COMMUNITY-BASED PARTICIPATORY RESEARCH: HIV IN AFRICAN AMERICAN MEN WHO HAVE SEX WITH MEN

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To date, traditional behavioral interventions have done little to reduce the prevalence and transmission of HIV among African American men who have sex with men (AAMSM), a highly at risk group. Some researchers theorize that the lack of success may be because these interventions do not address contextual factors among AAMSM. Community-based participatory research (CBPR) is one approach to research with the potential to lead to effective interventions in the future. CBPR is a collaborative, mixed-methods and multidisciplinary, approach to scientific inquiry, which is conducted with, and within, the community. The current study follows the CBPR approach to engage and develop a relationship with the African American communities in the Dallas/Fort Worth Metroplex. We discussed contextual issues in order to identify emerging themes regarding HIV health related issues among AAMSM to provide the groundwork for continued CBPR research and future interventions with AAMSM in the Dallas/Fort Worth Metroplex. To accomplish this goal, we began the CBPR process by conducting interviews and focus groups with a sample of approximately 62 (34 from key informant interviews, 28 from focus groups [gender balanced]) AIDS service organization leaders and workers, advocates, medical doctors and community members with first-hand knowledge of HIV health issues in the AAMSM community. We analyzed transcripts of these interviews and focus groups to identify emerging themes at the societal (religious doctrine, African American Culture, age-related norms and stigma), community (education, religious views/policy and community norms) and individual (disclosure, personal identity, sexual behavior/risk, accessing care and communication) levels. This data was used to create a holistic
narrative report that will be used to direct the community advisory board (CAB) and guide future research and interventions.
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# TABLE OF CONTENTS

**ACKNOWLEDGEMENTS** ........................................................................................................... iii

**LIST OF TABLES** ..................................................................................................................... ix

**LIST OF FIGURES** .................................................................................................................. x

**CHAPTER 1 INTRODUCTION** .................................................................................................. 1

HIV Statistics .............................................................................................................................. 1

HIV Health Disparity and Barriers ............................................................................................ 2

Minority Status and Stress ......................................................................................................... 3

Stigma ......................................................................................................................................... 4

Discrimination ............................................................................................................................ 8

Cultural Norms ........................................................................................................................... 9

Faith ........................................................................................................................................ 11

Mistrust .................................................................................................................................... 12

Socioeconomic Status (SES) ...................................................................................................... 13

The Road to Community-Based Research: Public Health ....................................................... 14

Intellectual Contributors to Community-Based Research ....................................................... 18

Kurt Lewin ............................................................................................................................... 18

Orlando Fals-Borda .................................................................................................................. 20

Paulo Freire ............................................................................................................................. 21

Community-Based Participatory Research (CBPR) ............................................................... 21
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBPR Methodology</td>
<td>23</td>
</tr>
<tr>
<td>Partnership Principles of CBPR</td>
<td>26</td>
</tr>
<tr>
<td>Levels of Partnership</td>
<td>27</td>
</tr>
<tr>
<td>Public Health Ethics</td>
<td>29</td>
</tr>
<tr>
<td>Previous CBPR Literature</td>
<td>30</td>
</tr>
<tr>
<td>The Current Study</td>
<td>34</td>
</tr>
<tr>
<td><strong>CHAPTER 2 METHODS</strong></td>
<td>36</td>
</tr>
<tr>
<td>Participants</td>
<td>36</td>
</tr>
<tr>
<td>Procedure</td>
<td>36</td>
</tr>
<tr>
<td>IRB Approval</td>
<td>36</td>
</tr>
<tr>
<td>Phase I: Key Informant Interviews</td>
<td>37</td>
</tr>
<tr>
<td>Phase II: Focus Group Interviews</td>
<td>38</td>
</tr>
<tr>
<td>Measures</td>
<td>38</td>
</tr>
<tr>
<td>Proposed Data Analyses</td>
<td>39</td>
</tr>
<tr>
<td>Phase I: Key Informant Interviews</td>
<td>39</td>
</tr>
<tr>
<td>Phase II: Focus Groups</td>
<td>40</td>
</tr>
<tr>
<td>Narrative Report</td>
<td>41</td>
</tr>
<tr>
<td><strong>CHAPTER 3 RESULTS</strong></td>
<td>42</td>
</tr>
<tr>
<td>Key Informant Interviews</td>
<td>42</td>
</tr>
<tr>
<td>Community Perceptions</td>
<td>43</td>
</tr>
</tbody>
</table>
# LIST OF TABLES

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Key informant demographic information</td>
<td>42</td>
</tr>
<tr>
<td>2.</td>
<td>Focus group demographic information</td>
<td>51</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Minority stress model</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Themes in society, community, and the individual associated with HIV prevention and treatment</td>
<td>58</td>
</tr>
</tbody>
</table>
CHAPTER 1

INTRODUCTION

HIV Statistics

According to the World Health Organization (2012), an estimated 34.2 million people worldwide are living with the human immunodeficiency virus (HIV). According to the Centers for Disease Control and Prevention (CDC, 2012a), approximately 1.2 million people (76% male) living with HIV reside in the United States, and from the general population an estimated 50 thousand people are predicted to contract HIV each year. Texas ranks fourth in HIV prevalence in the United States behind Florida, California and New York. The Dallas/Fort Worth Metroplex ranks second highest in HIV prevalence and transmission rates in Texas, Houston ranks first (TDSHS, 2010). Furthermore, the Dallas/Fort Worth Metroplex ranks the highest of any city in Texas in the rate of people living with HIV (561.8 per hundred thousand in the population; TDSHS, 2010).

The CDC (2012a) recently concluded the two most at risk subpopulations for HIV infection include African Americans and men who have sex with men (MSM). Currently, African Americans represent a major proportion of HIV prevalence and transmission rates in the United States. Despite only making up 12% to 14% of the population, African Americans account for 46% of people living with HIV in the United States and 44% of newly diagnosed cases of HIV (CDC, 2012a). African Americans also represent over one third of people living with HIV in Texas (CDC, 2012b; TDSHS, 2010). MSM is an etic term used to describe a unique subpopulation of men who are also at particular risk for HIV infection. Etic terms are typically created by researchers to describe and classify observable phenomena (e.g. behavior) or beliefs from a perspective outside of a culture or group. On the other end of the spectrum, emic terms
are also used to describe observable phenomena or beliefs, but from the point of view of a member of a particular culture or group. As an etic term, MSM is not used to describe sexual orientation; instead, MSM is a term that describes the behavioral method of HIV transmission through male to male sex. In 2009, MSM comprised 56% of people living with HIV in the United States and 61% of new HIV infections (CDC, 2012c). In Texas, male to male sex is the mode of HIV transmission for more than half of people living with HIV (TDSHS, 2010). Furthermore, the Centers for Disease Control and Prevention (2011) have identified African American men who have sex with men (AAMSM) as a significant at risk group; supporting the conjecture that a focus on prevention with AAMSM is critically needed. Indeed, male to male sex accounts for 73% of new infections among all African American males, which is higher than any other racial/ethnic group in the United States (CDC, 2011a).

HIV Health Disparity and Barriers

As a result of the high prevalence and transmission rates among AAMSM, previous research has attempted to explain why this significant health disparity exists. As Lightfoot and Milburn (2009) note, despite the intuitive utility of clinical interventions which focus on individual behaviors (e.g. safe sex practices), the number of HIV-positive African Americans has continued to grow. This persistence of HIV among African Americans suggests that contextual factors, not addressed by behavioral interventions, may act as barriers to HIV prevention efforts, thus facilitating increased prevalence and transmission rates of HIV among African Americans. As a result, identifying contextual factors in order to outline a future intervention that is culturally sensitive, community-based and relevant may prove beneficial to HIV prevention efforts.
Minority Status and Stress

The association between stress and poor psychological and physiological health has been well established (D’Andrea et al., 2011; Klainin, 2009; Lovallo, 2011). While stress is common, Meyer’s (2003) theory of minority stress posits minorities experience a unique layer of stress that results from inclusion in a minority group (Figure 1), and this layer of stress may help to explain the HIV health disparity among African American MSM. A minority group may be defined by race/ethnicity, sexual orientation, behavior or gender. According to this theory, minority stress occurs in addition to typical life stressors brought on by circumstances in the environment. However, among minorities, circumstances in the environment (e.g. contextual factors) also result in a stress process specific to a person’s minority status. For example, African Americans have traditionally experienced significant prejudice and discrimination that has curtailed their freedom and liberty (e.g. slavery, being denied the right to vote, segregation laws). Minority status may also lead to a stress process associated with a person’s minority identity. For example, some people may attempt to hide their minority identity due to negative associations with their minority identity. However, this process is likely influenced by the characteristics of a person’s minority identity. The combination of general stressors, minority stressors and the ability and resources (e.g. social support) to cope are believed to determine a person’s mental health outcome (Feinstein, Goldfried & Davila, 2012; Hatzenbuehler, Nolen-Hoeksema & Erickson, 2008; Lehavot & Simoni, 2011; Meyer, 2003; Wight et al., 2012). Minority stress is also relatively stable over time due to societal and cultural norms and expectations. Most importantly, minority stress is the result of social processes, institutions and structures. For example, the institution of slavery and the racism and prejudice that supported slavery were all
products of society and culture. AAMSM are at particular risk of experiencing minority stress due to race/ethnicity, but also sexual identity/behavior.

According to Meyer (1995) minority stress is differentiated into either distal or proximal stress. Distal stressors are external events or conditions which are objectively stressful (Meyer, 2003), and are due to external/social events. For example, losing one’s job is a distal stressor because unemployment often creates a financial strain and limits a person’s access to resources. Proximal stressors are the result of a person’s internalized perceptions and appraisals of external events or conditions. For example, a person may not want to disclose that they are HIV-positive out of the expectation that they will be shunned. While distal and proximal minority stressors may not directly explain the HIV health disparity among African Americans, minority stress underlies variables (e.g. stigma, discrimination, socioeconomic status, culture, faith) closely linked to the HIV health disparity.

![Minority stress model](image.png)

**Figure 1.** Minority stress model

**Stigma**

Within the African American community the stress of stigma is complex and pervasive, and stigma may help to explain why HIV is so prevalent among African Americans (Parker & Aggleton, 2003). Historically, the term stigma is used to refer to a mark or blemish on the body that communicates information about a person. For example, in the past such marks have been
used to advertise the wearer’s status as a slave, criminal or traitor. Today, the term stigma refers to a process by which the reaction of others negatively impacts a person’s identity. The negative reaction of others reflects disapproval of a particular person’s behavior or condition that is counter to societal and/or cultural norms/expectations (Goffman, 1986). For example, today stigma is sometimes associated with particular illnesses which may be perceived by others as being the result of poor moral choices or lack of personal responsibility, and are thus shameful (e.g. lung cancer, type II diabetes and HIV). HIV is one such illness and the source of HIV-related stigma may be external/social (distal) or internal (proximal) (Wolitski et al., 2009). External HIV-related stigma occurs when others express blame, disapproval, fear or other negative emotions related to a person’s HIV status (Herek, Widaman & Capitanio, 2005; Parker & Aggleton, 2003). External HIV-related stigma may lead to internal HIV-related stigma, or self-directed negative thoughts and feelings related to one’s HIV status (Lee, Kochman & Sikkema, 2002).

Among African Americans HIV-related stigma is especially salient (Fullilove & Fullilove, 1999). HIV risk is frequently associated with stigmatized behaviors and groups (Operario et al., 2011). For example, substance use is a stigmatized behavior due to the harmful nature of illicit substances and because most substances are illegal, and are therefore perceived as deviant (Dickson-Gómez, Knowlton & Latkin, 2004). Moreover, due to the high prevalence of substance use among people living with HIV, substance use and HIV have become incongruently linked (Brion et al., 2011; NIDA, 2012a; NIDA, 2012b; Reback et al., 2012). This pairing of substance use and HIV is particularly damaging to African Americans who not only represent a significant proportion of new HIV incidents, but also report a significantly higher rate of recent (e.g. in the past month) illicit drug use than the national average (9.5 versus 7.9).
Fortunately, interventions have begun to focus on the correlation between stigma and substance use disorders (Livingston et al., 2012). Among African Americans, an assumption about males may exist in which an HIV-positive status is indicative of a bisexual or gay sexual orientation. This belief may be due to the fact that when the HIV epidemic began gay men were the primary group affected by HIV. However, the face of HIV has changed over the past decade and African American women are one of the fastest growing HIV subpopulations (CDC, 2012). In fact, an estimated 1 in 32 African American women is estimated to be HIV-positive, a rate higher than any other female racial/ethnic group (CDC, 2012a). The taboo and stigmatized nature of a gay or bisexual identity within the African American community may be a result of heterosexism and/or cultural norms/values (Brooks et al., 2005), which hold a strong expectation of masculinity among African American males. Heterosexism refers to negative beliefs, attitudes and behaviors that devalue or stigmatize gays, lesbians and bisexuals (Herek, 1995). Furthermore, African American cultural norms/values appear to reflect a belief that being gay detracts from a male’s masculinity and character, and is thus shameful (Operario, Smith & Kegeles, 2008).

In general, the current literature suggests that stigma leads to negative health outcomes and poorer coping among people living with HIV. For example, people living with HIV who perceive the possibility of experiencing HIV-related stigma may avoid HIV testing services in order to protect themselves against stigmatization (Young & Bendavid, 2010). In this way, not knowing one’s HIV status may be psychologically protective, but physiologically harmful. This reasoning may explain why African Americans are more likely to be diagnosed with HIV during the later stages of the disease (CDC, 2012i). Moreover, an effortful avoidance of HIV-related stigma may also give a reason for the exceptionally high frequency of undiagnosed cases of HIV.
(60%) among all youth predicted to be living with HIV (CDC, 2012f). This statistic is especially troubling considering the prevalence of stigma within the African American community (Radcliffe et al., 2010), and the fact that young African American males make up the majority of new HIV infections (48%) among young people (CDC, 2012f). Interestingly, young African American males are more likely to have tested for HIV than their White/European American and Hispanic/Latino counterparts (CDC, 2012f). However, this difference may be the result of previous research and interventions which have focused intensely on HIV testing among African Americans (Halkitis et al., 2011; Nunn et al., 2012; Wallace et al., 2011). Following a diagnosis of HIV, internal and external/social stigma may deter some people from accessing care. For example, people living with HIV who experience stigma are more likely to report poorer access to healthcare facilities (Sayles et al., 2009). Furthermore, healthcare providers, who are potentially objective due to a greater understanding of the virus, may also be an unexpected source of stigma. Stigma from a healthcare provider has shown to deter some people living with HIV from accessing appropriate healthcare to manage the virus (Kinsler et al., 2007; Schuster et al., 2005). Once a person living with HIV engages in care stigma may also negatively impact a person’s ability to effectively self-manage. Research indicates people living with HIV who experience concerns related to external/social stigma are less likely to adhere to medication (Rintamaki et al., 2008), which could potentially lead to a medication resistant strain of the virus. Stigma is also a barrier to disclosure of one’s HIV status (Berger, Ferrans & Lashley, 2001). A recent study by Gaskins and colleagues (2011) found African American males reported reasons for non-disclosure which include: fear of a negative reaction, the person’s status being communicated to undesirable others, not being ready to disclose and a fear of burdening others. While valid concerns, these reasons for non-disclosure of one’s HIV status place male and/or
female sexual partners at an increased risk of contracting and transmitting HIV. In addition, a recent study by Bird, Finderhut and McKirnan (2011) found African American men are less likely to disclose their HIV status than their White/European American counterparts, which may help explain the dramatic rise of HIV among African American women since African Americans tend to have sexual partners of the same race/ethnicity (CDC, 2011). Without a greater understanding of stigmatized beliefs regarding HIV among African Americans, the disproportionate impact of HIV epidemic in the African American community will likely continue. As a result, researchers would be wise to collaborate with community members and leaders to determine how best to design and implement an intervention in order to mitigate stigma.

**Discrimination**

Discrimination, a form of stigma (Mahajan et al., 2008) which is both a distal and proximal stressor, is also associated directly and indirectly with factors which contribute to the HIV health disparity among African Americans (Bogart et al., 2010b). Discrimination occurs when an individual or group (e.g. race/ethnicity, gender, and religion) is treated unfairly or adversely based upon real or assumed characteristics (Mish, 2004). Racial/ethnic minorities, particularly African Americans, have historically experienced discrimination and continue to experience discrimination today (Borrell et al., 2007; Landrine et al., 2006; Williams & Mohammed, 2009; Williams, Neighbors & Jackson, 2003). A positive HIV diagnosis may only compound the stress of a minority status, which has important health implications particularly for those with a compromised immune system (Williams & Mohammed, 2009). While there are many different strategies used to cope with a stressor like discrimination, the most immediate and accessible coping strategies are not always adaptive. Previous research has linked
discrimination to maladaptive coping strategies (e.g. substance use) and an increase in risky thoughts and behaviors (e.g. willingness to engage in risky sex) (Bennet et al., 2005; Bogart et al., 2010b; Gibbons et al., 2012b; Gibbons et al., 2004; Martin, Tuch & Roman, 2003) which may potentially increase the likelihood of HIV transmission.

Cultural Norms

Another potential factor which may contribute to the disproportionate representation of African Americans in the HIV positive population may be cultural norms and expectations. Culture signifies an integrated patterned system that both characterizes and guides daily like, including language, actions, customs, thoughts, beliefs, symbols, values and institutions of a race/ethnicity, religion or social group (Cross et al., 1989). One example of a cultural norm or expectation is masculinity. Cultural norms and expectations indicate what is, or is not, considered masculine and reinforce masculinity among African American males. A study by Operario, Smith and Kegeles (2008) suggests many African American men feel pressured to maintain a “masculine” self-image which, according to African American cultural norms, is heterosexual (Thompson-Robinson et al., 2007). As a result of this pressure, some African American males may choose to hide their male to male sexual activity from others, or conceptualize male to male sex strictly as a behavior and not a component of personal identity (Operario, Smith & Kegeles, 2008). The term “down-low,” often associated with the African American community, is a term typically used to describe men who identify as straight and often maintain relationships with women, but engage in male to male sex in secret. Additionally, virility/hyper-sexuality is also considered a component of masculinity in the African American community (Operario, Smith & Kegeles, 2008). This expectation may lead some men, particularly young men, to engage in sexual relationships with multiple partners which may lead
to an increased risk for contracting and transmitting HIV. The pressure of virility/hyper-sexuality may also explain why a greater number of high school aged African American males (66.9%) report having engaged in sexual intercourse in relation to their White/European American (44%) and Hispanic/Latino (53%) counterparts (CDC, 2012e). Furthermore, a greater number of sexually active high school aged African American males (32.6%) also report having had four or more partners by high school than their White/European American (13.3%) and Hispanic/Latino (29.3%) counterparts (CDC, 2012e). Interestingly though, young sexually active African American males report greater condom use (75.4%) than their White/European American (66.3%) and Hispanic/Latino (63.4%) counterparts (CDC, 2012e). However, even when engaging in safe sex practices (e.g. sex with a condom) young African American males remain at greater risk for contracting HIV than their White/European American and Hispanic/Latino counterparts (Hallfors et al., 2007). This increased risk is likely due to the high prevalence of HIV among African Americans and the tendency of African Americans to have multiple partners of the same race/ethnicity (CDC, 2011). As a result, there is a higher probability that an African American male having unprotected sex will have a partner who is HIV-positive. Strong adherence to masculine norms may also lead to poor health outcomes. For example, maintaining a stereotypic masculine identity has been associated with an increased likelihood of experiencing a psychological disorder (Magovcevic & Addis, 2008) and increased risky sexual behavior (Santana et al., 2006). Sexual and racial/ethnic minorities, such as AAMSM, are also disproportionately affected by mental health problems (CDC, 2012g; Lewis, 2009). Moreover, African American adults are twice as likely as European Americans to experience serious psychological distress, and less likely to receive treatment (e.g. counseling and/or medication) for psychological disorders (CDC, 2012g). While cultural norms may
present some challenging barriers to HIV prevention work, culturally competent research and interventions may be more relevant, and thus powerful (New York State HIV Prevention Planning Group, 2010).

Faith

Faith-based institutions play a significant social role in many African American communities (Mattis et al., 2007), and faith-based institutions have often been a source of support in the African American community in the wake of significantly challenging events (Aten et al., 2010). However, according to a recent study by Nunn and colleagues (2012), conflicts of faith may be a source of stress within the African American community, which has contributed to the HIV health disparity for several reasons. HIV/AIDS is often associated with a number of factors that conflict with religious and moral attitudes of the church (e.g. premarital sex, substance use and homosexuality) (Francis & Liverpool, 2008). Also, sexuality (heterosexuality and homosexuality) appears to be perceived as a “risky” discussion topic among many predominantly African American faith-based institutions due to religious laws which oppose premarital sex and support an “abstinence only” policy. While many religious leaders acknowledge sex occurs within their communities, finding a way to address sexuality without appearing to condone premarital or male to male sex is difficult. Furthermore, discussion of safe sex practices (e.g. condom use) may also be avoided by leaders of faith-based organizations for similar reasons. As a result, the response of African American churches to the HIV epidemic has been slow. Early in the epidemic, the church’s lack of acceptance of male to male sexual activity served as a source of stigma among AAMSM (Herek & Capitanio, 1995). However, while churches may serve as a source of stigma, churches are also a hub of African American culture and society. Churches are also integrated into the social networks of many African Americans,
and churches serve as a source of support and are agents of social change within the African American community (Thrasher, Campbell & Oates, 2004). As a result, churches may also be a significant point of access to the community.

Mistrust

Mistrust of healthcare providers, government officials and researchers may also be a contributing factor to the HIV health disparity among African Americans. Mistrust among African American males, in particular, is associated with a belief that people taking antiretroviral medications are being used as test subjects (Bogart et al., 2010a). Mistrust of healthcare providers, government official and researchers among African Americans is not so surprising considering the events of the Tuskegee syphilis study (1932-1972), Florida dengue outbreak (1950’s) and the experiments of Marion Sims (1845-1849), just to name a few, in which African Americans were used as test subjects either against their will or without their knowledge (Washington, 2006). As a result, HIV-positive African Americans are less likely to trust healthcare providers than their White/European American counterparts, and African Americans are less likely to receive highly active antiretroviral therapy (HAART) when eligible (Saha et al., 2010). Also, mistrust among African Americans is associated with lower medication adherence (Bogart et al., 2010a; Sahae et al., 2010) and negative attitudes towards condoms and inconsistent condom use, which increase HIV risk (Bogart & Thorburn, 2005). Furthermore, mistrust may also contribute to the difficulties African Americans experience when attempting to obtain, process, and understand health information necessary to make adequate health-related decisions (Drainoni, 2008). As a result, input from the African American community on how to improve communication, understanding, and trust with healthcare providers, government officials, researchers may prove highly beneficial.
Socioeconomic Status (SES)

Many African Americans may experience a direct and indirect increased HIV risk and mortality due to low SES, though the literature is unclear on the mechanisms of this association (Cunningham et al., 2005). SES is determined by a combination of factors including: education, occupation and economic characteristics (e.g. income, assets) (Santrock, 2004). Previous studies show associations between low SES and minority status, low-levels of education, reduced medical care and, among people living with HIV, decreased early access to HAART medications (Shapiro et al., 1999; Andersen et al., 2000; Cunningham et al., 2000). While being African American does not preordain a low SES, unemployment among African Americans is approximately double that of White/European Americans. African Americans who are full time wage earners also earn roughly 72% of what their White/European American counterparts earn (Rodgers, 2008). Previous research indicates that low SES limits access to insurance, which in turn limits access to care, which potentially increases the rate of mortality (Bhattacharya, Goldman & Stood, 2003; Goldman et al., 2001). In addition to adequate care, low SES may limit access to other protective measures, like housing and HIV prevention education (Cunningham et al., 2005). Without these preventative measures, the stress associated with a low SES may lead some people to engage in riskier behaviors that increase the risk of contracting and transmitting HIV (CDC, 2011). Furthermore, past research demonstrates components of SES (e.g. education and income) are associated with, directly and indirectly, decreases in biological markers of health among people living with HIV (McMahon et al., 2011). Due to the potential limitations of a low SES and the prevalence of low SES within the African American community, researchers may benefit from collaboration with the community to
determine how to best design and implement an intervention to increase the accessibility of the intervention for the community.

Adequately Addressing the HIV Health Disparity and Barriers

Research indicates that these barriers, and others, have contributed to an increase in the prevalence and transmission of HIV among African American males and MSM despite previous intervention attempts. Some researchers suggest previous interventions focused on individual health behaviors have not resulted in a decrease in the HIV incidence among AAMSM due to a failure to address contextual factors (Lightfoot & Milburn, 2009). As a result, an approach that incorporates community support, involvement and resources into an intervention designed to address HIV health issues among AAMSM may be better suited to address the HIV health disparity among AAMSM (Cene et al., 2011). Community-based research is one such approach which adequately addresses contextual factors within the community and can serve as a catalyst for lasting behavioral change.

The Road to Community-Based Research: Public Health

Community-based research has been influenced by a number of disciplines and concepts, but the driving force behind community-based research throughout history has been an increased need for adequate public health, a population-based understanding of health and illness interventions (Blumenthal & Yancey, 2004). The concept of public health is by no means new; public health programs have existed for millennia. Furthermore, interest in public health has largely been associated with the progressive rise in urban populations, which are especially affected by disease. For example, the Romans built aqueducts to bring fresh drinking water to cities and towns, and sewer systems to carry waste away. Unfortunately, many of the methods used to safeguard public health were lost to Western civilization during the Dark Ages. As a
result, Europe was particularly vulnerable to the Black Plague which spread throughout Europe with devastating efficiency in the mid fourteenth century. The lost knowledge of the Roman civilization began to reappear during the Renaissance, which lasted through much of the fifteenth and sixteenth centuries. This rediscovered knowledge renewed an interest in public health projects which focused on sanitation as a means of improving the health of the community. The Renaissance also challenged how we conceptualized disease and illness, and inspired such works as *On Contagions and the Cure of Contagious Diseases* (Fracastoro, 1546) which disputed the belief that illness was the result of supernatural forces, and greatly propelled our modern understanding of infectious disease. As our understanding of public health evolved, so too did our use of public health metrics. For example, Edwin Chadwick (1842), of England’s Poor Law Commission, documented the prevalence and cause of preventable disease among London’s poor working class. Chadwick recorded statistics concerning illness, deaths, living conditions and clean water sources, which he argued had negative implications for economic growth and stability. Chadwick also made recommendations to address these issues which were later addressed with legislation. Around the same time John Snow (1849), who is widely considered to have conducted one of the earliest epidemiological studies, investigated the outbreak of cholera in London. Unlike many colleagues of his time, Snow refuted the miasma theory and observed that if cholera was an airborne illness it would follow a different path of progression. Instead, Snow proposed cholera was spread through contaminated water sources, particularly those exposed to sewage. He came to this conclusion based upon city sanitation, specifically the proximity of sewage outlets and drinking water sources. In addition, Snow made naturalistic observations and conducted interviews with community members stricken with cholera who, interestingly enough, attributed the illness to unclean drinking water. As a result of his work,
Snow made recommendations for changes in cleanliness and sanitation, which drastically reduced the incidence of cholera in London.

From the mid eighteenth century to the end of the nineteenth century, the world entered into a period of rapid innovation and growth known today as the Industrial Revolution. During this period urban populations saw rapid growth, but also unprecedented public health issues. In 1850 Lemuel Shattuck published his *Report of the Massachusetts Sanitary Commission* in which he reported morbidity and mortality statistics which he attributed to pollution, poor sanitation and a dense urban population. Until this period of time, most public health interventions utilized isolation and quarantine as mechanisms to control the spread of disease. However, as Shattuck remarks in his report, there is no escape from disease in an overcrowded and polluted urban environment. In his report, Shattuck also recommended the state create an organization of public health to enforce policy, record health statistics, supervise sanitation, study disease, educate doctors on preventative medicine and distribute health information. As a result of the high mortality and morbidity, urban centers in the United States began to establish special organizations to address public health issues. For example, towards the end of the eighteenth century, councils were established in Boston, New York and Baltimore to monitor public health and protect the population from infectious diseases (CSPHDHCSIM, 1988). Voluntary hospitals were also established in Philadelphia (1752) and New York (1771) to address public health issues. The goal of these organizations was not only to control the outbreak of an epidemic, but also prevent outbreaks of disease. As public health became a more salient issue and medical knowledge improved, so too did the scope of public health which quickly expanded from isolated local organizations to state run boards. In 1869 Massachusetts establishes the first state board of health. Following the publication of *The Sanitary Condition of the Laboring*
Population of New York (Griscom, 1848) New York established its own health department. By the end of the nineteenth century state health departments were widespread and effectively improving public health. Some public health organizations have even grown to the national level. For example, the Marine Hospital on Staten Island eventually became the National Institute of Health in 1912. The institution was divided in 1948 and its name was again changed to the National Institutes of Health (NIH), with each institute focused on a specific disease(s) (Blumenthal & Yancey, 2004). Today, NIH is comprised of 28 institutes with an annual budget of over $30 billion dollars. The Centers for Disease Control and Prevention and Prevention (CDC) was established in 1946 for the purpose of addressing malaria in the southeast (Blumenthal & Yancey, 2004). Over time, functions of the CDC have grown to include: health surveillance, prevention research, measure the effectiveness of public health policies, implementation of prevention strategies, promote healthy behaviors and provide leadership training. The current mission of the CDC is to promote health and foster the growth of expertise, knowledge and skills through collaboration, in order to prevent disease, injury and disability. The CDC now has multiple centers and offices throughout the country with an annual budget of over $11 billion (CDC, 2013).

By the mid twentieth century the concerted efforts of state and local health organizations had greatly improved the health of people living in the United States. Despite this success, new causes of morbidity and mortality arose. No longer were sanitation, hygiene and immunization adequate to deal with new health issues. As pneumonia, influenza and tuberculosis were replaced by heart disease, cancer and stroke, behavioral change became the means of primary prevention. Secondary prevention grew and evolved as new and improved methods became available to screen for markers of health risk (Blumenthal & Yancey, 2004). Though health
behaviors and information could easily be dispensed to the public through media and schools, researchers were unclear if these programs were effective and whether health information was reaching the target audience. As health statistics improved, clear racial/ethnic health disparities began to emerge that indicate racial/ethnic minorities are disproportionately affected by illness and health difficulties (CDC, 2012h). This disparity continues today despite many behavioral and educative interventions focused on a range of health issues. This continued disparity begs the question, what is an effective method of addressing public health in the twenty-first century?

Intellectual Contributors to Community-Based Research

*Kurt Lewin*

Participatory action research (PAR), an early name for community-based research, was influenced in large part by the work of Kurt Lewin, the father of social psychology. Social psychology is the study of how our thoughts, feelings and behaviors are influenced by others. Although Lewin was a psychologist, he believed social science was not the property of psychology. He believed properly conducted social research incorporated aspects of psychology, sociology and cultural anthropology. In his 1946 paper, Lewin wrote about the process and challenges of conducting action research, later referred to as PAR. The purpose and process of PAR was designed to establish a line of communication with experts and community members in order to build relationships. Through communication and relationships a plan of action evolves to address questions and issues significant to the community (Reason & Bradbury, 2008).

According to Lewin (1946), social science research addresses two types of questions: general laws of group life and the diagnosis of a specific situation. General laws refer to the study of the relationships between possible contextual variables (conditions) and their outcome (effects) for groups of individuals. Diagnosis refers to a study of the specific character of a
situation. In simplest terms, general laws may be thought of as “how” questions and diagnosis questions may be thought of as “what” questions. For example, a “how” question may investigate the influence of popular media in relation to the spread of HIV. While “what” questions investigate how HIV differs from other sexually transmitted infections (STI). Lewin argues that much of research is conducted with diagnosis questions in mind, and that this line of research alone is inadequate. Furthermore, Lewin felt that individual behaviors and traits of a group are deeply rooted in cultural norms, and change is dependent upon the group. As a result, Lewin suggests that research which integrates inquiry within the community, relationship building (social management), and objective measure of success will result in the most fruitful social science research.

According to Lewin, PAR is a multistep process involving social planning and action. In the social planning phase an inquiry must be made into the research objective and the resources available to achieve an objective. From this inquiry an overall plan of how to achieve the objective and first necessary action can be identified. During the action phase the first necessary action is initiated, and may then be followed up with additional inquiry (social planning). At this point the purpose of this secondary inquiry is to evaluate the action’s effectiveness, learn from the experience, make modifications to the overall plan based on what has been learned and plan for an appropriate next step. The process continues in this way until the objective, which has been identified by the community, has been successfully achieved. Without ongoing inquiry (fact-finding) and reevaluation, Lewin believes nothing can be learned from the research process. Lewin also notes that in order for action research to be successful, those involved in carrying out the directives to achieve the overall objective must be adequately trained. For those interested in conducting action research and social management an awareness of intergroup relations and
norms is also imperative to successfully conduct competent action research and promote real change. Furthermore, to improve relations between groups (e.g. the minority and majority), both must be studied. Although Lewin fervently supported PAR, he did acknowledge that some researchers may not feel action research yields a significant body of evidence to indicate the process is effective, an argument still voiced by some researchers today.

*Orlando Fals-Borda*

Fals-Borda, a Colombian sociologist, researcher, educator, and activist, made significant contributions to the conceptual and theoretical framework of PAR. His work involving PAR in Latin America (Fals-Borda, 1987) also helped to bring PAR to the international stage. Fals-Borda was an outspoken supporter of social justice, and he believed the mixed method and multidisciplinary approach of PAR is perhaps the best way to address social issues. According to Fals-Borda, higher education (e.g. college) was somewhat of a misnomer, because many researchers squander their education on endeavors with little to no value to society. For example, the moon landing was a momentous and technological achievement, but landing on the moon does nothing to ease the life of a poor woman who must travel a great distance to obtain clean drinking water (Fas-Borda, 2006). Fas-Borda believed that researchers have an ethical responsibility to focus on improving the lives of all peoples, not simply constructing archives of irrelevant information. Fas-Borda believed that in order to accomplish this goal, researchers must take the knowledge they have obtained and begin to involve themselves in the process of social action. He referred to this commitment to use knowledge to improve the lives of people as a praxis-inspired commitment (Fas-Borda, 2006).
**Paulo Freire**

Freire, a Brazilian educator and philosopher, influenced PAR through his work *Pedagogy of the Oppressed* (1968). In his book he discusses the relationship between oppressors and the oppressed and how freedom is the result of praxis in which theory and practice are balanced. He argues that many educators take a banking approach in which an educator deposits information in the mind of a student. Instead, Freire states that both the educator and the student are incomplete, and awareness of the gap between established knowledge and new perspectives will motivate each to fill this gap in a mutually beneficial way. He also proposed that open dialogue, through cooperation and unity, between researchers and the oppressed could be used to obtain freedom. His work has significant implications for the collaborative and action components of PAR.

**Community-Based Participatory Research (CBPR)**

CBPR is a collaborative, mixed-methods and multidisciplinary, approach to scientific inquiry, which is conducted with, and within, the community (Blumenthal & Yancey, 2004). The primary focus of CBPR is to prevent disease through the epidemiological study of a disease, identification of risk factors leading to the disease and the testing and evaluation of a health-based intervention designed to prevent and/or manage risk. Furthermore, CBPR functions at the community level to improve the health of the community, not just the individual. This distinction is what differentiates CBPR from traditional clinical research which focuses on improving the health of a single individual. The CBPR process aids change at the community level by aiding facilitation of changes in community health, systems, and programs or policies (OBSSR, 2010). In order for change to occur and community health to be improved, CBPR requires a partnership between professionals (e.g. researchers and healthcare providers) and
community members. By building a partnership based on trust and a common goal, research can be conducted within difficult to reach communities instead of the laboratory.

The collaborative nature of CBPR provides several advantages for research among minority and/or difficult to access populations, such as the AAMSM community (Burndine et al., 2010; OBSSR, 2013). First, CBPR fosters an eclectic partnership of members with varying areas of expertise to accurately identify and address complex public health issues. Second, conducting CBPR in a natural setting also allows for collection of richer data and an improved perspective and understanding regarding health issues experienced by the community. As a result, findings may better translate to real world issues and may better inform development of interventions and policy change. The CBPR approach not only helps to build a trusting relationship between the various partners, but also benefits the community and researchers through a mutual exchange of knowledge and resources. Due to the complexity of the HIV/AIDS epidemic, over the past decade researchers have recognized the need to allow community members to invest in the research process if change is to occur (Parker & Aggelton, 2003). CBPR offers an equal partnership between health practitioners/researchers and community members in which pertinent health issues within the community may be identified and addressed with the guidance of community members (Bird, Fingerhut & McKirnan, 2011; Bogart & Uyeda, 2009; Israel et al., 2005; Mutchler et al., 2010).

The potentially significant benefits that may result from CBPR for the health and well-being of marginalized communities (e.g. AAMSM) is likely why CBPR has quickly gained recognition and financial support from several federal foundations including the National Institutes of Health (Burndine et al., 2010; Office of Behavioral and Social Sciences Research, 2011; Wallerstein & Duran, 2006). Within the past decade an increasing number of grants have
been awarded to researchers using the CBPR methodology to investigate various health issues (e.g. obesity, cancer risk) among racial/ethnic and sexual minorities (Baskin, 2012; Swann, 2012; Terrance, 2012). In addition, several studies, which use the CBPR approach have published results on the CBPR process and interventions designed through CBPR (Griffith et al., 2010; Natele, 2008; Nunn et al., 2012; Rhodes, Yee & Hergenrather, 2006).

**CBPR Methodology**

CBPR, in its entirety, is a time intensive and rigorous process that is carried out over a number of phases with many unique mechanisms not found in traditional research. The first phase of CBPR is the planning phase which is expected to take approximately three years to complete (NIH, 2012; NIMHD, 2013). In this phase health practitioners/researchers devote their efforts towards developing a relationship with the community. This relationship is often developed over time through contact with community and community stakeholders and shows of support for the community. Developing a relationship with the community allows health practitioners/researcher to embed themselves within the community and gain access to populations that are often difficult to access. Through these connections to the community health practitioners/researchers are then able to conduct a community needs assessment/participatory community assessment, to identify community concerns, partners/local collaborators and potential barriers (Schensul, Berg & Nair, 2012; Sharma, Lanum & Suarez-Balcazar, 2000). The assessment can be conducted a number of ways. For example, key informant interviews may be conducted with individual community members or stakeholders who are knowledgeable about, and embedded in, the community of interest. Key informant interviews are typically semi-structured, open ended interviews that yield individual-level data (Schensul, Berg & Nair, 2012). Key informant interviews allow people from the community to
identify health concerns within the community which may be addressed through an intervention. Focus group interviews work much the same way; however, focus groups are typically comprised of 5-10 members from the community. Also, in a focus group, members come to a general consensus regarding the potential health concerns of the community. Lastly, a town hall, like a focus group, involves multiple participants from the community. Town hall meetings are also conducted in conjunction with, and a show of support from, community leaders and stakeholders. The purpose of a town hall meeting is to identify specific health concerns the community feels are most in need of attention. Traditionally, researchers may use either key informant interviews, focus groups, or a town hall meeting, or a combination there of, as a method of inquiry. As Lewin (1946) notes, researchers would be wise to continuously review and reassess the focus of the research study depending on information provided by the community. Next, several community leaders or stakeholders are selected from the town hall meeting to form a Community Advisory Board (CAB). The CAB is based on the partner model in which community leaders and social scientists are peers and partners in all aspects of the research process (Roche, Guta & Flicker, 2010). The relationship between CAB members and researchers is integral to the success of any CBPR based research, because this collaborative effort is responsible for identifying the research question, developing testable hypotheses and selecting an appropriate research design and measures to address the research question and collect quantitative data. CAB members are involved in all aspects of the research process, and CAB members are also integral to the recruitment and processing of participants from the community. The participation of members of the CAB, who are also members of the community, has shown past success in reaching difficult to access communities (Kelly, 2005). Lastly, CAB members are also heavily involved in the future dissemination of findings in
academia and the community. In this phase CAB members and researchers negotiate and plan an intervention for the community’s primary health concern. The intervention may also be pilot tested in order to refine the intervention prior to the next phase.

The next phase is the intervention phase, which occurs over a five year period (NIMHD, 2013). The intervention phase has several goals to accomplish during this time. First, the intervention that has been agreed upon by health practitioners/researchers and the CAB is implemented within the community. During this time, the intervention is continually reassessed and changes are made when necessary to improve the efficacy and maintain the quality of the intervention. Another goal of this phase is to shift ownership of the intervention from the partnership, to the community. This is an important departure from traditional research in which health practitioners/researchers take ownership of the research study. To empower community members to take ownership of the project, community members may be trained by health practitioners/researchers to carry out key roles and responsibilities. Next, health practitioners/researchers and the CAB endeavor to maintain and improve the established partnership through negotiation and re-evaluation of goals. Lastly, quantitative data is collected on variables such as intervention efficacy and effectiveness.

In the final phase, health practitioners/researchers and the CAB work to disseminate findings of the research study (e.g. intervention effectiveness) (NIMHD, 2013). Dissemination of findings may occur in a number of ways, which may include: journal publications, conference presentations (symposium, poster) or community meetings. Carrying out this phase is required according to the CBPR principles of partnership. Without this phase co-learning may not be achieved and the community may not have access to knowledge necessary to successfully address community health concerns.
Despite the importance of each phase and the utility of individual mechanisms not all aspects of the CBPR approach may be necessary or feasible in all instances (Bogart & Uyeda, 2009). Limited resources or lack of involvement with the community may limit the application of all aspects of CBPR. In some instances, not all steps are necessary to achieve a satisfactory outcome. For example, a community needs assessment may still be used to inform policy change necessary to address community concerns, without conducting a town hall meeting or instituting an intervention. Instead of focusing on including all aspects of CBPR, researchers should endeavor to discuss with the community of interest how best to obtain the specific goals of a project given restricted time and resources.

**Partnership Principles of CBPR**

According to Israel and colleagues (1998), eight principles are recommended in order for health practitioners/researchers to build a strong partnership with the community and conduct responsible CBPR. First, researchers must recognize the community as a measure of identity. The community may be defined by a geographic location, race/ethnicity, shared value/norms or even a desire to accomplish a particular goal. The process of CBPR may benefit health practitioners/researchers and the community by building cohesion through collective engagement. Second, health practitioners/researchers must utilize and improve community resources. Community resources may include people with certain skills or assets, social networks, groups and community hubs. In CBPR, health practitioners/researchers engage in reciprocal support of these resources to improve community health. Third, CBPR supports collaborative and equal partnership between all parties involved in the research process, regardless of whether or not a party is embedded within the immediate community. An equal partnership means that all parties have an equal voice in the research process (e.g. identify
research goals, collect and analyze data and use and disseminate findings). Fourth, CBPR aims to integrate knowledge gleaned from research into an action plan or community change efforts. Fifth, the CBPR process should promote co-learning between health practitioners/researchers and community members, and empower community members to reduce inequality (social and economical). Efforts to reduce these inequalities focus on knowledge building, information sharing, decision making, and support. Sixth, CBPR is conducted in a cyclical and iterative process that involves the following: partnership development and maintenance, community assessment, identification and definition of pertinent issues, research design, data collection and interpretive analysis, action planning and execution, dissemination of findings and evaluation and planning for intervention sustainability. Seventh, CBPR must address health from positive (physical, mental and social well-being) and ecological (biomedical, social, economical, cultural, historical and political) perspectives. Lastly, CBPR must involve a dissemination of findings and knowledge to all partners involved in the research process. Israel and colleagues (1998) recommend that findings be communicated to all parties in a manner that is clear and respectful. This principle also indicates all parties should discuss/negotiate publication of findings and acknowledgement of individual contributions to the research study.

**Levels of Partnership**

Within the field of public health the community is a partner and the client. However, many different models of partnership exist. Hatch and colleagues (1993) argue that four levels, not specific to CBPR, of collaboration and partnership exist between public health practitioners/researchers and the community. At the first level, no true partnership with the community exists between health practitioners/researchers and the community and community members have little understanding of, and no input in, the research process. While this level of
involvement in the community is not ideal, some lines of research do not involve the community because doing so will confound data collected. For example, researchers conducting an ethnographic study would not want to inform the community that they will be collecting data from a particular bar at a particular time as this knowledge may artificially inflate or deflate the number of people who typically gather at the bar at the specified time. At the second level, leaders from the community act as project advisors; however, researchers retain full control over the research study. In this capacity, the role of the community is limited to consultation work and does not actively engage in guiding the research study. The third level of partnership bases research within the community. Community leaders not only consult at this level, but also make recommendations for the hiring of community members to fulfill roles in the research project. However, despite engaging the community, at this level community members still do not contribute to the design of the study nor is the community involved in data analyses. Though at this level the community is not empowered or involved in the design of the study, this level may still produce valuable data. For example, in a successful community needs assessment community members are not necessarily essential to study design or data analyses. At the fourth and final level, community representatives are equal partners who collaborate with health practitioners/researchers in all aspects of the research process (e.g. identify research goals, collect and analyze data and use and disseminate findings). While this level of collaboration is positive, conflicts may arise between health practitioners/researchers and community members which will need to be resolved through negotiation. While these negotiations may challenge the partnership, successful conflict resolution may lead to greater understanding and trust between health practitioners/researchers and the community (Maoz & Ellis, 2008).
Public Health Ethics

The collaboration between researchers and the community also has the potential to infuse more ethical practices into research by providing additional oversight. This level of ethical concern has not always been the forethought of researchers, which has had disastrous consequences for community members and significantly damaged the relationship between researchers and the community. For example, from 1932 to 1972 the United States Public Health Service (USPHS) and Tuskegee Institute (now Tuskegee University) conducted a study within the African American community of Macon County, Alabama. The original purpose of the study was a short-term investigation of syphilis in a group of African Americans, who had already contracted syphilis, with the intention of treating them for the illness. However, what evolved was a long-term study that deceived and undertreated participants even after the discovery of penicillin, an effective treatment for syphilis, in 1945. The infamous Tuskegee syphilis study is a prime example of how misguided researchers may become without the ethical considerations.

Despite the unethical events of Tuskegee, the study did have several successes. For example, the researchers engaged community resources and gained the support of the president of the Tuskegee Institute (Robert Morton), the director of John Andrews Hospital (Dr. Eugene Dibble), 127 medical students and the Macon County Medical Society. Researchers were also able to sustain the research study involving 600 African American men for forty years with only a 17% attrition (Jenkins, Jones & Blumenthal, 2004). Sadly, despite these accomplishments the Tuskegee syphilis study clearly violated ethics standards and practices (e.g. respect, benefice and justice). Health practitioners/researchers violated the respect of participants’ autonomy by failing to adequately explain the experiment. Furthermore, participants were intentionally misled
by researchers who informed participants that they would be participating in a new kind of treatment, when none was ever planned. As a result, participants were not provided the necessary information to make an informed decision and were coerced into participating in the research study. Some researchers argue the ethical principle of benefice (e.g. non-maleficence) was not violated at the start of the study. These researchers argue that due to the risky nature of treatment for syphilis before the advent of penicillin, basic care may have been preferable to treatment. However, following the discovery of penicillin, benefice was violated because health practitioners did not treat participants with a drug known to be effective against syphilis. The ethical principle of justice was violated at the start of the study when researchers selected participants. Researchers targeted low SES African Americans as participants to bear the burden of the research study. By targeting this segment of the population without cause, researchers conducted an inequitable and unfair study in which participants were not provided with the appropriate treatment they deserved. Theories abound as to why the research study was carried on for so long despite its unnecessary nature. One possible explanation is that health practitioners/researchers placed their own priorities over the welfare of the population they were meant to serve.

Previous CBPR Literature

Previous CBPR based studies, which focus on HIV health issues, have successfully been conducted among different racial/ethnic groups of MSM to assess differences in HIV risk behavior (Rhodes, Yee & Hergenrather, 2006) and identify contextual factors which may contribute to HIV risk (e.g. substance use and MSM dating environment) (Natele, 2008). However, the majority of CBPR research involving primarily African Americans has been conducted through partnerships with African American faith-based organizations (e.g. Black
churches). Faith-based organizations are considered important points of access to the African American community and are often social hubs for the community, and some members of the African American community believe faith-based organizations should also be involved in HIV prevention and education in some capacity (Berkley-Patton et al., 2010). Furthermore, faith-based institutions are often a trusted source of information for youth and parents alike, and faith-based institutions are also more likely to be entrusted by parents to educate children on sensitive issues in a way that is consistent with the values of the community (Coyne-Beasley & Schoenback, 2000). As a result, previous CBPR research within the African American community has largely focused on involving leaders of faith-based organizations to address a variety of health issues (Ammerman et al., 2003; Aten et al., 2010; Griffith et al., 2010; Nunn et al., 2012). Recent literature indicates leaders of faith-based organizations have an expectation of an honest partnership with researchers which involve frequent communication, sensitivity regarding the church environment and discussion of study results (Ammerman et al., 2003). A previous study by Aten and colleagues (2010) explored this interest in a collaborative project between mental health professionals and Black church leaders in the wake of hurricane Katrina. Analysis of interviews with leaders identified an interest in education and outreach opportunities, engagement in research, clinical services and spiritual resources and support to meet the post-disaster needs of the community. In addition, church leaders offered unique perspectives and recommendations for how to most effectively engage the community. For example, members of the community may be more likely to invest in change if they feel empowered by leadership opportunities provided by mental health professionals. Other researchers have demonstrated the feasibility of CBPR through successful completion of the initial CBPR stages within the African American community regarding HIV/AIDS issues. For example, a recent study by Nunn and
colleagues (2012) investigated the response of Black churches to HIV/AIDS in the African American community in Philadelphia. Researchers conducted interviews with leaders of local faith-based institutions. These key informants provided information on barriers to discussing HIV/AIDS within the community, community needs and recommendations for involving faith-based groups in HIV/AIDS interventions.

Perhaps one of the most complete CBPR studies to date, which incorporates faith-based institutions and focuses on HIV/AIDS among African Americans, is based upon the YOUR Blessed Health (YBH) project (Griffith et al., 2010). The YBH project is the result of a combined effort between the YOUR Center (a local AIDS service organization), researchers (University of Michigan School of Public Health Faculty, UM-SPH) and leaders of faith-based organizations in the Flint, Michigan area. The overarching goal of the YBH program was to improve the ability of community leaders to address HIV and other sexually transmitted infections and improve the community’s awareness of HIV and other STIs while reducing behavior that places community members at higher risk of contracting HIV and other STIs. The YOUR Center first began YBH when the AIDS service organization noticed the community’s response to HIV needs of the community did not address the epidemic adequately. AIDS service organization leaders first reached out to the spouses of local pastors to discuss the possibility of conducting an HIV intervention in conjunction with the leaders of local faith-based organizations. During these initial meetings HIV was discussed as a health issue, not a moral or religious issue, and the importance of community involvement was emphasized. In addition, care was taken to discuss how best to present the issue of STIs while maintaining sensitivity to each organizations’ norms and expectations. YOUR Center also involved UM-SPH to help create the intervention proposal and assist in the implementation, reporting and dissemination of
findings. The initial YBH pilot study involved a focus on four separate strata of community members (young congregants, adult congregants, faith-based leaders and the congregation at large). Five week training sessions were conducted with youth and focused on HIV/AIDS/STI education, communication and negotiation training and the creation of individual risk reduction plans. A five week training session was also conducted with adults, which focused primarily on HIV/AIDS/STI education. In addition, 16 hours of training were conducted with leaders of faith-based organizations (pastors, pastor’s spouses and other identified leaders) during which leaders and researchers discussed basic HIV/AIDS/STI education. Leaders were also trained to utilize skills and resources to train other community members and conduct other HIV/AIDS/STI education activities within their organizations. Lastly, community activities, such as health fairs, were used to raise awareness of the community and improve HIV/AIDS/STI knowledge. At the end of the six month pilot study, researchers’ found low attrition and high satisfaction with the intervention’s sensitive approach to the norms of each faith-based organization. A total of 55 faith-based organization leaders were trained over the course of the study. In addition, these leaders demonstrated greater sexual health knowledge, improved skill and comfort discussing sexual health and the ability to create a safe/caring environment in which to promote sexual health among youth. When YBH was expanded to include a total of 42 area faith-based organizations and three housing communities, ownership of the program was shifted to the community. To help facilitate this shift, YOUR Center conducted a town hall meeting with faith-based organizations leaders from the YBH pilot study and other key leaders from the Michigan community to discuss how best to meet the needs of the communities. Unfortunately, further data from this study is not yet available. However, this study does represent the power of collaboration and equal partnership that the CBPR approach promotes.
Results of these studies suggest CBPR is a viable method of research which yields data richer than traditional quantitative research alone. Furthermore, CBPR is recognized as a reputable emerging research methodology, and CBPR based research is also currently funded by such federal organizations as the National Institutes of Health (Burndine et al., 2010; NIH, 2012; NIMHD, 2013; OBSSR, 2013; Wallerstein & Duran, 2006). In addition, web-based resources (e.g. cbprcurriculum.org) are also available as a resource for researchers which provide solutions for building and implementing CBPR methodology, which may be tailored to the particular needs of a community.

The Current Study

Previous research using CBPR to investigate AAMSM and HIV health issues is surprisingly sparse, considering the high prevalence of HIV among African American MSM, the lack of success of traditional interventions and the potential for success using CBPR. In addition, few studies on these topics have been conducted in the southern United States. As a result, the purpose of the current study is multifaceted. First, we follow the CBPR approach to engage and develop a relationship with the African American communities in the Dallas/Fort Worth Metroplex. In addition, we discuss contextual issues in order to identify emerging themes regarding HIV health related issues among AAMSM. From these emerging themes, we create a holistic and complex narrative report that outlines a community level perspective of the relationship between contextual factors and HIV health related issues. This community level narrative report provides the groundwork and serves as a guide for continued CBPR research with AAMSM in the Dallas/Fort Worth Metroplex. For example, the community’s narrative report directs researchers towards the most appropriate venue for a town hall meeting, guides the discussion of the town hall meeting and identifies which leaders of the community may be
uniquely suited to serve on the CAB. Furthermore, the community level narrative report directs the actions of the CAB and future interventions with AAMSM in the Dallas/Fort Worth Metroplex. In light of previous research, discussion of HIV health related themes will focus on the role themes play at the societal, community and with the individual levels.
CHAPTER 2

METHODS

Participants

Participants were a sample of approximately 62 (34 from key informant interviews, 28 from focus groups [gender balanced]) community members, AIDS service organization leaders, workers, advocates and medical doctors with first-hand knowledge of HIV health issues in the African American men who have sex with men (AAMSM) community. All participants were required to meet several inclusion criteria to participate in the study: above the age of 18, fluent in English, a resident of the Dallas/Fort Worth Metroplex and have an ability to speak to AAMSM HIV related health issues. Participants were recruited through chain referral/referral sampling, more commonly referred to as snowball sampling, which is often used in research to access difficult to reach populations (Penrod et al., 2003; Schensul, Berg & Nair, 2012). In addition, fliers were distributed with contact information and a brief statement regarding the purpose and goals of the study.

Procedure

IRB Approval

Community-based participatory research (CBPR) is a relatively new approach to research and the method by which data is collected is not common in the field of psychology. As a result, researchers took special measures to ensure transparency and accuracy in the application to the Institutional Review Board. Prior to crafting the IRB application for our study, researchers consulted with the IRB at the University of North Texas to determine how to best complete the IRB application for our research project. To aid the IRB, basic information on the process of CBPR (Appendix A) was provided to the IRB. After careful consideration of the information
provided on CBPR, the IRB suggested an amendment to the IRB application be submitted for each new phase of the research project.

*Phase I: Key Informant Interviews*

Approval was first obtained from the Institutional Review Board for this study. AIDS service organization leaders in the Dallas/Fort Worth Metroplex were then contacted and informed of the purpose and goals of our study (Schensul, Berg & Nair, 2012). Agreement to participate in our study was documented in a memorandum of understanding for each AIDS service organization (Appendix B). Following the agreement, leaders of each AIDS service organization acted as a referral source, in conjunction with fliers (Appendix C), to establish contact with key informants. Once key informants were contacted and agreed to participate in the study, participants were scheduled a time to meet at a partnering local AIDS service organization that was convenient to the participant. Approximately 35 key informant interviews, balanced by gender and city, were conducted. Each key informant interview was conducted individually and recorded using an audio recording device. The duration of each interview was approximately thirty minutes to one hour in length. Prior to the interview, informed consent was collected from each participant. Key informant interviews followed a semi-structured format using open-ended questions that focused on topics identified as being related to HIV health issues among AAMSM (see HIV health disparity and barriers above, Appendix D). Participants received a $25 incentive. Each audio recorded key informant interview was transcribed and analyzed by researchers to generate a more focused protocol for the next phase of the research project.
Phase II: Focus Group Interviews

Approval was first obtained from the Institutional Review Board for this study. Contact was reestablished with key informants who were identified as highly knowledgeable concerning AAMSM HIV related health issues and expressed a desire to continue collaborating with researchers. These key informants acted as a referral source, in conjunction with fliers, to establish contact with members of the community who are knowledgeable regarding AAMSM HIV related health issues. Once potential focus group participants were contacted and agreed to participate in the study, a time to meet at a partnering local AIDS service organization that was able to accommodate multiple participants was scheduled. A total of four gender specific (two male, two female) focus groups were conducted with approximately seven participants in each. Two focus groups (one male, one female) were conducted in the Fort Worth area and two focus groups (one male, one female) were conducted in the Dallas area. It should be noted that female groups were conducted in order to gain insight into AAMSM HIV related health issues from the unique perspective of women who have experience with AAMSM. Prior to each focus group, informed consent was collected from each participant. Each focus group was recorded using an audio recording device. The duration of each interview was approximately one hour to one hour and 30 minutes in length. Focus groups followed a semi-structured format using open-ended questions that focused on topics identified during analyses of key informant interviews. Participants received a $15 incentive. Each audio recorded focus group was transcribed and analyzed by a senior researcher.

Measures

Due to the qualitative nature of our project, participants were not be asked to complete any questionnaires. However, basic demographic information (e.g. race/ethnicity and gender)
was collected via oral report. This data will helped researchers better understand the diverse make-up of the AAMSM community and its affiliates.

Proposed Data Analyses

Phase I: Key Informant Interviews

All key informant interviews were recorded using an audio device. All audio recordings were transcribed, in duplicate, to a text file by two separate researchers. To ensure the quality of analyses, a senior researcher reviewed the duplicate transcription text files for each key informant interview to check for agreement and make a determination when transcriptions were in disagreement. In addition, a senior researcher used these duplicate text files to create a meta text file, that is whole and accurate, for each key informant interview. In order to analyze each meta text file, a coding sheet was constructed using a grounded theory approach. Grounded theory is a method of explaining phenomena based upon observations of the phenomena and accounting for the events of the phenomena (Krathwohl, 2009; pp. 694). To construct the coding sheet, two researchers first read through five identical meta text files and individually generate a list of themes and sub themes that each identified. The two researchers then compared the lists of themes and consolidated the list into one manageable, and mutually agreed upon, coding sheet (Edstrom & Devine, 2001). Each theme and subtheme was given a number to improve the speed of coding. Both researchers then read through five more identical meta text files, different than those previously read, and coded each interview using the coding sheet. Researchers then again discussed coding agreement and potential changes to the coding sheet.

Once the coding sheet was finalized, all meta text files were read and coded separately by two researchers. Researchers then meet to discuss inter-coder agreement. Cohen’s kappa, a statistic of inter-coder agreement, was calculated using the statistical package SPSS
Researchers continued to discuss coding until a significant level of agreement (kappa > .80) was achieved (Landis & Koch, 1977). All meta text files were then transferred into the computer based qualitative data analysis package ATLAS.ti where codes, as indicated by the coders, were be applied. ATLAS.ti is a data analysis package frequently used in qualitative research to analyze data such as field notes, interviews, text documents and more (Barry, 1998). Each section of coded text was extracted, by code, into a separate text document for analysis. A researcher read through each code text document and, using a grounded theory approach, identified emerging themes indicated by key informants that are most prevalent and in need of attention. This information was used to generate a more focused protocol for the next phase of the study.

**Phase II: Focus Groups**

All focus group interviews were recorded using an audio device. All audio recordings were transcribed to a text file. Using grounded theory, two researchers read through the focus group interviews and individually generated a list of themes and subthemes that each identified. The two researchers then compared the lists of themes and consolidated the list into one manageable, and mutually agreed upon, coding sheet. Each theme and subtheme was given a number to improve the speed of coding. Both researchers then coded the focus group interviews using the code sheet. Researchers met again to discuss inter-coder agreement. The coded group interviews were then transferred into the computer based qualitative data analysis package ATLAS.ti. Each section of coded text was then extracted, by code, into a separate text document for analysis. Researchers identified emerging themes indicated by focus groups that are most prevalent and in need of attention.
Narrative Report

The purpose of the narrative report is to provide members of the community advisory board (CAB) with a holistic and complex narrative that outlines a community level perspective of the relationship between contextual factors and HIV health related issues among AAMSM in the Dallas/Fort Worth Metroplex. The report begins with a brief overview of the purpose of the study and a description of the demographic make-up of participants. Then, each emerging theme identified during analysis of key informant and focus group interviews is discussed. Each emerging theme discussion includes an overview, with a balance of interpretation and recommendations (Miles & Huberman; pp. 298-306). The narrative report includes direct excerpts from community members to help illustrate the community level perspective.
CHAPTER 3

RESULTS

In general, key informants identified emerging themes surrounding HIV related health among African American men who have sex with men (AAMSM) associated with education, prevention and treatment. For HIV related health, education was generally regarded as having an accurate working knowledge of sex, sexuality, and STIs. Participants described prevention as a multipronged approach incorporating identification of HIV-positive persons and utilization of health behaviors designed to limit the spread of HIV. Treatment was depicted as broadly engaging in health behaviors that hinder the progression of HIV.

Key Informant Interviews

Key informants were 34 (75% male, 88% African American) community members, health professionals and stakeholders (Table 1.0). A grounded theory approach was used to conduct a qualitative data analysis, which identified 9 primary themes 14 subthemes (Appendix E) regarding HIV-related health issues. A total of 734 unique codes were produced. Themes below were organized by primary theme and associated subthemes, in descending order based on total number of codes for primary theme and associated subthemes. Average inter-rater reliability by key informant was .84, within the acceptable range, with a range of .8 to .96.

Table 1

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
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<th>Female</th>
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</tr>
<tr>
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<td>-</td>
</tr>
<tr>
<td>Latino</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>1</td>
</tr>
</tbody>
</table>
Community Perceptions

The majority of participants reported that within the African American community a perception exists that African Americans are disinterested in HIV health issues. In addition, participants reported misinformation about HIV and a belief that HIV is easily managed. Improvements in HAART medications were suggested to be associated with less concern regarding HIV related mortality. As one participant stated,

Because I have been a positive African-American MSM for almost 17 years and living a very healthy and productive life, that’s what I see HIV as, life. I no longer see it as death as it once was in the early eighties when HIV first came on the scene. I see it now as life. I see it now as life, with a few changes. Popping a few meds a couple times a day, that’s really the only change I see.

Participants communicated that HIV and MSM are associated with negative perceptions. Participants generally reported that within the African American community, having HIV or being MSM may be perceived as a weakness or as reflecting negatively on one’s character. For example, MSM may be perceived as being more feminine, and thus, weaker and lacking masculinity. Participants reported that some African American families may keep knowledge of an HIV-positive or MSM family member a secret from the community. As one participant reported,

Before my mother died she told me,” keep your business off of the street, whatever you do, and you’ll be alright,” and I don’t have no problems anywhere and I’ve been alright. When I got sick that’s the only time I had some problems, but I keep, I don’t run my mouth. You know, keep your mouth closed sometimes. You know about what you say and stuff, you know. Half of people don’t think, before they talk, and some of my friends, don’t none of my friends, well some of them know. Because I’ve been this way for about four to five years, and uh, they’ve never dis, I’ve never been disrespected. You know, I don’t get disrespected. I don’t get in nobody else’s business.

Participants suggested secrecy within the family may save face in the community and/or protecting a family member from potential physical harm or persecution. However, participants also reported some family members may alienate a family member who engages in male to male
sex or is HIV-positive by cutting off communication, creating physical distance or disclosing a family member’s secrets.

Participants reported people living with HIV may be perceived as unclean or deviant. Moreover, participants reported that within the African American community the belief exists that HIV is contracted through behaviors that are in opposition to cultural expectations (including male to male sex). Participants indicated that many African American churches may avoid education on HIV related issues. As one participant stated,

Trying to get the church to understand how you became HIV-positive, even getting them to understand HIV, first and foremost; because there’s not a lot of education in the churches, unfortunately. We do have some churches that are open to education here in the community, but it’s not enough. There has to be more education in the churches.

Participants also suggested some African American churches may oppose, silently or openly, male to male sex or teach that HIV is a punishment. Participants also voiced skepticism regarding the willingness of clergy to address the HIV epidemic within the African American community. However, many participants described African Americans churches as gathering points and a place of learning within the African American community.

Accessing Care

Participants indicated that care begins at the moment of diagnosis, and being linked to care at that point in time may be positively associated with future health behaviors. Case workers and other persons with knowledge of how to navigate the health system were described as useful points of contact in linking to care. However, participants reported that some AAMSM may be reluctant to utilize HIV-related services (i.e. testing and medical care) or deny risk. Participants identified endorsement of HIV-positive stereotypes as one potential barrier to AAMSM accessing services. As one participant reported,
Know why I didn’t go get tested? In March ’84 doctor told me we got a blood test, you have AIDS, and I said, “No that’s impossible. I don’t fit that profile.” People who don’t go get tested say it can’t happen to me. That’s one of the main reasons. I don’t believe that it can happen to me. I’m a good person. They don’t go get tested.

According to participants, being gay or promiscuous may also be components of HIV-positive stereotypes. Further, participants reported that HIV stereotypes are associated with a number of stigmatized behaviors. As one participant expressed,

If you have this disease, you must fit this certain stereotypical profile, and I thought the same thing. I said, “How do I have it? I’m not a gay white male.” And that’s bad. Promiscuity, and that’s bad. A drug addict, and that’s bad. Those kinds of things are what produces the stigma, because people look at you and say, “Nasty. That’s a nasty person’s disease”

Access to education was described as an important components of HIV prevention. Participants reported misinformation and myths about HIV and safe sex exist within the African American community. Schools and homes were identified as potential points of access for education; however, participants suggested resistance to HIV or safe sex education is likely in these environments as well. Resistance was attributed to a lack of knowledge, embarrassment or cultural norms. In addition, abstinence was identified by participants as the general approach schools take when addressing sex, and participants indicated that male to male sex is not discussed at all. Participants reported that the absence of education is associated with HIV risk among young African Americans. As one participant surmised,

Sex education is not nearly as extensive as it should be. I believe that giving, educating someone is not condoning something, it’s just giving them information. And so I think just getting people information and the tools in schools, I think we are fighting that. That may be an issue. The younger they are they don’t have the information so it’s a lack of, their perception of risk is not realistic. So they just go out and do things and they don’t recognize the risk they are putting on themselves. So I think those are the major barriers. Even if you do use sex education in schools, they aren’t talking about sex with two men. That’s not something they are going to touch on really. And so those things are kind of a barrier.
Realization About Being Gay/HIV-Positive

Participants indicated acceptance, of self or by others, may be an important component of African Americans’ reaction to an HIV diagnosis or comfort disclosing male to male sex. Acceptance of self was described as having an identity with little internalized stigma, whether for HIV-positive status or male to male sex. Acceptance by others was described as receiving unconditional support and compassion from others. Participants, particularly HIV-positive AAMSM, observed that unsupported AAMSM without support may have difficulty coping with an HIV-positive diagnosis and may avoid utilizing testing or returning for results. As one participant described,

Well I don’t want to know because I’m afraid of the unknown, because if it does happen I’ll deal with it when it happens.

In instances where acceptance of self or acceptance from family and friends is not obtained, significant conflict may arise. For example, participants suggested that among African American males internal conflict is common when actions do not meet cultural expectations (i.e. being straight). In an effort to cope with the stress and conflict, some AAMSM may engage in maladaptive coping. As one participant stated,

They turn to drugs, they turn to alcohol, they turn to risky sex because they’re struggling with the idea that I’m not being who I’m supposed to be and I’m displeasing to people that should be okay with me. So to fill that void or to cover that hurt up, put a band aid on it, then I would go to this, or I go to this person. You know I’ll just go to whatever I can to make me feel better for the moment, and to feel just okay for this just little this while.

Participants reported acceptance of self and social support are associated with management of HIV and utilization of health resources. Participants suggested that when resources are limited, some AAMSM may barter with sex. For example, participants shared stories of AAMSM who traded sex for shelter, food, or illicit drugs after being pushed out by family members following disclose of an HIV-positive status.
Barriers

Culture, mistrust and socioeconomic status were described as general barriers to research and interventions among African Americans. Cultural norms were described as deterring HIV-related education and interventions among African Americans and within predominately African American churches, primarily due to stigma surrounding HIV and male to male sex. Further, cultural expectations of African American men (i.e. hyper masculinity and straight) were identified as directing identity building among AAMSM into a specific direction that may conflict with male to male sex behaviors or a non-heterosexual identity. Mistrust developed over a history of unethical research practices (i.e. Tuskegee) was identified by several participants as salient within the African Americans community, and as a potential barrier to research. A history of abuse, exploitation and slavery was identified as a significant contributor to mistrust among African Americans. Low socioeconomic status was described as limiting access and opportunity. As one participant commented,

Well, the African-American community is a very unique community because we come with a lot of cultural baggage that has always been there. HIV has just added on to that baggage. In the African American community it’s historically that we are a poverty stricken community. So we’re dealing with poverty and low-income. We’re dealing with drugs and alcoholism. We’re dealing with addictions, period. We’re dealing with single parent homes, or the parent is not there. We’re dealing with abuse. We’re dealing with educational issues. We’re maybe not as educated as others have been. So, it’s a lot of barriers we face as a culture that only makes HIV, [these barriers] worsen the issues in our community.

What Researchers Should Know

Key informants discussed factors relevant to researchers and intervention efforts within the African American community. First, participants indicated that open discussion and acceptance regarding HIV and MSM is needed within the African American community. Participants also indicated that building trust through social and emotional support is important to bridging the gap between community members and researchers. As one participant stated,
It’s all about getting the person to trust you. That’s the bottom line. If that person can trust you, they’re going to stick to you. If they trust you, they’re going to call you when there’s a need.

In addition, collaborating with the community was identified as an important key to lasting change within the community. Further, demonstrating acceptance of those who are MSM or HIV-positive is important to building relationships with the community. Moreover, participants suggested that researchers be mindful of the real implications of socioeconomic status and access to resources among AAMSM, as these factors may influence relevance and sustainability of an intervention.

Motivators for Risky Sex

Participants reported male to male sex is typically perceived as taboo within the African American community. Participants reported some AAMSM may go on the down-low in order to achieve sexual fulfillment and avoid the stigma of male to male sex. For some, the down-low was associated with riskier sexual behavior. Risky sex may include a greater number of sexual partners, sex trade, substance use and increased risk of HIV acquisition. As one participant stated,

I didn’t find out till four years ago and they said I just recently got it but I was addicted to drugs and also prostituting and doing things I wasn’t supposed to be doing so I don’t know where I got it or how I got it, [maybe] from using needles or from unprotected sex.

Though condoms were identified as the primary method of engaging in safe sex, participants acknowledged condom use may be inconsistent. Participants reported in situations where HIV symptoms are not evident, or in cases where both parties are HIV-positive, condoms may be optional. Further, condoms and condom negotiation were described as barriers to pleasure, intimacy and sexual performance. For example,

I think it is more a mental thing then anything… when they put on a condom, their penis goes down, and when they take it off, it goes back up. It’s probably both psychological
and physical. It’s one of the most intimidating things in the world to start having sex with someone and you’re rock hard, then you put a condom on and, you know.

**Age Gap**

Participants indicated a generation gap in experience, history, and comfort disclosing sexuality and HIV status. The onset of the HIV epidemic was identified as a potential splitting point among AASMS (i.e. those who experienced the onset and those who did not). An increased likelihood of being on the down-low and decreased substance use was reported among older AAMSM. Younger AAMSM were described as thinking of themselves as invincible, living in the moment, and engaging in riskier behavior. Moreover, younger AAMSM were acknowledged as going through an adjustment phase of life, which involves coming out, forming an identity, and having many new experiences. As one participant stated,

I didn’t really start dating or having any sexual contact till I was age 23, and then after I moved to Dallas which was age 25 – 26, is when my sexual outburst came around. I had just never been around so many gay people in one area. I was just like a kid in a candy store. So it was just something new and exciting.

**Living with HIV**

Participants reported that many African Americans believe that a HIV-positive diagnosis leads to a short and uncomfortable life, attributed to either medication side effects or virus progression. It was suggested by some participants that those newly diagnosed may engage in substance/alcohol use to cope. Participants noted substance use and risky sexual behavior may be perceived as a means to enjoy life before an HIV-related death, while some suggested living with HIV is associated with finding new meaning. For example,

Nobody’s going to live forever, and that is one thing I do have guilt about occasionally when I pay insurance at the job for a number of years. All of this that it’s costing to keep me alive. I said I felt guilty, but I once felt guilty about the expense until the grand children were born. Now I definitely have some sort of purpose. So it’s life and death, nobody’s going to live forever, why sweat it.
Communication

Participants reported many African Americans may feel uncomfortable discussing topics associated with sex and sexuality. Some participants reported concern that discussing these topics may lead to isolation or rejection within their communities. In addition, participants indicated that discussing safe sex and HIV within a committed relationship may provoke suspicion of infidelity. However, participants reported that discussion of sex and sexuality within a familial context may be an effective venue for communication. Further, persistence and open dialogue were suggested as keys to successful initiation of communication. As one participant stated,

Sometimes I think it’d be very helpful for parents of gay kids to sit them down and talk to them about it, just bring it out into the open, and then maybe, the issue can be dealt with.

Focus Group Interviews

Focus groups included 28 (four groups, 50% male, 89% African American) members of the community, health professionals and stakeholders (Table 2.0). A grounded theory approach was used to conduct a qualitative data analysis, which identified 8 primary themes 14 subthemes (Appendix G) regarding HIV related health issues. A total of 332 unique codes were produced. Themes were organized from most to least frequent, denoted by the total number of codes for each primary theme and associated subthemes. Themes on Living with HIV were incorporated into other themes due to overlap and lack of codes associated with living with HIV. While responses from men and women tended to be homogeneous, women reported several issues not discussed by men. Average inter-rater reliability was .89, within the acceptable range, with a range of .8 to .95.
Table 2

*Focus Group Demographic Information*

<table>
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</thead>
<tbody>
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<td>Male</td>
<td>13</td>
</tr>
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</tr>
</tbody>
</table>

*Generation Gap*

Groups pointed out a division among AAMSM with respect to age (i.e. older versus younger). Participants indicated one difference between older and younger AAMSM may be related to the impact of HIV on the generation. As one participant reported,

> I am 33 and I have friends in their 50s and one thing I hear from them is that they don’t have peers in their peer group because of HIV. They say, everyone our age is gone. They have a friend who says we used to throw huge parties when we lived in LA, and they would take a picture and there would be 50 guys there, and he says he can count on one hand how many of those men are living. He’s only 57. So, the disease has wiped out almost an entire generation.

Conversely, younger AAMSM were described as knowing very little about the onset of the HIV epidemic. In addition, younger AAMSM, and African American women, were also described as more open, willing to disclose sexual orientation, less concerned about health and more likely to engage in casual and unprotected sex. Participants associated this perceived change in attitude with a shift in national norms, greater equality and living in the age of HAART medication.

*Disclosure Can Be Dangerous*

Disclosure of either HIV status or sexual orientation was described as difficult within the African American community. In both instances groups reported that disclosure may lead to being perceived by others as vulnerable or defenseless. Hiding HIV status or sexual orientation
was described by groups as being one possible method used to avoid being hassled or being the target of aggression by other community members. As one participant commented on his own experience,

They will come at you and try stuff and mess you over. You have to try and fight and prove that you’re not to be messed with. They’ve always done that. Not just with Blacks I mean, it’s everywhere.

Groups strongly endorsed the belief that disclosing HIV status or sexual orientation may lead to negative judgment and stigma, both inside and outside of the home. Groups reported that within the African American community, HIV is often associated with being unclean or deviant. Groups indicated that these perceptions may lead others to distance themselves from people who are HIV-positive or MSM. Thus, disclosing a HIV-positive status may lead to isolation and ridicule. As one participant reported,

I had a female roommate and I never disclosed to her that I was HIV positive because we were not sexually intimate. She got real upset because I didn’t tell her. I told her we’re not intimate and I’m not doing anything risky with you and I’m a very clean person. I don’t feel like I should have to disclose that.

Participants reported that experiencing stigmatized behaviors in the community may lead to a lower sense of self-worth, negative identity and a decreased likelihood of future disclosure. It is worth noting groups generally reported that disclosure to supportive others, particularly family, may be beneficial.

Prevention and Treatment

Male groups reported that condoms were readily accessible but not often used, while female groups reported a preference among men to engage in sex without a condom. Both male and female groups discussed reasons for engaging in sex without a condom, including a perception among African Americans that condoms may be too small, result in a loss of sensation or hinder performance. In addition, some male group participants suggested that using
condoms may interfere with intimacy, and both male and female groups brought up that condoms may lead to suspicion of infidelity or HIV-positive status. Groups also reported difficulty when negotiating condom use. Both male and female groups surmised that condom negotiation is potentially damaging to the relationship and may result in loss of resources or safety, while male groups also suggested condom negotiation may stop potential sexual intercourse. Both male and female groups indicated a belief within the community that if one does not show symptoms of HIV they must be HIV-negative and a condom is not necessary. For example,

I was like let’s use some condoms and he was like for what… what are we going to use condoms for cause you ain’t got nothing and I sure ain’t got nothing stuff like that.

HIV testing was acknowledged as an important component of prevention, though those group members with experience testing community members for HIV reported frequent difficulties with recruiting. Similar to avoidance of education, male and female groups reasoned some African Americans may avoid testing because they prefer to not know their HIV status. In addition, male groups discussed how AAMSM may feel they do not have the financial resources, social support or understanding of HIV to manage an HIV-positive diagnosis and make the life changes necessary to manage the chronic disease. Older African Americans, in particular, may avoid testing for fear of the life changes an HIV-positive diagnosis may bring or that being diagnosed will significantly reduce life expectancy.

Some people don’t want to know because they feel they’re not gonna live as long, or don’t have long to live. The other things that come with the virus, the swollen lymph nodes, getting sick, losing weight, things like that.

Conversely, male and female groups reported that younger African Americans may avoid testing due to a belief that HIV is not an imminent threat to survival. Male groups surmised that this perception may be partly due to the fact that people living with HIV are living longer and
experience/exhibit fewer HIV related symptoms. Male and female groups also indicated that African Americans tend to deal with problems that are only a high priority, and younger males tend to view themselves as invulnerable. As one participant stated,

I have dealt with that before, but a lot of people I deal with don’t care, it is what it is. They feel that they don’t have it and they do a lot of unprotected things with me or other people. They should test but they won’t get tested because they feel it can’t happen to them.

Male groups reasoned that not knowing their HIV status limits the potential of an unintentional HIV-positive status disclosure to the community, which likely allows AAMSM to avoid stigma. Mobile testing units were identified as highly accessible testing tools, as these units are able to move into communities that typically do not have sufficient access to transportation or health services; however, male groups strongly recommended that services be advertised as testing for a variety of sexually transmitted infections, to avoid HIV-related stigma among those who may be hesitant to test for HIV.

Male and female groups indicated that in the DFW Metroplex, HIV treatment services are readily accessible to most, and adequate support is often available to navigate the health system. Male groups generally attributed ease of access to case workers and AIDS service organizations providing multiple services under one roof. However, several factors were discussed that may limit access of services. For example, male and female groups reported some African Americans may not seek treatment because they do not feel they are at a point where treatment is necessary (i.e. lack of HIV related symptoms) or that receiving treatment would be acknowledgement of an HIV-positive status. As one participant noted,

A lot of people look in the mirror and say, “I don’t look sick, so I’m not in trouble. Until I start breaking down I’m not going to worry about it.” It’s another part of denial, if I don’t accept it then it’s not so.
Male groups also described a potential desire to avoid treatment in order to maintain a lifestyle. Specifically discussed was the concern that medications for HIV, and potential side effects, may have negative implications for quality of life. Lastly, male and female groups reported many AAMSM may not access services out of a concern for status disclosure. For example, male and female groups discussed how brick and mortar establishments of ASO’s are well known to many community members and may be avoided to limit potential disclosure of an HIV-positive status, or an association to the gay community. As one participant stated,

If you’ve got to go to a clinic somebody might see you, and then they are going to wonder what you’re doing there. Some people aren’t stupid, they’ll figure it out. Next thing you know, everybody knows. At work you’re surrounded. So then what’s the point of even going and finding out?

Education Needs

Male and female groups reported a need for HIV and safe sex education within the African American community. Male and female groups supported the belief that a lack of knowledge about safe sex and HIV exists within the African American community; however male and female groups reported that information on these topics is plentiful. Male and female groups indicated that information on these topics may not be accessed as these topics tend to be taboo. Male and female groups reasoned that a lack of HIV and safe sex knowledge were associated with HIV risk and incidence among MSM and straight people. Further, a lack of HIV and safe sex knowledge was perceived by male and female groups as a possible factor contributing to the misinformation and stigma within the African American community.

It’s like when you tell your family members. You may have good rapport with them, but if they are not educated about HIV they may think they can get it from touching the toilet seat and they may tell you to not use the toilet, or they may go behind you spraying and wiping.

Despite the reported need for education, male groups suggested that a lack of knowledge about HIV and safe sex knowledge may be preferred by those at higher risk of contracting HIV.
Male groups reasoned that a lack of knowledge may allow some AAMSM to enjoy sex with less concern, and psychologically distance AAMSM from HIV risk. Moreover, male and female groups reported that being knowledgeable about HIV and safe sex practices may be perceived by others as an indication of an HIV-positive status, infidelity and/or promiscuity. Male and female groups suggested that knowledge about HIV and safe sex passed down through the family may be the most successful route for dissemination of information; however, male and female groups noted some discomfort among community members discussing HIV and sex, particularly among males.

**Community Norms**

Both male and female groups reported a cultural expectation that African American males be strong, dominant and masculine. Male groups suggested that maintaining secrecy of male to male sexual experience (i.e. the down-low) and exhibiting hyper masculinity may protect against stigma and suspicion. Male groups discussed how African American males engaging in sex behaviors with other males may be perceived as weaker and less masculine than straight African American males. As one participant stated,

> I think that it’s a sign of weakness, especially if they supposed to be heterosexual. Some of the guys that I’ve had contact with, I’ve always liked the more masculine. I was never attracted to sleeping with gay men or having a relationship with gay man. The ones that I would have a relationship with they would never even think that they were gay, but the activities that they would perform was gay. It was a weakness, them identifying themselves as gay or bisexual, it leaves them open to being less than what a man is supposed to be.

**Religion and Religious Institutions**

Male and female groups both agreed that religious institutions are, traditionally, a major point of contact and a social link within African American communities. Male and female groups relayed experiences and suggested that many religious leaders and institutions (i.e.
churches) within the African American community support adherence to religious doctrine (i.e. no sex before marriage and male to female sexual relations). Male and female groups indicated that some religious institutions endorse the belief that HIV is a form of punishment for not following conservative religious doctrine (i.e. sin), and members of both male and female groups relayed stories in which they were told their faith would protect them from HIV. Moreover, group members with advocacy experience tended to identify conservative doctrine as a significant barrier to HIV and safe sex education within religious institutions. Additionally, male groups noted a growing rift in the make-up and values of congregations, primarily between an older and younger generation. Older African Americans were described as being more conservative, involved in church life and adherent to doctrine, while younger African Americans were described as less adherent to doctrine. As one participant described,

In times past in the African American community it has been very conservative primarily because of religion. We have seen a lot of younger people cast off the religion of their parents, which in turn has allowed them to be a lot more expressive and a lot more open with who they are. A lot of older men really struggle with their identity because of religion. Young people today tell me that, “well my parents are Christian, but I’m not.” No one would have said that 30 years ago, especially in the African American community. It is such an important part of the culture and we are seeing that diminish.
CHAPTER 4

DISCUSSION

HIV health related issues among African American (AAMSM) are complex and impact prevention and treatment/health behaviors in many different ways. The current study identified several emerging themes at the societal, community and individual level with implications for HIV health related issues among AAMSM (Figure 2). At the societal level, themes of religious doctrine, African American culture, and age related norms were described as interrelated and enmeshed with stigma. Furthermore, the contents of these themes were reported to have implications for interrelated community level themes of education, religious views/policy and community norms. Contents of themes at the community level were suggested to further enhance stigma and impact interrelated themes at the level of the individual. The following discussion addresses themes in the same manner, beginning with themes related to society, then community, and finally the individual. Themes for each level are discussed in no specific order.

Figure 2. Themes in society, community, and the individual associated with HIV prevention and treatment
Religious Doctrine

In general, participants reported religious doctrine is opposed to male to male sexual activity, which may reinforce stigma at a societal level. The underlying message being that MSM are inherently deviant, a perception consistent with previous research (Fullilove & Fullilove, 1999). As a result, religious doctrine likely has implications for communities’ perception of AAMSM. Furthermore, religious doctrine was perceived as failing to adequately address growing changes in society. Movement away from religion and religious doctrine described by participants, primarily among a younger generation, may be a reflection of a lack of fit between religious doctrine and broad changes in beliefs and values (Pew Research Center, 2010). Some researchers suggest this shift indicates a move toward spirituality versus religious affiliation (Sorett, 2013). Indeed, prior data does indicate decreased participation and growth among religious institutions (Hadaway, Marler & Chaves, 1993).

African American Culture and Identity

Participants acknowledged that themes related to African American culture have potential consequences for HIV-related health issues among AAMSM. For example, participants discussed societal expectations of a strong African American male. Strength for African American males was associated with masculinity, promiscuity and being straight. Interestingly, participants expressed that African American males assume a one to one relationship between masculinity and being straight, if you are one then you are the other and vice versa. This expectation sets up the perception that AAMSM are weaker or inferior, likely leading to stigma. In addition, HIV carries its own stigma. For example, participants pointed to a perception among the general population that incidence of HIV is the result of substance use, poor judgment or deviant behaviors. In addition, participants eluded to distrust among African Americans of
health professionals grounded in a history of harmful and unethical research. Potential fallout from this history is associated with a culture of avoidance of health professionals and conspiracy beliefs regarding HIV prevention and treatment (i.e. African Americans are being experimented on with HIV-related medications), views consistent with previous literature (Bogart & Thorburn, 2005). At a societal level these themes have strong implications for stigma and community level thoughts and behaviors.

In addition to cultural factors, both key informants and focus groups reported that within African American culture a persistent belief exists that MSM are, by default, HIV-positive. This conflation may be a carryover from a period of time when the HIV epidemic was at its peak and was considered by some to be a gay disease, as suggested by participants. However, another explanation may be related to the African American image. As Ford and colleagues (2007) explain, the conflation of HIV and MSM may be a way for the African American community to distance itself from stigma (e.g. immorality and deviancy) surrounding HIV and MSM communities. African Americans already face racism and injustice; by endorsing an African American image that is neither MSM nor HIV-positive, the African American image deflects stigma associated with MSM and HIV that would only compound current stigma within the African American community. As a result, this conflation may serve as a profound barrier to intervention efforts as addressing MSM and HIV health-related issues among African Americans may challenge the African American identity.

Age Related Norms

Age related norms include themes that are believed to have significant implications for HIV-related health issues among AAMSM. For example, participants endorsed the belief that younger people, particularly African American youth, tend to exhibit a high degree of sexual
activity and promiscuity, a belief consistent with current data (CDC, 2012e). Furthermore, lower perceived risk (i.e. a sense of invulnerability) was believed to be associated with risky sex among youth, a consistent finding in previous literature (Wickman, Anderson, & Smith Greenberg, 2008). Younger and older AAMSM were also described as differing in several ways. For example, younger AAMSM were described as being more open to disclosure of sexual orientation while older AAMSM indicated a greater amount of secrecy, which is consistent with previous literature on age and patterns of HIV disclosure (Emlet, 2006). Perceptions of HIV were also reportedly different. Older view HIV as life-threatening and HIV medications as harmful, AAMSM were more likely to views likely associated with the frequency of death at the onset of the epidemic and the early side effects of HIV medications. Younger AAMSM, tended to have little knowledge of the onset of the epidemic, view HIV as easily managed with medication, and perceive HIV as less of a threat to survival. Though not directly mentioned, this decrease in concern for the likelihood of a HIV-related death mirrors a general decline in HIV-related deaths (Palella et al., 2006). Despite these differences, participants reported that both generations experience stigma.

Societal Stigma

Stigma was consistently identified by participants as negatively associated with HIV-related health issues. Stigma at the societal level may be conceptualized as a broad barrier partially constructed of cultural norms and religious doctrine. Though other factors likely contribute, stigma may reinforce stereotypes and institutional avoidance of HIV-related health issues. Stigma at this level also has potential implications within communities, as societal constructs tend to impact community constructs (Courtenay, 2000).
Education (STI’s, Sex and Safe Sex)

While participants indicated information on STI’s (i.e. HIV), sex and safe sex is available to the African American community, showing an interest or having knowledge on these topics may be perceived as suspicious and as admission of personal information. For example, if you are reading about HIV you must have HIV. Moreover, under these circumstances, community members may be more likely to endorse inaccurate and fearful beliefs regarding HIV. For example, kissing or eating after someone with HIV will spread HIV. In addition, negative attitudes and perceptions regarding condoms (e.g. condoms ruin intimacy or are too small) may result in less frequent use, increasing the probability of infection. Despite negative implications that may arise due to a lack of knowledge on these topics, participants reported that institutions within the community (i.e. schools and churches) have been reluctant to address these issues beyond a policy of abstinence. While abstinence would likely lead to a significant decline in new infections, this policy does not take into account the current frequency of sexual encounters reported by young African Americans. Moreover, institutionalized education of the community on STI’s, sex and safe sex may also be misperceived by some as inferred support for younger people engaging in sexual intercourse or as an attack on community values. Therefore, participants suggested approaching families, which may be more open to sharing knowledge with their children within the privacy of the home. Also, by relaying information in a form which emphasizes real environmental factors and the safety and protection of children, parents may be more receptive to knowledge. Prior research suggests that delivering HIV-related information tailored to a community through community liaisons may also be a way to successfully disseminate knowledge (Kelley et al., 2012).
Religious Views/Policy

Religious institutions (i.e. Black churches) are a traditional gathering point within African American communities; however, for AAMSM and HIV-positive people, religious institutions may not be as welcoming. Participants indicated that within religious institutions, MSM are typically described as deviant and HIV may be a suggested punishment for deviancy. One potential reason for this view may be associated with southern churches’ tendency to interpret religious doctrine and read the bible in a conservative and literal manner (Sears, 2013). Participants reported that shaming of AAMSM and HIV-positive people likely contributes to movement, by some, away from religious institutions, a traditional avenue for support and knowledge within the community. In addition, stigmatized views of AAMSM and HIV have likely led religious leaders to avoid these issues and endorse traditional values regarding sex and sexuality. Unfortunately, these values do not appear to adequately address current needs of the community (i.e. HIV prevalence, growing MSM community). Despite these barriers, participants reported that involvement of religious institutions in addressing HIV-related health issues among AAMSM, and the community, is important. Prior research has identified a number of potential methods of engaging with Black churches which may be beneficial. For example, Hill and McNeely (2013) recommend data sharing, focus on equipping church leaders to tackle the issue (e.g. knowledge and training), look for points of cooperation and compromise, and work with popular opinion leaders. Regardless, of the aforementioned barriers religious institutions will likely play an important role in addressing HIV-related health issues among AAMSM.
Community Norms

In general, African American communities were described as endorsing African American cultural norms regarding HIV and MSM. In regards to HIV, African Americans may avoid/ignore risk or illness until addressing such issues is absolutely necessary. Moreover, participants indicated community members believe that people living with HIV look or act a particular way. Looking sick was often suggested to be an indicator, though the attributes of this sickness were not clearly identified. This belief that an HIV-positive person is easily recognizable is consistent with prior research on this topic (Essien, Meshack, & Ross, 2002). In addition, participants reported that community members are typically capable of readily identifying ASO brick and mortar locations. However, like knowledge of STI’s, traveling in the area of these organizations (i.e. getting off at the bus stop) may be perceived as an admission of personal information. For example, if you get off at the bus stop located near an ASO you must have HIV, a potential barrier to individual HIV-related health behaviors.

Families are also micro communities, which compose the broader community. Participants indicated that families play a significant role in the African American community, and are associated with HIV-related health issues among AAMSM. For example, family was described as providing a layer of protection against the community by providing support and safeguarding information about the family from the community. However, while this layer of protection may defend against stigma from the broader community, these same protections do not necessarily extend inward among family members. As a result, family secrecy may be conceptualized as a double edged sword. According to participants, maintaining secrecy involves projecting a certain image, typically consistent with cultural norms and values, and when a family member fails to uphold that image repercussions may occur. For example, many
participants recounted stories of negative outcomes (i.e. being displaced from the home) for African Americans who disclosed a HIV-positive status or MSM activity. Oddly, for women protection within the family may be even more precarious. As female participants indicated, when straight couples are diagnosed as HIV-positive women may bare the blame within African American communities and families. This blame indicates an inaccurate depiction of the typical direction of HIV transmission and further stigmatizes women. One explanation for community norms is that stigma associated with HIV motivates denial and avoidance as coping mechanism within the African American community. In fact, denial and avoidance were often described as being primary ways African American males address coming out, disclosing HIV status and HIV testing. In this way, stigma, which likely motivates avoidance and denial, creates a powerful barrier to linking African American communities to HIV-related health services. Negative outcomes within families were reportedly associated with a lack of education and stigma. However, despite these factors, African American families were often described as sources of support and resources. As several participants suggested, targeted interventions within families may be particularly effective for addressing HIV-related health issues among AAMSM. This concept of family involvement is proposed in other research as well (Fullilove, Green & Fullilove, 2000).

Community Stigma

Community level stigma may be conceptualized as arising from negative and inaccurate knowledge, thoughts, beliefs and actions associated with groups and institutions within a community. Societal stigma likely provides a level of justification for community stigma, which may result in further marginalization and compound minority status among AAMSM and HIV-positive African Americans. To cope with community level stigma, AAMSM and HIV-positive
African Americans likely engage in a variety of behaviors, which may have significant HIV-related health implications at the individual level.

Personal Identity

Prior research suggests that stigma impacts personal identity (Major & O’Brien, 2005), a conclusion echoed by participants. Moreover, participants suggested a link between personal identity and HIV-health related issues among AAMSM, particularly individual health behaviors. For example, those AAMSM who perceive male to male sex strictly as a behavior and not as an aspect of identity, were described as being more likely to be on the down-low. In addition, these males were also reported to be less likely to acknowledge risk behaviors, HIV status or utilize HIV-related resources. It is likely that denial and avoidance of HIV-related resources are ways down-low men compartmentalize and cope with an internal identity counter to a public persona. On the other hand, AAMSM who perceive male to male sex as contributing to identity may be more likely to engage in positive health behaviors regarding HIV (Malebranche, Peterson, Fullilove & Stackhouse, 2004). However, while these men tend to be more accepting of their identity, participants indicated that some AAMSM may still conceal their male to male sex from the community in order to protect themselves. These findings suggest that providing an environment of open disclosure where AAMSM are able to reconcile internal personal identity and public persona may be beneficial (Seal et al., 2000).

Disclosure

Another theme participants associated with HIV-related health issues among AAMSM is disclosure, particularly the belief that disclosure may be dangerous. Participants indicated that regardless of an individual’s circumstances, AAMSM are likely to be cautious when disclosing MSM activity or HIV status to others. This caution is likely related to cultural and community
norms, but also common stories in which a person was physically harmed following disclosure. In addition, another concern may be isolation from social support networks (i.e. church, friends and family). For example, some participants also relayed stories of AAMSM who were displaced from the home following disclosure, or had others discontinue contact/relations following disclosure. As a result, some AAMSM may go on the down-low to potentially limit disclosure. Unfortunately, participants and prior research suggest that fear of disclosure may also lead some AAMSM to avoid HIV health services (Wohl et al., 2011). Thus, participants and prior research suggest that a strong social support network and strict confidentiality may be the keys to improving utilization of health services (Seal et al., 2000; Wohl et al., 2011).

Sexual Behavior/Risk

Participants noted that for some, particularly young AAMSM, risky sex is more likely. Younger AAMSM were characterized as feeling invincible, though a lack of perceived mortality or immediate threat may be more accurate. Regardless of age, many AAMSM reportedly prefer to live in the moment during sex, which may motivate behaviors believed to lead to intimacy. For example, participants indicated that negotiation of sex/safe sex (i.e. condom use) interferes with intimacy and may result in a lost opportunity to engage in sex. For some AAMSM, substance use (i.e. alcohol and illicit substances) was a reported means to increase intimacy/sensation. Participants indicated that younger AAMSM are more likely to combine substance use and sex; however, not all AAMSM engage in sex to find intimacy. Participants reported that some AAMSM, often youth, engage in sex in order to procure resources (i.e. money, shelter, food and illicit substances). Prior research supports this notion that youth are at higher risk of engaging in sex trade (Outlaw et al., 2011). In these instances, those seeking resources are at a distinct disadvantage and their ability to negotiate sex/safe sex is limited. As a
result, these AAMSM may be coerced into engaging in risky sex. Similarly, African American females may not negotiate sex due to potential loss of resources or potential physical harm. Prior research suggests comprehensive HIV prevention programs targeting the above issues should address dating, intimacy, sex, substance use, personal identity and abuse/coercion, and identify community resources, mentors and safe havens (Seal et al., 2000).

Accessing Care

Accessing care is integral to HIV-related health issues among AAMSM. Participants noted that in order to access care, HIV-positive peoples must first be identified through testing. However, HIV stereotypes and denial were described as barriers to testing. Participants indicated that individuals may be more likely to test if blood tests were conducted for a variety of illnesses, not just HIV specifically. Participants also indicated that care begins at diagnosis and assisting newly diagnosed AAMSM to become linked to the care process is important. To this end, case workers were described as an integral part of this process, a conclusion supported by prior research (Gardner et al., 2005). However, despite a successful linkage to care, a number of reported barriers may explain why some newly diagnosed HIV-positive peoples choose to not access care. For example, participants described that among African Americans, a norm exists in which care is not accessed until absolutely necessary (i.e. threat to mortality). Likewise, participants indicated that some AAMSM may avoid testing or care due to potential financial burden or a perception that testing and treatment will lead to drastic lifestyle alterations. This reasoning may help explain why some African American tend to be diagnosed with HIV and engage in treatment later in the progression of the virus (CDC, 2014). In addition, participants alluded to potential mistrust of providers and myths surrounding HIV in the African American community (i.e. conspiracy beliefs) as barriers to service utilization, a sentiment consistent with
prior research (Bogart, Wagner, Galvan & Banks, 2010). Perhaps the most common barrier to utilization of health resources is concern that accessing health resources will result in an unintentional admission of personal information (i.e. HIV disclosure) to other community members who will disclose to the community. This is likely why participants expressed that maintaining anonymity is vital to utilization of health resources. Thus, effective utilization of case workers, creating and maintaining an open and honest relationship between the individual and the provider, and constructing an environment that maintains anonymity and confidentiality may improve the likelihood that AAMSM will access health services.

Communication

A lack of open and honest communication regarding sex and safe sex practices was noted among African American sexual partners. Discomfort with these topics was identified by participants as contributing to avoidance and lack of discussion. In addition, participants indicated that some African Americans may lack the proper knowledge and skill to facilitate discussion of sex with a sexual partner. Moreover, participants noted a power differential between sexual partners may contribute to difficulties discussing safe sex. Difficulties with communication between parents and children were also indicated. Like sexual partners, discomfort and lack of knowledge and skill were discussed as hindering communication regarding sex, sexuality, safe sex practices and HIV status. Participants suggested that parents are integral to addressing HIV-related health issues. Prior research also supports the notion that improved communication between parents and children reduces sexual risk (Hussen et al., 2014).

Limitations

Key informant interviews and group interviews identified relevant themes to HIV-related health issues among AAMSM. However, several factors may limit our findings. First, our study
was a sample of convenience. Participants are only from the Dallas/Fort Worth Metroplex and may not reflect the views and experiences of AAMSM who do not access AIDS service organizations. However, Texas is fourth in HIV prevalence within the United States and the Dallas/Fort Worth Metroplex ranks second in prevalence and transmission rates and first in the rate of people living with HIV, in Texas. Moreover, our study obtained data from an array of community members, AIDS service organization leaders, workers, advocates and medical doctors. For community members, access to transportation resources and familiarity of AIDS service organizations may be indicative of a sample that is better connected to community resources. In addition, obtaining more in-depth demographic information (i.e. income, profession, religious affiliation, etc.) may have allowed for an increased understanding of our samples. Another potentially limiting factor is the newness of community-based participatory research (CBPR) to the field of psychology. As a result, researchers are still refining the CBPR approach and identifying best practices that may improve the process phases. Lastly, continuation of the current study is a remote possibility at this time due to limitations in personnel capable of carrying out the next phase. However, lessons learned from this study regarding the CBPR process and AAMSM have been applied to other studies undertaken by the Center for Psychosocial Health Research. Moreover, discontinuation of the current study does not preclude dissemination community relevant findings (e.g. narrative report) to local ASO’s who engage in HIV prevention efforts and endeavor to provider more culturally competent/relevant services to AAMSM and HIV-positive African Americans.

Clinical Implications

As the incidence of HIV among AAMSM continues to rise, researchers and health organizations have endeavored to find more efficient ways to deliver effective interventions and
tools to the community. To our knowledge, our study is the first in the Dallas/Fort Worth Metroplex to use a CBPR approach to investigate HIV-related health issues among AAMSM. Key informant and focus group interviews illustrate a complex web of societal, community, and individual level themes regarding HIV-related health. Moreover, input regarding these themes provides valuable perspectives regarding potential means of addressing HIV-related health issues among AAMSM and the African American community at large. Considering the challenges of accessing minority populations, community informed and culturally competent interventions are greatly needed. As a result, the rich data collected from community members, AIDS service organization leaders, workers, advocates and medical doctors, is a valuable resource for future interventions.

Future Research

While the current study may be of limited scope, future interventions would likely benefit from creating targeted interventions which are sensitive to societal, community and individual factors. For example, future research should be aware of religious doctrine, consider the significance of culture and age related norms, present knowledge in an acceptable manner, collaborate with religious institutions, be mindful of community, protect the anonymity of participants, foster positive identity, understand sexual behaviors/risk and improve link to care and communication. In addition, researchers contemplating a CBPR approach should consider the significant time and resources necessary to successfully complete this approach. In addition, researchers should also consider the ethical implications of discontinuing CBPR at different phases. Lastly, although briefly mentioned in this study, additional research on issues impacting HIV-positive women are needed.
Conclusion

HIV health related issues among AAMSM impact prevention and treatment/health behaviors in many different ways. Moreover, these issues range in impact from the societal level to the individual levels. Researchers must consider this range and be mindful of the significant time and resources necessary to complete all three phases. However, CBPR holds the potential to be a valuable and powerful means of evoking change within communities, in a manner that takes into account the humanity of the community.
APPENDIX A

LETTER TO THE INSTITUTIONAL REVIEW BOARD
To the members of the Office of the Institutional Review Board,

My name is James Miller and I am a graduate student researcher for the Center for Psychosocial Health Research (CPHR) directed by Dr. Mark Vosvick. We are currently embarking on a new and exciting method of research commonly referred to as community-based participatory research (CBPR). We are writing you today for two reasons. First, since CBPR is relatively new we would like to provide you with information on what CBPR is, and the process of data collection associated with CBPR. Second, based on your experiences we would like your input regarding certain aspects of CBPR, since we will be submitting an IRB application that involves CBPR soon.

CBPR is an emerging research methodology recognized and funded by several federal foundations including the National Institutes of Health for use in prevention research. CBPR is a collaborative approach to research in which social scientists & community members mutually plan and carry out all aspects of the research process to improve community health. The collaborative nature of CBPR provides several advantages for research in the African-American Men who have sex with Men (AAMSM) community (the focus of our future study): 1) CBPR builds on community strengths and resources; 2) promotes co-learning among all partners; 3) emphasizes local relevance of problems and perspectives within that community; and 4) achieves a balance between research and action which serves as a mutual benefit for all partners. CBPR provides tangible benefits and results for both researchers and communities. Researchers have successfully conducted CBPR in HIV communities, specifically in subpopulations of men who have sex with men (MSM), which is our principle area of interest.

CBPR differs from traditional research as its methodology is collaborative in nature. First, CBPR employs a town hall meeting. The town hall will have two primary goals: to generate ideas and identify issues most pertinent to the target community, and identify members of the community to serve on our Community Advisory Board (CAB). Next, from the town hall 6-12 community members will be approached to serve on our Community Advisory Board. The CAB and researchers collaborate to translate community issues into research questions, develop testable hypotheses, select a design for the study that compliments the research question and select measures for data collection. Due to the nature of the model, we cannot provide the traditional details of our planned methodology since it grows out of the collaboration between the community members and the researchers. The CAB is an important recruitment tool and helps train community members to assist in the recruitment and processing of participants. Recruiters drawn from target communities are highly effective in difficult to access communities. In addition, members of our CAB will become colleagues in the research process and collaborate with the PI and Co-PI’s, graduate students and other CPHR members. They will also become a resource for organizing and running participants, screening data collection surveys and critiquing methodology techniques throughout the data collection process. CAB members will also assist in data analysis and dissemination through poster and manuscript creation, as well as bringing the findings back to the community. CBPR data collection is richer than traditional quantitative or qualitative data due to its use of a mixed methods approach.
CPHR recently received an internal UNT grant to conduct CBPR within the African American MSM community. As a result, we plan to submit an application to the Institutional Review Board to conduct our research. However, before we submit our application we would like to receive your input regarding several questions, in order to provide the most comprehensive and transparent application possible. Since the methodology will not be decided upon until the research question is agreed upon and a research question will not be decided upon until after the town hall and the CAB meets, how do we describe our approach? Will we need IRB approval in order to hold a town hall? If so, what will be needed in order to receive approval? Is informed consent necessary to conduct a town hall meeting? Will we need IRB approval in order to create the CAB? If so, what will be needed in order to receive approval? Is informed consent necessary to create the CAB? Will a separate application be necessary for both the town hall and the CAB? We look forward to your input and any other concerns or comments regarding the town hall and CAB.

Thank you and have a nice day,
James Miller, B.S.
APPENDIX B

MEMORANDUMS OF UNDERSTANDING
Mark Vosvick, Ph.D.  
Director - Center for Psychosocial Health Research  
University of North Texas  
1155 Union Circle #311280  
Denton, TX 76203-5017

March 6, 2012

Dear Dr. Vosvick,

Please consider this a memorandum of understanding between Resource Center Dallas for your research project entitled, ‘Community Based Participatory Research: HIV in African American Men Who Have Sex with Men.’

Resource Center Dallas is fully supportive of this proposal, as it addresses several key areas that we see as important to minority populations in our community. Community Based Participatory Research (CBPR), an emerging research methodology recognized and funded by federal foundations, is a collaborative approach to research that equitably involves all partners in the research process. The goal of CBPR is to combine knowledge and action for social change to improve community health and eliminate health disparities. Using CBPR to reach out to the African American community enhances the relevance and use of the research data by all partners involved and utilizes partners with diverse skills, knowledge and expertise in addressing complex problems. Most importantly, CBPR increases the possibility of overcoming distrust of research on the part of communities that have historically been ‘subjects’ of such research.

Resource Center Dallas is a non-profit organization that provides medical care, support services, and advocacy for underserved individuals in Dallas county. Resource Center Dallas was founded in 1983 in order to better serve lesbian, gay, bisexual and transgender (LGBT) communities and all people affected by HIV through improving health and wellness, strengthening families and communities and providing transformative education and advocacy. The increase in demand for HIV/AIDS resources in Dallas county and the growing need for services underscores the importance of your proposed research.

Our long-standing relationship with you and your research team paired with the previous research projects in which we have partnered, suggests a good outcome for your study and the feasibility of successfully completing this project. I am happy to be supportive of your efforts to address this very important issue for African Americans in the DFW area and look forward to collaborating with you on this project.

Sincerely,

CeCe Cox, J.D.  
Executive Director and Chief Executive Officer

Resource Center Dallas operates: John Thomas Guy & Lesbian Community Center and Nelson-Tobrux Health Center  
Main Office: 3700 Flora Street, Dallas TX 75219  
Mailing Address: PO Box 190809, Dallas TX 75219-0809  
Phone: 214-528-0144  Fax: 214-522-4604 - www.rcdallas.org
27 February 2012

Mark Voswick, Ph.D.
Director - Center for Psychosocial Health Research
University of North Texas
1155 Union Circle #311280
Denton, TX 76203-5017

February 22, 2011

Dear Dr. Voswick,

Please consider this a memorandum of understanding between Health Services of North Texas and the University of North Texas for your research project entitled, 'Community Based Participatory Research: HIV in African American Men Who Have Sex with Men.'

Health Services of North Texas is fully supportive of this proposal, as it addresses several key areas that we see as important to minority populations in our community. Community Based Participatory Research (CBPR), an emerging research methodology recognized and funded by federal foundations, is a collaborative approach to research that equitably involves all partners in the research process. The goal of CBPR is to combine knowledge and action for social change to improve community health and eliminate health disparities. Using CBPR to reach out to the African American community enhances the relevance and use of the research data by all partners involved and utilizes partners with diverse skills, knowledge and expertise in addressing complex problems. Most importantly, CBPR increases the possibility of overcoming distrust of research on the part of communities that have historically been 'subjects' of such research.

Health Services of North Texas (HSNT) is a non-profit organization that provides medical care, support services, and advocacy for underserved individuals in the North Texas region. HSNT was founded in 1988 in order to provide support to those affected by HIV/AIDS, and it has grown into a highly respected agency capable of providing comprehensive medical care at little or no cost to underserved individuals in the North Texas area. The increase in demand for HIV/AIDS resources in the North Texas region and the growing need for services underscores the importance of your proposed research.

Our long-standing relationship with you and your research team suggests a good outcome for your study and the feasibility of successfully completing this project. I am happy to be supportive of your efforts to address this very important issue for African Americans in the DFW area and look forward to collaborating with you on this project.

Sincerely,

[Signature]

Ronald G. Aldridge, Ph.D.,
Chief Executive Officer

www.healthntx.org
Mark Vosvick, Ph.D.
Director - Center for Psychosocial Health Research
University of North Texas
1155 Union Circle #311280
Denton, TX 76203-5017

February 23rd, 2011

Dear Dr. Vosvick,

Please consider this a memorandum of understanding between AIDS Outreach Center of Greater Tarrant County and UNT for your research project entitled, ‘Community Based Participatory Research: HIV in African American Men Who Have Sex with Men.’

AIDS Outreach Center County is fully supportive of this proposal, as it addresses several key areas that we see as important to minority populations in our community. Community Based Participatory Research (CBPR), an emerging research methodology recognized and funded by federal foundations, is a collaborative approach to research that equitably involves all partners in the research process. The goal of CBPR is to combine knowledge and action for social change to improve community health and eliminate health disparities. Using CBPR to reach out to the African American community enhances the relevance and use of the research data by all partners involved and utilizes partners with diverse skills, knowledge and expertise in addressing complex problems. Most importantly, CBPR increases the possibility of overcoming distrust of research on the part of communities that have historically been ‘subjects’ of such research.

AIDS Outreach Center (AOC) is a non-profit organization that provides care and support services, and advocacy for underserved individuals in Tarrant and several surrounding rural counties. AOC was founded in 1986 in order to provide support to those affected by HIV/AIDS, and it has grown into a highly respected agency capable of providing comprehensive medical care at little or no cost to underserved individuals in Greater Tarrant County. We currently serve 1800 people living with HIV and provide prevention and education services to over 4000 people annually. The increase in demand for HIV/AIDS resources in Tarrant and surrounding rural communities and the growing need for services underscores the importance of your proposed research.

Our long-standing relationship with you and your research team paired with the previous research projects in which we have partnered, suggests a good outcome for your study and the feasibility of successfully completing this project. It is with great enthusiasm that I offer AOC’s support of your efforts to address this very important issue for African Americans in the DFW area and look forward to collaborating with you on this project.

Sincerely,

Shannon Hilgart
Associate Executive Director
Mark Voswick, Ph.D.
Director - Center for Psychosocial Health Research
University of North Texas
1155 Union Circle #311280
Denton, TX 76203-5017

February 23, 2012

Dear Dr. Voswick,

Please consider this a memorandum of understanding between Legacy Counseling Center and the University of North Texas for your research project entitled, 'Community Based Participatory Research: HIV in African American Men Who Have Sex with Men.'

Legacy Counseling Center is fully supportive of this proposal, as it addresses several key areas that we see as important to minority populations in our community. Community Based Participatory Research (CBPR), an emerging research methodology recognized and funded by federal foundations, is a collaborative approach to research that equitably involves all partners in the research process. The goal of CBPR is to combine knowledge and action for social change to improve community health and eliminate health disparities. Using CBPR to reach out to the African American community enhances the relevance and use of the research data by all partners involved and utilizes partners with diverse skills, knowledge and expertise in addressing complex problems. Most importantly, CBPR increases the possibility of overcoming distrust of research on the part of communities that have historically been 'subjects' of such research.

Legacy Counseling Center (Legacy) is a non-profit organization that has provided quality mental healthcare, substance abuse treatment, and special care housing services to those with HIV/AIDS for over 20 years. Legacy offers various mental health services, ranging from individual therapy to group sessions. The increase in demand for HIV/AIDS resources in the North Texas region and the growing need for services underscores the importance of your proposed research.

As a service provider to those affected by HIV/AIDS, I am enthusiastic to support your efforts to address this very important issue for African Americans in the DPW area and look forward to collaborating with you on this project.

Sincerely,

Melissa Grove, Executive Director
July 18, 2012

Mark Vosvick, Ph.D.
Director - Center for Psychosocial Health Research
University of North Texas
1155 Union Circle #311280
Denton, TX 76203-5017

Dear Dr. Vosvick,

Please consider this a memorandum of understanding between AIDS Arms, Inc. and the University of North Texas for your research project entitled, 'Community Based Participatory Research: HIV in African American Men Who Have Sex with Men.'

AIDS Arms is fully supportive of this proposal, as it addresses several key areas that we see as important to minority populations in our community. Because this study addresses several key areas that we see as important to minority populations in our community and it employs Community Based Participatory Research (CBPR), a collaborative approach to research that equitably involves all partners in the research process, AIDS Arms is pleased to join this research effort that aims to combine knowledge and action for social change to improve community health and eliminate health disparities.

AIDS Arms is the largest non-profit HIV/AIDS service organization in North Texas. Since our inception in 1986, AIDS Arms has served over 15,000 HIV+ individuals, their partners and families. Our agency provides free testing and prevention services to anyone in the community, as well as case management, outpatient medical care, prison outreach and substance abuse and mental health treatment. As a service provider to those impacted by HIV/AIDS, AIDS Arms is pleased to support your efforts to address this very important issue for African Americans in the DFW area and look forward to collaborating with you on this project.

Sincerely,

Raeagle Nobles, MS, LPC, LMFT

Executive Director
APPENDIX C
RECRUITMENT FLIER
Dear Community Member,

We are currently launching a new study to learn about the health concerns around HIV that the African American community has. We want to approach this study in a new and exciting way, by working directly with you and others like you who are involved in the African American Community to learn what YOUR concerns are. Once you help us identify the issues, we want to work with members of the African American community to develop approaches to manage the identified health issues.

Who are we? We are the UNT Center for Psychosocial Health Research. We are a collection of faculty members and students who have worked in HIV/AIDS over the past 20 years and are committed to developing treatments to improve the wellness of people living with HIV and of people affected by HIV (family, friends, partners).

We believe that you are a member of the African American community or someone who works with this community who has knowledge and understanding of issues relevant to African American men who have sex with men. We would like to meet with you and discuss your thinking about current issues of concern about HIV transmission and living with HIV in the African American community.

What would working with us look like? We would meet with you for about an hour to an hour and a half. We would talk about your experiences and thoughts about HIV in the community. During this meeting we will use an audio recorder to record what you have to say. We would ask you if you know of other folks knowledgeable about the community who would like to work with us. Your privacy is important to us. While we will use audio recording, to protect your privacy we will not record any of your personal information (name, phone number, etc.) nor will we ever identify you as a participant in our study. At the end of the meeting, you would receive $30.

Once we have met with around 40 people, we will schedule some group meetings to explore health concerns in the African American community. All of this work is to help us truly understand what the issues are WITHIN the community.

We are excited about the opportunity to work with you and other members of the community using this new approach to community health research. Please let us know if you’d be willing to meet with us soon.

Thanks and I look forward to meeting you,

James Miller, M.S.
The Center for Psychosocial Health Research
Phone #: (940) 891-6844
e-mail: cph@unt.edu
APPENDIX D

KEY INFORMANT INTERVIEW SEMI-STRUCTURED PROTOCOL
### Priming/Experience

1. What is it like for you to be/work with an African American man who has sex with other men?

### Beliefs/Attitude in the Community

1. What do you think of when you hear “HIV/AIDS”?
2. Are there any sensitive or “taboo” issues that aren’t discussed in the African American community that are important in discussing HIV/AIDS?
   - I hear about men on the down-low all the time, can you tell me what you know about these men?
3. What kind of beliefs or attitudes do you feel like the community has about African American men who have sex with men and HIV/AIDS?
4. How is sexuality addressed in a religious or social/familial context in the African American community?
5. Do you feel there are different groups of people in the African American MSM community?

### Issues/Needs

1. What do you feel are the biggest issues in African American community, surrounding HIV/AIDS, right now?
2. Are there any issues or needs in the community you feel are not being addressed?
3. How do you feel the community response to HIV/AIDS could be improved?

### Access

1. Are there HIV/AIDS services within the African American community that could have better access to for community members?
2. How would you describe accessibility to medical care in the community?
3. Which services are utilized by the community most often?

### Barriers

1. What kind of barriers do you believe exist within the African American community?
2. What kind of barriers do you feel prevent access to services in the African American community?
3. Do you feel that there are things which prevent the use of safe sex practices?
4. Do you feel that there are barriers that prevent access to medical services?
5. What kind of barriers do you feel we might encounter if we try to reach out to African American MSM?
   - What about those on the down-low?
APPENDIX E

KEY INFORMANT GROUNDED THEORY CODES
Key Informant Codes

- Self-realization about being gay/coming out
  - Dow-low guys
  - Wanting relationships
- Perceptions within broader communities of: being gay, sexuality and AIDS/HIV
  - Fear, shame, stigma and denial
  - Religious institutions
  - Family
  - Getting tested
- Communication
- Age-related
- Self-described risky behavior and experiences, includes: motivation, safety, denial/risk, descriptives and substance use
  - Perceptions and attitudes about condoms
  - “The scene,” includes: bars, hookups, phone apps and parks
- Living with HIV and what it is like
  - Diagnosis reaction
- Access or a need for access
  - Access to care
  - Access to education
  - Access to opportunity
- What researchers should know
- Barriers to research and advice to researchers
  - Perceptions and misperceptions in communities about researchers and the government
    - Perceptions and misperceptions from researchers or government about these communities, includes: African Americans, gays and bisexuals, down-low men, etc.
Focus Group Questions

1. What are some reasons a person may not want to know they have HIV?
2. Are there any reasons an African American male may not want to tell other people he has sex with men?
3. What might prevent a person from getting treatment after being diagnosed with HIV?
4. What are some differences between older and younger African American men who have sex with men?
5. How are people linked to care once they are diagnosed with HIV?
6. What are some of the barriers in the African American community that may prevent people from learning about HIV?
7. Is there anything the African American community should know about HIV that they may not know right now?
8. What are some reasons the African American community might not want to talk about HIV of men having sex with men?
9. What might be some barriers to talking about HIV in a church?
10. What would improve access to HIV education among African Americans?
11. How do African Americans discuss sex with a partner?
12. Do substances like drugs or alcohol play a role in riskier sex?
13. What are some reasons a person might engage in riskier sex?
14. What are some reasons an intervention in the community may be ineffective?
15. What is missing in the community to deal with HIV health issues?
APPENDIX G

FOCUS GROUP GROUNDED THEORY CODES
Focus Group Codes

- Disclosure and associated dangers
  o Disclosure to family
  o Disclosure to others
- Education and myths
  o HIV education
  o Education barriers
  o Sex education
- Living with HIV
- Age-related
  o What it means to self
  o What it means to others
- Treatment and prevention efforts
  o Testing and barriers to getting people in the door
  o Treatment, linking to care and barriers
  o Sex and barriers to safe sex
- Community
  o Perceptions, norms and values
  o Demographic norms
- Religion and the Church
  o Values and perceptions
  o Religious and institution barriers
- Risky behavior
- Women’s issue
APPENDIX H

NARRATIVE REPORT
Narrative Report on Community-Based Participatory Research: HIV in African American Men Who Have Sex with Men

Study Purpose
To date, traditional behavioral interventions have done little to reduce the prevalence and transmission of HIV among African American men who have sex with men (AAMSM), a group identified by the Centers for Disease Control and Prevention as being at high risk for contracting HIV. Some researchers theorize that this lack of success may be because these interventions do not address contextual factors among AAMSM. Community-based participatory research (CBPR) is one approach to research with the potential to lead to effective interventions in the future. CBPR is a collaborative, mixed-methods and multidisciplinary, approach to scientific inquiry, which is conducted with, and within, the community. The purpose of our study was first to follow the CBPR approach to engage and develop a relationship with the African American communities in the Dallas/Fort Worth Metroplex. Second, we discussed contextual issues in order to identify emerging themes regarding HIV health related issues among AAMSM. The final goal of the study was to produce a narrative report, based on study findings, that serves as foundation for future CBPR research and interventions with AAMSM in the Dallas/Fort Worth Metroplex.

The following narrative report includes a description of the demographic make-up of participants. The report also discusses emerging themes at the societal, community and individual levels that were identified during analysis of key informant and focus group interviews. Discussion of themes includes a combination of brief overview, interpretation, community excerpts and recommendations.

Demographics
Qualitative data was collected via oral report during semi-structured interviews with key informants and focus groups. Key informants were 34 (75% male, 88% African American) community members, health professionals and stakeholders (Table 1.0).

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Focus groups included 28 (50% male, 89% African American) members of the community, health professionals and stakeholders (Table 2.0).

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Theme discussion
HIV health related issues among AAMSM are complex and impact prevention and treatment/health behaviors in many different ways. Several emerging themes were identified at the societal, community and individual level with implications for HIV health related issues among AAMSM (Figure 1.0). At the societal level, themes of religious doctrine, African
American culture, and age related norms were described as interrelated and enmeshed with stigma. Furthermore, societal themes were reported to have implications for community level themes of education, religious views/policy and community norms. Community level themes were suggested to further enhance stigma and impact themes at the level of the individual, including disclosure, personal identity, sexual behavior/risk, accessing care and communication.

![Figure 1. Themes in society, community, and the individual associated with HIV prevention and treatment](image)

**Religious doctrine**

Traditionally, African Americans have identified with Christian doctrine. In general, participants reported religious doctrine does not favorably address male to male sexual activity, which may reinforce stigma at a societal level. The underlying message expressed by participants and supported by prior research, being that MSM are inherently deviant (Fullilove & Fullilove, 1999). As a result, religious doctrine likely has implications for communities’ perception of AAMSM. Furthermore, current religious doctrine may not adequately address growing changes in society. Movement away from religion and religious doctrine, as described by participants, may be a reflection of a lack of fit between religious doctrine and broad changes in beliefs and values (Pew Research Center, 2010). As one participants stated,

> We have seen a lot of younger people cast off the religion of their parents, which in turn has allowed them to be a lot more expressive and a lot more open with who they are. A lot of older men really struggle with their identity because of religion. Young people today tell me that, “well my parents are Christian, but I’m not.” No one would have said that 30 years ago, especially in the African American community. It is such an important part of the culture and we are seeing that diminish.

This shift may indicate a growing population that is spiritual, but not necessarily religiously affiliated (Sorett, 2013). Indeed, past research indicates a decrease in participation and growth among religious institutions (Hadaway, Marler & Chaves, 1993). Regardless, religious doctrine may have implications for how AAMSM develop and engage in the community. As a result, awareness of potential religious affiliation and knowledge/importance of religious doctrine should be considered in intervention efforts.
African American culture and identity

African American culture and identity is unique in that African American culture and identity is connected to a long, and ongoing, history of inequality and justice. As a result, participants indicated that African American culture and identity includes themes of struggle and strength. Participants acknowledged that themes related to African American culture and identity have potential consequences for HIV health related issues among AAMSM. For example, participants discussed expectations of a strong African American male. Participants and prior research both suggest that strength among African American males is believed to be associated with masculinity, promiscuity and being straight (Operario, Smith & Kegeles, 2008; Thompson-Robinson et al., 2007). Interestingly, participants expressed that for African American males exists an assumption of a one to one relationship between masculinity and being straight, if you are one then you are the other and vice versa. This expectation sets up the perception that AAMSM are weaker or inferior, likely leading to stigma. As one participant stated,

I think that it’s a sign of weakness, especially if they supposed to be heterosexual. Some of the guys that I’ve had contact with, I’ve always liked the more masculine. I was never attracted to sleeping with gay men or having a relationship with gay man. The ones that I would have a relationship with they would never even think that they were gay, but the activities that they would perform was gay. It was a weakness, them identifying themselves as gay or bisexual, it leaves them open to being less than what a man is supposed to be.

Furthermore, culturally endorsed male promiscuity likely increases risk issues among young African American males and may explain why a greater number of high school aged African American males report having engaged in sexual intercourse and having had four or more partners by high school, than their White/European American and Hispanic/Latino counterparts (CDC, 2012e). In addition, HIV carries its own cultural stigma. For example, participants pointed to a perception among the general population that incidence of HIV are the result of substance use, poor judgment or socially unacceptable behaviors. In addition, participants eluded to distrust among African Americans of health professionals grounded in a history of harmful and unethical research (i.e. Tuskegee syphilis study, Florida dengue outbreak and the Marion Sims experiments). Potential fallout from this history is associated with a culture of avoidance of health professionals and conspiracy beliefs regarding HIV prevention and treatment (i.e. African Americans are being experimented on with HIV-related medications), views consistent with previous literature (Bogart & Thorburn, 2005). As one participant stated,

We don’t trust the health care community as a whole, generally. Then we don’t seek care or prevention. You can go to your doctor when you are sick, okay. See the problem with HIV, you can have HIV for many years and not be sick so why do I need some medication? So again, these are all cultural barriers that you encounter.

In addition to cultural factors, both key informants and focus groups reported that within African American culture a persistent belief exists that MSM are, by default, HIV-positive. This perception may be a carryover from a period of time when the HIV epidemic was at its peak and was considered by some to be a gay disease, as suggested by participants. However, another explanation may be related to the African American image. The automatic connection between HIV and MSM may be a way for the African American community to distance itself from stigma (e.g. immorality and deviancy) surrounding HIV and MSM communities. African Americans
already face racism and injustice; by endorsing an African American image that is neither MSM nor HIV-positive, the African American image deflects stigma associated with MSM and HIV that would only compound current stigma within the African American community. As a result, this conflation may serve as a profound barrier to intervention efforts as addressing MSM and HIV health-related issues among African Americans may challenge the African American identity.

**Age related norms**

Differences among AAMSM were not readily reported, except for differences between older and younger African Americans. Age related norms include themes that may have significant implications for HIV health related issues among AAMSM. For example, participants endorsed the belief that African American youth, tend to exhibit a high degree of sexual activity and promiscuity, a belief consistent with current data (CDC, 2012e). Furthermore, lower perceived risk (i.e. a sense of invulnerability) and a lack of knowledge was believed to be associated with risky sex among youth, a consistent finding in previous literature (Wickman, Anderson, & Smith Greenberg, 2008). As one participant surmised,

The younger they are they don’t have the information so it’s a lack of, their perception of risk is not realistic. So they just go out and do things and they don’t recognize the risk they are putting on themselves.

Younger and older AAMSM were also described as differing in several ways. For example, younger AAMSM were described as being more open to disclosure of sexual orientation, while older AAMSM indicated a greater amount of secrecy. Perceptions of HIV were also reportedly different. Older AAMSM tended to view HIV as life-threatening and HIV medications as harmful, views likely associated with the frequency of death at the onset of the epidemic and the early side effects of HIV medications. Younger AAMSM, with little knowledge of the onset of the epidemic, tended to view HIV as easily managed with medication and of little threat to survival. Despite these differences, participants reported that both generations experience stigma.

**Societal stigma**

Stigma was consistently identified by participants as negatively associated with HIV-related health issues. Stigma at the societal level may be conceptualized as a broad barrier partially constructed of cultural norms and religious doctrine. As one participant stated,

That fear of stigma, because you have this disease related to sex, so you have done something wrong. And the stigma comes from society’s viewpoint of morals, the morals that say, “if you have this disease you must fit this certain profile.”

Though other factors likely contribute, stigma may reinforce stereotypes and institutional avoidance of HIV-related health issues. Stigma at this level also has potential implications within communities, as general perceptions of society tend to impact perceptions within communities (Courtenay, 2000).

**Education (STI’s, sex, and safe sex)**

Since the beginning of the epidemic in the 1980s, health professionals have sought to provide information on HIV and safe sex practices to the general public. The traditional thought process being that the general population would be receptive to information, take in the information and alter behavior as a result. However, this strategy has not always accounted for barriers within communities which may hinder the spread of information. As a result, participants indicated knowledge on sexually transmitted infections (i.e. HIV), sex and safe sex is lacking within the African American community despite knowledge being readily accessible. Participants discussed that within the African American community showing an interest or
having knowledge on these topics is perceived as suspicious and as a personal disclosure. For example, if you are reading about HIV you must have HIV. Participants also indicated outdated beliefs exist regarding the spread of HIV. For example, kissing or eating after someone with HIV will spread HIV. Lastly, participants reported negative attitudes and perceptions regarding condoms. For example, condoms ruin intimacy or are too small. Despite negative implications that may arise due to a lack of knowledge on these topics, participants reported that institutions within the community (i.e. schools and churches) have been reluctant to address these issues beyond a policy of abstinence. As with personal knowledge, providing information to the community on sexually transmitted infections, sex and safe sex may be misperceived by some, and viewed as being supportive of younger people engaging in sexual intercourse or as an attack on community values. As one participant reported,

It’s hard to talk about condoms in the midst of church, because it’s almost like people think you promoting sex. You not. Like say for instance in the Catholic community, you know, they don’t really believe in using condoms. So you have to get past that.

To facilitate a spread of knowledge in spite of these concerns, participants suggested approaching families, which may be more open to sharing knowledge with their children within the privacy of the home. Also, by relaying information in a form which emphasizes realities within the community and the safety and protection of children, parents may be more receptive to knowledge. Prior research suggests that delivering HIV-related information tailored to a community through community liaisons/representative may also be a way to successfully provide information to the community (Kelley et al., 2012).

**Religious views/policy**

Religious institutions play a significant social role in many African American communities (Mattis et al., 2007), and faith-based institutions have often been a source of support in the African American community in the wake of significantly challenging events (Aten et al., 2010). Religious institutions (i.e. Black churches) are also a traditional gathering point within African American communities; however, for AAMSM and HIV-positive people, religious institutions may not be as welcoming. Participants indicated that within religious institutions, MSM are typically described as deviant and HIV may be viewed as a form of punishment for deviancy. One potential reason for this view may be associated with southern churches’ tendency to interpret religious doctrine and read the bible in a conservative and literal manner (Sears, 2013). As one participant commented,

With the faith based community, particularly in the Black community, because the bible says this. I was raised in a faith based family and I had some of the same issues, and that’s where shame comes into play, of the feeling that you have did something wrong. So you just had sex now, but you did something wrong to have this disease.

Participants reported that shaming of AAMSM and HIV-positive people likely contributes to movement, by some, away from religious institutions, a traditional avenue for support and knowledge within the community. In addition, stigmatized views of AAMSM and HIV have likely led religious leaders to avoid these issues and endorse traditional values regarding sex and sexuality. Unfortunately, these values do not appear to adequately address current needs of the community (i.e. HIV prevalence, growing MSM community). As one participant indicated regarding sex,
I think when you’re talking about the church, you know, what the word of G-d says, the word of G-d says you’re supposed to abstain from sex until you are married. Now, that’s what is said, but people in the church are not doing that, maybe some, but for the most part many people are not doing that. Despite these barriers, participants reported that involvement of religious institutions in addressing HIV-related health issues among AAMSM, and the community, is important. Prior research has identified a number of potential methods of engaging with Black churches which may be beneficial (Hill & McNeely, 2013). Regardless, of the aforementioned barriers religious institutions will likely play an important role in addressing HIV-related health issues among AAMSM.

Community norms

In general, African American communities were described as endorsing African American cultural norms regarding HIV and MSM. In regards to HIV, African Americans may avoid/ignore risk or illness until addressing such issues is absolutely necessary. Moreover, participants indicated community members believe that people living with HIV look or act a particular way. Looking sick was often suggested to be an indicator; however what being sick looks like is not clear. As one participant commented,

> There are people out there who still think that in this day and age you can just ask someone for casual sex. But I guess people still have that mentality and think, “well, I can look as somebody and tell whether or not they’re sick…”

This belief that an HIV-positive person is easily recognizable is consistent with prior research on this topic (Essien, Meshack, & Ross, 2002). In addition, participants reported that community members are typically capable of readily identifying physical locations of AIDS Service Organizations. However, like knowledge of sexually transmitted infections, traveling in the area of these organizations may be perceived as identifying as being MSM or having HIV. For example, as one participant illustrate,

> A lady stays here, and she doesn’t even have [HIV]. Because she stays here, she got classified as it on the bus and people were saying she telling folks she has HIV and all this… and she was like, “I don’t even have it.”

Though easy identification of services may be beneficial to those seeking services it may also act as a potential barrier to individual HIV-related health behaviors.

Participants indicated that families play a significant role in the African American community, and are associated with HIV-related health issues among AAMSM. For example, family was described as providing a layer of protection against the community through support and safeguarding information about the family from the community. As one participant reflected,

> I told my family and they was very open, protective. They didn’t disown me or anything. Only thing they were concerned about was my medical care… I think, you know, there is a good support system in most African American families.

However, while this layer of protection may defend against stigma from the broader community, these same protections do not necessarily extend inward among family members. As a result, family secrecy is complex. According to participants, maintaining secrecy involves presenting a certain image, typically consistent with cultural norms and values. When a family member fails to uphold this image, repercussions may occur. For example, many participants recounted stories of negative outcomes (i.e. being displaced from the home) for African Americans who disclosed a HIV-positive stats or MSM activity. Oddly, for women protection within the family
may be even more difficult. As female participants indicated, when straight couples are diagnosed as HIV-positive women may bear the blame within African American communities and families. This blame indicates an inaccurate depiction of the typical direction of HIV transmission and further stigmatizes women. One explanation for community this norms is that stigma associated with HIV motivates denial and avoidance as a way to cope within the African American community. In fact, denial and avoidance were often described as being primary ways African American males address coming out, disclosing HIV status and HIV testing. In this way, stigma, which likely motivates avoidance and denial, creates a powerful barrier between African American communities and HIV-related health services. Negative outcomes within families were reportedly associated with a lack of knowledge and stigma. However, despite these factors, African American families were often described as sources of support and resources. As several participants suggested, targeted interventions within families may be particularly effective for addressing HIV-related health issues among AAMSM. This concept of family involvement is proposed in other research as well (Fullilove, Green & Fullilove, 2000).

Community stigma
Community level stigma may be conceptualized as arising from negative and inaccurate knowledge, thoughts, beliefs and actions associated with groups and institutions within a community. Societal stigma likely provides a level of justification for community stigma, which may result in further marginalization and compound minority status among AAMSM and HIV-positive African Americans. To cope with community level stigma, AAMSM and HIV-positive African Americans likely engage in a variety of behaviors, which may have significant HIV health related implications at the individual level.

Personal identity
The environment in which AAMSM establish personal identity is complex. African Americans have long faced prejudice and discrimination that has curtailed their freedom and liberty (e.g. slavery, being denied the right to vote, segregation laws), and AAMSM are minorities among their own people. This layering of minority status is often associated with experiencing stigma. Prior research suggests that stigma impacts personal identity (Major & O’Brien, 2005), a conclusion echoed by participants. Moreover, participants suggested a link between personal identity and HIV health related issues among AAMSM, particularly individual health behaviors. For example, those AAMSM who perceive male to male sex strictly as a behavior and not as an aspect of identity, were described as being more likely to be on the down-low. As one participant described,

If you tell me that I’m gay, now I gotta start acting like it. There’s a certain way I gotta act if I’m gay. So that’s why it’s best if a guy is down-low. He’s still masculine, you can’t tell if he is or he is not [gay]. He does what he does and he is still a man. You know he may have sex with the woman, but he still has sex with men too. If you was to go to a guy and say, “you are gay,” they’re going to be like “nah I aint gay. I’m just a guy that likes to mess around men.”

In addition, these males were also reported to be less likely to acknowledge risk behaviors, HIV status or utilize HIV health related resources. It is likely that denial and avoidance of HIV health related resources are ways down-low men cope with an internal identity counter to a public persona. On the other hand, AAMSM who perceive male to male sex as contributing to identity may be more likely to engage in positive health behaviors regarding HIV (Malebranche, Peterson, Fullilove & Stackhouse, 2004). However, while these men tend to be more accepting of their identity, participants indicated that some AAMSM may still conceal their male to male
sex from the community in order to protect themselves. These findings suggest that providing an environment of open disclosure where AAMSM are able to reconcile internal personal identity and public persona may be beneficial (Seal et al., 2000).

**Disclosure**

A history of abuse and exploitation, hostile environment and community backlash has likely decreased the level of comfort many African Americans experience when disclosing personal information. Participants associated disclosure with HIV health related issues among AAMSM, particularly the belief that disclosure may be dangerous. Participants indicated that regardless of an individual’s circumstances, AAMSM are likely to be cautious when disclosing MSM activity or HIV status to others. This caution is likely related to cultural and community norms, but also concern about becoming a target of physical harm. As a participant described,

> They will come at you and try stuff and mess you over. You have to try and fight and prove that you’re not to be messed with. They’ve always done that. Not just with Blacks I mean, it’s everywhere.

In addition, another concern may be isolation from social support networks (i.e. church, friends and family). For example, some participants also relayed stories of AAMSM who were displaced from the home following disclosure, or had others discontinue contact/relations following disclosure. As a result, some AAMSM may go on the down-low to potentially limit disclosure. Unfortunately, participants and prior research suggest that fear of disclosure may also lead some AAMSM to avoid HIV health services (Wohl et al., 2011). Thus, participants and prior research suggest that a strong social support network and strict confidentiality may be the keys to improving utilization of health services (Seal et al., 2000; Wohl et al., 2011).

**Sexual behavior/risk**

Sexual risk has been a main focus of HIV research for some time now, due to the frequency of HIV transmission via sexual contact. The Centers for Disease Control (2012a) recently concluded the younger AAMSM are at a particularly high risk of contracting HIV. Participants noted that for some, particularly young AAMSM, risky sex is more likely. Younger AAMSM were characterized as feeling invincible, though a lack of perceived mortality or immediate threat may be more accurate. Regardless of age, many AAMSM reportedly prefer to live in the moment during sex, which may motivate behaviors believed to lead to intimacy. As one participant disclosed,

> Most sexual situations are spur of the moment. It’s not planned, we didn’t plan to do it. We just got hot and bothered, and then the next thing you know, there we are. Then we into it and we just don’t think about a condom.

Participants indicated that negotiation of sex/safe sex (i.e. condom use) interferes with intimacy and may result in a lost opportunity to engage in sex. For some AAMSM, substance use (i.e. alcohol and illicit substances) was a reported means to increase intimacy/sensation. Participants indicated that younger AAMSM are more likely to combine substance use and sex; however, not all AAMSM engage in sex to find intimacy. Participants reported that some AAMSM, often youth, engage in sex in order to procure resources (i.e. money, shelter, food and illicit substances). As one participant reflected,

> You know sex trade is really big, and not in the traditional sense of we have these red light districts where people are walking down the street. But yeah, I meet somebody online, or on A for A or what have you. They will give [sex] and tell me, “I need a place to stay, I got kicked out of my house.” My parents just kicked
me out and, and this person is gonna let me stay ad al I have to do occasionally is 
have sex with them, but he’s cute enough.”
Prior research supports this notion that youth are at higher risk of engaging in sex trade (Outlaw 
et al., 2011). In these instances, those seeking resources are at a distinct disadvantage and their 
ability to negotiate sex/safe sex is limited. As a result, these AAMSM may be coerced into 
engaging in risky sex. Similarly, African American females may not negotiate sex due to 
potential loss of resources or potential physical harm. Prior research suggests comprehensive 
HIV prevention programs targeting the above issues should address dating, intimacy, sex, 
substance use, personal identity and abuse/coercion, and identify community resources, mentors 
and safe havens (Seal et al., 2000).

Accessing care
Accessing care is integral to HIV health related issues among AAMSM. Without such 
access mortality rates would likely increase and African American communities would suffer 
greatly. Participants noted that in order to access care, HIV-positive peoples must first be 
identified through testing. However, HIV stereotypes and denial were described as barriers to 
testing. As one participant reported,
Know why I didn’t go get tested? In March ’84 doctor told me we got a blood test, 
you have AIDs, and I said, “No that’s impossible. I don’t fit that profile.” People 
who don’t go get tested say it can’t happen to me. That’s one of the main reasons. 
I don’t believe that it can happen to me. I’m a good person. They don’t go get tested. 
Participants indicated that individuals may be more likely to test if tests were conducted for a 
variety of illnesses, not just HIV specifically. Participants also indicated that care begins at 
diagnosis and assisting newly diagnosed AAMSM in the link to care process is important. To 
this end, case workers were described as an integral part of this process, a conclusion supported 
by prior research (Gardner et al., 2005). However, despite a successful linkage to care, a number 
of reported barriers may explain why some newly diagnosed HIV-positive peoples choose to not 
access care. For example, participants described that among African Americans, a norm exists in 
which care is not accessed until absolutely necessary (i.e. threat to mortality). Likewise, 
participants indicated that some AAMSM may avoid testing or care due to potential financial 
burden or a perception that testing and treatment will lead to drastic lifestyle alterations. As one 
described,
If I’m not sick, I’m not going to the doctor…I’m not going to go to the doctor cause 
I don’t know if I’ll be able to pay.
This reasoning may help explain why some African American tend to be diagnosed with HIV 
and engage in treatment later in the progression of the virus. In addition, participants alluded to 
potential mistrust of providers and myths surrounding HIV in the African American community 
(i.e. conspiracy beliefs) as barriers to service utilization, a sentiment consistent with prior 
research (Bogart, Wagner, Galvan & Banks, 2010). Perhaps the most common barrier to 
utilization of health resources is concern that accessing health resources will result in an 
unintentional admission of personal information (i.e. HIV disclosure) to other community 
members who will disclose to the community. This is likely why participants expressed 
maintaining anonymity is vital to utilization of health resources. Thus, effective utilization of 

Communication
A lack of open and honest communication regarding sex and safe sex practices was noted among African Americans sexual partners. Discomfort with these topics was identified by participants as contributing to avoidance and lack of discussion. In addition, participants indicated that some African Americans may lack the proper knowledge and skill to facilitate discussion of sex with a sexual partner. Moreover, participants noted a power differential between sexual partners may contribute to difficulties discussing safe sex. Difficulties with communication between parents and children were also indicated. Like sexual partners, discomfort and lack of knowledge and skill were discussed as hindering communication regarding sex, sexuality, safe sex practices and HIV status. However, participants suggested that parents are integral to addressing HIV-related health issues. As one participant stated,

Sometimes I think it’d be very helpful for parents of gay kids to sit them down and talk to them about it, just bring it out into the open, and then maybe, the issue can be dealt with.

Prior research also supports the motion that improved communication between parents and children reduces sexual risk (Hussen et al., 2014).

**Conclusion**

The above narrative report highlights emerging themes at the societal, community and individual levels that were identified during analysis of key informant and focus group interview. Themes were discussed via brief overview, interpretation, community excerpts and recommendations. The purpose of this report is not to direct but to inform and serve as a foundation for future CBPR research and interventions with AAMSM in the Dallas/Fort Worth Metroplex.
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