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Lisa M. Baumgartner  
*Northern Illinois University*

Keegan N. David  
*Northern Illinois University*

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# **“HIV is Only One Part of Me”: HIV and Its Effect on Other Identities**

Lisa M. Baumgartner, Northern Illinois University, USA

Keegan N. David, Northern Illinois University, USA

***Abstract:** The purpose of this study was to investigate the effect of the HIV identity on other identities. The spiritual and advocate identities increased in salience whereas work and sexual identities decreased. Younger participants fretted about physical appearance. Older participants focused on health. There are implications for adult educators.*

HIV infection is considered a manageable chronic disease in the United States because people have access to life-extending medications (Teague, 2007). As a result, an increasing number of individuals are living with HIV. In the United States, this number was estimated at 256,363 in 2007 (Centers for Disease Control (CDC), 2009), an increase from 179,678 in 2001 (CDC, 2006).

Because HIV is a chronic illness, people need to make it part of how they define themselves. Previous studies have examined the impact of HIV/AIDS on a person's work (Bedell, 1998), sexual/relationship (Gurevich, 1996), spiritual (Cotton et al., 2006) and body-image identities (Huang et al., 2006). These identities are all part of the larger Self (Stryker & Serpe, 1982). Prior studies have explored the impact of HIV/AIDS on other identities for those living with HIV/AIDS or have limited the investigation to a particular population (e.g. men or women). It is possible that living with HIV infection only (as opposed to living with AIDS) influences other identities. Therefore, the purpose of this study is to investigate the effect of the HIV identity on other identities.

## **Theoretical Framework**

Identity theorists assert that the self is composed of many identities (Serpe, 1987). The self is stable and develops because of its interactions with society. Identities are considered “parts of the Self—internalized positional designations that represent the person's participation in structured role relationships” (Stryker & Serpe, 1982, p. 206). People can have as many identities as they have role relationships, such as professor, brother, or person with cancer. These compose the stable self.

The more salient one's identity, the stronger and more numerous the relationships associated with it will be (Roberts & Donahue, 1994). The greater the identity's salience, the more likely it will be acted out in different contexts and the more committed the person will be to it (Stryker & Burke, 2000). Consider a woman named Geri, whose HIV identity is highly salient. When she meets new people, she announces that she is HIV-positive. She is a volunteer at an AIDS Service Organization (ASO). However, Geri's identity as a pianist is much less salient. She plays the piano on occasion, but she never talks to people about being a pianist.

## **Data Collection and Analysis**

Sample selection occurred through purposive sampling (Patton, 2002). Volunteers were sought from AIDS Service Organizations (ASOs) located in the Midwest. Selection criteria included:

(1) Age 18 or older, (2) HIV-positive for a year or longer (3) Diagnosed HIV-positive after 1995 with access to life-extending medications and (4) Did not have an AIDS diagnosis. We reasoned that those diagnosed HIV-positive for less than a year might not have had enough time to incorporate HIV into their self. Second, because it was important that all participants experience HIV as a chronic disease, only those diagnosed after the widespread availability of life-extending medications (e.g. protease inhibitors) were included in the sample. The sample consisted of 14 adults ranging in age from 25 to 52 years old. The average age was 42. Education levels ranged from high school graduate to some college coursework. Eleven of the 14 participants attended college or were college graduates. There were 3 African American men, 3 African American women, 1 African American male-to-female transgender, 5 White men, 1 White woman, and 1 Latino man.

An in-depth investigation of the effect of HIV on other identities warranted a qualitative methodology. Data collection consisted of 14 one and one-half to two hour interviews using a semi-structured interview guide. Data were analyzed inductively using the constant comparative method (Glaser & Strauss, 1967). Interviews were conducted and transcribed and we read, re-read and coded the transcripts and looked for themes within and across transcripts. Similar themes were organized into categories and refined. Strategies used to increase the reliability and validity of the findings included member checks, an audit trail, adequate engagement in data collection to achieve saturation, and peer review (Merriam, 2009).

## Findings

The HIV identity was not a primary or central identity for most participants. Participants' work, sexual, spiritual, advocate, and physical identities were affected by the HIV identity. The spiritual and advocate identities increased in salience whereas the work and sexual identities decreased in salience. Four men came to terms with being gay.

### *HIV Identity Not Central*

The HIV identity was never a central or primary identity for 9 participants. Brian's response was typical: "I don't think it needs to be my identity because that is just part of me...I'm so much more than that." Enrique noted, "I'm Enrique. I definitely would not talk about my HIV status. It's not an adjective that describes me. It doesn't define me at all. That's for sure." He continued, "This is not who I am. I'm not an HIV person. I'm a person affected by HIV. That is different." Blackberriz used an effective analogy to describe how HIV, once a more salient part of herself, had shrunk.

It's a smaller part but it's a part of me. I see it like Siamese twins. They are hooked and joined and that's how I feel about HIV. It's something that's there and I can't get rid of it. No doctor can get rid of it and it's just there. So, I've learned how live - we have to live together. So, I take care of my body and do what I have to do and have a healthier life.

### *Work Identity*

Seven participants were making work a less important aspect of themselves. Prior to and shortly after contracting HIV, they felt their work was their primary identity. When health-related issues made working impossible or they had a change in worldview, then they realized they were not their work and the work identity decreased in salience. Six participants disclosed that prior to diagnosis their entire identity and self-worth was tied to their job. Rich talked about how work

affected his self-worth, “My self-worth was what I produced. I threw myself into my work and made lots of money... when I found myself unemployed it affected my self-worth.” Work was always part Niecy’s life. She stated, “When I first turned 16, I was working at a [fast food restaurant]. I always kept a job. I believe that is why I’m depressed now because I’m not working.” Life for most participants consisted of work; however, after contracting HIV the majority of the participants had a change in perspective. Work became less important. An HIV/AIDS fundraiser and college student, Brian described how his work identity changed drastically after contracting HIV. “Living in New York you identify yourself as your job. That’s what New Yorkers do... Your job. Where you live.” Brian continued, “I needed a wake-up call. This is not real! [laughter]. It’s what you DO, it is not who you are. But, yeah, I don’t really identify myself as [my work].” Enrique added, “I don’t feel the need to work 65 hours a week. That changed a lot.”

### *Sexual Identity*

This category included a change in sexual desire and grappling with one’s sexual orientation. Fear of disclosure of their HIV-positive status affected dating. Brian stated, “I don’t really date as much as I used to [which I attribute to HIV]. You know the whole scare of, ‘I have to tell them.’” Eight respondents were celibate when interviewed and six were not in relationships at the time of the interview. In addition to fear of rejection from potential partners, participants indicated that they were working on different parts of themselves and that being physically intimate with another person had become less important in their lives.

In contrast to most of the participants, two participants maintained active sex/romantic lives. Niecey reported, “The [relationships] haven’t [changed]. You’d be surprised. I’m 33 years old. I’ve been engaged... eight times. And the last time I was engaged, I got married.”

Four participants grappled with being gay after being diagnosed with HIV. Clinton noted:

Prior to that [contracting HIV], I think being in the closet about my sexuality—being gay—but...very sexual. I was so promiscuous back then it was—I didn’t want to be involved with one person too long because I didn’t want people to get ideas about what was going on.

### *Spiritual Identity*

Being diagnosed HIV-positive increased the salience of 12 individuals’ spiritual identity. Spirituality seemed to help participants understand how to make HIV part of their lives. Participants’ spirituality grew through meditation or returning to church. Lee noted, “[My friend] showed me how to meditate properly and I started to meditate properly ...I realized that I was connected with a Higher Power. I knew there was a Higher Power who loved me just as I was in spite of being gay or HIV-positive.”

Although meditation was important to spiritual growth, church seemed to be the main avenue for spiritual growth. Terry indicated that he was trying to get back into church, “I’m back in church trying to get a spiritual self and trying to figure that out for myself right now.” Terry continued, “I’m learning to surrender. I still say, ‘God, I don’t like the way this feels.’...Even though it’s God’s plan, it’s not mine.” He, like most of the participants, believed that his spirituality was saving his life. Christina’s spirituality became more important to her:

I’m spiritually much more healthy. I made a motto, “Become a person that you want to be.” So I want to this, I want to do that.” Don’t WANT to do it. Just BE it. Be that person. That involved getting rid of the baggage, you know, the psychological baggage. It

involved practicing Christian values and morals and seeing God as a universal entity in all living things.

### *Advocate Identity*

Six of 14 people believed their advocate identity increased in salience because of becoming HIV-positive. Fear, lack of time, and not having a focus caused participants not to engage in advocacy for any cause prior to contracting HIV. However, after becoming HIV-positive, participants advocated for themselves and for others. Christina remarked:

I didn't give a rat's ass about HIV or anybody with AIDS. I really didn't. It was something that—you know—let the movie stars take care of that.... I've become really active. We have an HIV Day or AIDS Day that we go to [the state capitol.] Right now I'm the facilitator of the consumer group. So I go to as many conferences as I can attend and then I go to the Health Department quarterly advisory board meetings.

Participants advocated for HIV-related causes on the local, state and national levels. Some started small in ASO's while others went to Washington, D.C. or to the state capitol. Niecy said, Every day that I get up and talk to somebody about it I'm advocating. My state representative, H\_\_\_\_. Me and him sit up there. You would think we were buddies.... When I go to [the capitol city], he's like, "This is my favorite person." He takes me around the office. He says, "This lady has something to say and you have to listen to her because she knows things."

Serving as an advocate helped participants make a difference in the community. They knew they were part of something larger than themselves.

### *Physical Identity*

Younger participants were more concerned with the effect of HIV/AIDS medications on their bodies whereas older respondents said HIV prompted them to live a healthier lifestyle. R., age 25, discontinued her medications because she "lost her behind" and the medications "made her stomach stick out." She wanted to be attractive so she could date. In contrast, Terry, 49, noted that HIV had made him live a healthier lifestyle. He said, "I take better care of myself with HIV. I exercise. I run. I eat better. I'm much more conscious of living in this body now. It might last another 30 or 40 years." Enrique, 50, explained how contracting HIV forced him to make changes, "I have to find out more things and change my diet. Start exercising. That I haven't done very well lately [laughter]. I've never been good at that but now I am changing, definitely." Participants, both young and old, were concerned with their physical self. Some were concerned about their appearance, while others realized their bodies were going to last a lot longer than they had originally thought.

## **Discussion and Implications for Adult Education Theory and Practice**

The HIV identity affected other identities somewhat differently from previous studies because of historical time and access to life-extending medications. HIV was not a central identity for most unlike people living with HIV/AIDS who believed they were going to die shortly after diagnosis (Baumgartner, 2007). The work identity was neither relinquished (Bedell, 1998) nor reclaimed (Baumgartner, 2007) but was re-evaluated in light of new priorities of finding more meaningful work. Participants re-evaluated dating and intimate relationships as they grappled with issues of HIV-positive disclosure and with sexual orientation issues. Last, the salience of participants' spiritual and advocate identities increased. Spirituality is often used as a

coping mechanism (Cotton, et. al.). It should be noted that participants were solicited for AIDS Service Organizations which tend to promote self-advocacy (Guarino, 2003). In sum, because participants were reasonably healthy because of access to life-extending medications, they had time to re-evaluate various identities.

This study confirmed the value of identity theory in exploring how the onset of a chronic illness can affect other identities and it showed that their salience changed depending on the number of relationships associated with that identity. HIV/AIDS educators and counselors need to recognize that HIV impacts other identities. Assisting a person living with HIV might mean helping the person come to terms with a gay identity or providing assistance as to how and when to disclose one's HIV-positive status to a romantic interest. Since HIV/AIDS is a chronic disease, HIV/AIDS educators might also need to help a client re-enter the workforce, assist another in finding more meaningful work, and counsel another to change careers based on the client's current physical capabilities.

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