

HIV Status Disclosure among Older African American
Men Who Have Sex with Men and Women

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Abstract

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HIV has become a chronic illness rather than a terminal diagnosis over the past three decades. Increasing numbers of HIV infected adults are growing old while continuing to enjoy active sex lives. Older African American men who are HIV infected and have sex with men and women are an important group to focus on around prevention of HIV infections through disclosure because of their interactions with both genders. Existing theoretical models provide sparse guidance around how older African American (AA) men who have sex with men and women (MSMW) may experience the process of disclosing their HIV status; specifically, they offer little information about the cultural or community-based experiences that might mediate the disclosure experience for AA MSMW. This study used a directed content analysis approach based on an existing model and the experiences of nine AA MSMW over the age of fifty from a local HIV clinic. It is grounded in the Disclosure Processes Model of HIV status disclosure.

Chapter 2 examines the current literature as it applies to HIV status disclosure for older adults, African Americans, and men who have sex solely with men as well as those who have sex with men and women. Chapter 3 explores four models of HIV-status disclosure that sequentially describe the theoretical processes of disclosure that lead up to the Disclosure Processes model. Finally, Chapter 4 presents the experiences of HIV status disclosure of the participants of an online focus group and draws conclusions about these experiences enhance the current theoretical model as it applies to this unique population.

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CHAPTER 1

Introduction

For most of my life, I have embraced self-marginalization; sounds rather farcical coming from a white, able-bodied male from the US. While this has certainly carried over into my adult life in many stylistic ways, in my youth it was very much a life-preserving defense mechanism. I wanted to make myself as different as possible because, deep down inside I knew I really was and no one could *ever* know that secret. I hid that secret so well, even *I* soon forgot about it. See, there were very serious consequences for a queer youth growing up in Montana in the early eighties if someone were to find out about your dirty little secrets. In small-town Montana, a family had to move away if their daughter accidentally got pregnant in high school. That's nothing - one has only to recall the story of Matthew Shepard to know what the consequences could be for someone coming into their own sexuality in Montana during the early years of the "Gay Cancer."

Every time that I encounter someone for the first time, I have to make the mental decision of whether it will be safe to disclose my sexuality and that doesn't even include having to try explaining what it means to be pansexual without people thinking I'm just a player. In reality, my situation isn't all that bad compared to many others. Many in the queer community also have to make the decision whether they should disclose their HIV-status. Both of these carry with them a tremendous amount of stigma that shape and mold the experiences of every person who lives under these burdensome conditions. We now live in a world that should recognize that having HIV has absolutely nothing to do with one's sexual identity. It is also now an STI that is as effectively managed as other common STIs. And yet, people living with HIV still have to

make daily decisions about whether it is safe for them to disclose not only their sexuality but that they have a chronic infection that continues to be demonized in this world.

When I first started this program, I wasn't really sure where I wanted to go with research other than I knew I wanted to focus on something to do with HIV. It took several quarters of experimentation with assignments and a variety of classes before I began to find a niche in the research that I could relate to. I became fascinated by the struggles that are faced by people of color who are living with HIV. Why are they so disproportionately affected by HIV? What does concurrency mean? What does the "down-low" really mean? Is it a real thing or is it a term made up by researchers? Why are people of color so wary of research and researchers? How are they impacted by the stigmatization of being queer and being HIV positive? Does the stigma come from within their communities? Outside of their communities? Both? Do they feel like they are able to disclose their illness? Are they able to access the care they need? So many questions . . . a handful of theories . . . but no one seemed to be asking people of color about their experiences?

I was really struck by how all of these factors would play out – would they? Was there a common intersection? I began to explore the concept of disclosure and how that played out for people living with HIV. Emlet's work with older adults in his 2003 study of disclosure experiences really set the stage for what I was hoping to accomplish with my dissertation work. What caught my eye, in particular, was what he described as generativity – the desire for older adults to give back to others in their communities or to younger generations by sharing their experiences of being HIV positive. Was this true in African American communities where HIV was running a devastating course among the younger generations? Was this something that

could be facilitated? Would older men, reaching out to younger generations even be effective in African American communities? Had anyone even asked these questions? Not that I could find.

The other angle that caught my attention was the concepts of concurrency and the “down-low.” Did men who have sex with men or women exclusively, experience disclosure of their HIV status differently than men who have sex with both men and women? There were several studies out there that suggested that it was more difficult for men who are sexually involved with men and women to discuss their sexuality with women much less but scant amounts of information about whether HIV ever come up. If these men weren’t willing to talk about their sexuality would they be any more likely to talk about having an infectious disease? Would this hesitancy to disclose be the same for older African American men? Was it easier for them to disclose after being HIV positive for a number of years? What about those who were newly infected in their later years?

With all of these questions in mind, I set down the path to examine the HIV-status disclosure experiences of older African American men who have had sex with both men and women. The results of these endeavors are in the following chapters. Chapter two of this dissertation begins with a review of the literature and explores the experiences of HIV status disclosure for people living with HIV. Since there was such a paucity of literature for older African American men who have sex with men and women, the review looked at a variety of studies that included older adults, African Americans, men who have sex with men, and men who have sex with men and women – or any combination of these.

In chapter three, I examined the progression of theoretical models as they pertain to disclosure starting with disease-specific models that were developed in the late 50s by Jourard. It wasn’t until the late 90s when Kalichman developed a theory of disclosure that was specific to HIV and

that set the stage for several new models over the following years. This chapter starts by exploring Kalichman's Disease Progression Model then builds upon that by looking at the Consequences Theory of Disclosure Model developed by Serovich. The third model developed from the theories was the work of Derlega: The Model of HIV-Disclosure Decision Making. The final model used for this chapter, and the foundation of the directed content analysis that is the fourth chapter of this dissertation, is the Disclosure Processes Model that was developed by Chaudoir.

Finally, chapter four presents the results of an online focus group conducted with a group of older African American men who have had sex with men and women to discuss their experiences with disclosing their HIV to family, friends, and health care providers. Based on the Disclosure Processes Model, a directed content analysis was conducted to help interpret these experiences. The results of the analysis reveal that the experiences for these men are very similar to those of other older adults despite their racial and ethnic differences, though, there is still much to be learned beyond what this study was able to reveal.

Chapter five closes this dissertation and labor of love with some thoughts about the journey that brought me to the end of my academic career as a student and set me on the path for a future as a nurse educator and academician. In closing, I share some of my thoughts on what went well, what did not work so well along the way, and what can be done in the future to continue this research and branch off into new and unexplored territories.

CHAPTER 2

REVIEW OF THE LITERATURE

Background

Throughout the HIV epidemic in the U.S., gay and bisexual men have been at the center of attention as the key population at risk. Between 2008 and 2010, the number of new infections among gay and bisexual men increased 12% and, in 2011, despite making up only 2% of the U.S. population, gay and bisexual men accounted for 63% of new HIV infections among all people, and 79% of all new cases among men, aged 13 and older (Centers for Disease Control and Prevention [CDC], 2016a; CDC, 2016b).

In the United States, more than 1.1 million people are living with HIV/AIDS and nearly half of these are African Americans (>506,000); an increase of 7% in just two years from 2008 to 2010 (CDC, 2013a; CDC, 2013b). African Americans (AA; in HIV literature, this category includes blacks of African and Caribbean descent immigrated to the United States) make up 12% of the total population in America, yet they account for 44% of all new cases of HIV, eight times that of whites and twice that of Hispanics. They do not fare well on the HIV care continuum either. While 75% of AAs are referred to or seek care for HIV testing or HIV-related symptoms from a health care provider, only 48% are retained in care. Of those retained in care, 46% have been started on antiretroviral medicines and only 28% are being virally suppressed compared to 32% for whites; not a significant difference but still not an acceptable number (CDC, 2016a; CDC, 2016c). The highest rate of HIV infection is among AA men at 103.6 per 100,000; twice that of Latino men, the next closest group (CDC, 2012). Among gay and bisexual men, AA account for 36% of all new HIV infections compared to white men; yet, they make up 39% of

those who are diagnosed with AIDS compared to 34% for whites (CDC, 2016a; CDC, 2016c). Males make up 70% of new cases among all AA; in fact, the CDC predicts that, in their lifetime, one in sixteen AA men will be diagnosed with HIV. Using prevalence extrapolations, Stall and colleagues (2009), took current incidence rates reported for gay men and examined the potential implications for AA gay and bisexual men. They predicted that, by the age of 25, one out of four African American men will be infected with HIV and, by the time they reach the age of 40, nearly 60% of these men will be living with HIV (Andrasik et al., 2014; Stall et al., 2009).

Similarly, over the past decade there has been a marked increase in the number of people living with HIV as well as increased rates of infection for those over the age of 50, the standard cut off age to be considered old in HIV research and clinical care. The number of older adults in the United States living with HIV quadrupled from 65,445 in 2001 to 269,404 cases at the end of 2009. Between 2007 and 2009 alone, the number of people over the age of 50 living with HIV increased by 14.3% to 32.7%. As of 2013, the number had grown to over 350,000 and, as people continue to live longer with HIV, it is estimated that adults over the age of 50 will make up more than 50% of all HIV cases in the U.S by the year 2016 (CDC, 2013d; CDC, 2016d). Racial disparities are similar to that found in younger age groups. Infection rates among older African American men are 49.2 per 100,000 population, 12.6 times that of white men (CDC, 2013d). Interestingly, older AA men make up 24% of newly infected older adults; yet, only 15% identify as gay/bisexual (CDC, 2016d). New cases continue to go unreported because older AA men are less likely to discuss their sexuality with their provider or they are unaware of the importance of using protection. Because of the risk of stigma, many of these men outwardly identify as heterosexual yet, in reality, continue to have sex with both women and men (CDC, 2016d). Because AA men are less likely to disclose their HIV status and their sexual practices, they are

not being accounted for in current statistics or are being incorrectly categorized if they are reported at all (CDC, 2016d).

Increasingly, disclosure of HIV status is being recognized as a possible component of interventions to reduce the impact of HIV among AA in the U.S. However, studies that include older adults or men who have sex with men and women (MSMW) and explore how disclosure and non-disclosure affects the processes of living with HIV are sparse. Most researchers include these men in broader categories with their younger counterparts or they are mixed in with men who have sex with men (MSM); in fact, there are no studies in the literature that specifically examine the experiences of disclosure among older AA MSMW. As such, the purpose of this paper is to explore the available literature that informs the current understanding of how older African American men who have sex with men and women experience HIV status disclosure.

Methods

An extensive search for relevant literature was conducted using Medline/Pub Med, CINAHL, Web of Science, PsycINFO, and World Cat available through the University of Washington's Health Links Database. The initial search sought to identify English language, peer-reviewed articles using the search terms "HIV", "aged", "older adults", and "African American" from the year 1990 to the present. The search was then limited further by the addition of keywords including "bisexual", "men who have sex with men and women (MSMW)", and "disclosure". An additional internet search was then conducted using the Google Scholar search engine with the same set of terms. The most relevant articles found were vetted for accuracy and authenticity and added as appropriate. These searches, combined, yielded 357 articles. These articles were searched for inclusion criteria (see below), and their bibliographies scanned to identify additional publications not captured by the keyword approach.

This process was repeated until no new citations meeting study inclusion criteria were found. Inclusion criteria included: (1) publication in a peer-reviewed journal or book, (2) United States samples, (3) a focus on HIV-status disclosure as a part of the analysis, (4) a sample subgroup aged 50 and above, (5) a sample subgroup of MSMW and (6) a sample subgroup of African American men. For this study, literature reviews, expert opinions, letters to the editor, conference abstracts, essays, and case studies were excluded.

Results

Based on these criteria and limitations, a total of 14 articles were available for analysis. While many of the studies limited their samples to age 50 and older more than 40% had a much broader range of ages making it particularly challenging to identify and assess the influence of older age on a person's decision to disclose their HIV-status or keep it from others. Similarly, the selected articles had limited numbers of MSMW or AA in the sample. As no articles specifically focused on AA MSMW aged 50 and older, it is difficult to speculate on how this population actually discloses their HIV-status. Despite the paucity of literature, this review identified two broad categories that best describe how these men might manage their serostatus: disclosure and non-disclosure. Based on these journal articles, four main themes of disclosure and three non-disclosure themes were developed. The men in these studies disclosed or were inclined to disclose their HIV-status in order to enrich or support relationships; to garner social and practical support; for the purpose of personal growth and/or generativity; or someone in their life unintentionally (or intentionally) disclosed for them. On the other side of the spectrum, the men kept their silence or were inclined to do so to avoid confrontation and stigma; to protect relationships or make them easier; or because they wanted to protect their privacy.

Disclosure

Disclosure of HIV is a decision that confronts *all* infected people at some point in their disease process. They are faced with the difficult task of assessing how the revelation of their status will help or hurt them or the people they love (Gorbach et al., 2004; Poindexter & Shippy, 2008; Stutterheim et al., 2011). While there are many similarities in how younger and older generations of AA MSM and MSMW confront disclosure of HIV-status, the literature suggests that there may be some characteristics that could be unique to older adults who are African Americans and to those who have sex with men and women.

Relationships. There is a great deal of disparity in the literature as to whom PLWH will disclose their HIV status. It is generally recognized that MSM and MSMW are more likely to disclose their HIV status to friends and partners rather than family members (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Vance, 2006; Zea, Reisen, Poppen, Bianchi, & Echeverry, 2005). However, in four qualitative studies that included older AA men, some of which were MSMW, indicated that they are more likely to disclose to their families than to those in the community (Emlet, 2008; Foster & Gaskins, 2009; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003). Similarly, older adults are less likely to disclose their status than their younger counterparts regardless of whether it is to family, friends, or providers (Emlet, 2006a; Schrimshaw & Siegel, 2003; Shehan et al., 2005) (20-22). Studies have also shown that AA MSMW, young and old, are more likely to disclose to their male partners than female ones (Benoit & Koken, 2012; Bingham, Harawa, & Williams, 2013; Malebranche, Arriola, Jenkins, Dauria, & Patel, 2010; Shearer, Khosropour, Stephenson, & Sullivan, 2012; Siegel, Schrimshaw, Lekas, & Parsons, 2008). However, this may depend on the nature and status of the relationship. Tieu and colleagues (2012), in their study of 326 black men that included MSMW and older

adults in the sample, reported that nearly 85% of these men disclosed their positive HIV status to their female partners if they were the main partner. Similarly, Benoit and Koken (2012) in their qualitative study of 33 AA MSMW revealed that, despite being less inclined to disclose to their female partners, if the women identified as bisexual, the men were more likely to share their status.

The men in these studies also indicated the depth of their relationships and their commitment to their partner played a pertinent role in their decision to share their HIV status. Some men suggest that they are more inclined to reveal their serostatus to their female partners if they are in an intimate and committed relationship (Benoit & Koken, 2012; Wolitski, Tietmeijer, Goldbaum, & Wilson, 1998). Others commented that they would even be more inclined if they felt the relationship had the potential to become more significant (Poindexter & Shippy, 2010). Some of the men emphasized the importance of transparency in relationships; their desire to share their status as a means of being open and honest with those in their life (Emler, 2008; Poindexter & Shippy, 2012). Finally, studies suggest that some men feel it is their responsibility to share their status with their sexual partners, particularly those who have a negative or unknown status (Driskell, 2008; Foster & Gaskins, 2009).

Emotional and Practical Support. Emotional support pertains to the affective needs of a loved one, while practical support pertains to providing for the needs and activities of daily living; often taken for granted by those who are healthy. These tangible tasks might include shopping for groceries, picking up prescriptions, or cleaning the house (Shrout, Herman & Bolger, 2006). These two forms of social support often occur simultaneously, yet are quite distinct ways of providing support for a loved one with a chronic illness. This review found that

it is possible that older AA MSMW will opt to disclose in order to access social support, both emotional and practical, from loved ones as well as providers.

In a study of 25 older adults living with HIV, Emler (2008) recognized that social support is often a precursor to disclosure. He found that the men and women in his study were more inclined to disclose their HIV status if they had emotional support in place or a confidant they could trust. In a separate quantitative study that compared younger and older PLWH, when using disclosure as a dependent variable, he found that AA men and women were less likely to disclose and in a qualitative examination of the same group, he found that the men and women feel stigmatized and less likely to feel like they had the support of family and friends required to comfortably disclose their HIV status (Emler, 2006a; Emler, 2006b). Schrimshaw and Siegel (2003) supported this, finding that older adults felt they had less social support because many of their friends and family had passed away.

Emler (2006a) also found that older adults, including AA MSMW, who sought practical support from their health care provider were more likely to feel comfortable with disclosing their status. This corroborates with a study by Wohl and colleagues (2011) where older MSM and women were found to be more comfortable seeking practical support from their providers than family members and friends as they perceived less stress from their doctors and health care team. They also found that those who disclosed were more likely to be retained in care and being retained in care correlated with practical support in bivariate models.

Involuntary Disclosure. Not all disclosure is at the will or discretion of a person with a chronic illness; HIV in particular, because of insensitivity to the privacy of patients and the symptoms associated with the disease. Sadly, patient confidentiality is often violated by health care providers. Despite best intentions, many older adults feel betrayed when their health care

provider or someone of authority shares their HIV status with a family member or loved one. In some cases, it may not be a verbal disclosure but something as simple as a sticker on a medical chart that involuntarily disclosed the patient's HIV status (Emlet, 2008).

Hays and colleagues (1993), in a study of 163 men living in San Francisco, found that those men who were asymptomatic (54%) were significantly less likely than those who are symptomatic (66%), to disclose their status to family and friends. In the qualitative phase of the same study, the men who were symptomatic reported that they felt they had to disclose because their symptoms gave away their illness, they needed the social support, or they felt a responsibility to let their family know (Hays et al., 1993). For older men, including AA men, this is of particular concern because of comorbidities that are commonly associated with age, added trips to their health care provider, and multiple drug regimens (Emlet, 2008). In a focus group study of 34 older adults, three participants reported that family members and friends had figured out that they were positive before they had the chance to disclose and found it to actually be a relief (Poindexter & Shippy, 2010).

Personal Growth and Generativity. For many people with a stigmatizing disease such as HIV, disclosure can be an opportunity for personal growth. Emlet (2008) described disclosure of HIV to significant others as an opportunity for personal growth. For some of the older adults in this study, disclosing their HIV status provided such a relief from the burden of keeping their secret that it felt as if they were going through a cathartic process. They described disclosure as an opportunity to build their self-esteem and their self-efficacy. However, cultivating these traits before one has disclosed their status might be even more beneficial. Moskowitz and Seal (2011), in a survey of 1,468 gay and bisexual men, found that high self-esteem was positively correlated with HIV status disclosure. Similarly, in his study of 194 HIV positive men, Driskell (2008)

found self-efficacy was the strongest indicator of disclosure across all sexual partners based on the partner's HIV status.

In his study of older men and women with HIV, Emlet (2008) reported that several of the participants he interviewed chose to disclose for the good of the public. He explained that, for some older adults living with HIV, there is often a need or desire to educate others who are experiencing HIV for the first time or who might be at risk for HIV. This generativity reflects the concern shown to others that develops during middle age as described in Erickson's (1950) model of psychosocial development. In this model, Erickson describes how people in their forties, fifties, and sixties seek to nurture and guide future generations or go through a period of stagnation. Older adults share their experiences of HIV, by speaking in schools for younger generations and at community events for with older generations, to help others in their community better understand what it means to be HIV positive (2008). In a qualitative study of 25 older adults, Emlet, Tozay, & Raveis (2011) found that older adults disclosed because they saw themselves as advocates for the community and society in general. It was an opportunity to provide a selfless act in support of their communities. For others, it was an opportunity combat stigma by deliberately revealing their status to younger generations. In two separate qualitative studies, older adults who were interviewed reported reaching out to local high schools and colleges to mentor and educate younger generations about prevention; to simply share their wisdom and insights about life and living with HIV (Emlet et al., 2011; Poindexter & Shippy, 2011).

Non-Disclosure

While there are PLWH who choose to disclose their status to manage their situation, there are those, too, who choose silence as a means of management. Emlet (2006a; 2008)

described non-disclosure as a form of protective silence; a means of controlling one's environment and situation. It has also been described as a means of managing or minimizing stigma; a way to keep one's self safe and maintain confidentiality (Foster & Gaskins, 2009; Poindexter & Shippy, 2010). It might also a means of escape whereby PLWH self selectively isolate themselves from others so as they do not have to take responsibility for the others around them. In this way they also avoid facing themselves with how they have chosen live their lives (Foster & Gaskins, 2009; Hays et al., 1993; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003).

Avoidance of Fear and Stigma. For many, non-disclosure is a protective measure, as Emlet (2008) described, used to ward off threats whether they are direct or perceived. One such threat is the fear of rejection from loved ones; in particular, among AAs and older adults. African American MSM/MSMW often report being on the “downlow” out of fear of being rejected by their female partners and/or family members. Rejection from the female partner can lead to both emotional and physical abuse by the partner and their family; non-disclosure, therefore is a means of protection (Foster & Gaskins, 2009; Hays et al., 1993; Poindexter & Shippy, 2010). Schrimshaw & Siegel (2003) found that older adults are more inclined to non-disclosure than their younger counterparts for fear of being rejected by loved ones and colleagues. They posit that this is due to generational stigmatization, as older generations are often thought to be more conservative and condemning towards illnesses that are commonly stigmatized. For many, it is just a matter of not wanting to hurt the feelings of those that they hold dearest (Benoit & Koken, 2012). On the other hand, some opt to conceal their status because they feel they cannot trust their loved ones to keep their secret. In a qualitative study of 24 older men and women with HIV, participants suggested that it was just human nature for

friends and family to want to tell others when they told them about their illness; they chose to stop disclosing rather than risk further disclosure that they could not control (Foster & Gaskins, 2009).

Similarly, PLWH may live in fear of rejection and stigmatization from the community in which they strive to coexist. In particular, rejection can lead to public ridicule in the black community should their secret be revealed (Benoit & Koken, 2012). In Foster and Gaskins' (2009) study of 24 black men and women 50 years and older, not a single participant had disclosed to their church. One participant commented that, "The church is the worst place you can be for gossipers.'" (pg. 1309) Several studies found that older men and AA conceal their HIV status because they fear the possibility of disrupting the normalcy of their relationships both personally and in the community (Doll et al., 1994; Hays et al., 1993; Poindexter & Shippy, 2010). Many older adults who choose to not reveal their status do so to avoid being treated differently and to protect themselves from evoking negative reactions from others (Foster & Gaskins, 2009; Poindexter & Shippy, 2010). For African Americans, young and old, it is often more a concern of being labeled as "homosexual" by those in their community. In a qualitative study of 12 gay and bisexual men, Bowleg (2013) found that nearly two thirds of the men felt that AA communities are deeply rooted in heterosexism. Even those who didn't feel that they were exceptionally marginalized saw others in the community as sometimes being two-faced. As one participant described it, "They tend to like the ones they know and interact with, but as a whole, homosexuals, gays, they're against it" (pg.671). Regardless of whether they identify as bisexual or heterosexual, they risk losing status within their community because of the stigmatized label of being gay (Benoit & Koken, 2012). As such they are forced to live a double standard life, trying to exist in their communities where they struggle to exist as a gay man while

simultaneously trying to exist in the LGBT community where they struggle against racism (Hill, 2014).

Stigma and fear management with health care providers is equally relevant for PLWH. One study revealed that people will choose to not reveal their status to their clinical staff because they feel there is an expectation of normalized behavior and any deviation from that will lead providers to treat them differently (Doll et al., 1994). Stigmatization is of grave concern across the board and is a major reason cited for non-disclosure found in the majority of peer-reviewed literature. People of all ages, ethnicities and sexual identities will conceal their status to protect themselves from even the possibility of stigma. People will base this on any number of reasons including past experiences of their own or even the experiences of others in the community (Emlet, 2008; Foster & Gaskins, 2009; Hays et al., 1993; Poindexter & Shippy, 2010). One study suggested that older adults who feel isolated because of being old enough to have had most of their family and friends pass away may choose to not disclose their HIV status to manage their environment; to keep from feeling further excluded due to their age (Schrimshaw & Siegel, 2003).

Personal Matters. Some of the studies in this review found that non-disclosure can be a result of an inner personal struggle or a matter of privacy. Bingham et al., (2013) in a study of AA MSMW, discussed the role of sexual identity in the disclosure process. They revealed that participants were more likely to not disclose their HIV status if there was confusion about whether to identify as bisexual, heterosexual, or homosexual. Race alone can be a reason for someone to choose to not reveal their HIV status. Emlet (2008) found that African Americans were more inclined to non-disclosure than their white counterparts. Several studies identified personal privacy as a prime reason for not disclosing one's status. Some participants said their

HIV status was simply no one else's business unless they decided it should be (Emlet, 2008; Foster & Gaskins, 2009). In Emlet's study of 25 older men and women, one participant felt it was no one else's business because, "the more people you share information with, the more you have to understand that information will be used in ways you might not appreciate" (pg. 713). For others, there is a belief that their medical situation should be a private matter and was no one else's concern (Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003).

Discussion

The purpose of this literature review is to consolidate the experiences of Black men who have sex with men and women and older adults as pertains to HIV status disclosure and may be pertinent to the experiences of older AA MSMW. In this integrated review, disclosure appears to consist of two components rather than a singular action. Disclosure is generally described as a two-fold action that can include either disclosure or non-disclosure or a combination of the two as a means of management and protection. There are many benefits to disclosure, yet, there are often many reasons why a PLWH would need to maintain a protective silence. Revealing one's HIV status to others can have a therapeutic effect. It increases the possibilities of accessing social support (Hays et al., 1993), has been associated with increased adherence to ART (Klitzman et al, 2004), and it can serve to improve a person's relationships, mood, image, and life (Derlega, Winstead, Greene, Serovich & Elwood, 2004). It is equally important that PLWH feel safe and protected. Non-disclosure allows them to shield themselves from stigma, rejection, and abuse from family, friends and even health care providers. However, those who chose not to share – for whatever reason – are often categorized incorrectly in research studies as was observed in a study by Singh, Wheeler, and Hall (2014). Using data from the National HIV Surveillance System and self-reported data from Supplement to HIV/AIDS Surveillance, they

found that though original data classified nearly 70% of the participants as MSM only, nearly 60% of that number had to be reclassified after interviews.

Much can be learned from this review about how older African American men who have sex with men and women *might* experience HIV status disclosure but, in actuality, very little can be directly associated to them. While all the articles in this review include, to some degree, participants who are older, AA, and/or MSMW, there are no articles in the extant literature that are directly focused on this population. It is important to keep this in mind in the analysis of these results. There are many apparent similarities in how everyone experiences HIV status disclosure, yet, some qualities and experiences are unique to older adults, some to MSMW, and some to Africans Americans.

This review revealed that older adults are less likely to share their status with others compared to their younger counterparts. Specifically, Nokes et al. (2000) found that adults over 50 years old were significantly less likely to disclose their HIV status ($df=705$, $T=3.97$, $p=0.000$) and Shehan et al (22) found that the same age group is significantly less likely to reveal their status to their mothers ($OR=0.9$, $p=0.01$). This could be due to the conservative nature of older generations or it could be that their family and friends have died long before them leaving them with no one they trust to garner support. Another trait unique to older adults is the desire to give back to their community and/or younger generations. Perhaps because of their stage in life or because of the number of years they have lived with HIV, some older adults are less concerned with the stigma associated with HIV and more focused on sharing their wisdom and experiences of living with HIV. It is difficult, however, to assess whether these aspects of disclosure carry over to AA men or MSMW based on the literature to date.

While older adults are likely to disclose to friends and lovers, AA MSMW are more likely to disclose to their family if they disclose at all; they are more inclined to non-disclosure than other ethnicities. Because of the stigma associated with being gay in African American communities, they will not willingly share their status or they will turn to their families if and when they reach a stage in their illness where they must rely on others. While their behaviors may still be frowned upon, family is very important in AA communities, particularly the bond between men and their mothers. Interestingly, they are also less likely to turn to their church family despite the importance of faith communities to many AAs. They will embrace their faith and prayer but are unlikely to reveal their status to friends and community members who might be a support system to them. As for partners, AA MSMW have been shown to disclose more frequently to their male partners than their female partners. However, if their main partner is female and identifies as bisexual, they are more inclined to share their HIV status than if the partner is heterosexual.

Unfortunately, the literature as it pertains to the experiences of HIV status disclosure among older AA MSMW has significant limitations. Generally, sample sizes are too small to identify differences between age groups and/or racial groups. Most samples had a wide range of ages, small numbers of AAs and tend to combine MSMW with MSM in the analysis. Studies that focus on AA MSMW tend to have a wide range of age or have a very small percentage of men over the age of 50 in the analysis. Studies that pertain to older adults tend to pool sexual identity into broad categories such as MSM/MSMW and/or the number of AAs recruited to the study is minimal.

With the burden of HIV racial disparity in the United States becoming more and more apparent, it is incumbent upon researchers to become actively involved in discussions about

sexuality in African American communities. Peer reviewed literature suggests that bisexual behavior and HIV status disclosure are important factors in the discussion of HIV among young AA men; however, disclosure behavior and this particular gender identification are not exclusive to younger generations and needs to be more fully examined among older generations. Older AA MSMW have unique circumstances both racially and culturally that likely affect their ability and desire to disclose their HIV status. With the majority of PLWH being over the age of 50 years, it is important that we understand their experiences, both positive and negative, with HIV status disclosure. Interventions should draw from the experiences of the community members who have been through and understand the benefits and barriers of sharing their status. Their shared knowledge should be the foundation of interventions that will work towards helping not only older AA MSMW but younger generations as well.

CHAPTER 3

HIV DISCLOSURE FRAMEWORKS AND THEIR APPLICATIONS

Introduction

Over the past three decades, African Americans (AA) in the U.S. have been disproportionately affected by HIV infection. This population, despite making up only 12% of the total population, account for 44% of new cases of HIV, eight times that of whites and four times that of Hispanics. Among AAs, men make up 70% of these new cases and, of note, account for 39% of new cases among all gay men. In their lifetime, 1 in 16 AA men will be diagnosed with HIV (CDC, 2014a; Centers for Disease Control and Prevention, 2016b). Gay and bisexual men have the highest rates of HIV infection in the U.S., accounting for 79% of all new cases in 2011 (CDC, 2016c). In 2014, it is estimated that older adults make up more than 50% of all HIV cases in the U.S. and, as of 2010, AA men in this category had an infection rate of 41.6%, 11 times that of white men (CDC, 2016a; CDC, 2016b). Despite these numbers, the CDC (2016b) estimates that, among men who have sex with men, AA men only account for 15% of newly diagnosed cases that are reported. This is likely because AA men are less likely to disclose both their HIV status and their sexuality (Emler, 2006; Shearer et al., 2012; McKay & Mutchler, 2011). Thus new cases go unreported or, because these men identify as heterosexual but have sex with women as well as men, they are not being accounted for or are incorrectly categorized if they are reported at all.

Disclosure of HIV status is a key aspect of curbing the HIV epidemic among AA in the U.S. While studies have been conducted that examine younger AA men, little has been done to explore the impact of the epidemic on older generations and how disclosure and non-disclosure

affects the process. There has yet to be a study conducted that specifically examines the experiences and/or rates of disclosure among older AA MSMW as these men tend to be absorbed into broader categories based on age or sexuality. They are clumped into a range of ages or grouped in with MSM if they are included at all. Studies in which they have been included in the analysis suggest that they might be less likely to disclose than their younger counterparts because of a concern for how their community might react and the fear of being rejected. Because of this, when they do disclose, they are more likely to do so with family than with friends (Emlet, 2008; Foster & Gaskins, 2009; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003) and with partners with whom they have or potentially will have a meaningful relationship with (Poindexter & Shippy, 2010). When they do disclose, it is an opportunity for them to grow – a catharsis of sorts – and to garner social support (Emlet, 2006a; Emlet, 2008). Many older AA feel an obligation to their community and younger generations to be open and honest; to share their wisdom and experiences of being HIV positive (Emlet, 2008; Emlet, Tozay, & Raveis, 2011; Poindexter & Shippy, 2010).

Black men living with HIV have diverse reasons for disclosing their HIV status to others in their life. In a study of 42 young minority black men in the Netherlands, Sarah Stutterheim (2011) and her research team revealed that the men chose to disclose to varying degrees depending on the situation and to whom they were sharing. These included full disclosure, partial disclosure, or to not disclose at all. For young black people living with HIV (PLWH) in the first decade of the HIV epidemic, particularly before the advent of triple combination Antiretroviral Therapy (ART), disclosure of HIV was a means of explaining their rapid physical decline (Calin, Green, Hetherington, & Brook, 2007; Kalichman, 1998). Disclosure of HIV status for young African American MSM offers the opportunity that they will receive support from

people who are important in their lives. For example, they may tell certain members of their family and friends in expectation of emotional and spiritual support (Calin et al., 2007; Derlega et al., 2004; Serovich, 2001; Valle & Levy, 2009) or their health care provider, employer, or family and friends to cover financial, housing, and other basic needs (Valle & Levy, 2009). Disclosure can also be for personal reasons. Hiding sexual identity and/or HIV status can create a tremendous amount of stress, depression, and/or anxiety – particularly for black men – and disclosure may be a means of emotional catharsis (Calin et al., 2007; Derlega et al., 2004). Disclosure might also be relational; a way of being fully transparent in a close and supportive partnership (Calin et al., 2007; Derlega et al., 2004; Gorbach et al., 2004) or a perceived duty to inform their sexual partners to curb the spread of HIV (Calin et al., 2007; Derlega et al., 2004; Gorbach et al., 2004; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004; Serovich, 2001; Serovich & Mosack, 2003). Fully disclosing may also fulfill the desire to educate or mentor others about sexual risk taking to prevent HIV transmission (Derlega et al., 2004; Emlet, 2008; Frye et al., 2009; Serovich & Mosack, 2003).

As Stutterheim et al. (2011) describes, black men sometimes choose partial disclosure or non-disclosure as a means of protecting themselves and/or those around them. People living with HIV experience fear of stigmatization, discrimination, and other negative reactions to their disease. For example, young MSM may choose to withhold their HIV status to avoid the possibility of rejection, abandonment, or even physical and psychological abuse (Calin et al., 2007; Derlega et al., 2004; Frye et al., 2009; Gorbach et al., 2004; Serovich & Mosack, 2003; Valle & Levy, 2009). In a study of African American youth in the Chicago area, investigators documented that 52% of young black MSM have experienced HIV-related, community-based violence, which caused significant psychological distress (Quinn, Voisin, Bouris, & Schneider,

2016). Young MSM describe feelings of shame regarding their status and fear that others will blame them for their infection if they tell them (Calin et al, 2007; Derlega et al., 2004; Serovich, 2001; Serovich & Mosack, 2003; Valle & Levy, 2009). Some African American men have had previous experiences with disclosure that led to stigma or they have observed others being stigmatized for disclosing their status leading them to withhold their own status (Calin et al., 2007; Frye et al., 2009). Many older PLWH and AA men describe wanting to protect those they love from worry and/or stigma (Calin et al., 2007; Derlega et al., 2004; Serovich, 2001; Valle & Levy, 2009), or fear that their confidant might tell others if they were to confess to them (Calin et al., 2007; Serovich & Mosack, 2003), or simply believe that their status is a private matter that no one needs to know about (Derlega et al., 2004; Gorbach et al., 2004; Serovich & Mosack, 2003; Valle & Levy, 2009). Then there are those who aren't able to find a way to bring it up with others or their relationship just is not worth making the effort (Derlega et al., 2004; Serovich & Mosack, 2003).

Theoretical Models and their Relevance to the Lives of AA Men

While the many reasons for PLWH to disclose their HIV status have not changed drastically over the time that living with HIV has transitioned from a fatal to a chronic disease, the theories of the processes of disclosure have changed significantly. Disclosure of HIV can be thought of as a person's reasoned assessment of how the revelation of their status will help or hurt them or those they love (Gorbach et al., 2004; Stutterheim et al., 2011). Disclosure may not always be voluntary, though, as others might inadvertently reveal their situation, their physical condition might betray them, or someone may deduce their disease by external cues such as medicine bottles or frequent trips to the doctor (Derlega et al., 2004; Emler, 2008; Serovich, 2001; Valle & Levy, 2009). A number of theories have been developed over the last 30 years to

explain how HIV status disclosure occurs among people living with HIV. For the majority of these three decades, HIV has been considered a disease that affected white men who have sex with men. Not until the past decade has the recognition of the impact on African American communities come to the forefront of the research community. As such, models of HIV status disclosure have not examined the cultural impacts of the phenomena as they pertain to specific ethnicities. In this paper we will introduce four HIV-specific disclosure models that were all developed from white scholars that theorize the process as they propose would apply to the general population. Each model systematically builds off the previous model in the following order: Disease Progression Model, Consequences Theory of Disclosure Model, Model of HIV-Disclosure Decision Making, and Disclosure Processes Model. These theoretical models were selected because they build on the qualities of the other models, highlight the pertinent aspects of HIV-specific disclosure and, by the final model, account for progression of the phenomenon over time and introduce the possibility that community and cultural processes might mediate the process of disclosure. Finally, we will critique whether the models adequately address cultural and ethnic mediators specific to African American MSM and MSMW and examine whether new models should be developed based on the cultural and community-based experiences of African American men, as an ethnicity experiencing the greatest impact of HIV at this time.

Disclosure Models

The modern day exploration of the concept of disclosure began in the 1950s with the development of the Self-Disclosure Questionnaire (Omarzu, 2000). Sydney Jourard (1958), who described disclosure as a means by which a person makes themselves known to a target person, designed the instrument to measure the amount and content one is willing to share. These early investigations from within the framework of psychoanalysis, led to the development of more

disease-specific models of disclosure (Omarzu, 2000). These first disease-specific frameworks addressed the processes of disclosure from a variety of perspectives including the maintenance of mental and physical health, a person's social interactions, and as a strategy of controlling one's social environment (Derlega et al., 2004; Omarzu, 2000; Serovich, 2001). These formative studies set the groundwork for future studies that investigated disclosure in terms of chronic or terminal illnesses, particularly HIV (Omarzu, 2000).

Disclosure of HIV has been affected by dramatic changes in treatments and prognosis that have occurred over the past 36 years. Disclosure of HIV in the 1980s and early 1990s carried with it – in most instances – the imminent death of the person disclosing, and many PLWH were terrified to inform family and friends about this truth (Levy, et al., 1999). This tragic reality has changed with the availability of better antiretroviral therapies (ARTs) and the resulting significant reduction in mortality and morbidity from the disease (Chaudoir, S. R., Fisher, J. D., & Simoni, J. M., 2011; Derlega et al., 2004; Serovich, 2001). Early HIV disclosure models in the early 1990s, such as the Disease Progression Model and the Consequences Theory of Disclosure Model, focused on the disease process and how that affected an individual's decision to reveal their illness to family, friends, or sexual partners. With improved treatments and better survival rates, disclosure models, such as the Model of HIV-Disclosure Decision Making, shifted towards the antecedents that led a person to disclose or withhold their information. Finally, more recent models, such as the Disclosure Processes Model, recognize the need to look at outcomes, mediating and moderating factors as well as the antecedents of a disclosure event. The next sections explore each of these models in more detail.

Disease Progression Theory

The first disclosure model in HIV was published in 1998 and was based on the early work of Seth Kalichman who is professor of social psychology at the University of Connecticut and the editor of *AIDS and Behavior*. Prior to the advent of ART, people living with HIV had great concerns about disclosing their HIV diagnosis for fear of losing their job, their housing, their friends and family, and their social standing, especially after an AIDS diagnosis. Being diagnosed with AIDS meant for many that their death was imminent within the next 6 months and friends and family often left them with no social, emotional, or financial support. Many families, especially very religious families saw HIV and AIDS as a punishment from God, and a just punishment for living a gay or a drug-using lifestyle (Kalichman, 1998; Serovich, 2001). Kalichman (1998) theorized that a person's need to disclose their HIV status was determined solely by where they were in the progression of their illness. This simple model (Fig. 1) suggested that as a result of the progression of HIV, the individual had to reach out to others out of necessity. Time since diagnosis was a key antecedent in this model as it was

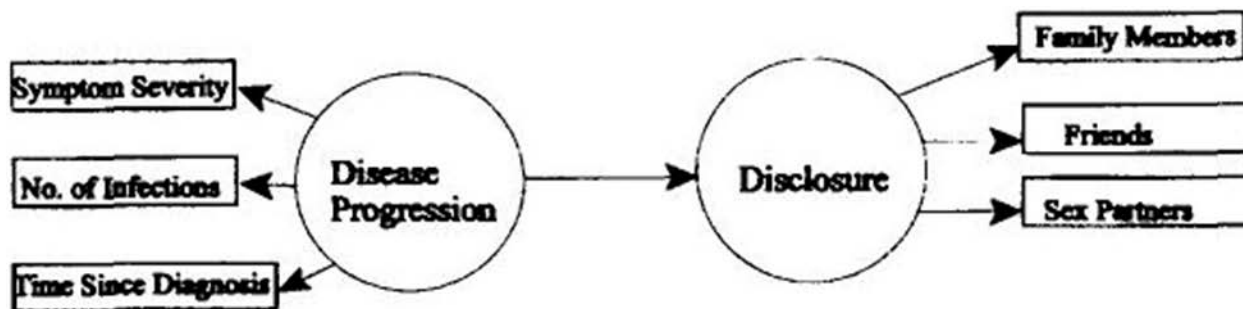


Figure 3.1: Disease Progression Model

much easier for a person to conceal their illness in the early stages of infection, delaying the need to let others know. As the patient progressed, though, they were no longer able to keep their

illness secret or it became necessary to seek support from others (Kalichman, 1998; Serovich, 2001). The progression of the illness generally resulted in frequent hospitalizations and physical deterioration after having had debilitating opportunistic infections with visible physical signs and symptoms such as physical wasting, paralysis, skin discolorations, and blindness that mandated their disclosure (Babcock, 1998; Kalichman, 1998). If PLWH were not forced to reveal their diagnosis as a result of telltale symptoms or infections, eventually, they reached a point where they were no longer able to care for themselves or were near death and, therefore, forced to reveal themselves to access the support of those closest to them (Serovich, 2001).

In the disease progression model, Kalichman suggested that the much needed support would most often come from family members, friends, and sex partners; however, when trying to prove this hypothesis he could not confirm all of the anticipated relationships. While many PLWH turned to their family and friends for social, emotional, and economic support this was not true of sex partners. Casual sex partners often do not freely offer support, as the blame for infection was placed on the person who was first to be diagnosed rather than the person who might actually have caused the infection (Calin et al, 2007; Derlega et al., 2004; Serovich, 2001; Serovich & Mosack, 2003; Valle & Levy, 2009). Also, the model did not take into account the intense stigma that was associated with knowing, or caring for someone, with HIV and disclosure was often not welcomed with any form of support but with intense rejection, shunning, and stigma (Serovich & Mosack, 2003; Valle & Levy, 2009). While this model addressed the basic needs that drive a person to disclose, it did little to address the psychosocial and cultural factors that come into play. It failed to account for the positive and negative consequences of disclosure and did not recognize the emotional reciprocity of the encounter. The model assumed that all participants have equal interest in the disclosure and assumed that all

those involved would have similar reactions. The model also assumed that support is the given outcome when one is forced to disclose due to physical signs of illness when, quite often, exactly the opposite is the common reaction.

Consequences Theory of Disclosure

As the HIV epidemic progressed into the era of ART, theorists became aware that there were more dimensions to the process of HIV disclosure than previously theorized. Julianne Serovich (2001), a psychologist and Dean of the College of Behavioral and Community Sciences at the University of South Florida, saw the need for a more concise model. Using the early works of Kalichman to develop a new theory of HIV disclosure, she posited that disease progression of HIV is moderated by the need for individuals to balance the benefits and the costs of divulging their illness to family, friends, and sexual partners. In addition to the disease progression theory, she employed the core assumptions of the social exchange theory, which suggests that people are more likely to seek positive relationships and behaviors if they anticipate high rewards and low costs (Thibaut & Kelley, 1959). The core assumption of the theory is that as PLWH progress through their illness, they reach a point where they feel the need to seek support emotionally, physically, and/or socially. To find this support, they must consider the consequences of disclosure. These decisions then influence to whom and how much a person will reveal about their illness (Fig. 2). Serovich suggests that the costs of disclosure might include stigma, ostracization, fear, anger, abuse, rejection and isolation (Calin et al., 2007; Derlega et al., 2004; Frye et al, 2009; Gorbach et al., 2004; Serovich & Mosack, 2003; Valle & Levy, 2009). In addition to emotional concerns, physical safety, and social retributions, people with HIV face the reality of potential interferences with work, housing, and health care (Ostrom, Serovich, Lim, & Mason, 2006; Valle & Levy, 2009).

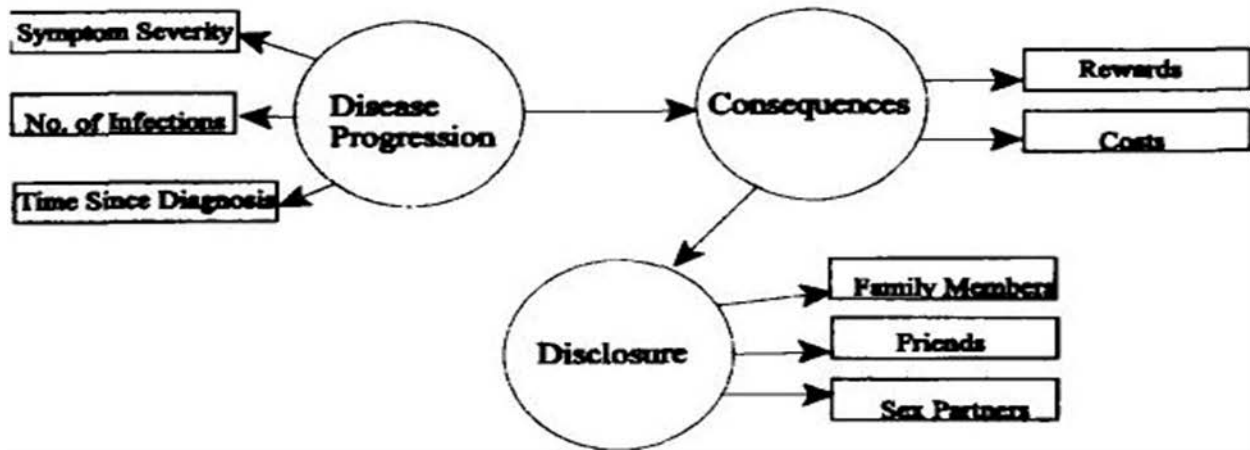


Figure 3.2: Consequences Theory of Disclosure Model

She balances the threat of rejection with the rewards of disclosure such as social and spiritual support from family, friends and their community (Calin et al., 2007; Derlega et al., 2004; Valle & Levy, 2009). Disclosure might also result in benefit if it elicits support of medical needs such as access, information, and adherence issues (Ostrom et al., 2006; Valle & Levy, 2009). Once a person has carefully considered these costs and benefits they will balance these with where they are in their disease progression and determine whether they feel safe in confiding in another person.

Serovich's Consequences Theory of Disclosure model is more complete than what we saw in the Kalichman model, yet is still lacking in many ways. Her theory is based upon intrapersonal decision-making and does not address the influences introduced by social processes within a community or a culture. The effects of HIV disclosure such as stigma, rejection, and isolation are borne not only by the individual but also by family, friends, and the community (Chandra, Deepthivarma, & Manjula, 2003; Li et al., 2007; Sonwathana & Manderson, 2001). The model fails to demonstrate the psychosocial reciprocity of disclosure between PLWH and their family, friends, sexual partners, and the community in which they live. It does not capture

the negotiation of the new reality after the disclosure nor how the disclosure will affect future decisions to disclose.

Model of HIV-Disclosure Decision Making

In 2004, Serovich joined Valerian Derlega’s team of researchers who set out to explore the processes of HIV status disclosure based on the work of psychologist, Julia Omarzu (2000), who developed the disclosure decision model to determine how and when people self-disclose. Their model of HIV-Disclosure Decision Making (Fig 3) posited one level where individuals reflect on their situation and the outcomes they hope to achieve. In the following three stages,

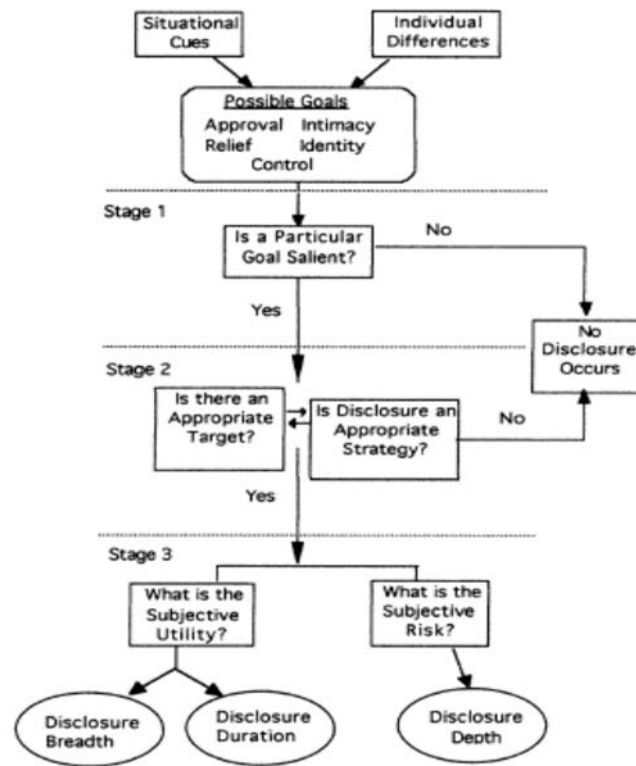


Figure 3.3: Model of HIV-Disclosure Decision Making

the individual then determines the saliency of their projected outcomes, whether disclosure is the appropriate option for all those involved, and the scope of their disclosure.

Derlega and colleagues (2004) theorized that there were two main factors that initiate the process of one's decision to disclose their HIV status; determining their reasons for disclosure. In this first phase of the model, PLWH must reflect on the external social and cultural factors that drive their need to disclose or not disclose. This may include close relationships between the discloser and the disclosed; family and friends may direct anger, fear, or shame at the individuals for having what is considered a shameful illness (Calin et al, 2007; Derlega, et al., 2004; Valle & Levy, 2009). Or there may be social and cultural norms that dictate what is and is not proper to share; for example, in AA communities it is often acceptable for one's family to be aware a man is gay or on the "down low" but it is not to be talked about or allowed to be known by others (Chandra et al., 2003; Sonwathana & Manderson, 2001). They then measure these social and cultural factors against their own personal situation and beliefs: what they hope to achieve by disclosing. For many PLWH, disclosure is an opportunity to relieve the stress and anxiety of keeping a secret: to take control of their life and garner support (Calin et al., 2007; Derlega et al., 2004). For others, it might be a means of strengthening their relationship with a loved one: building trust, saving them from the emotional impact, or simply seeking approval (Calin et al., 2007; Derlega et al., 2004; Gorbach et al., 2004). Based on these reflections, PLWH must determine whether their goals are pertinent to themselves, their family, and their social network as seen in stage one of the model (Fig 3). Their decision to disclose may strengthen a relationship by trusting them with a burden, bring a family together to support their loved one, or mobilize a community to talk more about the disease and change perceptions of PLWH (Derlega, 2004, Haas, 2002) whereby, they would move on to the second stage. If they are unable, however, to find saliency in their decision to disclose, the process stalls and requires further reflection and goal setting.

The second and third stages have to do with the context in which the person decides to disclose including relationships, time frames, and personal characteristics. The individual must examine their circle of family and friends and those in their community to determine whether they were ready and/or willing to be supportive and understanding. Derlega's study and other research studies (Calin et al., 2007; Valle & Levy, 2009; Stutterheim et al., 2011) suggest that PLWH will choose to disclose or not disclose based on how they perceive it will benefit or jeopardize themselves, others, and/or their relationships. When they are able to balance their choice of who they will disclose to and the context in which they will disclose, they must assess how their own personal characteristics and goals align with those to whom they might disclose and how that will affect their reaction, thus, guiding how much they will share (Derlega, et al., 2004).

This model demonstrates the progression of our understanding of the processes of HIV disclosure emphasizing the importance of PLWH balancing the benefits and the costs of disclosure as they pertain to not only themselves but to loved ones as well before deciding whether disclosure is right for them and their particular situation. It does not, however, specifically address the direct outcomes of disclosure and how this affects future decisions to disclose.

Disclosure Processes Model

Psychologist Stephenie Chaudoir, an assistant professor and director of the Concealable Stigmatized Identities (CSI) Lab at College of the Holy Cross (2010) recognized that earlier models of HIV disclosure focused on the behaviors of disclosure rather than the consequence and outcomes of disclosure. To address these questions, she and her colleagues examined the disclosure processes model (Fig 4) in the context of PLWH to address not only how and why a

person decides to disclose but, ultimately, how the decision will positively or negatively affect them. This model recognizes that each disclosure event is but one in a continuous cycle of disclosure that crosses the lifespan of one's illness. It is a continuous learning process where each stage of the decision making and outcome processes determines the likelihood that the person will be more or less willing to disclose or conceal their HIV status on future occasions.

In line with previous models, Chaudoir and colleagues (2010) employed a model that included a decision-making process. They suggest that the process begins with weighing

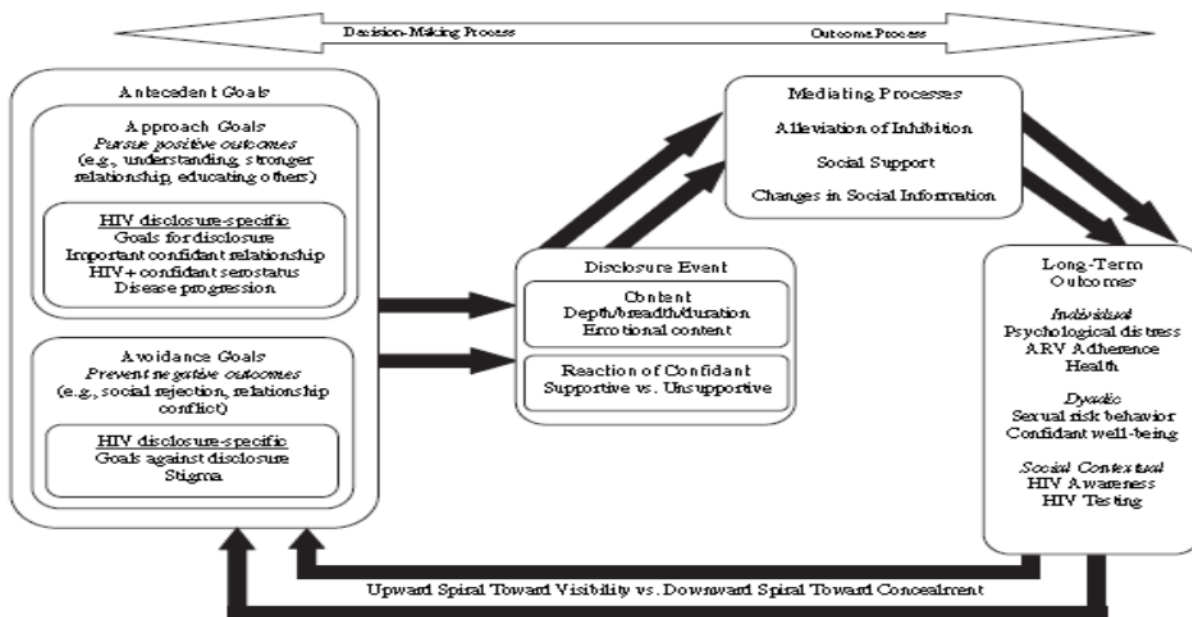


Figure 3.4: Disclosure Processes Model

antecedent goals similar to that of Derlega's model. They described PLWH as having what they call "approach" or "avoidance" goals. Approach goals, such as building stronger relationships, curbing the spread of HIV, or educating others, are those set by a person who foresees a positive outcome and is determined to work to disclose with that in mind (Calin et al., 2007; Derlega et al., 2004; Emlet, 2008; Frye et al., 2009; Gorbach et al., 2004; Serovich & Mosack, 2003).

Avoidance goals are set when one feels that there will be a negative outcome such as rejection, stigma, and, abuse and lead a PLWH to choose non-disclosure or partial disclosure (Calin et al., 2007; Derlega et al., 2004; Frye et al, 2009; Gorbach et al., 2004; Serovich & Mosack, 2003; Valle & Levy, 2009). The goals set in this phase of the model are considered the decision-making process part of the model and set the stage for each of the following steps in the model.

In the disclosure step there are two factors that lead to the targeted outcomes. First, the disclosure communication – whether it is verbal, written, or through social media – will be measured in terms of duration, extent of shared information, time it takes to deliver, and the emotional content. These measures are determined by the goals set in the decision-making phase of the model. The second factor involves the reaction of the person who is being disclosed to. Chaudoir and colleagues posited that those who chose to disclose with approach goals are more likely to elicit a positive response from the confidant, whereas those with avoidance goals are less likely to communicate effectively, eliciting a neutral response at best.

The process of disclosure, according to this model, is mediated through three possible factors, shaping and determining the long-term outcomes of the disclosure event: alleviating inhibiting factors, building social support, and changing community perspectives (Chaudoir, et al., 2011). For example, disclosure can affect certain outcomes because it can be cathartic, relieving the mental and physical inhibitors caused by suppression (Calin et al., 2007; Derlega et al., 2004; Strachan, Bennett, Russo, & Roy-Byrne, 2007). Disclosure also might provide much needed support from those that are confided in (Calin et al., 2007; Derlega et al., 2004; Kalichman et al., 2003; Serovich, 2001; Valle & Levy, 2009) or it may raise social awareness of HIV in the community (Derlega, 2004, Haas, 2002).

Unlike earlier models, Chaudoir and her team (2011) bring the main focus of the model around to the potential outcomes that can occur as a result of disclosure. They posit that outcomes occur in a reciprocal manner, through mediating processes, which impact not only the person who is confiding but those with whom they have close relationships as well as those in their community. For example, researchers have been able to show that individuals were found to have less psychological distress when social support is a common factor in their disclosure process. They measured this for disclosure to family and disclosure to friends finding reduced psychological distress with both groups (df [1], $F [19.6]$, $p < 0.0001$ with disclosure to family; df [1], $F [11.70]$, $p < 0.001$ with disclosure to friends) (Stutterheim et al., 2011; Zea et al., 2005). Studies have also demonstrated that ART adherence is significantly correlated to the number of family and friends to whom a PLWH has disclosed (0.15 and 0.16 respectively, $p < 0.05$) (Stirrat et al., 2006; Waddell & Messeri, 2006). In partner relationships, studies show that self-disclosure and partner disclosure can strengthen the dyad if the partner is responsive to the information being shared (Laurenceau et al., 2005; Manne et al., 2004). In terms of community and social contexts, some PLWH report that they disclosed to educate others about the virus and to dispel misinformation that leads to stigma (Derlega et al., 2004; Emlet, 2008; Frye et al., 2009; Serovich & Mosack, 2003).

Finally, the model is the first to present a feedback loop, suggesting that a single disclosure event will positively or negatively affect future disclosure goal setting. That is, when an individual experiences a positive outcome that improves their experiences with their disease, they are more likely to disclose in the future. However, if that person experiences a negative outcome and is detrimental to their well-being, they may be less likely to disclose in the future (Clair et al., 2005; Greene et al., 2006; Ragins, 2008).

Applying Disclosure Theories to Older African American MSMW

Studies focused on disclosure processes among older adults, MSMW or AA men have based their work on a variety of theoretical foundations in addition to those discussed in this paper, including Social Exchange theory (Doll et al., 1994), Resilience theory (Emlet et al., 2011), Social Constructionist theory (Wheeler, Lauby, Liu, Van Sluytman, & Murrill, 2008), and the Stress and Coping Theory (Hult, Wrubel, Branstrom, Acree, & Moskowitz, 2012). While these studies focused on some aspect of older AA MSMW, such as older adults or AA MSMW, the models are, for the most part, very broadly applied to mostly heterogeneous populations. The theoretical frameworks discussed in this paper are functional for exploring this phenomenon among AA and older adult populations. Yet, there are certain factors that pertain to older AA MSMW that may be overlooked or not addressed using the current models.

Chaudoir et al.'s disclosure processes model (Fig 4) is the most complete model, taking components from each of the preceding models, and is most suited as a framework for examining the disclosure processes of older AA MSMW men. However, it is unclear whether there are other factors that might influence the disclosure decision-making processes for this specific population. In studies that included older men, older AA gay men and older bisexual men, some participants described feeling more comfortable with where they were in life and with their illness, hence making them more comfortable with sharing their diagnosis and illness experience with family members and providers (Emlet, 2008; Foster & Gaskins, 2009; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003). This fits in with the feedback loop theory of the disclosure process model suggesting that, over time, these men may have had experiences that have led them to set approach goals; however, research has not been clear on what these experiences are. Future studies will need to explore the life and illness experiences that lead certain men to make

a commitment to be consistently open about being HIV-infected as a means of resisting the stigma that is associated with their sexuality, their age, and having HIV.

Ethnic and cultural factors have also been posited to be important to disclosure of HIV status. Derlega and his research team (2004) suggested that ethnic variations in disclosure behaviors affect the predictability of disclosure as well as the outcome. The disclosure processes model, however, failed to consider this in any of the four stages. This is particularly meaningful for a population where cultural norms dictate behaviors surrounding the act of disclosure. For example, AA MSMW have been shown to be more likely to disclose to their male partners than their female partners, sometimes referred to as “the down low” (Dodge, Jeffries, & Sandfort, 2008; Malebranche, 2008; Millett, Malebranche, Mason, & Spikes, 2005; Sandfort & Dodge, 2008). Using the Disclosure Processes model to consider this finding, it may be that AA MSMW are setting both approach and avoidance goals based on a social norm that dramatically affects the disclosure event and mediates the outcome process.

Another mediating factor that may need to be considered with this population is generativity, which is defined by Merriam-Webster as “a concern for people besides self and family that usually develops during middle age; *especially*: a need to nurture and guide younger people and contribute to the next generation.” Older adults with HIV have expressed their sense of obligation to help others, particularly those who are newly infected and younger generations, by disclosing their status and sharing their experiences (Emlet, 2008; Emlet et al., 2011; Poindexter & Shippy, 2010). In the disclosure processes model, this would greatly influence the long term outcomes on the dyadic and social contextual levels. Theoretically, in this framework, older AA MSMW would be more likely to focus on raising awareness in their communities as a means of giving back while building potential meaningful relationships. Future studies should

focus, not only on the context in which this might play out but how sexuality as well as cultural and social norms mediate or moderate this interaction.

Social versus familial support is another key factor in AA communities that can be examined through the lens of the Disclosure Processes model. Though AA older adults are not as likely to disclose to their church family, the church plays a critical role in their lives particularly around emotional and spiritual support (Foster & Gaskins, 2009). However, unlike other ethnicities, some AA men with HIV report that they would be more likely to disclose to their families than to those in their community (Emlet, 2008; Foster & Gaskins, 2009; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003). Research will need to consider how and to what extent social and familial support might mediate the disclosure process and affect long term outcomes. While social support is still a vital part of the process, the family may play a bigger role than what is seen with white MSM and MSMW in understanding disclosure for this population.

Conclusion

Three and a half decades into the epidemic and there remains a paucity of research surrounding the disclosure habits of older AA MSMW, yet they are among the most impacted population in the U.S. While a great deal of emphasis is given to a cure and medical interventions, the importance of considering behavioral interventions is slowly coming to the forefront. HIV disclosure is a key component of behavior change and prevention, which could significantly lower the continuous spread of the epidemic. More studies are needed to examine disclosure in all populations, but particularly in older AA MSMW who have been given little attention in research. By understanding their experiences and working within the community, interventions could be designed to support older and younger generations to understand the

power of knowing your HIV status and reducing the community viral load. To accomplish this, theoretical foundations must be tested and adapted. This review of HIV related theoretical models lays the groundwork to guide future exploratory and intervention research with older AA MSMW living with HIV.

CHAPTER 4

HIV-STATUS DISCLOSURE EXPERIENCES

Introduction

In the United States, more than 1.1 million people are living with HIV/AIDS and nearly half of these are African Americans; an increase of 7% in just two years from 2008 to 2010 (CDC, 2016a; CDC, 2016b). African Americans (AA) in HIV literature includes blacks of African and Caribbean descent who have immigrated to the United States. While AA make up 12% of the total population in America, they account for 44% of all new cases of HIV, eight times that of whites and twice that of Hispanics. The highest rate of HIV infection is among AA men at 103.6 per 100,000; twice that of Latino men, the next closest group (CDC, 2012). Among gay and bisexual men, AA account for 31% of all new HIV infections compared to 43% for white men; yet, in 2014, the incidence for AA MSM was over 11,000 compared to 9000 for white MSM (CDC, 2016c; CDC, 2016d). Males make up 70% of new cases among all AA; in fact, Stall et al. (2009), found that, by the age of 25, one out of four African American men will be infected with HIV and, by the time they reach the age of 40, nearly 60% of these men will be living with HIV (Andrasik et al., 2014; Stall et al., 2009).

Similar to the increase in HIV infection rates among African American men, over the past decade there has been a marked increase in the number of people over the age of 50 living with HIV. In HIV and AIDS research and clinical care, 50 has been used as the cut off age to denote older adults. Currently, it is estimated that older adults now make up more than 50% of all HIV cases in the U.S. (CDC, 2016c; CDC, 2016d). Similar to younger generations, racial disparities are clearly evident among older adults with infection rates among older African American men (49.2 per 100,000 population) 12.6 times that of white men (CDC, 2016c).

Interestingly, older AA men account for 24% of newly infected older adults; yet, only 15% identify as gay/bisexual (CDC, 2016d). New cases of HIV among this group continue to go unreported because older AA men are less likely to discuss their sexuality with their provider or they are unaware of the importance of using protection. Because of the risk of stigma, these men outwardly identify as heterosexual yet, in reality, continue to have sex with both women and men (CDC, 2013d). Because they are not disclosing their HIV status and sexuality, they are not being accounted for or are being incorrectly categorized if they are reported at all (CDC, 2016d; Shearer et al., 2012; McKay & Mutchler, 2011).

Increasingly, disclosure of HIV status is recognized as a key component of psychosocial interventions to reduce the impact of HIV among AA in the U.S. However, studies that include older adults or men who have sex with men and women (MSMW) and explore how disclosure and non-disclosure affect the processes of living with HIV are sparse. Most researchers include these men in broader categories with their younger counterparts or they are mixed in with men who have sex with men (MSM); in fact, there are no studies in the literature that specifically examine the experiences of disclosure among older AA MSMW.

Theoretical Framework

Living with HIV has changed dramatically over the past two decades, transitioning from being fatal to being a chronic disease. There are many reasons for PLWH to disclose their HIV status and the theories of this processes have changed significantly as the way people experience their illness has changed. Disclosure of HIV is a process - a thorough assessment of how sharing their disease will benefit or harm them and those they hold dear (Gorbach et al., 2004; Stutterheim et al., 2011). Disclosure is usually an action considered to be a decision made by an individual to share something, however, it is not uncommon for PLWH to have their status

become known inadvertently. For example, family or friends might reveal their situation, their physical condition might raise suspicion, or external cues such as medicine bottles or frequent trips to the doctor might reveal their illness (Derlega et al., 2004; Emlet, 2008; Serovich, 2001; Valle & Levy, 2009). A number of theories have been developed over time to explain how HIV status disclosure occurs, each systematically building on previous models. Similarly, this study focuses on the Disclosure Processes Model as a template for examining and explaining the experiences of HIV status disclosure as it occurs with older AA MSMW.

Disclosure processes model. Early theories of HIV disclosure focused on the *behaviors* of disclosure rather than the consequence and outcomes of disclosure. To address these questions, psychologist Stephenie Chaudoir, an assistant professor and director of the Concealable Stigmatized Identities (CSI) Lab at College of the Holy Cross, developed the disclosure processes model (Fig 1) in the context of PLWH to address how decisions of sharing

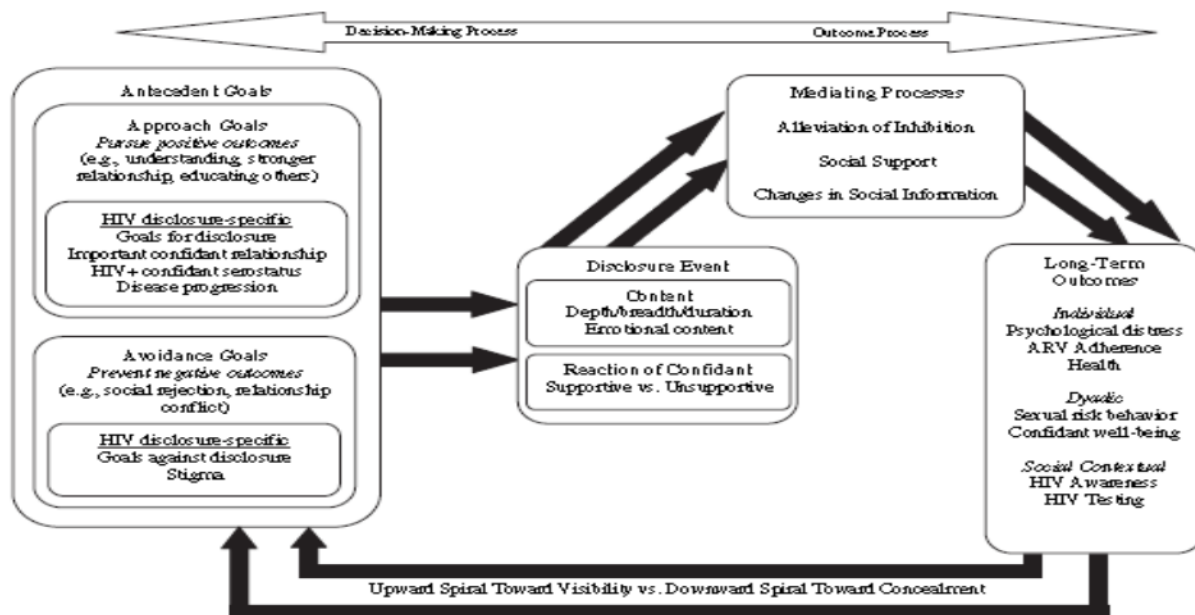


Figure 4.1: Disclosure Processes Model

one's disease will positively or negatively affect them and how this decision impacts future decisions. The DPM describes each disclosure event as but one in a continuous cycle of disclosure that crosses the lifespan of one's illness (Chaudoir & Fisher, 2010).

Chaudoir and her colleagues (2010) describe PLWH as having what they call "approach" goals, such as forming and enriching relationships, protecting others from the spread of HIV, or educating others about living with HIV. They describe these as specific goals that are set by those who are working with a positive outcome in mind as a result of disclosure (Calin, Green, Hetherington, & Brook, 2007; Derlega et al., 2004; Emler, 2008; Frye et al., 2009; Gorbach et al., 2004; Serovich & Mosack, 2003). Chaudoir and colleagues also described "avoidance" goals, which are set in anticipation of a negative response to a potential revelation. PLWH will choose non-disclosure or partial disclosure for many reasons; for example, when there is a risk of rejection, stigma, or abuse (Calin et al., 2007; Derlega et al., 2004; Frye et al., 2009; Gorbach et al., 2004; Serovich & Mosack, 2003; Valle & Levy, 2009).

Unlike previous models, the DPM describes potential factors that might mediate the outcomes of disclosure. They give examples that fit well with the population in this study: alleviation of inhibiting factors, development of social support, and changing community perspectives (Chaudoir, et al., 2011). For example, disclosure can be a cathartic experience, relieving the mental and physical inhibitors caused by suppression and oppression (Calin et al., 2007; Derlega et al., 2004; Strachan, Bennett, Russo, & Roy-Byrne, 2007); social programs might provide much needed support that they might not otherwise have (Calin et al., 2007; Derlega et al., 2004; Kalichman et al., 2003; Serovich, 2001; Valle & Levy, 2009); or there might be a movement in their community to raise social awareness of HIV (Derlega, 2004, Haas, 2002).

Chaudoir and her team (2011) also suggest that the process of disclosure is a reciprocal event, in that, the experience impacts not only the person who is confiding but to those with whom they have close relationships as well as those in their community. PLWH must carefully weigh their decisions not only on how it will affect them, but their family and friends as well as their desire to help others in their community.

Finally, the model suggests HIV status disclosure works as a feedback loop, in that a single disclosure event would positively or negatively affect future disclosure goal setting. That is, when an individual experiences a positive outcome that improves their experiences with their disease, they would be more likely to disclose in the future. However, if that person experiences a negative outcome that is detrimental to their well-being, they may be less likely to disclose in similar situations (Clair, Beatty & MacLean, 2005; Greene, Derlega, & Mathews, 2006; Ragins, 2008).

Ethnic variations in disclosure behaviors may affect the predictability of disclosure as well as the outcome. The disclosure processes model, however, failed to consider this in any of the stages. This is a particularly meaningful factor with this population where cultural norms might dictate behaviors surrounding the act of disclosure. One such phenomenon, sometimes referred to as “the down low,” suggest that AA MSMW are more likely to disclose their illness to their male partners than their female partners (Dodge, Jeffries, & Sandfort, 2008; Malebranche, 2008; Millett et al., 2005; Sandfort & Dodge, 2008). If we were to examine this with the DPM, it might be hypothesized that they would be setting both approach and avoidance goals that could be seen as affecting the disclosure event as well as mediating the outcome process.

Another factor that may be unique to this older population is the desire to inform and teach others in their community. This has been described in other studies as generativity, which is defined by Merriam-Webster as “a concern for people besides self and family that usually develops during middle age; *especially*: a need to nurture and guide younger people and contribute to the next generation.” These studies describe disclosure as a means of helping others, particularly those who are newly infected, by disclosing their status and sharing their experiences (Emlet, 2008; Emlet et al., 2011; Poindexter & Shippy, 2010). In the case of older AA MSMW, disclosure of their HIV status might be a means of raising awareness in their communities and building potential meaningful relationships.

Social support is another consideration for AA MSMW that should be examined with this model. In a study of 24 older AA men, participants indicated that they were less likely to disclose to their church family, however, the church still played a large role in their lives as far as emotional and spiritual support (Foster & Gaskins, 2009). Similarly, older AA men have reported that they were more likely to disclose to family than to friends and colleagues (Emlet, 2008; Foster & Gaskins, 2009; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003). This is another factor that should be considered as a mediating process affecting long term outcomes. While social support is still a vital part of the process, hypothetically, the family could play a much bigger role in a model for this population.

Based on the studies that have examined older adults and African American MSM and MSMW, it would appear that the Disclosure Processes Model is a strong framework for examining the experiences of HIV status disclosure for this population. The pertinent questions that must be examined are whether older AA MSMW experience HIV status disclosure as other older adults do or do they have different reasons for disclosing and have different expectations

for outcomes. Is the DMP a proper model for examining this or are there aspects of their experiences that merit a new model? With these questions in mind, the purpose of this study was to examine HIV status disclosure as it is experienced by older African American men who have sex with men and women.

Methods

Sample and Recruitment

Recruitment of African Americans in medical research studies is a known challenge. Multiple studies have identified barriers to research recruitment of this particular population. Mistrust, built on years of racial and ethnic discrimination and abuses in scientific experimentation, is a foremost barrier and occurs at the individual, group, and community level, all of which must be addressed to effectively recruit participants (Freimuth et al., 2001; Shavers, Lynch, & Burmeister, 2002; Silvestre et al., 2006; Yancey, Ortega, & Kumanyika, 2006). Mistrust may be perceived differently at each level. For example, members of the AA community may see research as a means of benefitting scientists and academic institutions rather than meeting the needs of the community or even a means of belittling the AA community (Silvestre et al., 2006; Yancey et al., 2006). Specific groups may be more or less affected by historical events such as the Tuskegee Syphilis experiments. While these events are often brought up as a major barrier (Freimuth et al., 2001), some studies suggest historical wrongs are not always a deterrent to participating in research (Shavers et al., 2002; Yancey et al., 2006). For individuals, there may be the perception that providing informed consent relinquishes rather than protects one's rights (Silvestre et al., 2006; Yancey et al., 2006). There may also be logistical and other barriers in addition to distrust, including literacy level, transportation, time, and unstable housing, which may hinder individuals from participating in research studies (Silvestre

et al., 2006). Other factors, such as being MSM or MSMW, can magnify fear, isolation, and mistrust further distancing potential research subjects from medical and social research that might benefit them (Silvestre et al., 2006). These assumptions were incorporated into a recruitment plan designed to a) build trust from the onset of this study, b) maintain open and honest communication and c) work to create a community-focused setting throughout the study (Freimuth et al., 2001; Shavers et al., 2002; Silvestre et al., 2006; Yancey et al., 2006).

Several studies have suggested that community ties and experience of the research team are of greater value than cultural and ethnic similarities when recruiting African Americans (Freimuth et al., 2001; Silvestre et al., 2006; Yancey et al., 2006). Hence, two purposive sampling techniques were used to recruit AA participants for the online focus group. First, key contacts in community clinics located in the greater Puget Sound region of Washington State and serving patients who potentially met study inclusion criteria were approached to assist with recruitment. Community clinic contacts were asked to distribute flyers inviting participation in the study to potential research subjects. Flyers provided a brief description of the study, inclusion/exclusion criteria, the approximate time commitment, study compensation (\$50 Amazon gift card), and an email contact to participate. Second, a snowball approach was used to increase recruitment. Participants were asked to invite other prospective community members to participate in the study and were offered \$5 incentive gift cards for each recruited referral. Inclusion criteria for study participation included: 1) 50 years old or older, 2) African American (including African or Caribbean immigrants), 3) HIV positive, 4) sexually involved with men *and* women, 5) ability to read and write, and 6) access to the internet. Potential participants were excluded if they were unable to communicate (writing/typing) using the English language.

Potential participants for the online focus group were sent an email describing the study in more detail including confidentiality and anonymity protections, voluntary nature of research, and a restatement of the inclusion and exclusion criteria. Participants were asked to attest to their willingness to participate and that they met all study criteria per return email. Upon receipt, they were sent an email with a link to a Catalyst survey and directions to complete a brief survey of 15 demographic and personal characteristic items. Once recruitment was complete, participants were sent a link to an online discussion board. Participants received an electronic code for a \$50 gift card from Amazon via email after data collection as an incentive for participation in the research study.

In addition to the online focus group, a small number of key informants were recruited for individual interviews. Key informants were recruited from staff at the HIV clinics attended by the focus group participants using a snowball technique. The primary provider, who originally helped dispense flyers to the potential focus group participants, assisted with recruitment by forwarding an email from the research personnel to potential key informants inviting participation in the research study. Inclusion criteria included staff who 1) had worked with clients from the HIV clinic and 2) had an understanding of the programs that were available to these clients. Interested staff were asked to contact the lead researcher via email to arrange a 10 to 15 minute phone interview. Key informants received a \$20 Amazon gift card as an incentive for participation.

All study procedures and data collection instruments were reviewed and approved prior to use by the University of Washington Human Subjects Division.

Data Collection

The evolution of social environments in online settings has led to both innovation and anxiety in the application of methods that have formerly been reserved for face-to-face research. Following the lead of marketing researchers, communications and media studies began conducting online focus groups (OFG) and social science researchers were quick to follow suit (Stewart & Williams, 2005). As online discussion boards have become more commonplace, researchers have begun to explore the use of university learning management systems (LMS) such as “Blackboard” and “WebCT” to conduct focus groups. Studies using this sort of platform have found that it allows for greater management and facilitation of groups as well as the use of the university infrastructure for security purposes (Hughes & Lang, 2004; Stewart & Williams, 2005; Turney & Pocknee, 2005). This study utilized a secure, university-managed LMS – Canvas – to conduct an asynchronous focus group using an open discussion board.

The focus group data collection instrument was informed by the Disclosure Processes Model (DPM) and consisted of five thematic questions, and related clarifying questions, designed to allow for separate discussion threads among participants (Appendix A). Discussion questions one and two were designed to address the first part of the model that examines the precursors to disclosure: setting goals, who is on the receiving end of the disclosure, and what was the reaction to the disclosure. The third question pertained to the mediating factors that may have played a role in the disclosure experience. The final two questions were developed to examine the outcomes of the experiences of disclosure and how this might have affected the way participants reported planning to manage future disclosures.

Prior to the start of focus group data collection, participants were provided with a unique Gmail username and password allowing them temporary access to the University of Washington

(UW) Canvas system and detailed instructions on how to access and navigate the website where data were collected. A researcher (SS) was available to participants by phone or email at any time to troubleshoot technical issues related to accessing the study website.

The study focus group website had three navigable pages: 1) Home page, containing discussion board etiquette for the focus group, 2) Discussion Board separated into five sections, each pre-populated with questions allowing for separate discussion threads (see Appendix A), and 3) Announcement page, available for group messages regarding the study. Data collection began when recruitment goals were met and was conducted over a four-week period providing ample time for initial responses, responses to posts of other participants, and replies to follow-up questions from researcher. The four-week period was designed to allow adequate time without overburdening or inducing study fatigue in research participants.

Minimal researcher moderation of the focus group discussion board was needed for data generation. Participants were provided with a list of discussion board etiquette guidelines on the website; no breaches in etiquette occurred (Kenny, 2004; Nicholas, et al., 2010; Stewart & Williams, 2005; Synnot, et al., 2014). The data that emerged regarding the experiences of disclosure of their HIV status were derived from the initial questions (Appendix A) as well as follow-up questions from other participants and the researcher. The researcher interacted with study participants by keeping conversations on track and encouraging the men to elaborate on new ideas that appeared unique to this population or not found in the DPM model.

In addition to the data collected via the online focus group, data also were obtained from four key informants recruited from among staff members at the HIV clinic where the online discussion group participants received care. Key informants were asked a set of six questions exploring three general topics: 1) what programs were provided by the clinic for PLWH, 2) key

informants' perceptions of what these programs offered PLWH, and 3) key informants' perceptions of how clinic programs may support (or not support) disclosure (Appendix B). Interviews were conducted by phone, lasted approximately 15 minutes, were audio-recorded and field notes were taken concurrently. Data collection was stopped after three key informants as data saturation had occurred.

Data Analysis

This study used a directed content analysis approach. The researcher used existing DMP theory to develop an initial coding scheme prior to data analysis (Appendix C). The purpose of employing a directed content analysis approach was to clarify, extend and refine the Disclosure Processes theory as it applied to a new population, Older African American MSMW (Hsieh & Shannon, 2005). Data were obtained from two distinct sources: online focus group participants and staff key informants. Data analysis for both sources is described below.

Data from the online focus group participants was analyzed first using a step-by-step approach. First data were read as a whole and coded using the initial coding scheme (Appendix C). Next, data were read a second time to identify emerging new concepts, which were separated into new codes as well as subcategories of existing codes. Third, each code was examined individually to assure that the concept fit the code and that there was no overlap between codes. The multiple levels of coding and analysis were particularly useful to identify unique experiences of disclosure for this population helpful to further develop, expand, and enrich the original model.

After coding the data, the results were shared with mentors who also reviewed the data for accuracy of coding. The purpose of this review was to enrich understanding of themes and to

reduce the risk of researcher bias, an important consideration in directed content analysis because of the use of existing theory or prior findings. Based on multiple readings of the data, several themes were identified, particularly within mediating factors, that enriched the original DPM. In addition, several new themes emerged that appear unique to this population and perhaps others.

After the online focus group data were analyzed, the key informant data were approached. First, these data were read through to obtain a sense of the whole. Next, the data were examined based on the coding scheme that emerged from the focus group data analysis. In particular, data from the key informants were used to deepen understanding, explore differences, and extend relationships between the codes.

Credibility. Credibility was addressed through multiple strategies. With a directed content analysis approach, it was important to remain aware of preconceived biases and to test and defend emerging concepts at each stage of the analysis (Lincoln & Guba, 1985). For example, such bias could lead to finding ideas and concepts that are supportive rather than in contrast to the original model or focusing over intently on the concepts of the original model could lead to overlooking new aspects of disclosure. It was important to address these issues to assure confirmability of trustworthiness (Lincoln & Guba, 1985). To assure that credibility was maintained, the researcher (SS) conducted several peer debriefing sessions with mentors to examine and review findings. In addition, select codes and analysis were shared with two study participants as a method for member-checking. Key informant interviews with clinic staff provided an additional means to triangulate data shared by the focus group participants.

Findings

Participant Characteristics

A total of 20 men responded to flyers and requests to participate in the study. Of these, nine chose to complete the demographic survey and then participated in the online focus group. The age of the participants ranged from 53 to 65 with a mean of 58 years (SD 4.15) and most were born in the continental US except for one born in the US Virgin Islands. With the exception of one man who had a doctorate, all of the men had either a high school diploma or associate degree. Only two of the participants were employed at the time of the study; eight had an annual income of \$24,000 or less while one's income was greater than \$48,000 annually.

At the beginning of the study, none of the men were living with a significant partner, however, four indicated that they were in a long term relationship with either a man or woman. All of the men indicated that they had had sexual contact with both men and women in the past. Four identified as *homosexual*, two as *heterosexual*, and three as *other*. None identified as bisexual though this was a possible option on the survey. All participants indicated they were actively involved with the health care system due to viral suppression and treatment with antiretroviral therapy (ART).

The four key informants were staff members from the clinic where the men were recruited and included a nurse practitioner (primary care provider for the HIV clinic), registered nurse, licensed practical nurse, and social worker. All worked full-time and had direct interactions with the participants in the focus group.

The Process of Disclosing One’s HIV Status for African-American Men Who Have Sex with Both Men and Women

The two overarching stages theorized in the Disclosure Processes Model – “The Decision Making Process” and “The Outcome Process” – were affirmed by the participants in this study. Within these stages, there are underlying mechanisms that describe the experiences of HIV-status disclosure. This study found eight new themes that fit within these overarching stages and subthemes that may be unique to AA men who have sex with men and women. Each are described below along with the stages and mechanisms of the DPM.

The decision making process. All participants in this study discussed the decision-making process they faced in making the choice to disclose their HIV status. Affirming the DPM model, participants talked about planning for the disclosure prior to the actual disclosure process. The decision-making process is theorized within the DPM to have two concepts: antecedent goals and the disclosure event. *Antecedent goals* are theorized to have both approach and avoidance goals. Similarly, the participants had to face the decision of what content was to be shared prior to disclosure; this included setting goals. These goals were set based on their desire to either share their disease or keep it a secret. Three new themes emerged from the focus group that fit well into the decision making process phase of the model: *Support*, *Nobody’s business*, and *Relief of Burdens*. The second sub-theme in the original model pertaining to the disclosure event had two parts: the “Depth, Breadth, and Duration of Content,” and the “Emotional Content” of the planned disclosure. None of the data that emerged in this study fit within the disclosure event theme of the decision making portion of the original coding.

Antecedent goals. Two themes emerged for setting “approach goals”: *Support* and *Relief of Burdens*. All participants described choosing to disclose to their health care providers

out of an overwhelming need for *support*. As one participant expressed, “I was just so sick. I knew I was gonna die if I didn't do something soon.” For one man, it was the first opportunity to share his illness, “I didn't share with anyone at first except for like [the doctors], I mean I had to tell them.” For another participant, the doctors were the only ones who had a need to know, “I talk to the doctors and that's it . . . I just do my thing to be healthy.” Several men also sought the support of their family, “They [family] are the ones who are going to be there for me so I wanted them to know why I was sick so it would just be out in the open and not like I was keeping secrets from them.” Another man sought out the *support* of his sister despite knowing that she disapproved of his lifestyle choices, “I made the decision to tell her because I knew she'd be supportive.” There were only a couple of men who sought out the *support* of friends at first, “I never told my family, I knew there was no way that they would ever be able to even wrap their heads around it. It was mainly friends that I talked to about it, those I could trust to be positive.” Those who did share with friends expressed how they had to be selective with who they disclosed to, “Even though they were my friends, I knew that they would feel the need to judge me so I was very careful about picking and choosing who I told.” Interestingly, only one of the men brought up the idea of *support* regarding a partner and that was more about being there *for* the partner rather than seeking the *support* of the partner, “In the first case, I told him [partner] because I wanted to educate him . . . I wanted him to know that I could die.” In fact, most of the men agreed that telling a sexual partner about their HIV status was more commonplace than in the past because being virally suppressed and using pre-exposure prophylaxis (PrEP) allowed them to be sexually active despite being HIV positive. As one participant put it, “In the beginning it was very hard to share with sexual partners. Now, most partners expect to share this information.”

The participants also discussed the *relief of burden* that sharing brought them; of being motivated to set “approach goals” because of the prospect of *relieving the burden* of keeping secrets and hiding things from their family and friends. For one man, sharing “allowed me to exhale and release fear of rejection, shame, and stress of not being fully known by the people close to me.” He went on to explain how he came to realize that he could not control how others responded to his revelations, “I have learned that rejection and a negative reaction is not something that I can control so worrying does not serve me emotionally.” Similarly, another participant shared that he, too, no longer had to keep secrets, “It was kind of a relief because I wasn’t having to keep a secret anymore . . . it was like the world was lifted off my shoulders.” One man shared that making the decision to tell others about his experiences was cathartic, in a sense, for him, “I felt so much better like a switch had been turned on . . . I wanted to live again and to be healthy.”

Not all men set “approach goals” though preferring to use “avoidance goals.” While this may appear to be a negative approach, many men chose this option as much for themselves as to protect others from the burden of knowing about their illness. For some, there was only a select group of people who needed to know about their diagnosis. Other than their health care provider and their family, it was *nobody’s business*, “No one but my family and the doctors here need to know anything about my health.” Similarly, another man continued the conversation, saying, “I really didn’t want to share at first because I didn’t think it was anyone’s business so I just didn’t talk about it. I didn’t even tell my family for about 4 years and one day I wrote my mother and told her.” For other men, not even family needed to know, “It ain’t nobody’s business whether I’m sick or not. Nobody needs to know but me, I just deal with it on my own.” Some participants liked the idea of being involved in the HIV community but still didn’t feel the need

to share their status, “I don’t really need support but I like to get involved. But I don’t need to share my illness with anyone to help.” Another man in this discussion thread responded with, “If it comes up, it comes up. I mean, I don’t mind talking about it but it doesn’t really come up. Nobody ever asks me if I’m HIV positive but if it were to come up I wouldn’t hide it.”

The outcome process. Much of the discussion in the focus group centered around the outcome process of the DPM. The first part of the outcome process in the original model was the disclosure event, which was branched into a “Supportive” or “Unsupportive” response. There were three themes that emerged from the focus group that fit well into this part of the model: *Nothing’s Changed*, *Unintentional Disclosure*, and *Mutual Silence*. The outcome process of the DPM also included “Mediating Factors” and “Outcomes.” Three new themes emerged in this study that related to “mediating factors” including, *educational programs* and *street/prison education* as well as *the role of religion and the church*. In the original model, “outcomes” were further divided into, “Individual,” “Dyadic,” and “Social Contextual” results. The participants in the current study spoke frequently of *education* as both a “mediating factor” and an “outcome.” *Education*, as an emerging theme was expressed on all of the “outcome” levels that were described in the original DPM.

Supportive disclosure event. Some of the men spoke of “supportive” experiences, many of which were discussed above and were motivation for the men to set “approach goals” for future disclosure events. Other examples that emerged in this study had to do particularly with *relieving burdens* and receiving *support*. For example, as one participant expressed, “Things did get better because they knew.” For others, the situation may not have gotten completely better but they had the support that they needed, “I don’t know if it got better but it got easier.” One man described how family may not like their lifestyle but approved of the man they were

becoming, “My sister still don't really like what I am or what I did now but I can tell her now how i'm being safe and helping other people and she likes that.”

Non-supportive disclosure events. Non-disclosure came up in several forms throughout the discussion board. One particular theme emerged from the focus group where, as they described it, *nothing changed*. For some, this meant that their family didn't support them before and their family didn't support them after they disclosed. As one man described it, “Nothing really changed to be honest, some people [family members] can handle hearing the truth and others just can't.” For others, the hope was that sharing would change the way people in their community viewed them, “Nothing has changed ... people are saying things that are so uncomfortable to hear. When someone finds out they don't have anything good to say. They think I'm gonna get them sick even though CD4 counts are super high.” One participant in this thread expressed how sometimes you don't share simply because you aren't ready, “This whole disclosure thing or talking about HIV is difficult. It takes awhile to get the courage to share.”

Another set of “non-supportive” disclosure events that emerged in this study often occurred simultaneously, *Unintentional disclosure and mutual silence*. Many of the men shared how the process of disclosure wasn't always a decision that was given to them to make. They explained how their family had figured out that they were sick before they ever had the chance to reveal their secret. For these men, more often than not, their family opted not to say anything, “They knew something was going on, I think my sister may have seen my medicine bottles in my bedroom once or something . . . they are family, so they helped but they don't want to hear about it.” Another participant had a similar situation with his family, “I think maybe my sister knew cause one time she saw my medicines and asked me about them but we never really talked about it.” Some men expressed how, even though they disclosed their status, the person they told

didn't care to hear about it and simply said nothing, "My sister was the first person I told. She was just silent." One man described a similar incident with his partner, "It was the same I guess with my partner, he never liked to hear negative things so he just didn't want to even address it." These particular men felt it was best for their family members, friends, or partners to forego disclosing further for the sake of maintaining the relationships as they stood.

Mediating factors. Many of the men spoke of the church and their religion and the role that it played in their decisions to disclose; overwhelmingly, this perception was negative in regards to the church. The men were clear that their faith in God was not what faltered but rather, their faith in the church; most of them suggested that the church was not a safe place for them to seek support. One man, in discussing his process of deciding with whom to share said, "That [the church] is NOT a safe place to share and my family is too far away;" another added, "I believe in the God and all but the church is not a safe place to share." For one gentleman, the concern was being judged, "They [the church] demonize everything;" but, he went on to add, "If they think ill of me that is on them, not me."

Education, on multiple levels, was an important theme that emerged in the disclosure process for these men. The negative experiences of learning about HIV from mediating sources that the men experienced on the street and in the prison system led them to make both approach and avoidance goals. These men weren't able to share their disease because they didn't feel that they knew enough about it to have an educated discussion with those they cared for the most. Not only were they being given misinformation but, in some cases, told that they shouldn't share their status. While some kept their secrets until they were forced into the clinic because of their health, others deliberately sought out a new source of information. As the staff from the clinic who were interviewed explained to me, "from the very first appointment, every patient at the

HIV clinic is inundated with resources within the clinic and throughout the community.” They provide intensive services that are provided by onsite staff and others from the community that address issues of their health and HIV, how to manage their disease, as well as how to deal with other life issues such as mental health and addiction. One man described how their provider gave them this information and then asked him what he wanted to do – he said it literally made him tear up, “It was the first time someone had asked me what I wanted to do rather than telling me what I should do.”

This was the most prominent emerging theme from the focus group relating to mediating factors; specifically, what the men learned about HIV on the streets and in prison and what the men learned about their disease in clinics and other programs offered through the clinics that influenced their disclosure experiences. A few of the men discussed that what they were learning on the street greatly impacted their reasons for not disclosing and for seeking out information from their clinic. As one participant described it, “People like to talk about things they don’t understand and make people feel like crap.” Another gentleman followed that up with, “There is so much bullshit out on the street, no one knows what is real and what’s bs. See everyone on the street wants to tell you what’s up and really it was just a bunch of bs so I just shut up. I didn't understand so I come to the clinic and started learning.” One man described how, in the early days of the epidemic, if you were in the prison system your education was quite harsh, “I was scared and the nurses in the jail had very little info to give except that I had 6months to a year to live . . . they just told me not tell anybody because of the fear around HIV/AIDS back then.”

On the other end of the spectrum, many men spoke of the impact of their involvement with health care and social services and how it enabled them to open up about their disease with

people that were important in their life. One program, in particular, was praised by several men. Key informants shared more details about the program including that it was started approximately three years prior and that men were invited to come together in a group setting once a week. Sessions were facilitated by an RN, but the men were free to guide the discussion. The program had become a forum where participants can learn from and support one another through their own experiences. For some of the men, this was their first experience with sharing their disease with people other than their providers. In the focus group, participants suggested that this program was a critical learning experience for them and empowered them to share their HIV status with others. As one man said, “It was actually the clinic that kind of opened the door for me,” in regards to sharing with his family. Several men followed up on this thread, supportive of positive experiences that helped with their experiences of disclosure, “I’ll tell you though, the people I have met in health care along the way have made a huge difference in my life.” Another man talked about his experiences with other men in his programs, “I started going to a men’s group . . . they just had so many services available that made my life so much easier. Attending meetings with peers made decisions more comfortable and safe.” One participant went a little deeper in the discussion talking about how the learning he experienced at the clinic shaped his ability to talk with others about his disease, “They are really great here and they really helped me learn. They got me involved in the group sessions and I didn’t talk at first, I just listened and learned. That’s what this is really all about is learning. The more I learned the easier it is to talk.”

Outcomes – self, dyadic, and social/contextual. One of the more involved discussions of the focus group revolved around helping one’s self by learning about your disease and improving the lives of others by sharing one’s own experiences. As one participant put it, “See if you

educate yourself then you don't have to be scared anymore. What they teach you is that it is your life and only you can actually do the things to make you better.” One discussion thread spoke about learning in group sessions,

“They got me involved in the group sessions and I didn't talk at first, I just listened and learned. It was guys just like me, they had been where I was and they had learned what's up. I listened and let other people teach me so I would know how to tell other people. You can't talk to people about your HIV if you don't know what's going on yourself and these guys had been doing this for years. What did I know.”

The discussion thread then moved into how this set the stage for them to share with others, “Now I feel like I can talk to other people about it better cause I know what I'm talking about.”

The conversation of helping others started with a perfect transition thread from the previous discussion about educating one's self, “I did it for me but I did it for others too. I wanted to be able to talk to my friends about it because they were dying. I even carry condoms with me now so if I talk to someone about it I can give it to them. I really want to help others become aware that HIV does not mean you are going to die.” Another participant's experiences were similar, “At the time I got sick, options for treatment were terrible and so the combination of all of this, mostly fear, prompted me to speak out. I wanted my friends to be safe. I guess it was seeing other people around me who were still doing things that would lead to HIV that drove me to start sharing with others.” And another man shared how, “Now I tell everyone cause I can tell them you don't have to die. I tell them you don't have to avoid people if you're careful, use condoms and take your pills. You can be just like everyone else. I feel blessed and want to be able to let others who are newly diagnosed that they can feel this way to.” For one gentleman it

was about paying it forward, “It's the people that need to hear about it though. They just need someone to be there for them like my friend was [for me], they need support and I can do that for them.”

The experiences of HIV status disclosure that were shared by the participants of this study aligned well with the two overarching stages theorized in the Disclosure Processes Model – “The Decision Making Process” and “The Outcome Process.” This was particularly evident in the goal setting that they applied in the decision making process, seeking support and finding relief from keeping secrets being major factors in their decisions to disclose. Support also played a big role in the outcome process but the most unique factor that emerged in this area of the model was the desire of the participants to educate themselves and to educate others.

Discussion

To our knowledge, this is the first study that has been conducted to examine the experiences of HIV status disclosure by older African American men who have sex with both men and women. This is an important population to focus on because of the disproportionate HIV disease burden borne by this group. The purpose of this study was to examine the fit of the Disclosure Processes Model as a framework to explore how, why, and with whom older African-American men who have sex with both men and women share their HIV disease status. A key finding was that the DPM was an effective model for describing the experiences of disclosure for MSMW who are also older African American adults. This is an important finding because it supports the transferability of the DPM to populations such as AAMWSMW. Equally important, the study revealed new perspectives of disclosure that impacted the decision making processes and outcomes for this particular group of men. These findings suggest new themes that may inform understanding of HIV disclosure among other populations as well.

This study highlights some of the more significant reasons why retention in care is so important, particularly for older AA MSMW. African American men have been overwhelmingly and disproportionately affected by the HIV epidemic in the United States among nearly every subpopulation except for gay men; until recently. In 2014, AA men who have sex with men (MSM) surpassed the incidence rate of HIV infection of white men for the first time among gay populations (CDC, 2016a; CDC, 2016b). This increase may partly be accounted for by better access to care due to the Affordable Care Act. In 2012, 86% of African Americans living with HIV were able to receive a diagnosis. More were learning about their infection, however, they weren't being retained in care; only 37% were provided with ART and only 29% were able to reach viral suppression (CDC, 2016a).

A key finding from this study was that AA MSMW appear to face additional or unique barriers to disclosure, which may prevent them from receiving timely care provider and family support. Fekete and colleagues found an association between low family support and decreased CD4 counts, however, family is a vital resource for older AA MSMW. Even if they do not feel that they will receive support, these men almost always turn to family for their disclosure events. Fosters & Gaskins (2009) supported this in their study of 24 older AA PLWH, revealing that older adults were more likely to disclose to their families. Their participants also revealed that the church, on the other hand, is considered a place that was never safe to reveal being HIV positive. This raises an important conundrum for older AA MSMW since the church is a vital source of spiritual and emotional support within the African-American community. This raises concerns for AA MSMW who may have greater avoidance to disclosure in their communities and hence, be at greater risk of poorer outcomes from chronic HIV infections as are reflected in the CDC findings. Some men use non-disclosure to manage or minimize stigma, keeping one's

self safe while maintaining confidentiality, while for others, they are able to selectively isolate themselves from others so as not to take on responsibility for the well-being of others around them (Fosters & Gaskins, 2009; Poindexter & Shippy, 2010; Schrimshaw & Siegel, 2003). This study revealed however, that even when PLHIV perceived that their faith communities would not be a source of support for them, there were other community resources that were identified as helpful.

The men in this study did not feel the need to rely on the church or their friends and didn't want to burden their family for support, however, they recognized that they needed some type of support if they were going to effectively manage their disease. Emlet (2008) described how the older adults in his study were more likely to disclose their status if there was someone in their lives that they could trust; an emotional confidant or someone they could trust. For the men in this study, that turned out to be their health care providers. Wohl and colleagues (2011), who examined disclosure among AA and Latino MSMW, also found that their participants were more likely to disclose practical needs pertaining to their illness to their health care providers sharing that they would feel less stress than disclosing to family or others in their community. Because the participants were unable to manage their illness on their own and were not willing to burden their family, they turned to their health care providers. For these participants, not only was this their first disclosure but it was their only disclosure for many years. The important factor here, is retention in care and, in this case, the key was education. The findings of this study suggest that programs that provide accurate sources of education and support may be a powerful source of self-confidence that empower the participants to change their lifestyles and impact the lives of others. A meta-analysis conducted by the HIV/AIDS Prevention Research Synthesis (PRS) Team, found that programs that provide educational programs for their clients were effective in

significantly reducing risky behaviors (Crepaz et al., 2006). The educational programs were particularly empowering to the participants when the clients provided education for one another based on their own experiences. Medley and colleagues (2009) in a meta-analysis of peer education programs for HIV interventions found that peer education interventions were significantly associated with increased HIV knowledge (OR:2.28; 95% CI:1.88, 2.75).

Education is not only important in the sense of self-care though. These findings also revealed a motivation toward altruism, or to give to others, that was not previously identified in the DPM. All but one of the participants spoke of his desire to take what he had learned about HIV and share his experience with others. Emlet (2008; 2011), in a study of 25 older adults with HIV, described the need to give back to the community, particularly to younger generations and those newly infected, as the drive to achieve a sense of generativity as originally described in Erickson's stages of development (Erickson, 1950). Poindexter and Shippy (2010), in their study of 34 HIV infected adults over 50, found full disclosure of HIV was a means of resisting stigma. Similarly, the participants in this study resisted the stigma that they encountered on the streets by educating themselves and sharing with others about their experiences of being HIV positive.

Overall, the experiences of HIV status disclosure for older AA MSMW are very similar to those of most PLWH over the age of fifty. However, some authors have raised the concern that men who have sex with both men and women, particularly AA and other cultural groups, may be more willing to share their HIV status with male sex partners than with female (Bingham, Harawa, & Williams, 2013; Malebranche, Arriola, Jenkins, Dauria, E., & Patel, 2010; Shearer et al., 2012). This is concerning as it would place women at greater risk of infection. Interestingly though, in this small sample, participants described being equally willing, or reluctant, to disclose their HIV status to their sexual partners regardless of gender. These

findings are reassuring but deserve further exploration. While the men in this study indicated that the progression in disease management had changed their attitudes towards disclosure, more research confirming actual disclosure practices is needed.

Limitations

This study has several limitations. First, participants were recruited from a single HIV clinic serving a specific population in a single geographic region. Therefore, the experiences of these men may be very different to the experiences of men from other regions of the US. However, the HIV clinic utilized best practices for HIV and AIDS care, incorporating an interprofessional team to deliver evidence-based treatment to a traditionally underserved population. This type of community clinic and other similar programs are found across the nation serving similar populations and therefore may provide useful lessons that are transferable. A second limitation was the format for data collection, which represented a novel method for this topic but had a number of challenges. It is unknown how the findings might differ if traditional focus group or individual interview methodology had been used. However, online discussion groups offer a unique method for addressing highly personal or stigmatized health issues while maintaining anonymity. Finally, data analysis was built upon a single theoretical model, the DPM. This model was used to develop the initial discussion board questions and to develop the coding scheme. In spite of this limitation, the DPM represents the state of the science in theoretical models for HIV disclosure; however, future research on HIV-status disclosure among older African American MSMW should continue to include new and alternative models and theoretical frameworks.

Conclusion

The participants in this study shared many similarities in their ethnicity, their age and their sexual identities and practices. However, these participants differed greatly in other aspects of their disease and lives. Some were newly diagnosed while others had been positive for years, some were highly educated while others were not, and some had family they could depend on for support in addition to their care clinic while others depended entirely on their health care team. Yet the important lesson was that for the majority of these men, the disclosure process became easier with time. These men shared that when they were linked to a care provider team and provided with programs that helped them to better understand their disease, they felt more capable to explain and discuss their situation with others. By providing a space where they could share their experiences, these men appeared to develop a greater desire to act altruistically in helping others avoid HIV infection. With more than 50% of all PLWH being over the age of 50, and with an increasing percent who are African American, it is incumbent upon the research community to better understand disclosure among older AA adults. Working *with* communities to develop programs and ideas can be an effective strategy to empower groups to overcome health disparities that stem from stigma such as HIV status, age, race and sexual orientation.

CHAPTER 5

Conclusion

I have always been one to march to the beat of my own drum. Generally, when someone tells me that something must be done a specific way, I tend to do exactly the opposite. This journey has been no different, much to the chagrin and annoyance of my committee I'm sure. As with most of life, some of my choices went well and according to plan while others . . . well, it turns out they knew what they were talking about after all. While I will never wallow in regret over the decisions I have made, there are a number of things that I would do differently in the future as I reflect back on this experience. There are also some aspects that went better than I could have ever expected and merit further investigation. Good or bad, this experience as a whole has been life-transforming for me and there is not a single thing that I would change about how it actually played out – *every* lesson was valuable.

Recruitment for this study was more of a challenge than I could have ever imagined, yet, not at all for the reasons that I had expected. There are many studies that would support the idea that my biggest barrier to recruitment of older African American men into a research study would be the fact that I am a middle-aged white male. My interactions with the men were actually the best part of doing this whole study. The difficulties with recruitment came with my reliance on colleagues and fellow clinicians to help with drawing attention to my study among their clients. I am guessing this was large-part naivety on my part, lack of time on their part to be able to help, or simply their concern over the privacy of their patients. Given more time and the knowledge that has come with this experience, I would want to change my tactics to rely less

on others and focus more on canvassing local community resource centers with flyers and actually talking to people. That said, this study would not have happened without the help of one particular clinician and her persistence in letting her clients know about the study.

Data collection was another challenge that really ended up being another “learn-as-you-go” process. Part of the problem here was in the system that was used as a tool to collect data, Canvas through the University of Washington. Equally important was the way that I worded my inclusion criteria and thus, my recruitment flyers. I used the phrase, “must have access to the internet” with the idea in my head that this meant “has access to a computer with internet access;” big mistake. Computer access was certainly a big concern for me with this population because of both poverty and a lack of interest in learning modern technology, yet they *all* had internet access through their phones. It never occurred to me that it would be extremely difficult to access UW Canvas as a guest when attempted using a phone. It ended up that I had to meet several of the men at the clinic to help set them up on a computer where they were able to work in the discussion groups. It was a necessity but very frustrating as the whole point of the online format was for the sake of anonymity. If I had it all to do over, I would consider actually doing individual interviews or a set of focus groups in person. If done correctly though, I believe the online format would be effective with this age group and is something that I would like to study more and try again.

Finally, this study really brought to light the importance of education about HIV for this particular population. I would very much like to explore this in more depth. Do education programs impact other aspects of living with HIV? Is it different for people of different ages or gender? What do these education programs look like? I think that science in this field really needs to work with community members as well to determine how best to help them reach out to

others as peer educators. These men, in particular, despite not having computer access are very savvy when it comes to the use of technology on their phones. It would be worth further investigation to see how their skills could be used to help them with outreach and to better understand how disclosure impacts them and those in their communities.

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Appendix A – Discussion Board Questions

Discussion Question 1. What was your first experience with sharing or not sharing your HIV status like? Why did you make the decision to share or not share?

- a. If you chose to share your HIV status with someone, who was it (e.g. partner, friend, family, healthcare provider)? [please do not use actual names]
- b. What was their reaction/response (positive or negative)?

Discussion Question 2. What led to your decision to share or not share your HIV Status?

- a. What were the specific goals that you hoped to achieve?

Discussion Question 3. What role, if any, did your family and community play in your decision to share or not share your HIV status?

Discussion Question 4. What got better or worse as a result of sharing or not sharing your HIV status?

- a. How did things turn out for you, your relationships, in your community?

Discussion Question 5. How has the way you share or do not share your HIV status changed since the first time?

- a. What are the reasons why you are more or less likely to share now?

Appendix B – Survey Questions for Clinical Staff

- 1) Could you please describe the services and programs that are available to older African American men with HIV at the clinic?

- 2) Are any of these services and programs focused on educating clients about their disease?
 - a) Would you please elaborate on the structure and format of these educational programs?

- 3) Are programs available to promote social and/or familial support?
 - a) Would you please elaborate on the structure and format of the support programs?

- 4) Are there specific aspects of these programs and services that focus on enabling and empowering clients to discuss and disclose their HIV status?
 - a) Would you please elaborate on these aspects?

- 5) Can you please give a couple of examples describing how these programs and services help enable and empower clients to discuss and disclose their HIV status?

- 6) Please share anything else you can think of that is available to these men in their encounters with the clinic that might encourage or empower them to disclose their HIV status.

Appendix C – Initial Coding Map
Based on Disclosure Process Model

