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#### Abstract

The purpose of this study was to investigate the experiences of African American men living with HIV/AIDS. The questions guiding the study were: (a) How do African American men incorporate HIV/AIDS into their identities? and (b) How do contexts affect the incorporation process? Data from this study was taken from a larger study concerning HIV/AIDS identity incorporation. Twelve self-identified African American men living with HIV/AIDS participated in 1.5-2 hour in-depth interviews. Participants traversed through a four or five step incorporation process. In addition, a disclosure process occurred. The contexts that influenced the incorporation process included the interpersonal context (e.g., support and stigma), sociocultural context, (e.g., race, class, sexual orientation), the temporal context (historical time), and situational context (e.g., a personal history of chemical dependency) (Ickovics, Thayaparan, & Ethier, 2001). These contexts intersected and affected participants' integration of the HIV/AIDS identity into the self. Study findings have implications for HIV/AIDS educators and health professionals

#### Keywords

HIV/AIDS, African American Men, Identity Incorporation, Contexts

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#### "I Heard He Got the Package": African American Men's Experiences of Living with HIV/AIDS

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The purpose of this study was to investigate the experiences of African American men living with HIV/AIDS. The questions guiding the study were: (a) How do African American men incorporate HIV/AIDS into their identities? and (b) How do contexts affect the incorporation process? Data from this study was taken from a larger study concerning HIV/AIDS identity incorporation. Twelve self-identified African American men living with HIV/AIDS participated in 1.5-2 hour in-depth interviews. **Participants** traversed through a four or five step incorporation process. In addition, a disclosure process occurred. The contexts that influenced the incorporation process included the interpersonal context (e.g., support and stigma), sociocultural context, (e.g., race, class, sexual orientation), the temporal context (historical time), and situational context (e.g., a personal history of chemical dependency) (Ickovics, Thayaparan, & Ethier, 2001). These contexts intersected and affected participants' integration of the HIV/AIDS identity into the self. Study findings have implications for HIV/AIDS educators and health professionals. Keywords: HIV/AIDS, African American Men, Identity Incorporation, Contexts

Since the widespread availability of life-extending medications including protease inhibitors such as Crixivan, and more recent multi-class combination drugs such as Atripla, HIV/AIDS has been considered a chronic illness in the United States (Allday, 2011). Consequently, more individuals are living with HIV/AIDS. In the United States, approximately 50,000 individuals are diagnosed with HIV annually and 1.2 million individuals are living with HIV/AIDS (National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention, 2012).

The experiences of people living with HIV/AIDS (PLWHAs) and, more specifically, how people incorporate HIV/AIDS into their identities, has been the subject of several studies (e.g., Baumgartner, 2007; Dozier, 1997; Gurevich, 1996; Lewis, 1997; Sandstrom, 1990; Tewksbury & McGaughey, 1998). However, the experiences of African American men has not been the focus and since an increasing number of African American men are living with HIV/AIDS, it is important to focus on their experiences (National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention, 2011).

Individuals do not experience living with a disease in a vacuum (Meleis, 2000). Various contexts including the interpersonal context (e.g., support and stigma), sociocultural context (e.g., race, class, gender), temporal context (e.g., historical time and developmental stage), and situational contexts (e.g., pregnancy) (Ickovics, Thayaparan, & Ethier, 2001) affect people's experiences of living with HIV/AIDS. For example, Dovidio and Fiske (2012) explored how racial bias against people of color contributed to "health disparities" (p. 945). They noted that implicit physician and patient biases contributed to disparate medical treatment.

Contexts not only affect how individuals live with HIV/AIDS but also how they make it part of who they are. Identity theorists assert that individuals are comprised of many roles or identities that form a stable self (Serpe, 1987). When a person contracts HIV or AIDS,

he/she must make their HIV/AIDS role or identity part of his/her larger Self. Race, class, (Baumgartner, 2012a) and various aspects of time (Baumgartner, 2012b) were shown to influence access to resources and/or the disclosure process of PLWHAs which affected the HIV/AIDS identity incorporation process. In addition, support and stigma have been shown to influence the HIV/AIDS incorporation process (Gurevich, 1996).

Although, the effects of various contexts on the HIV/AIDS identity process have been researched, the studies concern the experiences of very few African American men. Since African American men account for 70% of the new infections among Blacks in the United States, it is important to know their experiences of living with HIV/AIDS (National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention, 2013), . Specifically, I wanted to know how African American men incorporated HIV/AIDS into their identities and how various contexts affected the incorporation process.

#### **Literature Review**

Researchers have studied the experiences of African American men living with HIV/AIDS regarding risk behaviors (Bond, Wheeler, Millett, LaPollo, Carson, & Liau, 2009; Spikes, Purcell, Williams, Chen, Ding, & Sullivan, 2009), anti-retroviral adherence and discrimination of African American men (Bogart, Wagner, Galvan, & Klein, 2010), and factors that affect HIV-positive men gay and bisexual men living with HIV/AIDS (Han, Lauby, Bond, LaPollo, & Rutledge, 2010). In contrast, HIV/AIDS identity incorporation studies have focused on women (Dozier, 1997; Gurevich, 1996), primarily or exclusively White gay or bisexual men (Lewis, 1994; Sandstrom, 1990; Tsarenko & Polonsky, 2011) primary White men and women (Baumgartner, 2007), and African American and White men and women (Baumgartner & David, 2009). Themes common to the incorporation process included: diagnosis with an accompanying emotional reaction (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Tsarenko & Polonsky, 2011), learning more about HIV/AIDS (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997) and eventual acceptance or integration of the disease into one's identity (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Sandstrom, 1990; Tsarenko & Polonsky, 2011).

The ramifications of various contexts on the lives of People Living with HIV/AIDS (PLWHAs) has been documented. The effect of the interpersonal context, stigma and support, (Ickovics, Therapayan & Ethier, 2001) among African Americans (Galvan, Davis, Banks & Bing, 2008) and on PLWHA's quality of life (Holzemer, et al., 2009) and has been investigated. The influence of race and gender on the experience of living with HIV/AIDS has also been explored (Rao, Pryor, Gaddist, & Mayer, 2008; Squires, Hodder, Feinberg, Bridge, Abrams, Storfer, & Aberg, 2011). In addition, how time influences the experiences of living with HIV/AIDS has been noted (Merriam, Courtenay, & Reeves, 2001).

Regarding the effect of various contexts on HIV/AIDS identity incorporation, interpersonal contexts such as stigma and support affected disclosure of the disease to others which impacted integration of the HIV/AIDS identity (Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Sandstrom, 1990). Likewise, researchers investigated the consequences of historical time on the incorporation of the HIV/AIDS identity (Baumgartner, 2012b; Baumgartner & David, 2009; Lewis, 1994) as well as the influences of race, class, gender, sexual orientation and culture (Ickovics, Tharaypan, & Ethier, 2001) on the process of HIV/AIDS identity incorporation (Baumgartner, 2012a). However, since few of the participants in previous research were African American men, what remains of interest are their experiences living with HIV/AIDS. Specifically, I wanted to know how African

American men incorporated HIV/AIDS into their identities and how various contexts affected that process.

#### **Position of the Researcher**

I have conducted research concerning HIV/AIDS, learning and identity development since 1998. Although I was concerned about the lack of attention those living with HIV/AIDS received from the Reagan Administration in the 1980s, my first foray into conducting qualitative research concerning the lives of PLWHAs was as a doctoral student. I joined a research team that examined how PLWHAs made sense of their illness using Mezirow's (1991) transformative learning framework. My interest in how such a stigmatized illness shaped learning and development continued and I investigated how participants made HIV/AIDS part of their respective identities, how various contexts influenced that incorporation process, and how having HIV/AIDS affected other aspects of one's self.

Through the course of my research, I noticed that the experiences and voices of African Americans living with HIV/AIDS seemed to be somewhat underrepresented. Studies concerning African Americans' risk behaviors (e.g., Bond, Wheeler, Millett, LaPollo, Carson & Liau, 2009) and adherence to medication (e.g., Bogart, Wagner, Galvan, & Klein, 2010) seemed to be more prevalent than the experiences of living with the disease particularly as it related to the incorporation of HIV/AIDS into one's identity. Yet, the need to learn about these experiences was great since African Americans continue to be disproportionately affected by the disease (, National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention, 2013).

#### Method

Qualitative research focuses on the lived experiences of individuals, the meaning they make of these experiences "placed in its context" and "provides understanding of a sustained process" (Tracy, 2013, p. 5). This flexible research method works well for uncovering the experiences of African American men living with HIV/AIDS and how context influences the incorporation process. In addition, the flexible nature of qualitative research allowed me to ask follow-up questions particular to the participant. For example, gay African American men discussed the experience of being triply stigmatized whereas heterosexual African American men spoke about different concerns and I could ask different follow-up probes of each individual.

#### **Data Collection and Analysis**

The data for this study were derived from a larger study on HIV/AIDS and identity incorporation. The original study was comprised of thirty-six participants. Purposive sampling was used to select participants for this study. After receiving institutional review board (IRB) approval from the institution at which I was employed at the time (Northern Illinois University), I contacted AIDS educators associated with AIDS Service Organizations (ASOs) in the Midwestern United States who gave my name and contact information to participants they believed qualified for the study. Snowball sampling also occurred as several participants told their friends who called me to inquire about the study. Participants contacted me via telephone or email to arrange an interview time and location. When potential respondents contacted me, I made certain they met the criteria for the study before arranging to meet with them. For inclusion in the study, participants had to be 18 years old or older and had to have been diagnosed with HIV and/or AIDS for a year or more. It was reasoned that

participants needed at least a year to make sense of their diagnosis and make HIV/AIDS part of their respective identities.

Prior to the interview, I provided participants with a consent form. The purpose of the study, confidentiality issues, participants' right to withdraw from the study at any time, and contact information for the Office of Research Compliance at the institution where I worked at the time (Northern Illinois University) were addressed. Institutional Review Board regulations did not allow participants to sign the consent form but they agreed orally to the terms of the consent form. Participants received \$ 30 for their time.

I used a semi-structured interview approach to preserve the flexibility inherent in this approach and to maintain consistency across interviews. Interviews occurred between October 2009 and April 2010 and were tape-recorded. Initial questions included, "Tell me about your HIV/AIDS diagnosis." "What challenges have you faced as a person living with HIV/AIDS?" and "What experiences have helped you make HIV/AIDS part of who you are?"Interview questions were utilized verbatim or slightly modified from a past study that explored HIV/AIDS identity incorporation (Baumgartner, 2000). Questions that probed the influence of context on the incorporation process were written to include the contexts mentioned in the literature namely sociocultural, interpersonal, temporal and situational contexts (Ickovics, Thayaparan, & Ethier, 2001). Examples included: "What, if anything, has helped you come to terms with HIV/AIDS?" "What might have hindered your ability to come to terms with HIV/AIDS, if anything? Interviews lasted between 1.5 to 2 hours. Perhaps because most participants were current or past HIV/AIDS support group members and some participants participated in groups for those recovering from chemical dependency, most participants were accustomed to talking about their HIV/AIDS-related experiences. Hence, most respondents told their stories in a direct, matter-of-fact way. On occasion, several cried when discussing their relationships with family members. After each interview, I provided summaries of their responses and asked each participant to affirm my perceptions or correct any misconceptions I had. In this way, I was able to conduct a member check during the Twelve of the 36 participants interviewed for the larger study self-identified as interview. African American men. At the time of the interview, the African American men ranged in age from 25 to 66. The average age was 50. Their education level ranged from 11th grade through a master's degree. The range of income was less than \$10,000 a year to \$40,000 a Six participants earned between \$ 10,000-20,000 a year. Eight individuals were year. diagnosed before the widespread use of life-extending medications in 1996. All respondents received their HIV or AIDS diagnosis between 1985 and 2005.

I conducted the interviews and transcribed them verbatim. Spradley's (1980) four-part method of transcription was used because I have found that this method is beneficial in the initial coding process. Initial field notes were taken that concerned answers to the interview questions. I also took brief notes during the interview concerning the participant's attitude, physical appearance and non-verbal communication such as body language. After the interview, I wrote initial notes that contained my impressions of how the participant incorporated HIV/AIDS into their respective identities and how various contexts might have influenced that process. I also compared and contrasted participants' incorporation process and the different contextual factors that influenced the process. The analysis of these notes gave me an initial idea of the HIV/AIDS identity incorporation process as well as contextual factors that influenced incorporation.

Next, data were analyzed inductively using the constant comparative method (Glaser & Strauss, 1967) to do initial coding. I looked for themes within and between interviews. Incident coding was followed by focused coding where I decided which initial codes best categorized my data (Charmaz, 2006). Themes were categorized and refined. Participants received a copy of their respective transcript. They were asked to document changes, send

comments or make corrections. No participants expressed concerns about their respective transcript although several participants did not receive their transcript because they could not be located. In addition, in this study, rich thick description, and an audit trail were utilized to enhance trustworthiness and consistency (Merriam, 2009).

#### **Findings**

#### HIV identity incorporation process

The HIV/AIDS identity incorporation process consisted of four or five phases including: diagnosis, post-diagnostic turning point, immersion in or consultation with the HIV/AIDS community, a post-immersion turning point for those who were immersed in the community and integration. Disclosure to others was also an aspect of the HIV/AIDS identity incorporation process.

#### Diagnosis

Seven of 12 participants did not expect to be diagnosed with HIV or AIDS whereas five respondents were not as surprised to be diagnosed HIV-positive because they suspected they had engaged in risky behaviors. Three men were tested prior to incarceration. Other respondents were diagnosed after complaining about symptoms, taking a routine HIV test or giving blood. For everyone, the diagnosis was the beginning of the HIV/AIDS identity incorporation process and prompted emotional reactions including depression, shock, denial, fear, anger, and relief. Eight of the 12 participants, regardless of the year they were diagnosed, believed they were going to die soon after diagnosis. Many respondents were depressed. Steve's reaction was typical: "I was very, very, depressed and remorseful. My immediate feeling was, 'Life is over. I give up.'" James Brown experienced denial and then became depressed.

[I was in] denial. I was like, 'No, I ain't got no HIV.' And the doctor brought a social worker in and she was giving me places where I can go and he [the doctor] recommended me to get on medication and he gave me a prescription to get the meds and I said, 'No.'. Then it kind of clicked in and I got an overwhelming depression. I'm like, 'Wow. Man.' I'm like, 'Man, I really do [have] this'. The thought came, 'I'm going to die. So I might as well live it up because I'm going to die anyway.' But the feeling was just so DEEP and HURTING. Now I'm like, 'I can't have sex with nobody no more because I'll give it to them and I can't tell nobody. What am I going to do?' I went into a deep depression.

Octavius was diagnosed in prison in 2005 at the age of 25. He was afraid and confused at diagnosis.

[I was] confused. Angry. I just—I didn't know anything about it. I mean everything—what little I did know about it was that it was just something bad to have that led up to death. So, I felt like you know, I may not even make it out of [prison] alive. I may die tomorrow or die tonight or something. That's how I was feeling. . . I was uneducated about it so I didn't know. I was really just angry and confused going through the whole, 'Why me?' thing. What am I going to do? So I was lost then. I was really lost.

Unlike Octavius, Michael was relieved. Although relief was not a common reaction to the HIV-positive diagnosis in this sample, perhaps that reaction could be more indicative of the larger HIV/AIDS community. Michael stated, "I was relieved [when I was diagnosed]. I got an answer to why this stuff is coming out of my ear. Before I was unsure but now, 'OK. Good.' We could work toward solutions."

In addition to the initial emotional reactions, there were behavioral reactions to the diagnosis. Chemically dependent participants tended to increase their drug use for a period after diagnosis. Others went on spending sprees. Wene's reaction was typical for those struggling with chemical dependency issues prior to diagnosis:

They just said I was HIV-positive. What happened was, when they told me that I said, 'Ok.' I went out on my own suicide mission because I was under the impression [that] I was going to die. Freaked me out. Give me bottle of Jack. Just leave it. . . I'd say for about the first year, I was under the impression that I was going to die. Nobody told me anything different, OK? So, I'm going out here celebrating like 1999. Pass the marijuana. Pass the booze. Hey, let's do this, OK? I had nothing to lose now, brother.

These initial emotional and behavioral reactions lasted from several days to several years until an event or occurrence propelled them from their initial reaction after diagnosis. This "turning point" was generally the second phase of the HIV/AIDS identity incorporation process.

#### **Post-diagnostic turning point**

For nine of the 12 men, education about the disease served as a turning point from their initial reaction. Ed stated, "The recovery program had us going to where we talked about different HIV medications and we talked about how people are living longer with HIV and AIDS. . . It gradually started to dawn on me that I wasn't going to die from HIV and AIDS."

For others, serious illness, seeing long term survivors, or living with the disease for a period was the turning point. Kelven credited an HIV/AIDS support group for African American gay or bisexual men for educating him, providing him an opportunity to educate others and for showing him that individuals survived and thrived with the disease. He noted,

The turning point for me was—[names support group for gay and bisexual African American men] at [an AIDS Service Organization]. . . Then I started going to that agency. That was my turning point. Somebody said, 'You are too smart to keep feeling sorry for yourself. You need to help somebody else.' They started sending me out and volunteering and doing outreach the bathhouses. I'd never been in a bathhouse in my life. I gave out condoms and they ask questions about transmission of HIV. That was the changing point. So, it was seeing other people who were not waiting to die. The feeling of knowing that there's hope. There is a way and helping somebody else.

Seeing other long-term survivors was the turning point for Michael. He stated, "What made me really come to terms with it was when I saw people with 20-25 years that had the disease that were still living. Some of them had never even taken medication ever."

#### Immersion in or Consultation with HIV/AIDS community

The post-diagnostic turning point was followed by immersion in or consultation with the HIV/AIDS community. In another study on HIV/AIDS identity incorporation, individuals immersed themselves in the HIV/AIDS community because they wanted to give back to their communities and they expected to die reasonably soon from the disease (Baumgartner, 2007). Immersion in the community consisted of being extremely involved in ASO activities, claiming HIV/AIDS as a primary identity, and educating oneself and others on HIV/AIDS (Baumgartner, 2007). Individuals sought the HIV/AIDS community as a refuge. In another study that examined the incorporation of the HIV identity only, an immersion phase did not occur (Baumgartner & David, 2009). In this study, immersion in the HIV-community was sometimes based on fear of imminent death and a need to give back-especially for those diagnosed before the advent of life-extending medications. However, immersion occurred just as often because of a situational circumstance such as placement in chemical dependency recovery homes for individuals living with HIV/AIDS or living in housing for HIV-positive individuals. The immersion phase occurred for seven of the 12 individuals. Octavius's comments were typical of individuals immersed in the HIV/AIDS community and living in a drug recovery home for PLWHAs. Octavius noted,

I stay at a recovery home but everyone in there is [HIV] positive. It's also drug-related. [My HIV identity] is up there because that's what my life is consisting of. I go to school I go to AA meetings. Right now that's all that's going on in my life.

Equally as often, participants consulted the HIV/AIDS community by obtaining information from programs and services at ASOs. Many respondents also taught others about HIV/AIDS. However, HIV/AIDS was an *aspect* of their lives but it was not all-consuming. James Brown attended HIV/AIDS and Alcoholics Anonymous support group meetings and educated others but HIV/AIDS was not a primary identity. He stated, "[HIV] is something I have but not something I am. I have it. I am dealing with it. . .I go to my support groups and I take my meds and I go to the doctor."

#### **Post-immersion turning point**

Whereas three respondents described themselves as *currently* immersed in the HIV/AIDS community, four individuals of the seven immersed in the HIV/AIDS community stated that they were no longer immersed. The turning point from immersion in the community was time dependent. In addition, for one person the advent of life-extending medications was a turning point. Participants had successfully lived with the disease for a period and realized that HIV/AIDS did not have to be the focus of their lives. Steve's story was typical. His doctor had said Steve had five years to live after diagnosis. When Steve lived beyond the doctor's prediction, Steve began to realize he might live long-term with this disease. He stated,

It didn't happen like, "Snap!" I would say after the fifth and then the sixth and seventh year came up, I started thinking that I'm not going to die. . . I started gradually re-thinking my future and my perception of how. . . how much HIV and AIDS—you know how much of a central issue that was in my life.

#### Integration

Nine of 12 participants had integrated the HIV/AIDS identity into their selves. Some respondents had not experienced the immersion phase whereas others had. Integration was marked by a lessening in importance of the HIV/AIDS identity. Integration was also assisted by participants educating others concerning HIV/AIDS. Michael noted that he could freely discuss being HIV-positive with others.

A lot of people aren't comfortable with it but then when I become comfortable with it and I talk about it. I don't care about what you think. I'm comfortable with myself and that's when I started learning more about it and I knew I could become a voice for it. Lots of times nobody wants to say [anything] about it. . . In the Black community don't nobody want to say they are HIV positive and they [don't have] a face for it. Now if somebody comes out like me—Man, I'm the face for it. Lot of times when I'm at an AA meeting I talk about my HIV and I tell them about support groups.

Michael said that HIV was not his primary identity although it was one of his identities. For those individuals who had been immersed the recognition of a less salient HIV/AIDS identity signified that HIV/AIDS was a more integrated identity. Steve stated that time had helped with incorporation of the HIV/AIDS identity. He said, "People are living longer and healthier and for me, it's time to focus on living and not be so consumed with. . . HIV. It's not much of an issue with me."

#### **Disclosure Process**

Throughout the incorporation process, individuals disclosed their HIV-positive status. The disclosure process initially included participants disclosing to professionals (e.g., counselors and medical doctors), family, and close friends. Later, respondents revealed their status in support groups or in more public settings. Third, a few individuals stated that they disclosed more selectively after disclosing in the support group. Al first told a close friend:

[I told a] close friend of my, who was gay, you know. I told him and he said, "Guess what? I have HIV too." I didn't know. This whole time I didn't know. . . He was the one that turned me on, besides my case manager, about the [HIV/AIDS support] group because he invited me to group. That's how I really go into it. He really helped me out.

Since participants were solicited from an AIDS Service Organization (ASO), it is not surprising that most participants had disclosed their HIV/AIDS status in an HIV/AIDS support group and/or a support group for people struggling with chemical dependency issues and HIV/AIDS. Michael initially disclosed his HIV-positive status in a support group. He said,

Eventually, I started talking about [my diagnosis]. I ended up going to [a chemical dependency center]. . [A counselor] started his own little class like every Tuesday because his class was all the people that were infected. We talked about it and then I met more counselors who were HIV-positive, long term, 20 years. 25 years.

A few respondents shared their HIV-positive status as needed after the more public announcement to the support group. James Brown worked in the HIV/AIDS community and was a counselor. So, he shared his status at work and had shared his status very publicly to a newspaper. Yet, outside of his work setting, he appeared to share his status more selectively.

He said,

Some people still [have] stigmas. I'd rather for the person to get to know me before they judge me. Once they get to know me and I know them then I share with them. 'You know, man. I'm HIV-positive. Just to see their reaction from them really knowing me. Most of them accept me.

In sum, the incorporation process included:

- 1) a diagnosis followed by an emotional and behavioral reaction,
- 2) a post-diagnostic turning point,
- 3) immersion in or consultation with the HIV/AIDS community,
- 4) a post-immersion turning point and
- 5) integration.

Disclosure was also an integral aspect of the incorporation process.

In the next section the influence of various contexts on the HIV/AIDS identity incorporation process are discussed. These contexts include the interpersonal context (e.g., support and stigma), sociocultural context (e.g., race, class, gender, sexual orientation and culture), temporal context (e.g., historical time), and situational contexts (Ickovics, Theraypan, & Either, 2001).

#### Contexts

#### **Interpersonal context: Support**

Everyone received support around their disease from support groups, family and friends. Support from others permeated many phases of the incorporation process. For some, support was a turning point from the initial emotional reaction and it as a large part of the immersion phase for others. Last, support from non-HIV positive individuals also assisted with integration of the HIV/AIDS identity.

James Brown was active in support groups for individuals with HIV and chemical dependency issues. At this point, he was immersed in the HIV/AIDS community. He stated,

Are you familiar with the R\_\_\_\_ Center? It's for alumni and your case manager is there. They serve breakfast and lunch and when I was in the HIV and AIDS treatment facility, we could get on the van and go to the community center and they would have groups. Support groups. We would have support groups from like 9 [a.m.] until 3-4 o'clock [p.m.] and we sit down and talk about how we are taking our medication and how was our visit at the doctor and what is our goal as far as leaving the center and getting our own place? Did we meet with our family? Did we tell our family we are HIV positive? How did our kids take it? Are we communicating with our kid? Are we looking for work? These are things we do there. You get to hear other people going through their thing and also if you go through something you get to get advice from other people that have been through what you are going through. I go religiously every week. . . I go to one on Tuesdays and I go to one on Wednesdays and Thursdays I do a one-on-one with my case manager.

For others, emotional support and information gained in the support group served as a turning point from the initial reaction to the diagnosis. Octavius learned about HIV/AIDS and saw other long-term survivors which served as a turning point from the initial reaction to the diagnosis.

[After my diagnosis, medical staff] suggested that I come for the HIV support groups for people who are positive. Everybody that is in there is positive like myself. They suggested I come there and meet other people who are living with HIV and learn more about it instead of just being to myself and not knowing because they felt that would help me out to be amongst others who were living with it for a long time so I could see that there's still hope. That I'm not going to die. That as long as I take care of myself that I can live for 20 years or be one of the people that says I've been positive for 20 years or 25 years just like the people in the group and stuff.

Last, support from others helped with integration of the identity as individuals revealed their status to friends or potential romantic partners and were accepted. Being accepted by family and friends helped participants accept the disease. Ed told two women that he was HIV-positive. He stated,

I told two women that I was HIV- positive and having them still accept me. That to me was something very special because I don't know if I could have done that if the shoe was on the other foot. I don't KNOW if I could have.

Debonaire added,

When I moved back to [a Midwestern city], and I got involved in the HIV community, I was dating a female and she knew. I told her and she was going to accept it and she was an older woman. So, that helped [me accept being HIV-positive].

Support from others encouraged HIV/AIDS identity incorporation. However, stigma delayed the HIV/AIDS identity incorporation process. Fear stymied HIV/AIDS education, disclosure, and seeking treatment for HIV/AIDS.

#### **Interpersonal context: Stigma**

Every participant had a stigma story. Stigma decreased disclosure to others which impeded the incorporation process. A lack of disclosure to others meant a lack of support, increased fear and isolation, and in some cases refusal of medical care. Octavius's story best exemplifies how stigma can stymie support, education, and treatment in a prison environment.

I could have seen a therapist or something like that. But I didn't want to. I was afraid of putting that out there and letting anybody know [about my HIV diagnosis]. People who I knew from the streets that were [in prison] with me

and just all of us being amongst each other and me being around them and hearing conversations we all had. They be talking about: "Yeah, he got that stuff." "He got that package." Or "He messed up.". . . I just didn't feel like being talked about and a little bit different. . . I didn't get medication based on the fact that I didn't want anybody even knowing that I was up there getting in the medication line. They would be like, "What you taking meds for?" So I figured that I wouldn't let nobody know. [Prison officials] offered me medicine. I told them I didn't want it. . .I didn't want to be seen in those groups. I just didn't want my status being out. Just hearing people talk about people, man. I just didn't want [anybody] looking at me and talking about me like that.

Five of the 12 participants mentioned the triple stigma of being Black, HIV-positive and gay which meant Black gay men failed to get adequate support around their diagnosis until they worked through the stigma. Al asserted that African Americans are less likely to discuss being HIV-positive. Kelven agreed that an HIV-positive status in a Black man meant he also had to carry the stigmatized identity of being gay. He stated, "If I'm HIV-positive in the BLACK community it means you are gay. . . The bigger Black community thinks HIV equals gay. Being gay is a stigma. . . Even [Black] gay men now who have HIV don't TALK to each other. Yeah! Today! I go into a bar and half [the people there] are positive and they are best friends and they still don't tell each other they are positive." Debonaire confirmed Kelven's perceptions.

But it is still an issue in the Black gay community and the Black straight community. Very, very few of us are courageous enough to talk about these stigmatizing type of issues that keeps us stuck and not be able to grow. I think I just wanted to grow. I know I had wings and I wanted expand them now. And I have to get to a point where it didn't matter what you thought of me. I have to love myself first and make sure that I'm being the best person I can be so if you are thinking something negative about me without getting to know me that's not my issue, it's yours. I had to get to that place. But a lot of Black men are scared to go through the process to get to that place because they've got to deal with these issues within them. We're socialized to do and don't talk.

Whereas it is clear that race, sexual orientation and HIV-positive status was triply stigmatizing for African American gay men, it also affected African American heterosexual men. Tiger Claws said,

Race-wise—a lot of people in my race...They believe that if a Black man has it then he must be gay or he has had gay encounters. They don't believe that it could be heterosexual. They don't believe it is a heterosexual disease. They believe it's a gay disease. Most of the people in my race. They believe it comes from gay people. It affected me at first until I learned better.

#### Sociocultural contexts: Race

Clearly, race in combination with sexual orientation and HIV-status stigmatized individuals. However, race alone also influenced treatment in the larger medical community. It is difficult to know how this affected the integration of the HIV/AIDS identity. However, it

certainly affected the experience of living with HIV/AIDS as an African American man. Debonaire spoke to the disparate treatment African American men received in the medical community. He said,

Based on my observations with other African American males who may not have the educational thing that I had going on. I have seen them treated differently. They seem to not know any better. It's like a... It's more like a....get you in and get you out with no feeling behind what is being done. There's no feeling behind the people who are trying to do things for you. Because I'm sensitive. If you aren't treating me as a human, I'm going to speak.

Steve added,

I think there is a disparity in the....how do I want to put it...the medical profession. I think we are treated differently. I think this is why we have to do our homework and when we go to our medical providers we have to be prepared to push questions and not assume—I think everyone should do that but I think African Americans in particular and I think it's almost a subconscious racist thing that doctors do that. I don't know why or what it is. Most of the healthcare providers I've had, *all* of them, really, I think are very competent and try to do their job but they become overwhelmed and a lot of times it's a public clinic and they—I'm trying to give them the benefit of the doubt, but I do feel at times that if I don't push for the best care or best service out of them that I won't get it. I can't just sit back and let myself go through a conveyor belt, you know.

Interestingly, although personal treatment of African Americans in the medical system was seen as inferior, no one indicated that access to medications differed between races. In fact, four individuals explicitly mentioned that both African Americans and Whites had equal access to medications. Michael noted, "I really haven't had too many challenges. I've always been able to get my medication. Doctors. Personally, some of my doctors—they are on top of their game."

Race combined with class when individuals discussed resources for HIV/AIDS in the African American community. Michael's observation captured several participants' sentiments:

I've never understood that. In the Black community why we don't got all them [names ASO]. All the [names service organization]. Then again, I do know why too. Because in the early days when HIV/AIDS first came out there was a lot of people with money that they knew somebody and they started giving money into these places like here. . . Poor people got no money. . . A lot of their stuff comes from corporates. People that have trusts because somebody in their family had HIV and AIDS and they put money into it. Now, in the Black community there [isn't anyone] that's got a lot of money. They don't want to talk about it. I think that's one reason. But I think they could partner with somebody like they could partner with [names hospital] and have some place where they could come in and get tested. Get some money from them and get tested.

#### **Sociocultural Context: Class**

Individuals noted that being poor meant HIV/AIDS was on their minds more. However, some were thankful for the medical programs that provided them access to medications. Al was glad he was a veteran and could obtain his medications fairly easily.

The advantage I had is that I was a veteran so I get all my meds through the VA. That was the good thing. Then when I found out that I didn't have to pay for them—I don't want that to sound bad—because even if I wasn't a vet I wouldn't have to pay for them but by me being a veteran, I get my meds through them.

In contrast, Octavius forewent medications in jail because he believed that as a poor prisoner, that he would not be given good medication. He believed the prison system would treat him like a "guinea pig." Regarding being poor and living with HIV, he stated,

It would probably have been a little easier to deal with it [as a wealthy person] because I would have known for sure, well they aren't going to guinea pig me. I have a lot of money. They would make sure to give me the right stuff. If I do decide to use a therapist I could use Dr. Phil or something [laughter].

For Steve, just struggling to live was difficult being poor. He confided,

It's made it more of a challenge to navigate the healthcare system to get financial aid to pay for my medications to get good quality doctors. Living. To have a decent place to live, I've had to struggle with that for a long time.

Tiger Claws believed HIV was more on his mind because he was poor:

And by the economy being the way it is now they are cutting a lot of programs too because that makes it difficult because you never know when your turn is going to come when the program you are in might be cut. Then you are like, "What am I going to do after that?"... It makes you want to prepare for that. Save money. Live better and be prepared for the worst. Because if it happens, I'm preparing myself and when it *does* happen I'll be able to move on from it and move on to something hopefully better even if I have to move to another city or move back to M\_\_\_\_\_ or do something that it's going to keep me stable.

Although it is difficult to know how economics affected the HIV/AIDS identity integration process, it appears that poorer individuals spent energy navigating the healthcare system and worrying about funding for HIV/AIDS medications which might have meant that HIV/AIDS was on their minds more than it would have been if they had adequate funds.

#### Sociocultural context: Sexual orientation

Although only four individuals commented on the influence of sexual orientation as a separate positionality affecting their experience of living with HIV/AIDS, it is worth noting. Three participants indicated that gay individuals perhaps had an easier time in the gay community discussing HIV/AIDS. Al stated,

Yeah. Yeah. In the gay community, you are around gays OK. You can talk. Being in the straight community, you can't do all that talking because a lot of people don't understand. They don't know how to accept this. There are still some people out there today that can't accept this. They think it's a BAD thing. God is punishing you.

Steve stated, "Well, the....ah....I go to another support group. . . and we had some heterosexual people who were diagnosed that had HIV and they said at the group meetings that they felt that gay people more services and we get more stuff than they get. It might be true. I think it's because we are more in order.

Ed, a heterosexual, found his experience in support groups less helpful because he is heterosexual. He admitted,

It was still problematic because sometimes I would be one of two straight men in a room of five to 12 men and maybe one female or one [male-to-female] transgender. . . Their issues are not really my issues. . . Their issues are like totally different. How do you tell a woman that's straight who doesn't have HIV who wants to have kids—wants to have a future that you are HIVpositive? A gay man doesn't even have a concept of what to say and even if he does, his ideas are like totally off. . . I think the ideal support group would be for me to be in a group with women, heterosexual women and heterosexual males all talking about how hard it is to meet each other.

Whereas heterosexual men felt marginalized in HIV/AIDS support groups in some cases, everyone contracted the virus at a particular point in historical time. Interestingly, because of a lack of correct information about the disease, most participants saw the diagnosis as a death sentence.

#### **Temporal context: Historical context**

The historical context of diagnosis did little to alleviate the fear and depression at diagnosis because of the lack of access to accurate information about HIV/AIDS. In short, individuals diagnosed after the widespread use of life extending medications in 1996 were just as likely to assume they were going to die shortly after diagnosis as those diagnosed prior to 1996.

Booker was diagnosed in 1989, when individuals in the gay community were "dropping like flies." The images of those earlier days of the disease stayed with individuals diagnosed after the widespread use of life-extending medication. For example, although Kelven was diagnosed HIV-positive in 1999, he had seen the gay community shattered by the disease in the 1980s and 1990s. He was "devastated" when he was diagnosed. He said, "I gave up on life. . . I still had images of AZT and wasting away."

#### Situational context: History of alcohol and/or drug use prior to diagnosis

Ten of the 12 respondents reported a history of alcoholism and/or drug use prior to diagnosis. This situation caused participants to make unwise choices and perhaps put themselves in situations that made them more susceptible to HIV/AIDS. This finding is perhaps not that surprising since the ASO from which they were solicited also served individuals struggling with chemical dependency issues. This situational context certainly

influenced the behavioral reaction to their diagnosis. Prior to diagnosis, they had coped with life's challenges by using alcohol and drugs and this way of coping was familiar.

It is possible that the pre-diagnostic situational context of alcoholism increased participants' risk for contracting HIV/AIDS (Shillington, Cottler, Compton, & Spitznagel, 1995) and needing to incorporate the HIV/AIDS identity in the first place. Additionally, some participants indicated that their continued alcohol use meant they did not always practice safer sex even after they were diagnosed which confirms findings other studies (Stein, Herman, Trisvan, Pirraglia, Engler, & Anderson, 2005).

#### Situational context: Beliefs about HIV/AIDS affected incorporation process

Although seven individuals were diagnosed before 1996, four of the seven were diagnosed in 1994 and 1995 when AZT was readily available and some individuals had access to protease inhibitors in 1995 as the Federal Drug Administration had approved their use (History of HIV/AIDS in United States, 2012). Yet, most participants believed they were going to die soon after diagnosis. Octavius was diagnosed with HIV in 2005. He said, "I just—I didn't know anything about it. I mean everything—what little I did know about it was that it was just something bad to have that led up to death. So, I felt like you know, I may not even make it out of here [prison] alive. I may die tomorrow or die tonight or something. That's how I was feeling." Steve, diagnosed in 1995 stated, "I didn't know very much at all. I was ignorant like most people are around that era. I didn't know what T-cells were or protease inhibitors were. I knew nothing. I was ignorant. I thought you could get it by someone sneezing on you. . . I think it was just fear because I didn't know. The fact that I didn't know, you know, when people are afraid, your imagination runs wild and then I would just conceive these things in my mind about what HIV and AIDS was. Because we didn't really talk about HIV. Everybody was AIDS. There was no precursor. It was just AIDS."

The lack of knowledge of treatments for the disease meant individuals lived in fear of imminent death when treatments were available for the virus. This lack of correct information perhaps delayed their turning point from the initial reaction to the diagnosis.

#### **Conclusions and Implications**

#### **The Incorporation Process**

The HIV/AIDS identity incorporation process uncovered in this study largely confirms results of previous studies (Baumgartner, 2007; Baumgartner & David, 2009). Study findings mirror the incorporation process of those in the larger current study from which this population was taken. Further, the findings confirm the reactions of individuals diagnosed with HIV/AIDS in other studies. For example, shock and fear are common reactions to an HIV/AIDS diagnosis (e.g., Dozier, 1997; Sandstrom, 1990) and other chronic diseases such as multiple sclerosis (Kralik, Brown, & Koch, 2001).

An interesting twist in this study is the reaction of relief to the diagnosis. In another study (Baumgartner, 2007), a participant experienced relief because he felt doomed to contract the disease and the diagnosis was the confirmation of what he thought was inevitable. In this study, the respondent felt relief because now knew why his ear had a discharge. He could begin to address his health issues because they were properly diagnosed. This finding is more reminiscent of other diseases such as lupus or fibromyalgia (Mendelson, 2006; Schaefer, 1995) in that a correct diagnosis brings relief because individuals can take action instead of wondering what ailment they suffer from. However, unlike fibromyalgia, which is sometimes misdiagnosed, HIV/AIDS is more easily diagnosed.

The evidence of a post-diagnostic turning point after the initial reaction to the diagnosis confirms findings of other HIV/AIDS incorporation studies (Baumgartner, 2007; Baumgartner & David, 2009) as well as the larger chronic illness literature. Meleis (2000) states that "Critical points were often associated with increasing awareness of change or difference or active engagement in dealing with the transitions experience" (p. 21). Likewise, transitioning from an ordinary life to a more extraordinary one is discussed in Kralik's model of transitions which is found in the larger chronic illness literature (Kralik, 2002). In sum, support and education about HIV/AIDS were vital to the post-diagnosis turning point.

The few participants that immersed themselves in the HIV/AIDS community and experienced a post-immersion turning point mentioned that living with the disease for a period served as a post-immersion turning point. This is in contrast to another study (Baumgartner, 2007) that found that the advent of highly antiretroviral therapy (HAART) was the post-immersion turning point in addition to "burn out" in the HIV/AIDS community (Baumgartner, 2007, p. 925). The finding that living with the disease for an extended period was a turning point might indicate that HIV/AIDS is being perceived and experienced as a truly chronic illness such that time alone serves as a turning point. This finding was also reflected in the larger study from which this population came. Last, this finding confirms findings concerning identity development and cancer (Mathieson & Stam, 1995) and depression (Karp, 1994). However, perhaps caution should be used when considering this finding. Paterson (2001) conducted a metasynthesis of 292 qualitative studies on chronic illness and concluded there were three perspectives on chronic illness. The "illness in the foreground" (p. 23) perspective was commonly seen in newly diagnosed individuals where the focus was on loss and complete absorption in the illness. The "wellness in the foreground" perspective is evidenced by objectifying the body and realizing the body is not one's entire identity (Paterson, 2001). Individuals who are in the wellness perspective often teach others about the disease and have an increased appreciation for life because they feel in control of their disease (Paterson, 2001). The difference between the illness and wellness perspectives is the idea of controlling the illness. The shifting perspectives model acknowledges that wellness can be the foreground sometimes and illness can be in the foreground sometimes and that shifts occur. Hence, although this study generally shows that individuals traversed from an "illness in the foreground" to "wellness in the foreground" perspective, it is possible that a perception of a lack of control over the disease could shift individuals back into an "illness in the foreground" perspective (p. 23) and the actual amount of time living with the disease would be irrelevant to integration. Individuals might return to the immersion phase where the disease was forefront in their mind and a large part of their identity. Hence, time living with the disease is not entirely indicative of a permanent integration.

Those immersed in the HIV/AIDS community joined support groups, had HIV/AIDS as a central identity, learned about HIV/AIDS and taught others just as those had in an earlier study (Baumgartner, 2007). However, in the earlier study, immersion in the community was not seen as a matter of situational context in that individuals were not housed in HIV-positive housing nor living in chemical dependency centers for HIV-positive individuals. In the earlier study, individuals flocked to ASOs because they were a clearinghouse of information on the disease and a refuge from a larger community where HIV-positive individuals were stigmatized. In this study, which was reflective of the larger population used for this study, the situational context that these men found themselves , namely housing for HIV-positive individuals who were and were not chemically dependent, almost forced an immersion in the HIV/AIDS community for a time. Perhaps this result speaks more to the resources available for HIV-positive individuals now as opposed to earlier in the history of the disease. In

addition, all but one of the 12 African American men in this study lived in a large metropolitan area where such resources were readily available.

Integration was marked by a lessening in importance of the HIV/AIDS identity, and by participants educating others and being accepted by others. This finding confirmed the decentralizing aspect of integration of the previous study (Baumgartner, 2007) and the importance of education in the integration stage (Baumgartner & David, 2009). An interesting addition in this study was that the acceptance of the disease by significant others helped the integration process.

In sum, the HIV/AIDS identity incorporation process was similar to processes found in previous studies (Baumgartner, 2007; Baumgartner & David, 2009). However, some individuals in the immersion phase might have been in that phase due to situational circumstances such as living in HIV/AIDS housing. In the next section, the effect of other contexts on the incorporation process will be discussed.

#### **Contexts and the Incorporation Process**

The interpersonal contexts of support and stigma (Ickovics, Thayaparan, & Ethier, 2001) were evident throughout the incorporation process. Support from others was a turning point from the initial reaction, part of the immersion phase, and it also helped with integration of the HIV/AIDS identity into the self. Accurate information about HIV/AIDS and emotional support from group members helped individuals move from their initial reactions to the diagnosis to dealing with the disease. This finding is also shown in kidney patients' experiences in support groups where group members benefited from information from others with the disease and positive role models for living with the disease (Hughes, Wood, & Smith, 2009). Additionally, other studies mentioned that joining the HIV/AIDS community promoted integration of the HIV/AIDS identity and immersion in the community was a way to deal with the stigma part of the process (Lewis, 1994; Sandstrom, 1990). Family, peer and instrumental support were mentioned as part of the identity transition process of individuals living with HIV/AIDS (Tsarenko & Polonsky, 2011).

Clearly, support is integral to incorporation. However, support might be especially necessary for those living with stigmatized conditions. The need for support throughout the process of integration of what, arguably, is a socially stigmatized identity is evident in other literature. For example, Cass (1979) discusses gay identity development and the need for contact with other gay individuals who validate and "normalize their behavior" (p. 231).

Whereas support assisted the HIV/AIDS identity incorporation process, stigma impeded the process in that stigma prevented individuals from seeking support from others and disclosing to others which was integral to incorporation of the HIV/AIDS identity. Other HIV/AIDS identity studies have also found that stigma delayed disclosure which impeded the incorporation of the HIV/AIDS identity (Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). In addition, the sociocultural stigma of being African American, gay and HIV-positive initially prevented individuals from reaching out for support. In this way, individuals in this study perhaps had the most difficult time dealing with their disease. This population was less likely than those from other demographics in the larger study or in other studies (Baumgartner, 2007) to disclose their status in very public ways such as discussing their status on television or in newspapers. They tended to be more careful about the disclosure of their status. Participants also mentioned that African American men did not discuss their status as easily as those from other demographics because of HIV/AIDS being associated with gay individuals. Even disclosure amongst gay African American men seemed to be more guarded than for other groups represented in the larger study. This finding supports literature has shown that HIV-positive gay, Black men and Latino men are stigmatized in their communities (Brooks, Etzel, Hinojos, Henry, & Perez, 2005) and that HIV/AIDS is more stigmatized in the Black community in general (Baumgartner, 2012a).

Regarding the influence of race, class, and sexual orientation on the HIV/AIDS identity incorporation process, some participants mentioned that Black men in general were not treated as well as Whites in the larger medical community. Further, race and class meant poor Blacks had less access to information and resources. They did not directly connect a lack of resources or poorer treatment in the larger medical community to the incorporation of HIV/AIDS into their identities but it is possible that a lack of care in the larger medical community could mean less access to resources which can affect the post-diagnosis turning point, disclosure and integration of the HIV/AIDS identity. In addition, being from a lower class kept HIV/AIDS on some individual's minds which reflected the findings of the larger group (Baumgartner, 2012a). Participants mentioned that they feared federal and state HIV/AIDS programs were going to be cut which might affect access to medication. As a poor Black male prisoner, Octavius believed he could not trust that he'd receive proper medical treatment in prison and that they would "guinea pig" him with experimental medications. Hence, he did not disclose his status in prison, receive counseling or medication for his disease and waited until he was released from prison to access HIV/AIDS resources. Although Octavius did not explicitly mention his hesitation for accessing medication in prison, others in the larger study mentioned the impact of the Tuskegee Syphilis Experiments on the general psyche of African Americans. Hence, this attitude of Octavius's is not in isolation and is well-documented as a reason that African Americans do not participate in experimental drug trials as readily as Whites (Freimuth, Quinn, Thomas, Cole, Zook, & Duncan, 2001). It is important to mention that the other African American men in the study did not evidence a lack of trust in their medical treatment. In fact, Booker indicated his annoyance with the African American community for foregoing research opportunities and citing the Tuskegee Syphilis Experiments as an excuse.

In the larger study, 28% of the participants believed that HIV/AIDS was easier to discuss in the gay community (Baumgartner, 2012a) which roughly reflected the percentage of Black men that agreed with this supposition. This finding stands in contrast with research that indicates that racism in the gay community makes the experience of living with HIV/AIDS harder for gay, Black men (Han, Lauby, Bond, LaPollo, & Rutledge, 2010). Also, in general disclosure of one's status as an African American, gay HIV-positive man has been seen as harder to do because of the stigma associated with being gay in the Black community (Han et al., 2010). It is possible that participants did not reveal this finding in this study because of the positionalities of the researcher (a White woman). It should also be noted that participants who were part of a support group for gay, Black men really appreciated the group because they could freely discuss issues related to their situation which helped them integrate the HIV/AIDS identity into their selves.

Although participants ultimately received adequate information about the disease, initially, a lack of correct information about HIV/AIDS initially meant individuals diagnosed before the advent of HAART and individuals diagnosed after the widespread use of life-extending medication reacted similarly to the diagnosis. This lack of correct information meant that some individuals needlessly lived in fear for a period. This finding was also confirmed in the larger study (Baumgartner, 2012b) and in a study concerning the experiences of HIV-positive men (Han et al., 2010). However, my study showed how previous experiences and memories from the past influenced perceptions of HIV/AIDS. Han et al.'s (2010) study showed how the media had downplayed the seriousness of HIV/AIDS and young Black men were not hearing the dangers of the disease.

Although the results from this study contribute to HIV/AIDS literature on identity, the study has limitations. First, the participants were associated with AIDS Service Organizations. Respondents not associated with AIDS Service Organizations might have a different HIV/AIDS identity incorporation process. Second, all but one of the men were from a large, metropolitan area. The experiences of individuals living in rural areas might differ. Last, this study is not longitudinal. A longitudinal study would provide greater depth and change could be seen across time instead of relying on retrospective accounts of experiences at one point in time.

In sum, although results of this study largely confirmed findings of the larger group of 36 individuals, and findings from other studies, the stigma of being Black, gay and HIV-positive appeared to influence disclosure of the disease to others which impeded the incorporation of the HIV/AIDS identity into the self.

These study findings have implications for HIV/AIDS educators and health care providers. First, in many ways, the HIV/AIDS identity incorporation process was similar to the process found in previous studies (Baumgartner, 2007; Baumgartner & David, 2009) and in the larger study from which this data was extracted. An HIV or AIDS diagnosis is a disorienting experience-especially for individuals unfamiliar with current treatments. Health care providers need to acknowledge the emotional reactions that the diagnosis can have and provide patients positive information concerning living with the disease. Second, since obtaining correct information about HIV/AIDS is vital to the HIV/AIDS identity incorporation process, and not everyone is aware of the services offered at ASOs, culturally relevant HIV/AIDS education is needed in contexts outside of ASOs at places of worship, outreach centers for homeless and/or drug addicted individuals and sex workers. Last, gay African American men are not disclosing their status as readily as those from other demographics because of the multiple layers of stigma associated with being an African American gay man living with HIV/AIDS. This means these men might not receive the support they need around the disease. Strategies to address the stigma that gay, African American men face are needed.

Participants in this study were associated with an AIDS Service Organization in a large metropolitan area. Additional research is needed on individuals living in rural areas who are not associated with an AIDS Service Organization since it is possible that their experiences of living with HIV/AIDS would differ. Further, differences in experiences between heterosexual African American men and gay African American men should be an area of future research.

#### References

- Allday, E. (5 June 2012). HIV: A chronic disease, not a death sentence. Minneapolis StarTribune Retrieved from <u>http://www.startribune.com/nation/123164753.html</u>
- Baumgartner, L. M. (2000). *The incorporation of HIV/AIDS into identity over time* (Unpublished doctoral dissertation). University of Georgia, Athens, GA.
- Baumgartner, L. M. (2007). The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research*, *17*(7), 919-931. doi: 10.1177/1049732307305881
- Baumgartner, L. M. (2012a). The perceived effect of the sociocultural context on HIV/AIDS identity incorporation. *The Qualitative Report*, *17*(45), 1-21. Retrieved from <u>http://www.nova.edu/ssss/QR/QR17/baumgartner45.pdf</u>
- Baumgartner, L. M. (2012b). The perceived effect on time on HIV/AIDS identity incorporation. *The Qualitative Report*, 17(46), 1-22. Retrieved from <u>http://www.nova.edu/ssss/QR/QR17/baumgartner46.pdf</u>

- Baumgartner, L. M., & David, K. N. (2009). Accepting being poz: The incorporation of the HIV identity into the self. *Qualitative Health Research*, 19(12), 1730-1743. doi: 10.1177/1049732309352907
- Bogart, L. M., Wagner, G. J., Galvan, F. H., & Klein, D. J. (2010). Longitudinal relationships between antiretroviral treatment adherence and discrimination due to HIV-serostatus, race, and sexual orientation among African-American men with HIV. *Annuals of Behavioral Medicine*, 40, 184-190. doi: 10.1007/s12160-010-9200-x
- Bond, L., Wheeler, D. P., Millett, G. A., LaPollo, A. B., Carson, L. F., & Liau, A. (2009). Black men who have sex with men and the association of down-low identity with HIV Risk Behavior. *American Journal of Public Health*, *99*(S1), S92-95
- Brooks, R. A., Etzel, M. A., Hinojos, E., Henry, C. L., & Perez, M. (2005). Preventing HIV among Latino and African American gay and bisexual men in a context of HIVrelated stigma, discrimination and homophobia: Perspectives of providers. *AIDS Patient Care and STDs*, 19(11), 737-744.
- Cass, V. (1979). Homosexual identity formation: A theoretical model. *Journal of Homosexuality*, 4, 219-235.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage Publications.
- Dovidio, J. F., & Fiske, S. T. (2012). Under the radar: How unexamined biases in decisionmaking processes in clinical interactions can *contribute* to health care disparities. *American Journal of Public Health*, 102(5), 945-952.
- Dozier, J. K. (1997). *Lived experience of HIV-positive women* (Doctoral Dissertation) Retrieved from ProQuest. (Order No. 9816200)
- Freimuth, V. S., Quinn, S. C., Thomas S. B., Cole, G. Zook, E., & Duncan T. (2001). African Americans' views on research and the Tuskegee Syphilis Study. *Social Science and Medicine*, 52, 797–808.
- Galvan, F. H., Davis, E. M., Banks, D., & Bing, E. G. (2008). HIV stigma and social support among African Americans. *AIDS Patient Care and STDs*, 22(5), 423-436. doi: 10.1089/apc.2007.0169
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Hawthorne, NY: Aldine de Gruyter.
- Gurevich, M. (1996). *Identity renegotiation in HIV-positive women* (Doctoral dissertation). York University, North York, Ontario, Canada. Order number: AAT NN20387 Retrieved from https://www.ulib.niu.edu:9443/login?url=http://proquest.umi.com/pqdweb?did=73650 0011&sid=1&Fmt=6&clientId=8829&RQT=309&VName=PQD
- Han, C., Lauby, J., Bond, L., LaPollo, A. B., & Rutledge, E. (2010). Magic Johnson doesn't worry about how to pay for medicine: Experiences of Black men who have sex with men. *Culture, Health and Sexuality, 12*(4), 387-390. doi: 10.1080/13691050903549030
- History of HIV/AIDS in the United States. Retrieved from: http://www.avert.org/history-hiv-aids-us.htm
- Holzemer, W. L., Human, S., Arudo, J., Rosa, M. E., Hamilton, M. J., Corless, I., ... Maryland, M. (2009). Exploring HIV stigma and quality of life for persons living with HIV infection. *Journal of the Association of Nurses in AIDS Care*, 20(3), 161-168. doi: 10.1016/j.jana.2009.02.002
- Hughes, J., Wood, E., & Smith, G. (2009). Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations*, 12, 396-406. doi: 10.1111/j.1369-7825.2009.00568/

- Ickovics, J. R., Thayaparan, B., & Ethier, K. A. (2001). Women and AIDS: A contextual analysis. In A. Baum, T. A. Revenson, & J. E. Singer (Eds.), *Handbook of health* psychology (pp. 817-839). Mahwah, NJ: Erlbaum.
- Karp, D. (1994). Living with depression: Illness and identity turning points. *Qualitative Health Research*, *4*, 6-30. doi: 10.1177/104973239400400102
- Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, *39*(2), 146-154. doi: 10.1046/j.1365-2648.2000.02254.x
- Kralik, D., Brown, M., & Koch, T. (2001). Women's experiences of being diagnosed with a long-term illness. *Journal of Advanced Nursing*, 33(5), 594-602. doi: 10.1046/j.1365-2648.2001.01704.x
- Lewis, J. (1994). *Identity transformation: The experience of positive gay men.* (Doctoral dissertation). University of Ontario, Ontario, Canada. Order number: AAT NN97219 Retrieved from https://www.ulib.niu.edu:9443/login?url=http://proquest.umi.com/pqdweb?did=74090

4021&sid=2&Fmt=6&clientId=8829&RQT=309&VName=PQD

- Mathieson, C. M., & Stam, H. J. (1995). Renegotiating identity: Cancer narratives. *Sociology* of Health and Illness, 17(3), 283-306. doi: 10.1111/1467-9566.ep10933316
- Meleis, A. I. (2000). Experiencing transitions: An emerging middle-range theory. Advances in Nursing Science, 23, 12-28.
- Mendelson, C. (2006). Managing a medically and socially complex life: Women living with lupus. *Qualitative Health Research*, *16*(7), 982-997. doi: 10.1177/1049732306290132
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- Merriam, S. B., Courtenay, B. C., & Reeves, P. M. (2001). Time as an integrative factor. *Journal of Adult Development*, 8, 173-182. doi: 10.1002/ace.8408
- Mezirow, J. (1991). *Transformative dimensions of adult learning*. San Francisco, CA: Jossey-Bass.
- National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention. (November, 2011). HIV among African Americans. Atlanta, GA: Centers for Disease Control. Retrieved from http://www.cdc.gov/hiv/topics/aa/PDF/aa.pdf
- National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention. (March, 2012). HIV in the United States: At a glance. Atlanta, GA: Centers for Disease Control. Retrieved from http://www.cdc.gov/hiv/resources/factsheets/PDF/HIV\_at\_a\_glance.pdf
- National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention. (February, 2013). HIV among African Americans. Atlanta, GA: Centers for Disease Control. Retrieved from: http://www.cdc.gov/hiv/pdf/risk\_HIV\_AAA.pdf
- Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, 33(1), 21-26.
- Rao, D., Pryor, J. B., Gaddist, B. W., & Mayer, R. (2008). Stigma, secrecy and discrimination: Ethnic/racial differences in the concerns of people living with HIV/AIDS. AIDS Behavior, 12, 265-271. doi: 10.1007/s10461-007-9268-x
- Sandstrom, K. L. (1990). Confronting deadly disease: The drama of identity construction among gay men with AIDS. *Journal of Contemporary Ethnography*, *19*, 271-294. doi: 10.1177/089124190019003002
- Schaefer, K. M. (1995). Struggling to maintain a balance: A study of women living with fibromyalgia. *Journal of Advanced Nursing*, 21, 95-102.
- Serpe, R. T. (1987). Stability and change in self: A structural symbolic interactionist explanation. *Social Psychology Quarterly*, 50, 44-55.

- Shillington, A. M., Cottler, L. B., Compton, W. M., & Spitznagel, E. W. (1995). "Heavy drinking" and HIV high risk sexual behaviors among general population subjects. *The International Journal of the Addictions*, 30(11), 1453-1478.
- Spikes, P. S., Purcell, D. W., Willams, K. M., Chen, Y., Ding, H., & Sullivan, P. S. (2009). Sexual risk behavior among HIV-positive Black men who have sex with women, with men or with men and women: Implications for intervention development. *American Journal of Public Health*, 99(6), 1072-1076.

Spradley, J. P. (1980). Participant observation. New York, NY: Holt, Rinehart, and Winston.

- Squires, K. E., Hodder, S. L., Feinberg, J., Bridge, D. A., Abrams, S., Storfer, P., & Aberg, J. (2011). Health needs of HIV-infected women in the United States: Insights from the women living positive survey. *AIDS Patient Care and STDs*, 25(5), 279-285. doi:10.1089/apc.2010.0228
- Stein, M., Herman, D. S., Trisvan, E. Pirraglia, P., Engler, P. & Anderson, B. J. (2005). Alcohol use and sexual risk behavior among human immunodeficiency virus positive persons. *Alcoholism*, 29(5), 837-843.doi: 10.1097/01.ALC.0000164363.40533.E0
- Tewksbury, R., & McGaughey, D. (1998). Identities and identity transformation among persons with HIV disease. *Journal of Gay, Lesbian, and Bisexual Identity*, *3*, 213-232. doi: 10.1023/A:1023243032307
- Tracy, S. J. (2013). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact.* Oxford, England: John Wiley and Sons, Ltd.
- Tsarenko, Y., & Polonsky, M. J. (2011). 'You can spend your life dying or you can spend your life living': Identity transition in people who are HIV-positive. *Psychology and Health*, 26(4), 465-483. doi: 10.1080/08870440903521761

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