The Perceived Effect of the Sociocultural Context on HIV/AIDS Identity Incorporation

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Abstract

Contexts influence the experience of disease. In this study, I examined how the sociocultural context (e.g., race, class, gender, and sexual orientation) affected the experience of living with HIV/AIDS and the incorporation of the HIV/AIDS identity into the self. I interviewed 36 individuals living with HIV/AIDS. Findings indicate that race, socioeconomic status, and sexual orientation affected access to HIV/AIDS resources and/or the disclosure of one's HIV-positive status that, in turn, influenced the integration of the HIV/AIDS identity into the self. Additional research concerning the impact of gender on the HIV/AIDS identity corporation process is warranted.

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Contexts influence the experience of disease. In this study, I examined how the sociocultural context (e.g., race, class, gender, and sexual orientation) affected the experience of living with HIV/AIDS and the incorporation of the HIV/AIDS identity into the self. I interviewed 36 individuals living with HIV/AIDS. Findings indicate that race, socioeconomic status, and sexual orientation affected access to HIV/AIDS resources and/or the disclosure of one's HIV-positive status that, in turn, influenced the integration of the HIV/AIDS identity into the self. Additional research concerning the impact of gender on the HIV/AIDS identity incorporation process is warranted. Key Words: HIV/AIDS, Race, Poverty, Social Identity, Basic Qualitative Study.

The human immunodeficiency virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) is considered a chronic illness in countries where combination antiretroviral therapy (cART) is available (Edelman, Gordon, & Justice, 2011). The number of people living with HIV worldwide has increased from 26.2 million in 1999 to 33.3 million in 2009. In North America, it has risen from 1.2 million in 2001 to 1.5 million in 2009 (UNAIDS, 2010). In the United States, AIDS-related deaths decreased 69% between 1994 and 2007 (UNAIDS, 2009).

Individuals live with HIV/AIDS in a variety of contexts. These contexts include the sociocultural (e.g., race, class, gender, and culture), interpersonal (e.g., support and stigma), temporal (e.g., historical time or developmental stage in an individual's life), and situational (e.g., contexts specific to a person's experience such as pregnancy) (Ickovics, Thayaparan, & Ethier, 2001). Contexts influence the experience of living with HIV/AIDS. For example, a person's race affects access to healthcare. African Americans generally receive lower "quality health care than Whites, even after adjusting for income, education, and health care plan characteristics" (Klonoff, 2009, p. 49). Research studies showed that African Americans living with HIV/AIDS received life-extending medications, specifically protease inhibitors (PIs), later than Whites (Wong et al., 2004). African Americans and poor individuals perceived discrimination from health care providers when being treated for HIV/AIDS (Bird, Bogard, & Delahanty, 2004). In addition, scholars noted that women and minorities did not have as equal access to HIV/AIDS experimental drug trials as White men (Jones, Messmer, Charron, & Parns, 2002). Race and gender affect the experience of stigmatization in people living with HIV/AIDS (PLWHAs). African Americans living with HIV/AIDS tended to believe they were more discriminated against or morally judged for having HIV/AIDS whereas Whites feared interpersonal rejection (Rao, Pryor, Gaddist, & Mayer, 2008). Women living with HIV/AIDS believed they are more stigmatized because they are held to a higher sexual standard than men and judged more harshly for contracting HIV/AIDS (Lekas, Siegel, & Schrimshaw, 2006).

Context not only influences the experience of living with HIV/AIDS; it affects how individuals incorporate the HIV/AIDS identity into the self. Because HIV/AIDS is a chronic illness, individuals need to make it part of who they are. Identity theorists maintain that people possess multiple identities that form a stable self (Serpe, 1987). The self is formed through interaction with others and remains stable. Identities are "parts of the Self—internalized positional designations that represent the person's participation in structured role relationships" (Stryker & Serpe, 1982, p. 206). Identities are synonymous with role relationships. For example, a man could have the identities of father, partner, tennis player, and prostate cancer survivor. These identities make up a stable self. In addition, the salience of each identity depends on the strength of relationships associated with that identity (Serpe, 1987). A highly salient identity is invoked in a greater number of social situations than an identity with lower salience.

Researchers have investigated the incorporation process of the HIV/AIDS identity into one's self (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998). Most of the scholarship that discusses HIV/AIDS identity incorporation and context concerns the impact of the interpersonal context on the process (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998). There is less research on the impact of sociocultural context on the incorporation of the HIV/AIDS identity into the self.

The influence of class is of particular interest since it is a positionality whose influence is intermingled with other positionalities and is sometimes overlooked. How does class affect access to information on HIV/AIDS or interaction with the HIV/AIDS community? How is the HIV/AIDS identity affected if individuals must rely on state and federally funded programs for HIV/AIDS medications and support?

Although there is some evidence that the sociocultural context affects the experience of living with HIV/AIDS, a more thorough investigation of the connection between the sociocultural contexts, the experience of living with HIV/AIDS, and the incorporation of the HIV/AIDS identity into the self is needed. Therefore, the purpose of this study is to explore the influence of the sociocultural context on the experience of living with HIV/AIDS and how these experiences affect the incorporation of HIV/AIDS identity into one's self.

Literature Review

Context and the Experience of Living with HIV/AIDS

Ample research exists on the effect of the sociocultural and interpersonal contexts (e.g., stigma and support) on the experience of living with HIV/AIDS. Researchers noted the impact of HIV/AIDS discrimination on the mental and physical health of African American women (Wingood et al., 2007), differences in coping mechanisms between rural African Americans and Whites (Heckman, 2006), challenges of mothers living with HIV/AIDS (Murphy, Marelich, Stritto, Swendeman, & Witkin, 2002), and the relationship between socioeconomic status and access to HIV/AIDS treatment (Tsai, Chopra, Pronyk, & Martinson, 2009). Sexual orientation literature related to HIV/AIDS concerns risk behavior in gay men (e.g., Operario, Smith, & Kegeles, 2008). Regarding

the effect of stigma and support on the experience of living with HIV/AIDS, topics included a literature review of nurses' attitudes toward people living with HIV/AIDS (Pickles, King, & Belan, 2009), the layering of multiple stigmas related to race, class, and gender with HIV-related stigma (Sandelowski, Barroso, & Voils, 2009), and the role of social support in adjustment to HIV (Pakenham, Dadds, & Terry, 1994).

Although literature on the influence of the sociocultural context on the experience of living with HIV/AIDS exists, there is little information linking the influence of the sociocultural context on the experience of living with HIV/AIDS with the incorporation of the HIV/AIDS identity into the self. This investigation will add depth to the HIV/AIDS identity literature.

Context and Chronic Illness Identity Incorporation Other Than HIV/AIDS

Context affects the incorporation of an illness into one's identity. Most often, researchers noted the influence of the interpersonal context (e.g., stigma and support) on the identity incorporation of an illness. Support from friends and family helped the identity incorporation process of individuals with diabetes, chemical sensitivity, epilepsy, and depression because participants disclosed their illness and received support, whereas stigma prevented disclosure and inhibited the incorporation process (Allotey & Reidpath, 2007; Gibson, Placek, Lane, Brohimer, & Lovelace, 2005; Goldman, 1997; Karp, 1994; Lempp, Scott, & Kingsley, 2006). A few scholars discussed the impact of time on the identity incorporation process. The passage of time allowed for the illness to move from the foreground to the background in individuals living with cancer (Mathieson & Stam, 1995) and depression (Karp, 1994). A relapse precipitated the illness returning to the foreground in people's lives (Karp, 1994). In addition, a cancer diagnosis in adolescence could disrupt educational or marriage plans (Abraham, Silber, & Lyon, 1999) and cause individuals to be "off time" regarding societal expectations (Neugarten, 1976, p. 20).

Context and HIV/AIDS Identity Incorporation

Several researchers explored the incorporation process of HIV/AIDS into identity (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998). The findings were based primarily on in-depth interviews with White gay men or White heterosexual women. With the exception of one study (Baumgartner & David, 2009), most participants were diagnosed before the widespread use of protease inhibitors. Most research concerned the influence of the interpersonal context (e.g., support and stigma) on the HIV/AIDS identity incorporation process. Stigma prevented or delayed disclosure to others, which was integral to the incorporation process (Awa & Yamashita, 2008; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990), and individuals immersed themselves in the HIV/AIDS community to cope with the stigma (Lewis, 1994, Sandstrom, 1990). The support of family, friends, and support groups helped integration (Awa & Yamashita, 2008; Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998).

Few scholars explored the effect of the temporal context (e.g., historical time and developmental stage) on the incorporation of the HIV/AIDS identity into the self (Ickovics, Thayaparan, & Ethier, 2001). Regarding historical time, the increased availability of information about HIV/AIDS and the effect of life-extending medications on identity incorporation were mentioned briefly (Baumgartner & David, 2009; Lewis, 1994). Lewis (1994) found that older gay men were less upset by an HIV/AIDS diagnosis than those who were younger, suggesting that the developmental stage in life affected the HIV/AIDS identity incorporation process.

Little was found on the effects of the sociocultural context (e.g., race, class, culture, or sexual orientation) on the HIV/AIDS identity incorporation process. Scholars discovered that women living with HIV/AIDS worried about disclosing their illness to their children and taking care of their children (Dozier, 1997; Gurevich, 1996). This reluctance to disclose the HIV/AIDS diagnosis hindered the incorporation of the HIV/AIDS identity into the self.

Position of the Researcher

My interest in learning more about HIV/AIDS began when I realized that this then terminal illness seemed to be disproportionately affecting gay men and hemophiliacs in the early 1980s. I remembered that President Ford had readily responded to the threat of Legionnaire's disease and in sharp contrast, President Reagan seemed silent on a disease that initially appeared to affect marginalized populations. As a high school junior, I wondered how individuals were coping and what they feeling if they had this disease.

Many years later, as a second-year doctoral student, I was asked to join a research team that was investigating meaning-making in HIV-positive adults. I jumped at the opportunity. I read everything I could on conducting qualitative research studies and on HIV/AIDS. The research team experience was wonderful. I listened to the meaning-making experiences of individuals living with HIV or AIDS and learned how to conduct a basic qualitative research study.

The present study is my third concerning HIV/AIDS and identity incorporation (Baumgartner, 2007; Baumgartner & David, 2009). The study's findings emerge from a larger study concerning the influence of various contexts on HIV/AIDS identity incorporation and learning. I originally examined the incorporation of the HIV/AIDS identity into oneself over time by conducting interviews with the same participants over time. All participants were already diagnosed with AIDS at the time of the interview. All participants were originally diagnosed with HIV/AIDS in the 1980s or early 1990s before the widespread use of antiretroviral therapy (Baumgartner, 2007). My second study concerned how people living with HIV after the widespread use of antiretroviral medications incorporated HIV/AIDS into the self (Baumgartner & David, 2009).

Method

This basic qualitative study's findings were part of a more comprehensive investigation on HIV/AIDS identity incorporation. A basic qualitative methodology was chosen because I wanted to conduct an in-depth investigation of how context affected the

incorporation of the HIV/AIDS identity and I needed to learn the perspectives of those living with HIV/AIDS (Merriam, 1998).

Volunteer participants were selected by purposive sampling (Patton, 2002) from AIDS Service Organizations (ASOs) in the midwestern United States. I sought to include individuals who were (a) age 18 or older and (b) diagnosed as being HIV-positive or with AIDS a year or longer. I reasoned that a person diagnosed less than one year might not have had sufficient time to incorporate the HIV/AIDS identity into the self.

The sample consisted of 36 adults ranging in age from 25 to 66 at the time of the interview. Participants were interviewed between October 2009 and April 2010. The median age was 47. Fifteen participants were HIV-positive and 21 lived with AIDS. Participants were diagnosed between two years and 24 years prior to being interviewed. Nineteen respondents were diagnosed after the widespread use of life-extending medications (e.g., protease inhibitors) in 1996. Thirty participants lived in a large metropolitan area in the Midwest and six respondents lived in a rural area in the Midwest. Participants self-identified their race, gender, and sexual orientation. Twelve African American men, 11 African American women, nine White men, one Latino man, two biracial women (African American/Puerto Rican and White/Mexican) and one biracial man (White/Native American) were interviewed. Fourteen men were gay, eight were heterosexual and one was bisexual. Eleven women were heterosexual and two were bisexual.

Education levels ranged from eighth grade through master's degree. Sixteen had attended college or were college graduates. All men had received a high school diploma or General Equivalency Degree (GED). Seven of the 8 individuals without a high school education or GED are African American women. Fourteen of the 19 participants with post-high school education or training are men. Twenty-eight respondents were not employed at the time of the interview.

Income was reported in a range (e.g., $10,000-20,000 a year). Twenty-two participants reported an income of less than $10,000 per year. Thirty-two respondents reported an income of $20,000 or less per year. The range of household income for African Americans was less than $10,000 a year to $30,000 to $40,000 a year. The range of household income for Whites was less than $10,000 to $100,000 per year. The median income for Whites was $10,000-$20,000 a year and for African Americans was less than $10,000 a year. All those with less than a high school education reported an income of less than $10,000 a year.

Data Collection and Analysis

It is essential that ethical procedures for data collection and analysis are followed (Richards & Schwartz, 2002). The institutional review board (IRB) at the university at which I am employed approved the study. Prior to the interview, each participant read a consent form that addressed the purpose of the research, explained how confidentiality would be maintained, and discussed the participant's right to withdraw from the study at any time without penalty. The consent form stated that the interview would last one to two hours and that it would be tape recorded and transcribed. If participants experienced psychological discomfort, they could terminate the interview, and, with their permission,

I would refer them to a social service agency. Participants read that they would be compensated $30 for their time.

I verbally reiterated aspects of the consent form including the purpose of the research. In addition, I explained how confidentiality was maintained. Namely, I told participants that they would choose a pseudonym for purposes of the interview so that their responses would not be identifiable in any research report or publication or in the storage of information. I also informed participants how data would be collected and stored to ensure they would not be identified individually. I told participants they had the right to withdraw from the research at any time without penalty. I noted that the consent form contained my contact information and the contact information of the Office of Research Compliance, which approved my study. I encouraged participants to contact me with any questions or concerns that arose after the interview. They were also free to contact the Office of Research Compliance if they desired. The participants stated they understood the consent form and orally consented to be interviewed because the institutional review board forbade a signature on the consent form. Participants were given a $30 money order at the conclusion of the interview.

Interviews lasted between one and two hours. Two participants were re-interviewed because recording equipment did not record the initial interviews. I used a semi-structured interview guide. The topics investigated included the process of identity incorporation, the influence of contextual factors on the identity incorporation process, the nature of learning about HIV/AIDS, and how HIV/AIDS affected other identities. Throughout the interview, I periodically summarized what each participant told me and asked participants if my perception of our conversation was accurate. This served as an informal way to conduct member checks. I took field notes using Spradley's (1980) four-part method of transcription. First, I took very brief notes during the interview itself. Second, after the interview, I made detailed supplemental notes of my impressions during the interview. A third set of notes contained impressions, hunches and tentative findings, and a fourth set of notes contained a tentative analysis and explanation of results.

The data were analyzed inductively using the constant comparison method (Glaser & Strauss, 1967). I conducted and transcribed the interviews. I read, reread, and coded transcripts looking for themes across them. Similar themes were organized into categories and refined. After I analyzed the data, I conducted a member check. I provided participants with the interview transcripts and a summary of final findings that detailed the contextual factors that affected the identity incorporation process as well as the implications of the study. Several participants could not be located to receive the interview transcript and/or findings. Those who received transcripts and final findings were asked to make comments and either return the transcript or discuss any issues or concerns with the interviewer. None of the participants expressed concerns about their interview transcript or the findings.

Results

To discuss the influence of context on identity incorporation, a brief overview of the components of the incorporation process is necessary prior to revealing the results of this study. The four-component process included diagnosis, a post-diagnosis turning point, immersion into the HIV/AIDS community, and integration. Diagnosis included an

initial emotional reaction (fear, anger, sadness, denial, shock, and relief) and a behavioral reaction (e.g., increased drug/alcohol use and/or isolation from others). The turning point jarred people from their initial reactions and included entering a treatment center that served chemically dependent individuals living with HIV/AIDS, learning about HIV, and attending HIV/AIDS support groups. Immersion consisted of involvement in the HIV/AIDS community and making the HIV/AIDS identity central. Integration included the education of self and others about HIV/AIDS, acceptance of HIV status by others, and the passage of time. HIV-positive individuals were less likely than participants living with AIDS to become immersed in the HIV/AIDS community or to have HIV as a central identity. Disclosure was integral to the incorporation of the HIV/AIDS identity. Individuals generally disclosed to friends and relatives first, then they made a more public disclosure (generally individuals disclosed in HIV/AIDS support groups or larger groups of people), and then they selectively disclosed to others as needed.

An example of this identity incorporation process and some of the meaning-making that occurred as a result of contracting HIV/AIDS is evident in Kelven's narrative. In addition, the impact of various positionalities on Kelven's incorporation process is mentioned. Kelven is a gay African American man. He was 48 at the time of the interview. He attended college for awhile and had worked in the banking industry. He had seen many of his friends, who had contracted AIDS, die in the 1980s and 1990s. He tested positive for HIV in 1999 at the age of 38 and was devastated by the news. His drug and alcohol use elevated for several years and he became deeply depressed.

Several years after Kelven's diagnosis, his mother encouraged him to learn more about HIV/AIDS. He attended a retreat at a local AIDS Service Organization (ASO) and became involved in a support group. This event was a turning point from his initial behavioral and emotional reactions to his diagnosis. He learned he could live with the disease. He is currently immersed in the HIV/AIDS community. He counsels HIV-positive individuals. He is working in social services and is a counselor and advocate for those living with HIV/AIDS.

Kelven's positionalities affected his HIV/AIDS identity incorporation process. In the 1980s and early 1990s, Kelven saw many of his friends die from the disease. When he was diagnosed HIV-positive in 1999, after the advent of life-extending medications, Kelven held on to old images of the trajectory of HIV/AIDS. He had misinformation about the disease which caused him to believe he was going to die from the disease very soon. This misinformation caused him to remain in the initial reaction stage longer than needed. He believed that the lack of discussion of HIV/AIDS in the Black gay community, especially amongst poor African Americans, contributed to his lack of knowledge about the disease at the time of his diagnosis.

As a result of contracting HIV, Kelven's worldview has changed. He noted, "HIV gave me a purpose." He continued, "[HIV] gave me an appreciation. . . of life." He also recognized the "value of volunteering". He is a happy, productive member of society. Kelven's new priorities and worldview confirms previous research on the meaning-making of those living with HIV/AIDS (Baumgartner, 2002; Courtenay, Merriam, & Reeves, 1998).

Sociocultural Context: Race

Although the findings are presented in discrete categories of race, class, and sexual orientation, participants inhabit these positionalities simultaneously and they interact to impact the incorporation of the HIV/AIDS identity into the self. Participants' education level is also interwoven with other positionalities. Most often, participants reported that race and class combined to affect their experience of living with HIV/AIDS as well as the HIV/AIDS identity incorporation process.

Nineteen participants indicated that being a person of color, either African American or Latino/a, affected their experience of living with HIV/AIDS negatively and being White was as an advantage. Some participants believed that race affected the way they were treated in the medical community. Debonaire observed that education level, class, and race intersected and less educated, poor, African Americans received inferior treatment by the medical profession.

> 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 more like [those in the medical profession] 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.

Sherry concurred that Whites got better treatment and more respect with medical professionals. "[Whites] get top treatment. [They] are looked at, first of all, with respect." She continued,

> "[The pharmacist says to the White person] 'you know, this med right here, baby, we are out of it! But you know, I'll give you a call and oh by the way, you can't have grapefruit juice with it.' I have stood there and heard it—not only the HIV. Hepatitis. Hypertension. 'Oh this is for your blood pressure. Take this. Oh, if you have any questions, please call me.' I didn't get that [treatment.]. I got, "Let me get this nasty person out of here and oh by the way let me let everybody know this is an *infected* person."

Sherry's medication is now delivered to her home and she says she is treated well by the pharmacy staff.

Ken mentioned that access to medical help was easier for Whites than for Blacks or Hispanics. He believed that Whites were at an advantage "Medically. Information-wise. Support-wise". He knew of little support in the Latino/a community for people living with HIV/AIDS. He added, "You go to see a Black doctor in the urban setting in the African American community or Hispanic community and they have no clue about HIV or AIDS." Steve agreed, "I think there is a disparity in …the medical profession. If I don't push for the best care or best service out of [medical professionals], I won't get it." Tony agreed that Whites got better treatment in the medical community than Blacks because they had better insurance, generally. Therefore, racism interacted with class to produce poorer treatment in the medical community for poorer people of color.

In addition to disparate treatment by the medical profession, 14 participants, including Latinos, African Americans, and Whites agreed that HIV/AIDS was more stigmatized in the African American community than in the White community. The stigma of having HIV/AIDS, particularly as an African American gay man, often meant that people did not seek information about the disease or disclose their status because of the stigma. Gerald thought that African Americans and Latinos/as who were living with HIV/AIDS were more stigmatized in their communities, which kept them from reaching out for education and hindering integration of the HIV/AIDS identity into the self. He stated,

> Because even with the Black people and Hispanic men--they are so stigmatized by being HIV-positive that their family will find out and stuff like that because their families are just totally—you know it's not a thing for them to know. I think that the advantage that I've had is that I've been able to obtain an education about it and to seek information out and I don't think they do because of the stigma.

Twelve participants agreed that HIV/AIDS was more stigmatized in the African American community which meant people did not discuss it. Linda agreed that it was more difficult to talk about HIV and AIDS in the Black community but that discussion of HIV/AIDS was becoming more common. She asserted that African American gay men were particularly stigmatized in the African American community and she stated it would be harder for them to talk about their status. Likewise, Greg stated, "Hispanics don't want their homeys knowing that they are gay or positive and it's the same in the Black community. You are looked down upon. In the White community, I don't see it as much." Bill agreed, "There's not much education in the Hispanic community. It's a very 'hush hush' thing in the Hispanic community." He added that the stigma of being gay and of the disease still being associated with gays meant Latinos were less likely to talk about the disease. Although many participants thought Blacks and Whites had equal access to HIV/AIDS medications, Janet said African American families were less likely to discuss HIV/AIDS than White families.

A second race-related disparity concerned access to HIV/AIDS-related information and resources. Generally, poor African Americans reported less access to HIV/AIDS resources than wealthier Whites. This meant that some participants with fewer resources received accurate information about HIV/AIDS later than those who had resources. This dearth of correct information about HIV/AIDS and available treatments meant some participants lived with their emotional reaction to the diagnosis much longer than was necessary. Correct information about HIV/AIDS was often a turning point from the initial emotional reaction. Some participants might have started integrating the HIV/AIDS identity into their selves sooner if they had known there was medication available and had the support of family and friends.

Michael noted that race and class intersected and that the HIV/AIDS agencies that started were largely funded by wealthy Whites and the reason these resources did not exist in the Black community was because "in the Black community there [is not] anybody who has that kind of money". Joe reported that when he asked why there was

not the level of HIV/AIDS services where he lived as compared to another part of the city he was told, "That's where minorities live. You figure the rest out."

Kelven saw how race, class, and educational level affected access to information about HIV/AIDS, which affected integration. He stated,

> There is the world and there is Black men. We are on the trickledown effect [regarding information about HIV/AIDS]. The White [gay] boys got the information [about HIV/AIDS] first. [Then] Black boys who date White boys and are in the White community. Then those who have a certain education and socioeconomic level and then you got the folk. I was the folk.

Kelven's mother worked at an HIV/AIDS clinic and urged him to get connected to knowledge about HIV. Kelven reported that his mother said, "There are some gay White boys [in the predominantly White area of town] that are living happily with HIV. You need to go find out what they are doing and do it." This participant's access to this information via an AIDS Service Organization was a turning point for him from the initial emotional reaction. He said,

> If I had been White, I think I would have access to better services and a [wider] array of services . . . There are two things that separate us [Blacks and Whites]: Access to services and we need to be re-educated because there are cultural barriers that says we don't tell White people what is going on in our community. I coined that as "Post Traumatic Slave Syndrome".

Derek agreed that race, class, and educational level affected access to treatment and how people were respected. He said,

> There are certainly advantages [I have]. I'm very grateful for those. I think they are really obvious as being a White man. Most of us, and I'm not one of them, but most of us are better educated than people of color, I think, in rural areas anyway which leads us to better healthcare which leads us to better communication at the doctor's [and] makes us become better advocates for ourselves.

He added that situational factors such as a stable, drug-free family also made it possible for him to communicate with doctors. He thought most HIV/AIDS educational efforts were now going toward Blacks so the "pendulum was swinging [the other way]". Pearl agreed. She stated, "Probably the only advantage that I have is that in so many facilities and workshops and clinics and stuff there is more of us [African American women]. More of us are coming out and more accepting it than other races."

Joe 2 stated that race and economics interact to make it harder to learn about HIV/AIDS in poor, minority communities. He said, "[Because I am] a White guy, I think it's even easier [to integrate HIV/AIDS into one's identity] because there's more

education. In the [poor] minority neighborhoods you don't get as much information and services provided to you."

One participant was especially concerned about HIV/AIDS services for individuals such as herself. She stated that HIV/AIDS services for African American women were lacking considering that African American women are disproportionately affected by HIV/AIDS. She noted the lack of resources for African American women, the ignorance of some people in the African American community concerning HIV/AIDS, and the lack of respect given to her by those who provide HIV/AIDS services. She stated,

> I am associated with [name of program] which is the only program in the city that caters to women—women of color. Can you believe that? The only one. We got—but for [gay men] you got [names several HIV/AIDS agencies]. I mean that is just how it is. You know what I'm saying? It's sad. Because this is not where the numbers are.

She concurred with other respondents that talking about HIV/AIDS in the Black community was still frowned upon. She said, "Because what's happening is, especially in my community, it's still hush, hush." She added, "Lots of ignorance in my community. Chosen ignorance. People just don't want to know or talk about it." She continued, "There aren't many places for women of color to really go and get helped without being talked down to, made to feel less than, made to feel ignorant, made to feel like they have to beg and crawl for services that everyone else gets just because."

Eleven participants indicated that access to medication and information was not affected by race but by situational factors. These participants believed that they were privileged to have access to some of the best HIV/AIDS resources in the nation and if people showed some initiative, race did not matter. Ed stated, "I was fortunate enough to be here in [a large metropolitan city] where you know, the County [names agency] has always been the forefront. It's just a matter of getting up off your butt and going down there and getting what you need because it has always been available."

Booker believed that access to medications was not affected by race. He said, "I think the give me the same meds they give a Caucasian." He lamented that people in the African American community did not participate in medical studies at the rates that Whites did because they cited the Tuskegee Experiment as a reason to avoid participation in medical studies. He noted, "There are medications that affect African Americans differently than they do Whites and it's because we do not participate in the studies as much as Whites.…Everybody brings up [the] Tuskegee [Experiment]." Derek agreed that the Black community avoided doctors because of the Tuskegee experiment and said, "A lot of it with Black communities is they still go back to the Tuskegee incident and I often think, 'When are you going to let that go and save your life?'"

Eleven participants, both African American and White, stated that race did not affect their experience with HIV/AIDS. Chanel believed those who said they were receiving less support around HIV/AIDS "don't try to do [anything] for themselves". She added, "I got a lot of support. A lot." Deborah agreed that doing some work yourself helps you get services easier. "I've been treated fairly. Maybe I have to work a little harder…If you do some footwork and work with your case manager it is going to come together." She thought race was less to blame for unequal treatment than personal

initiative. Octavius acknowledged that he thought more resources existed for HIV/AIDS in a predominantly White area of the city, but he said, "Since I've been up here I've had the same opportunities and options as other races do. I have the same opportunities. I don't feel [any] different. I don't feel left out. The same opportunities and doors they get to walk through I get to walk through."

In sum, 19 individuals thought African Americans received poorer treatment in the medical community, were more stigmatized for having HIV/AIDS than their White counterparts, and had fewer HIV/AIDS resources. Since access to correct information about HIV/AIDS and disclosure helped the integration of the HIV/AIDS identity into the self, these disparities because of race affected the integration process for some. Eleven participants stated that situational factors, such as a personal lack of initiative and willingness to remain ignorant about HIV/AIDS were to blame.

Sociocultural Context: Class

HIV/AIDS, though not a central identity for many, was a more salient personal identity because of economics for some participants. Class made HIV/AIDS a more central concern for 7 participants than it might have been if they had had a higher income. The threat of cutbacks to HIV/AIDS-related programs concerned participants because they relied on federally or state-funded programs to obtain HIV-housing, medication, and transportation to medical appointments. Tiger Claws noted, "It makes it difficult because you never know when your turn is going to come when the program you are in might be cut. It makes you want to prepare for that. Live better and be prepared for the worst." Al stated, "[The government] wants us to start paying for our meds since they are cutting funds. It's going to get bad." This situation kept HIV/AIDS on his mind. Mother said, "They keep saying they are cutting programs…I pray they don't cut the services we need." Tina worried about her future. She said,

> If I were richer, I'd feel more secure. I'm getting older and I receive SSDI [social security disability insurance] and social security. I'm afraid social security is going to be privatized. So, I'm thinking with me being HIV-positive and I am a younger woman receiving disability so I'm wondering if it will affect me later in life."

The centrality of the HIV/AIDS identity was not only affected by fears of losing state and federal programs because of funding, but the HIV/AIDS identity was more central to those who were economically challenged because they were treated less well by the medical profession. Gerald lost his job and health care benefits and was unable to afford private insurance. He said, "I had better medical care when I was going to a private HIV doctor… [My current doctor] is overworked and I can only see her on certain days. I have waited hours at the clinic." He thought more about HIV/AIDS because his economic situation had gotten worse. Greg was treated rudely by a pharmacist. He said, "When they find out [payment] is on a medical card, they are kind of crappy but I won't put up with that."

Some participants who were economically challenged had access to fewer resources which kept HIV/AIDS on their mind. Octavius refused to take HIV/AIDS

medication when he was diagnosed in prison because he "didn't want to be [a] lab rat because I'm an inmate". He reasoned that if he were wealthy he "would have known for sure they weren't going to guinea pig me. I'd have a lot of money so they'd make sure to give me the right stuff." He did not seek medication for HIV while in prison and lived in fear of dying of HIV/AIDS because he did not avail himself of information about the disease. This delayed his integration of the HIV/AIDS identity into his self. Ken lived on a disability income and this meant some alternative therapies for HIV/AIDS were too expensive to investigate. He said,

> Alternative therapies and pretty much a lot of it is shut out because it interacts with the HIV meds. But there is stuff out there. But again, somebody in my position—now if I was working it might be different but someone in my position can't really afford a lot of that stuff because none of it is covered by insurance.

Surprisingly, a couple participants saw advantages in being poor because it made them connect to the HIV/AIDS community for support rather than having the luxury of hiring individuals to support them such as a private doctor and therapist. Pearl stated, "If I… [could] afford things, I [would not] need this support group. I could get a therapist. I don't think I'd interact with people. I wouldn't be able to share these experiences." Steve observed that being poor meant "it was more of a challenge to navigate the healthcare system to get financial aid to pay for [his] medications". His activism behind HIV/AIDS was partially motivated because "you have to fight for things you need". He continued, "If I had everything handed to me on a silver platter than I would get very lazy and complacent." Indeed, reaching out to others was important in the integration of HIV/AIDS into one's identity. Immersion in the HIV/AIDS community was integral to the incorporation process. Reaching out, learning about HIV/AIDS and helping others were foundational to the integration of the HIV/AIDS identity into the self.

In sum, some economically challenged participants living with HIV/AIDS believed that the HIV/AIDS identity was more central for them because they had to think about the disease more often than their wealthier counterparts. All those mentioning class as an issue in the experience of living with HIV/AIDS had a household income of less than $20,000 per year. Cutbacks in HIV/AIDS funding, less respect by the medical community, and needing to seek support from individuals in community programs meant the HIV/AIDS identity was viewed as more central by some poorer individuals.

Sociocultural Context: Sexual Orientation

Ten participants indicated that it was easier to be talk about HIV/AIDS in the gay community than in the heterosexual community. Al admitted that it has been harder to discuss being HIV-positive in the Black community than in the White community but that it was becoming more acceptable to discuss HIV/AIDS in the African American community. He acknowledged,

> 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.

Michael noted:

If you are gay or homosexual they know it is very prominent and then [potential gay partners may be more likely to say]: 'All right. No problem.' But a straight male, you know what I'm saying…A lot of them won't say nothing. They will just throw the condom on instead of talking about it.

Greg stated:

I don't know but how many straight guys are at the bar partying and ask the woman, 'Are you positive?' before they have sex with them? Or does the woman turn around and ask them, 'When is your last AIDS test?' Now, if you are going to bed with a guy it's like, 'Are you positive?' 'When was your test?' 'Suit up, buddy.' We'll ask. We aren't afraid to.

Matt agreed:

I think the fact that the gay community has really kind of—being gay you have the support of the whole gay community and HIV and AIDS has been an issue for gays before anything. That was the—everybody thought it WAS a gay disease. So, having the support of the gay community would be the biggest advantage of having HIV compared to being straight and getting it.

In sum, roughly 28% of the participants believed it was easier to disclose one's HIV-positive status as a gay man. Other participants did not address sexual orientation regarding living with HIV/AIDS or did not think sexual orientation affected their experience of living with HIV/AIDS. Participants living in a rural area were more likely to state that gay men had an easier time disclosing their status than heterosexual men.

Discussion

This study's findings partially confirm Siegel and Raveis's (1997) study concerning "access to HIV-related information, care and services among infected minority men" (p. 9). In the early 1990s, 93 gay men (47 Puerto Rican men and 46 African American men) in the greater New York City metropolitan area completed surveys and interviews. African American men found it difficult to obtain "relevant illness and treatment-related information…within their communities" (p. 15). Like participants in the current study, Siegel and Raveis's participants indirectly acknowledged racism for the disparity in treatment and recognized that some individuals within the African American community were unwilling to seek information. They noted

that there was more ignorance in the Latino community regarding HIV/AIDS. In contrast, in the current study, Latinos and African American participants spoke of an ignorance of HIV/AIDS in their respective communities. In addition, the current study confirms Siegal and Raveis's (1997) finding that poor, African American gay men had less access to quality health care and expands the findings to include poor individuals in general. Moreover, in the current study both African Americans and Whites acknowledge the disparity in medical care between the two groups.

Findings from the current study indicate that about 28% of those interviewed believed that gay men had an easier time talking about HIV/AIDS than heterosexual men, which helped integration of the HIV/AIDS identity into the self. In addition, four gay men and two heterosexual African American women mentioned that they thought gay men had more access to resources than other groups. Siegal and Raveis (1997) did not mention any advantages for gay men regarding support around having HIV/AIDS in comparison to those in the heterosexual community. Perhaps this is because all participants in Siegal and Raveis's study (1997) were gay and participants in the current study were gay and heterosexual which allowed for comparisons. It is interesting to note that the stigma of having HIV/AIDS as a heterosexual man was mentioned more by men living in rural areas than for those living in urban areas. It is possible that the stigma of having HIV/AIDS in a rural area is more difficult because there are fewer resources for people living in rural areas. Furthermore, the few gay men interviewed in rural areas seemed to have support in their small gay community whereas the heterosexual men felt stigmatized by having the disease because having HIV/AIDS was associated with being gay.

Participants in Siegal and Raveis's (1997) study reported that AIDS Service Organizations did not serve minority members as well as "White middle class clients" (p. 22). This finding was not replicated in the current study. Most of the participants in the current study indicated that they received good services and were treated well at AIDS Service Organizations. This might be because in the intervening 13 years between the current study and Siegal and Raveis's study, the face of AIDS has changed. An increasing number of people living with HIV/AIDS are people of color and AIDS Service Organizations have tried to meet the needs of people of color in addition to serving White clients. The dissatisfaction that was mentioned by a few participants concerning AIDS Service Organizations involved a need for more programming for African American women.

The results from this study add to the literature on HIV/AIDS identity incorporation by showing that race affects the incorporation of HIV/AIDS into identity. Nineteen participants believed that race affected their experience of living with HIV/AIDS. Among these participants, African Americans, Latinos/as and Whites agreed that people of color had access to fewer HIV/AIDS resources and had to work harder than their White colleagues to access information about HIV/AIDS. Because learning correct information about HIV/AIDS served as a turning point from the initial emotional reaction of diagnosis in the incorporation of the HIV/AIDS identity into the self, this poorer treatment and lack of access to information affected participants' integration of the HIV/AIDS identity.

Both Blacks and Whites agreed that HIV/AIDS was most stigmatized in the African American and Latino/a communities as opposed to the White community, which

meant that people of color were less likely to disclose their HIV-positive status or seek HIV/AIDS-related information than their White counterparts. This lack of disclosure to others and the lack of information-seeking also impacted the incorporation of the HIV/AIDS identity into the self.

Whereas race appeared to privilege Whites and disenfranchise some African Americans and Latinos/as regarding access to HIV/AIDS information and services which, in turn, stymied the integration of the HIV/AIDS identity into the self, class had a more nuanced effect on the integration process. In some cases, poorer participants had less access to care and information than wealthier participants. However, some economically challenged participants also claimed HIV/AIDS as a more central identity because they thought about HIV/AIDS more often. Because they relied on local, state, and federally funded programs for their HIV/AIDS care and some of these programs were in danger of being cut because of lack of funding, they reported that HIV/AIDS was more on the forefront of their minds than if they did not have to rely on these programs. Hence, the centrality of the HIV/AIDS identity, in some cases, was partially dependent on the participant's economic status.

Prior research on identity incorporation and the centrality of the HIV/AIDS identity indicated that the identity was more central when individuals were immersed in the HIV/AIDS community (Baumgartner, 2007; Baumgartner & David, 2009). The salience of the identity was also time and health dependent. The longer individuals lived with HIV/AIDS, the less salient it became as an identity (Baumgartner, 2007; Baumgartner & David, 2009). An HIV/AIDS-related health scare could increase its salience (Baumgartner, 2007; Baumgartner & David, 2009). The results from this study added another possible reason for increased salience of the identity: class. Those participants reliant on local, state, and federal HIV/AIDS programs worried about funding for these programs which kept their HIV/AIDS status on their minds. Some participants reasoned that if they were wealthier and could afford to pay for programs and medications, they might be less focused on their HIV/AIDS status. In addition, previous studies on HIV/AIDS identity incorporation suggest that joining an HIV/AIDS community promotes integration primarily because the HIV/AIDS community provides support (Baumgartner, 2007; Baumgartner & David; 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). The results from this study indicate that reaching out to the HIV/AIDS community might also be somewhat related to class. Participants did not have the finances to hire personal therapists and relied on the HIV/AIDS community for support.

Only five participants mentioned gender influencing the incorporation of the HIV/AIDS identity into the self. All participants mentioned issues that women might have that could influence the incorporation process including a lack of services for African American women, the issue of caring for children and having difficulty disclosing one's status to children, coping with one's own diagnosis of HIV/AIDS in addition to caring for HIV-positive children, and the belief that women were more stigmatized for having HIV/AIDS than men. Hence, the limited data that appeared confirmed issues mentioned in previous studies concerning the influence of caring for children on one's own process of identity incorporation (Dozier, 1997) and women being more stigmatized for having HIV/AIDS (Green, 1996). It is possible that gender would be a greater concern for a different sample of participants. Because this sample contained

a sizable number of economically challenged African American participants, these positionalities appeared to affect the experience of living with HIV/AIDS and the incorporation of the HIV/AIDS identity into the self more than gender.

Last, the findings of this study demonstrate the intersection of various positionalities on the experience of living with HIV/AIDS. Race and class were most often linked by participants as positionalities that influenced access to resources and how one was treated by the larger medical community. Race and sexual orientation also affected disclosure because gay African American men living with HIV/AIDS felt more stigmatized in the African American community than gay White men.

Although the results from this study contribute to the literature on the influence of the sociocultural context on HIV/AIDS identity development, it has limitations. First, most participants were associated with an AIDS Service Organization. It is possible that individuals not associated with an AIDS Service Organization could have a different awareness of the influence of race, class, gender, and sexual orientation on their experience of living with HIV/AIDS and on their incorporation of HIV/AIDS into their identity. Second, participants responded to cards and flyers distributed at AIDS Service Organizations or by individuals associated with AIDS Service Organizations. They volunteered to participate in the study and their perceptions might differ from those individuals who chose not to participate. It is possible that volunteer participants are more outgoing, physically healthier, and have better coping skills than non-volunteers. Third, 22 of the 36 participants reported an income of $10,000 or less. Thirty-two participants of the 36 reported an income of $20,000 or less per year. Hence, the experiences of wealthier individuals might be somewhat different. Fourth, 30 of the 36 individuals lived in a large metropolitan area.

Future research should investigate the experiences of people living with HIV/AIDS considering additional positionalities. Additional research is needed on participants with HIV/AIDS in rural areas to see how that context influences the incorporation of HIV/AIDS into the self. The limited data in this study suggests that individuals living with HIV/AIDS in rural areas have less access to HIV/AIDS resources than those living in large metropolitan areas and they believe they are more stigmatized which prevents disclosure to others and inhibits the incorporation of the HIV/AIDS identity into the self. A more thorough investigation of the relationship between sexual orientation and the incorporation of the HIV/AIDS identity is also warranted. The results from this study showed that some participants believed gay men living with HIV/AIDS were less stigmatized than heterosexuals. However, within the gay community, gay African American men were thought to be more stigmatized for living with HIV/AIDS than gay White men. However, most participants did not mention sexual orientation as a factor affecting HIV/AIDS identity incorporation. Third, a more thorough investigation of the effect of class on HIV/AIDS identity incorporation is needed. Most of the participants in this study made less than $20,000 a year. Many lived on a disability income. In order to see the effect of class on the experience of living with HIV/AIDS, and its intersection with other positionalities, a more economically diverse sample is required. Last, the impact of the level of formal education on the experience of living with HIV/AIDS is warranted. Several participants mentioned how their higher education levels helped them mitigate the negative effects of race on their experience of living with HIV/AIDS.

In conclusion, the findings from this study demonstrate that the incorporation of the HIV/AIDS identity into the self is influenced by the sociocultural context. The results from this study adds depth to previous studies on the incorporation of HIV/AIDS into the self by showing how various positionalities can influence the experience of living with HIV/AIDS which can in turn affect the incorporation of the HIV/AIDS identity into the self. Unlike in other HIV/AIDS and identity incorporation studies, results from this study suggest that African Americans disparate treatment in the medical community and increased stigma of having HIV/AIDS might affect the integration of the HIV/AIDS identity into the self. In addition, some participants noted that a lack of initiative and an unwillingness to learn more about HIV/AIDS might stymie the incorporation process.

Research not only makes theoretical contributions but also has practical implications. Although it appears some AIDS Service Organizations are doing their best to address the concerns of racial minorities and the poor, participants in this study reported that African Americans and poor individuals living with HIV/AIDS received inferior treatment by the larger medical community. This not only made the experience of living with HIV/AIDS more difficult, but it also affected how they integrated the HIV/AIDS identity into the self. Medical professionals working with those living with HIV/AIDS need to recognize how this differential treatment regarding race, class, and sexual orientation can affect those living with HIV/AIDS.

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