

CONTACT FOR QUESTIONS

If you have any questions, problems or research-related medical problems at any time, you may call Roger Blackwell, principle investigator at 423-302-3539, or Dr. Mary Ann Littleton, Associate Professor, Department of Community Health at 423-439-5247 or the ETSU College of Public Health at 423-439-4332. You may call the Chairman of the Institutional Review Board at 423/439-6054 for any questions you may have about your rights as a research subject. If you have any questions or concerns about the research and want to talk to someone independent of the research team or you can't reach the study staff, you may call an IRB Coordinator at 423/439-6055 or 423/439/6002.

CONFIDENTIALITY

Every attempt will be made to see that your study results are kept confidential. A copy of the records from this study will be stored in the principal investigator's personal residence for at least 5 years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a subject. Although your rights and privacy will be maintained, the ETSU IRB and personnel particular to this research (Roger Blackwell) have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above.

By verbally consenting, you confirm that you have read or have had this document read to you. You will be given a copy of this informed consent document. You have been

given the chance to ask questions and discuss your participation with the investigator.
You freely and voluntarily choose to participate in this research study.

APPENDIX C: Demographic Information

Demographic Information

1. What is your current age? _____
2. In regards to gender, are you: _____ Male _____ Transgender (FTM)
3. How would you describe yourself racially? (You may select more than one option)
_____ Black or African American
_____ White or Caucasian
_____ Asian or Indian Subcontinent
_____ American Indian or Alaska Native
_____ Hawaiian or other Pacific Islander
_____ Unknown
4. How would you describe yourself ethnically?
_____ Hispanic, Latino or of Spanish Origin
_____ Non-Hispanic
5. In what city and state do you currently reside?

6. What is your current relationship status?
_____ Single _____ Married (to female) _____ Married (to male)
_____ Partnered (to female) _____ Partnered (to male) _____ Separated
_____ Divorced _____ Widowed
7. What is the highest level of education that you have received?
_____ High School _____ College _____ Graduate School
_____ Professional

8. What is your HIV status?
 _____ HIV+ asymptomatic _____ HIV+ symptomatic _____ AIDS (CDC defined)
9. What year did you receive your first positive HIV test result?

10. What year did you receive your diagnosis of AIDS (as defined by the CDC)?

11. What is your latest CD4 count? _____
12. What is your latest viral load count? _____
13. What type of health insurance do you have?
 Medicaid? _____ yes _____ no
 VA Medical Benefits? _____ yes _____ no
 Private Insurance? _____ yes _____ no
14. Are you currently on antiviral drug therapy? _____ yes _____ no
15. If you answered yes to question 14, what sort of regimen are you currently taking?

16. Approximately how long have you been taking antiviral medications?
 _____ Years
17. Are you receiving case management services from any AIDS service organizations?
 _____ yes _____ no

APPENDIX D: Interview Instrument

Health Service Utilization among HIV-Positive Men-Who-Have-Sex-With-Men (MSM) in Appalachia

Roger Blackwell MPH

Department of Community Health; College of Public Health; East Tennessee State University

Interview Guide

I. Introduction

A. Welcome

My name is Roger Blackwell, and I am a graduate student and doctoral candidate at East Tennessee State University. I am writing my doctoral dissertation about the experiences of HIV-positive men-who-have-sex-with-men (MSM) in Appalachia. Specifically, I am looking at health services utilization and issues that may impact it such as your religious or spiritual practices, HIV-related stigma, and homophobia.

B. Thank you for agreeing to participate in this research project. Your participation in this study will remain completely confidential. I will never identify you by name, and there will be no way to connect your responses. Remember, there are no right or wrong responses; simply answer the questions as accurately as possible.

1. Do you have any questions before I begin taping this conversation?

C. Each interviewee will be given an informed consent statement, but not asked to sign it.

D. Taping begins.

II. Interview Questions

Let's start with some background questions about your religious or spiritual beliefs.

A. Please describe the religious affiliations and beliefs of your parents or caregivers during your childhood?

1. How would you describe your family's involvement in church or worship services?

2. How important were religious activities (e.g., Sunday school, revivals, festivals, holidays, etc) to your family?

3. How did your family's beliefs and practices affect you as a child?

- B. Please describe your current religious affiliations and beliefs to me.
 - 1. Prompt: Do you believe in God or a higher power?
 - 2. Prompt: How often do you currently attend religious services?
 - 3. Prompt: How often do you pray privately or at religious services?
- C. How has religion or spirituality influenced your sexual activity or identity as a MSM?
 - 1. Prompt: Did your religious upbringing cause any feelings of shame or guilt regarding your sexual activity or identity? If so, please explain how.
 - 2. Prompt: Are your current religious or spiritual affiliations and beliefs accepting of your sexual activity or identity as a MSM?
 - 3. Prompt: Have you ever received religious or spiritual support in regard to your sexual activity or identity?
- D. How do your religious or spiritual upbringing and current religious practices affect the management of HIV/AIDS and other health conditions?
 - 1. Please identify any specific spiritual or religious practices that you feel assist you manage your HIV – positive status?
 - a. Prompt: Do you use prayer or meditation to cope with HIV?
 - 2. What kinds of emotional or spiritual support have you received from your spiritual advisor (e.g., minister) as a result of your HIV- positive disclosure?
 - 3. What kinds of emotional or spiritual support have you receive from a religious or spiritual group as a result of your HIV- positive disclosure?

III. These next questions involve your experiences and perceptions of living in Appalachia. Let's start with your general observations about life in Appalachia, and then we'll move on to what it's like being an HIV-positive MSM in this area of the United States.

[PROVIDE A MAP OF APPALACHIA FROM AN OFFICIAL SOURCE]

- A. Please take look at this map of Appalachia. As you can see, we are currently situated in South Central Appalachia.
 - 1. Have you always lived in Appalachia?
 - a. Prompt: If you have lived elsewhere, please provide a brief account of the different places you have lived.
 - i. Prompt: How long did you live in each of these areas?

IV. Now I'd like to shift the focus of our conversation from culture to the social experiences that you've had as a HIV-positive MSM.

A. First though, let's talk about your self-perceptions as a MSM.

1. How do you feel about being a MSM or sexual minority (e.g., gay, bisexual, transgendered) person?
 - a. How did you come to terms with your sexual orientation?
 - i. Prompt: Do you consider yourself to be "out?"
 - ii. Prompt: Describe your coming out experience to me.
 - b. Do you feel any guilt or shame about your sexual activity or identity? If yes, please explain why.
2. In what ways have you been treated badly (or differently) by people in your family for being MSM or a sexual minority male?
 - a. Is your family aware of your sexual orientation?
 - b. Describe your coming out experience to your family for me.
3. In what ways have you been treated badly (or differently) by people in your community at large for being MSM or a sexual minority male?
 - a. Prompt: For example, community members may include; coworkers, teachers, neighbors, law enforcement, religious leaders, etc...
 - b. How "out" are you in your community?
 - c. Can you recall an instance where your sexual orientation has been revealed to others within your community without your consent?

B. Next let's discuss your self-perceptions as being HIV-positive.

1. How do you feel about being HIV-positive?
 - a. How did you come to terms with your HIV – positive diagnosis?
 - i. Prompt: Do you consider yourself to be "out" concerning your HIV-positive status?
 - ii. Prompt: How did you feel when you were first diagnosed as being HIV-positive?

- b. Do you feel any guilt or shame about being HIV-positive? If yes, please explain why.
 - 2. In what ways have you been treated badly (or differently) by people in your family for being HIV-positive?
 - a. Is your family aware of your HIV –positive status?
 - b. Explain how you told your family that you were HIV-positive to me.
 - 3. In what ways have you been treated badly (or differently) by people in your community at large for being HIV-positive?
 - a. Prompt: For example, community members may include; coworkers, teachers, neighbors, law enforcement, religious leaders, etc...
 - b. How “out” are you in your community about your HIV-positive status?
 - c. Can you recall an instance where your HIV status has been revealed to others within your community without your consent?
- V. Lastly, let’s take a few minutes and finish up our conversation here today discussing your experiences in accessing and using health care services here as an HIV-positive MSM living in Appalachia.
- A. First, let’s begin by talking about what health care services you utilize in the management of HIV.
 - 1. What sorts of services do you use in the treatment and management of HIV?
 - a. Prompt: Where do you receive treatment?
 - b. Prompt: Are you under the care of one physician or a team of doctors?
Do you see the same physician or team each visit?
 - c. Prompt: How often do you see your doctor in relation to the management of your HIV?
 - 2. Are health care services that you use located in an easily accessible area?
 - a. Tell me about the location of where you receive services.
 - b. Is this location known in the local community for servicing those living with HIV/AIDS?
 - i. Prompt: Is there any local advertisement for HIV/AIDS related services for this site location?

- ii. Prompt: Is there any outside signage designating this location as serving HIV/AIDS related
 - c. Can you recall any instances where you were concerned about being seen entering this treatment establishment?
 - i. Prompt: Do you have any concerns as an HIV-positive MSM about being recognized entering or leaving a treatment site known locally in the community for servicing HIV/AIDS clients? Tell me about your concerns.
 - 3. Approximately how far do you travel to see your physician?
 - a. Prompt: How do you get there? For example, do you drive yourself? Does someone assist you with transportation to and from the site? Do you use public transportation?
 - i. If someone else assists you in transportation to or from your doctor visits, does this person(s) know the reason for your visit?
 - b. Has there ever been a time that you were unable to keep an appointment due to transportation difficulties? If so, tell me about that.
- B. Next, let's discuss your experiences with health care professionals that you interact with during the course of your treatment for HIV/AIDS related issues.
- 1. Tell me about any negative past experiences you have had with health care providers because of your MSM status.
 - i. Prompt: Can you recall a time when you felt you were treated differently (or badly) because of your MSM status? How did this make you feel? How did you respond?
 - ii. Prompt: Have you ever been refused treatment because of your MSM status?
 - iii. Prompt: Have you ever been refused a referral to another agency because of your MSM status?
 - 2. Tell me about any negative past experiences you have had with health care providers because of your HIV-positive status.
 - i. Prompt: Can you recall a time where you feel you were treated differently by providers because of your HIV status? How did this make you feel? How did you respond?

- ii. Prompt: Have you ever been refused treatment because of your HIV status?
 - iii. Prompt: Have you ever been refused a referral to another agency because of your HIV status?
 - 3. Tell me about any concerns you may have about patient privacy and confidentiality in a health care setting.
 - i. Can you recall an instance where your sexual orientation or HIV-positive status was revealed to others in a health care setting without your consent?
 - 4. Can you recall any instances where you were given incomplete or inaccurate information or treatment guidelines related to the management of your HIV/AIDS condition?
 - a. Tell me about any adverse reactions you experienced due to this inaccurate or incomplete information or treatment guidelines.
 - b. Did you discuss this with your health care provider? If so, how was this resolved? If not, why not?
- C. I'd like to talk with you for the next couple of minutes about the medicines that you take to manage your HIV/AIDS and some various experiences you have had with them.
 - 1. How important are antiviral medications in maintaining your overall health?
 - a. Tell me how you came to begin taking antiviral medications.
 - i. Prompt: Did you consider or try any alternative therapies before beginning HAART regimen?
 - ii. Prompt: What was your initial reaction when your doctor indicated that they wanted to start you on anti-viral medications?
 - 2. Tell me about the various types of medications that you take related to your HIV/AIDS condition.
 - a. What sort of side effects have you experienced in taking your anti-viral medications?
 - i. Tell me about any medications that you have stopped taking because of side effects.

- b. Tell me about any challenges that you have faced in obtaining approval for anti-viral medications recommended by your physicians.
 - i. Prompt: Has ADAP ever refused to supply a particular medication to you because it was not approved by their formulary?
 - ii. Prompt: (if private insurance) Has your insurance provider ever refused to pay for any anti-viral medications prescribed by your health care provider?
- 3. I'd like to talk to you briefly about issues related to adherence to your HAART medication plan.
 - a. Are there things you don't tell your doctor related to taking your medications?
 - b. What are some of the reasons that you might miss even one dosage of your medication?
 - c. Has there been some time when you just couldn't take the medications prescribed to you at all?
 - d. Are there any people in your life who are an influence to whether you take your medication or not?
 - i. Prompt: For example, are there any people whom you would purposely avoid taking your medications around?

XI. Conclusion

- A. Here are the main points that I gleaned from our conversation today. Do you concur?
- B. Any final thoughts or comments?
- C. Turn off recorder. Do you have any off-the-record comments?
- D. Thank you for your participation.

APPENDIX E: Complete Node Hierarchy

COMPLETE NODE TREE HIERARCHY

RELIGION

- Beliefs of Caregivers
 - Caregivers Involvement in Religious Activities
 - Importance of Religious Activities
 - Influence of Caregivers Religious Beliefs/Practices on Participant
- Current Beliefs
 - Frequency of Prayer: Public or Private
 - Frequency of Involvement
- Sexual Identity or Practice
 - Guilt
 - No Guilt
 - Support of Identity
 - No Support of Identity
 - Religion Not Affected Sexual Activity or Identity
- Influence in Managing HIV/AIDS
 - Specific Practices
 - No Specific Practices
 - Spiritual Support
 - No Spiritual Support
 - No Influence in Managing HIV/AIDS

- Returning to Faith
- Childhood / Youth Involvement in Religious Activities
- Religious Affiliation Past and Present
 - Past Religious Affiliations
 - Current Religious Affiliations

APPALACHIA AS CULTURE

- Enculturation
 - Time Frame in Appalachia
 - Always Lived in Appalachia
 - Define Appalachia
 - How Would They Describe Appalachia to Others
 - Self Identification
 - Do Not Identify as Appalachian
 - Features of Appalachia That Affect Daily Life
- Situational Access to Health Care
 - Social Experiences of MSM in Appalachia
 - Personal Experience
 - ◆ Prejudice from Gay Community
 - Anecdotal
 - ◆ No Anecdotal Prejudice Reported
 - Opportunity Structures
 - LGBT Issues Socially Supportive Groups

- Internalized Homophobia
- Living in Appalachia HIV/AIDS Care
 - Available Health Services
 - ◆ Pharmacy Services
 - Health Services Comfort
 - Quality of Care

LIVED EXPERIENCE OF HIV POSITIVE MSM

- MSM Self Perception
 - Comfort Level of MSM Label
 - Ways of Dealing with Same Sex Attraction
 - Coming to Terms with Sexual Orientation
 - MSM Associated Guilt or Shame
 - No MSM Guilt or Shame
 - Treated Differently/Badly by Family Members
 - Family Awareness of Sexual Orientation
 - Not Treated Differently/Badly by Family Members (MSM)
 - Treated Differently/Badly by Community
 - Not Treated Differently/Badly by Community (MSM)
- HIV Self Perception
 - Feelings About Being HIV Positive
 - HIV Positive Associated Guilt or Shame
 - No HIV Associated Guilt or Shame

- Treated Differently/Badly by Family Members
 - Family Awareness of HIV Positive Status
 - ◆ Family Members Also HIV Positive
 - Not Treated Differently by Family Due to HIV Status
- Treated Differently/Badly by Community
- Testing Positive
 - Testing Positive as a Result of Seeking Out HIV Testing Proactive
- Coming Out
 - Openness About Sexuality
 - Being Outed by Others
 - Coming Out about MSM and HIV Simultaneously
- Social Support Services for HIV Persons
 - Tennessee Support Services
 - Western North Carolina Support Services
 - South Carolina Support Services
- Violence
 - MSM Related Violence
 - HIV Related Violence
 - Molestation
- Coming Out About HIV
 - HIV Status Outed by Others
 - HIV Status Not Out Outed by Others
 - HIV Status Outed by Health Care Professionals

- HIV Status Outed by Social Service Professionals
- Openness about HIV Status
 - Disclosure of HIV Status to Sexual Partners
 - Disclosure of HIV Status: Possible Exposure Situations
 - Not Out About HIV Status
- Work Related Issues and HIV Disclosure
- Seroconversion

HEALTH CARE SERVICES

- Health Care Services Used for HIV/AIDS Management
 - Where for Treatment
 - Who Delivers Care
 - Under Care of Same Health Care Professional Each Time
 - Number of Visits
 - Every 2-3 Months
 - Every 4-5 Months
 - Every 6 Months
- Distance/Time to Access Health Care Services
 - Distance to Health Care Services
 - Under 10 Miles or 30 Minutes to Care
 - Over 10 Miles or 30 Minutes to Care
 - Means of Transportation
 - Transportation Other Than Own Vehicle

- Transportation Difficulties
 - No Transportation Difficulties
- Experiences With Health Care Professionals
 - Negative Past Experiences Because of MSM Status
 - Treated Differently/Badly
 - ◆ Not Treated Differently or Badly Because of MSM Status
 - Not Refused Treatment Because of MSM Status
 - ◆ Refused Treatment Because of MSM Status
 - Refused Referral
 - No Negative Experiences Because of MSM Status
 - Negative Past Experiences Because of HIV Status
 - Treated Differently/Badly
 - ◆ Not Treated Differently Badly Because of HIV Status
 - Refused Treatment
 - ◆ Not Refused Treatment
 - Refused Referral
 - No Negative Experiences Because of HIV Status
 - Privacy/Confidentiality in Health Care Setting
 - MSM/HIV Status Revealed Without Consent
 - ◆ Not Revealed Status in Health Care Setting
 - No Concerns About Privacy/Confidentiality
 - Inaccurate Information or Treatment Guidelines
 - Adverse Reactions

- ◆ No Adverse Reactions
- Health Care Provider Confronted
- No Inaccurate Information or Treatment Guidelines
- Positive Experiences with Health Care Professionals
 - Tennessee
 - North/South Carolina
- Negative Past Experiences with Health Care Professionals Because of MSM/HIV Status Combined
 - Treated Differently/Badly Because of MSM/ HIV Status Combined
 - ◆ Not Treated Differently/ Badly
 - Refused Referral MSM/ HIV Combined
 - Refused Treatment Because of MSM/SHIV Status Combined
 - ◆ Not Refused Treatment MSM/HIV Status Combined
 - No Negative Experiences Due to MSM/HIV Status Combined
- Location of Health Care Services
 - Where
 - Community Knowledge of HIV Related Services Offered
 - Signage and Advertisement of Services
 - ◆ Local Advertisements of HIV Related Services
 - No Local Advertisements
 - ◆ On Premise Signage Advertising HIV Related Services
 - No on Premise Signage for HIV Related Services
 - No Community Knowledge Of HIV Services Offered

- Concerns Being Seen at Treatment Site
 - No Concerns Being Seen at Treatment Site
- Easily Accessible Health Care Services
 - Not Easily Accessible Health Care Services
- HIV Care and General Care Issues

HIV/AIDS RELATED MEDICINES

- Importance of Antivirals
- Patient Regimen
 - Side Effects Experienced
 - Antivirals Discontinued Because of Side Effects
 - ◆ No Antivirals Discontinued Because of Side Effects
 - No Side Effects Experienced
 - Challenges in Obtaining Medicines
 - ADAP Refused to Fill Medicines
- Medicine Adherence
 - Full Disclosure to Health Care Professionals
 - Not Fully Disclosing to Health Care Professionals
 - Missed Dosages
 - Influence of Others on Adherence
 - No Influence from Others
 - Purposely Avoid Taking HIV Medicines Around
- Beginning to Taking Antivirals – Circumstances

- Initial Reaction When Told to Begin Taking HIV Medicines
- Alternative Therapies
- Time Frame for Taking Antivirals

OTHER

- Illicit Drug Usage
- Social Desirability
- Depression
- Issues of Race
- Incarceration
- Isolation
- HIV Criminal Prosecution
- Serosorting
- Alcohol Use
- Transgender
- Partner and Relationship Issues
- Advocacy
- Finances
- Erroneous Beliefs About HIV

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