

---

2-25-2013

## The Perceived Effect of HIV/AIDS on Other Identities

Lisa M. Baumgartner

Northern Illinois University, Lbaumgartner@niu.edu

Eric Niemi

Northern Illinois University, ericniemi@hotmail.com

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>



Part of the [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#), and the [Social Statistics Commons](#)

---

### Recommended APA Citation

Baumgartner, L. M., & Niemi, E. (2013). The Perceived Effect of HIV/AIDS on Other Identities. *The Qualitative Report*, 18(8), 1-23. Retrieved from <https://nsuworks.nova.edu/tqr/vol18/iss8/1>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact [nsuworks@nova.edu](mailto:nsuworks@nova.edu).

---

A promotional banner for the Qualitative Research Graduate Certificate at Nova Southeastern University. The banner has a dark blue background on the left with the NSU logo and text: "Qualitative Research Graduate Certificate", "Indulge in Culture", "Exclusively Online • 18 Credits", and a "LEARN MORE" button. On the right, a photograph shows six diverse individuals sitting on a stone ledge in front of a building with "NOVA SOUTHEASTERN" visible on the wall.

**Qualitative Research Graduate Certificate**  
*Indulge in Culture*  
Exclusively Online • 18 Credits  
**LEARN MORE**

NSU  
NOVA SOUTHEASTERN  
UNIVERSITY

NOVA SOUTHEASTERN

## The Perceived Effect of HIV/AIDS on Other Identities

### Abstract

The onset of a chronic disease influences other roles or identities. For example, an HIV or AIDS diagnosis can affect a person's work identity (Bedell, 1997). In this article, we explored how living with HIV/AIDS shapes other identities. Thirty - six individuals living with HIV/AIDS (PLWHAs) participated in semi - structured interviews. Participants' work, sexuality / intimacy, spirituality, advocate, self - esteem, addict/ recovering addict and parent identities changed after being diagnosed with HIV or AIDS. In general, respondents' advocate and recovering addict identities emerged and gained salience after being diagnosed with HIV or AIDS. Further research on how HIV/AIDS affects identities and their salience is warranted especially for lower income individuals with a history of chemical dependency.

### Keywords

HIV/AIDS, Identities, Roles, Identity Theory, Basic Qualitative Study

### Creative Commons License



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

## The Perceived Effect of HIV/AIDS on Other Identities

Lisa M. Baumgartner and Eric Niemi  
Northern Illinois University, DeKalb, Illinois USA

---

*The onset of a chronic disease influences other roles or identities. For example, an HIV or AIDS diagnosis can affect a person's work identity (Bedell, 1997). In this article, we explored how living with HIV/AIDS shapes other identities. Thirty-six individuals living with HIV/AIDS (PLWHAs) participated in semi-structured interviews. Participants' work, sexuality / intimacy, spirituality, advocate, self-esteem, addict/recovering addict and parent identities changed after being diagnosed with HIV or AIDS. In general, respondents' advocate and recovering addict identities emerged and gained salience after being diagnosed with HIV or AIDS. Further research on how HIV/AIDS affects identities and their salience is warranted especially for lower income individuals with a history of chemical dependency. Keywords: HIV/AIDS, Identities, Roles, Identity Theory, Basic Qualitative Study*

---

Once considered a death sentence, HIV or AIDS is now considered a chronic illness because of widespread availability of life-extending medications in the United States (Kirton, 2011). The average life expectancy after an HIV diagnosis has increased from "10.5 years to 22.5 years from 1996 to 2005" (Harrison, Song, & Zhang, 2010, p. 125). Thirty-four million individuals are living with HIV worldwide which is a 17% increase from 2001 figures (UNAIDS World AIDS Day Report, 2011). In North America 1.3 million individuals are living with HIV compared to 980,000 in 2001 (UNAIDS World AIDS Day Report, 2011). Because individuals are living longer, it is important to understand how the incorporation of the disease affects people's identities.

Chronic diseases last more than three months and cannot be cured or prevented by medication (MedicineNet, 2011). Examples of chronic illnesses include obesity, diabetes, asthma, arthritis and heart disease among others (Centers for Disease Control, CDC, 2010). The onset of a chronic disease such as HIV or AIDS often precipitates a re-definition of self (Charmaz, 1991). Identity theorists believe that a person's self is comprised of other identities or roles (Stryker & Burke, 2000). The onset of a chronic disease might affect a person's work, spiritual or parent identity, for example. Since individuals have multiple identities, their salience, or the likelihood that they will be acted out across different situations varies (Stryker & Serpe, 1994). The more salient one's identity, the more committed a person will be to that identity and the more likely it will be acted out in different contexts (Stryker & Burke, 2000). The prominence of a particular identity might also be influenced by the intrinsic or extrinsic rewards received for enacting that identity (McCall & Simmons, 1978). For example, Kate has a highly salient identity as a musician. She teaches band at the local junior high school, gives private piano lessons in her home, and conducts the local community band. Her artist identity is much less salient. She takes an occasional watercolor course at the local community college and paints watercolors for her own enjoyment but does not discuss being an artist with many people. The rewards she receives in her community are related to her identity as a musician and not as an artist. As such, her musician identity is more salient and, thus, more likely to be recognized by the community.

An HIV or AIDS diagnosis means the incorporation of that identity into the self. In addition, HIV/AIDS affects other identities or roles. Although scholars have investigated how HIV/AIDS affects sexuality and relationships (e.g., Keegan & Lambert, 2005), work (e.g., Conyers, 2004), spirituality (e.g., Ironson, Stuetzle, & Fletcher, 2006) and motherhood (e.g.,

Sandelowski & Barroso, 2003), little is known about how HIV/AIDS affects other identities. What is the effect of HIV/AIDS on fatherhood? How does an HIV or AIDS diagnosis affect those who identify as addicts? What new identities emerge as a result of being diagnosed with HIV/AIDS? If Kate, for example, becomes infected with the virus, how does that change the salience of her musician or artist identity? Hence, the purpose of this study is to explore how contracting HIV or AIDS affects other identities.

## Literature Review

### *The Effect of Chronic Illness on Other Identities*

The diagnosis of a chronic disease affects other roles or identities. Scholars who investigated the effect of a chronic illness on one's occupation have examined the negative effect of the loss of the work identity due to chronic illness (Asbring, 2001; Thornhill, Lyons, Nouwen, & Lip, 2008), renegotiation of the work identity (Alsaker & Josephsson, 2003), concerns of those considering returning to work (Brooks & Klosinski, 1999; Martin, Brooks, Ortiz, & Veniegas, 2003) and issues for individuals who left paid employment due to their illness and returned (Allen & Carlson, 2003; Jakobsen, 2001). For example, the diagnosis of congestive heart failure meant the loss of a work identity which affected younger participants more negatively than older participants (Thornhill, Lyons, Nouwen, & Lip, 2008). Individuals missed the meaning they derived from work (Thornhill et al., 2008, ) as well as the social contacts they had through work (Asbring, 2001). For Persons Living with HIV/AIDS (PLWHAs) who returned to work, allowances for adaptations at work and family assistance at home helped individuals remain employed (Jakobsen, 2001). Some participants feared they would be stigmatized if their illness was discovered by coworkers (Allen & Carlson, 2003). The loss of a positive social identity such as a work identity due to a chronic disease meant that individuals were afflicted with two negative social identities (unemployed person and chronically ill) in cultures that hold individuals responsible for their health which made returning to work quite challenging (Walker, 2010).

In addition to HIV/AIDS changing the salience of the work identity, the onset of a chronic disease meant the re-negotiation of a person's sexuality/relationship identity for some participants. A literature review of chronic neurological, vascular and hormonal chronic diseases revealed that these illnesses negatively affected sexual functioning and sexual well-being either directly or indirectly (Verschuren, Enzlin, Dijkstra, Geertzen, & Dekker, 2010). Regarding sexual well-being, individuals with multiple sclerosis had a negative self-image and feared rejection from partners (Fletcher, Castro-Borrero, Remington, Treadway, Lemack, & Frohman, 2009 as cited in Verschuren et al., 2010). Female loss of attractiveness and male loss of autonomy also adversely altered the sexuality of stroke survivors (Verschuren et al., 2010). Poor body image also contributed to lack of sexual desire (McCabe & Taleporos, 2003, as cited in Verschuren et al., 2010).

Other identities altered by chronic illness included one's sociable identity and spiritual identity. Generally, one's spiritual identity gained prominence when a person was diagnosed with a chronic illness (Ambs, Miller, Smith, Goldstein, Hsiao, & Ballard-Barbash, 2007; Tanyi & Werner, 2008). Chronic illness meant a loss or diminishment of a person's propensity to socialize (Asbring, 2001; Stanley-Hermanns & Engebretson, 2010; Thornhill et al., 2008).

### *The Effect of HIV/AIDS on Other Identities*

Like the general chronic illness literature, the HIV/AIDS literature reflects the disease's effects on various identities or roles including sexual desire and behavior among PLWHAs. Findings have included concerns about libido, (Keegan & Lambert, 2005; Maticka-Tyndale, Adam, & Cohen, 2002) disclosure to potential partners (Keegan & Lambert, 2005; Maticka-Tyndale et al., 2002; Relf et al., 2009), and condom use (Maticka-Tyndale et al., 2002; Relf et al., 2009; Keegan & Lambert, 2005; Wilson et al., 2007). In addition, partner selection and sexual activity of HIV-positive men (Relf et al., 2009) and women (Keegan & Lambert, 2005; Wilson et al., 2007) were explored. Relf et al. (2009) interviewed 18 HIV-positive gay urban males and found that some avoided sex for fear of infecting someone, others had sex with random partners without disclosing their respective serostatus and a third group disclosed their HIV-positive status to partners with which they were developing a relationship or were in a committed relationship and engaged in safer sex practices. Keegan and Lambert (2005) also found that some women avoided relationships after being diagnosed HIV-positive whereas others negotiated safer sex practices without disclosing their HIV-positive status. Participants had no preference regarding their partner's serostatus but wanted to be accepted by their respective partner (Keegan & Lambert, 2005).

Much like the varied effects of HIV/AIDS on relationships, the HIV/AIDS diagnosis affected participants' spirituality in a variety of ways. Researchers have written quite extensively about spirituality and HIV/AIDS. Spirituality has served as a "context for perspective shifts" or new meaning-making (Peterson, Johnson, & Tenzek, 2010, ¶ 20) and a source of support (Peterson et al., 2010; Ridge, Williams, Anderson & Elford, 2008; Tuck, McCain, & Elswick, 2001). Scholars have noted that spirituality contributes positively to HIV-positive individuals' mood and better health (e.g., Cuevas, Vance, Viamonte, Lee, & South, 2010), slower disease progression (Ironson, Stuetzle, & Fletcher, 2006). In addition, sex and race differences in spirituality of those living with HIV/AIDS (Cotton et al., 2006) have been discussed and faith development PLWHAs has been examined (Courtenay, Merriam, & Reeves, 1999). Studies investigating a change in self-reported religiosity or spirituality are mixed with some reporting no difference between HIV-positive and HIV-negative individuals regardless of age (Cuervas et al., 2010) whereas others indicate an increase in spirituality or religiosity for 66% of those surveyed (Cotton et al., 2006). However, another study showed an increase in spirituality for 45% of those surveyed, no change for 42% and a decrease in spirituality or religiosity for 13% (Ironson et al., 2006).

In addition to spirituality, the effect of an HIV or AIDS diagnosis on work has been of interest. Research on work and HIV/AIDS has included exploring how various constructs (e.g., individual, environmental, and mediating) affect one's career trajectory (Conyers, 2004). Those with a strong vocational identity (a mediating factor) tend to want to remain employed or seek employment (Conyers, 2004). Other individuals *must* remain employed for financial reasons although their HIV medications make them biomedically strong and physically weak (Alcano, 2009). A second research strand examined factors involved in considering a return to work or a return to work after a period of unemployment (Adams, Maticka-Tyndale, & Cohen, 2001; Braveman, Kielhofner, Albrecht, & Helfrich, 2006; Ghaziani, 2004; Nixon & Renwick, 2003). Often, participants' work identity decreased in salience after receiving the HIV or AIDS diagnosis because they thought they were going to die. When they realized they were going to live, the desire to work increased (Ghaziani, 2004).

Parenting is also considered work. Several studies have been conducted on the effects of HIV/AIDS on motherhood. Sandelowski and Barroso (2003) compiled a metasynthesis of qualitative studies on motherhood and HIV-positive women. They categorized study findings

into two categories: “reproductive decision making” and the “experience of motherhood” (p. 159). Topics address in the former category included whether or not to have children, factors influencing whether or not to have children (HIV-related and non-HIV related), and justifications for having or not having children. The “experience of motherhood” (p. 159) category included findings on the positive and negative impact of HIV on motherhood, “conditions of mothering work” (p. 160) such as the age, race, gender, HIV-status of the child, disclosure issues, preparing children for a future without a mother, and the “objects of mothering work” such as “protection of children and preservation of identity as a good mother” (p. 160). Wilson (2007) found that coping with the effect of HIV/AIDS stigma on one’s children and an increased determination to be a good mother preoccupied participants. Scholars also investigated the activities mothers miss with their children as a result of having HIV (Murphy, Roberts, & Herbeck, 2011), and how children of HIV-positive mothers assume more of a parenting role (Tompkins, 2007).

Researchers have studied the effect of HIV/AIDS on motherhood but less research exists on HIV/AIDS and fatherhood (Sherr, 2010). A review of the literature revealed that although fathers with HIV express an interest in having children, HIV-negative fathers express more of an interest in having children than do HIV-positive men. Men who have sex with men also want to be fathers but recognized they would experience discrimination. Other topics included drug use and fathering, fathers’ support of HIV-positive mothers, paternal disengagement, and the impact of HIV-positive fathers on child development (Sherr, 2010). She notes, “Fatherhood in the presence of HIV infection of the father and drug use in developing and resource-constrained countries, and for MSM [men having sex with men], is not fully understood. Yet the loss of a father severely impacts on multiple facets of child development” (p. 9). The author calls for increased attention to fatherhood and HIV/AIDS.

In sum, researchers have studied the impact of chronic illness on relationships, motherhood, work and spirituality. However, less is known about other roles that are affected or emerge as a result of contracting HIV/AIDS. The findings from this study can make practical contributions to the HIV/AIDS literature and inform HIV/AIDS counselors and educators.

### **Positions of the Researchers**

My (Lisa M. Baumgartner) abiding focus on HIV/AIDS, identity, and meaning-making issues since 1998 is rooted in wanting to know more about how individuals deal with an illness that still remains stigmatized, my memory of the Reagan Administration’s seeming lack of reaction to this health crisis especially early in the epidemic, and also because I personally know individuals living with the disease. However, my interest in examining HIV/AIDS and identity issues began when, as a doctoral student, I was asked to join a research team that was investigating HIV/AIDS and meaning-making in 1998. This led to my dissertation research about the integration of HIV/AIDS into a person’s identity using an Eriksonian framework where identity was conceived of as “a persistent sameness within oneself (selfsameness) and a persistent sharing of some kind of essential character with others” (Erikson, 1980, p. 109).

Several years after I completed my dissertation, I read articles by Stryker and Serpe (1994) and Stryker and Burke (2000) that opened my eyes to their conceptualizations of identity theory where individuals possessed various roles or identities that comprised a stable self. I started wondering how an HIV or AIDS diagnosis affected other roles or identities. Did any emerge after the HIV/AIDS diagnosis? Did any disappear or become dormant? My interest grew and ultimately resulted in this study.

I (Eric Niemi) started this project to gain experience in qualitative research and methodology. My M.A. is in Cultural Studies, and this study offered me a chance to examine and study a culture that I only had limited prior knowledge. Additionally, it afforded me an opportunity to examine various power and meaning-making structures contained within this discourse of HIV/AIDS. The research focus on HIV/AIDS and identity development intrigued me because my dissertation research examines how people make meaning and development through semiotic mediation of cultural artifacts. I looked at this project as a chance to apply some of my knowledge and theory to a project for the experience in being able to conduct my own larger project in the future.

I remember growing up learning about the Ryan White Story and sitting in several classes teaching us about HIV/AIDS and how to avoid contracting the disease. As my present 32-year-old self looked back at my 12-year-old self going through these classes, I realized I was more cognizant of contracting HIV/AIDS through intravenous drug use or blood transfusions than via sexual intercourse with another man. It encouraged self-reflection as to the power dynamics that would cause me to omit such a huge, vital part of this discourse community. To me, this critical analysis underscores how certain meanings are privileged within discourse and get replicated, while others do not.

Thus, I began to look at and for other power dynamics of HIV/AIDS that are marginalized or suppressed in this discourse. Further, I wanted to look at how people become aware of this information and how it affects their learning and development. Obviously, this is a kairotic moment for the participants and significantly impacts how they define themselves. In short, how does a single moment produce long-term effects on their growth and development?

## **Method**

Qualitative research is a flexible, inductive method that recognizes that knowledge is constructed (Patton, 2002). This method is especially helpful to explore individuals' experiences with HIV/AIDS from their perspective. The flexibility of this research method was excellent for this exploratory study because my (Lisa M Baumgartner) follow-up probes to the main interview questions could more specifically get at the particular participants' experiences. Further, since qualitative research is an inductive method, the interview guide could be altered as needed to obtain the most relevant information for this study. For example, some individuals discuss how HIV/AIDS affected their addict identity whereas others did not have a history of drug use so they spoke about different concerns.

The investigation of the effect of HIV/AIDS on other identities or roles was initiated by the first researcher who designed the study and collected the data. A basic qualitative methodology was used because basic qualitative studies are used to learn "(1) how people interpret their experiences, (2) how they construct their worlds, and (3) what meaning they attribute to their experiences" (Merriam, 2009, p. 23). Of interest were the participants' perceptions of their respective realities and a basic qualitative method helped to uncover these perceptions.

## **Data Collection and Analysis**

I (Lisa M. Baumgartner) decided on the methodology and conducted the interviews. A purposive sampling technique was used to select participants from an AIDS service organization (ASO) located in the Midwestern United States. AIDS educators informed qualified clients about the study, and they forwarded my name and contact information. In order to participate in this study, participants had to be 18 years of age, and had to have been

diagnosed with HIV/AIDS for at least one year. This last requirement stemmed from the assumption that participants with less than one year may not have had time to adequately reflect upon the effect of HIV/AIDS on their identities. Additionally, a snowball sampling technique was used as participants recommended friends and acquaintances to participate in the study. Additionally, a person at an ASO located in a mid-size city referred 6 individuals for the study.

Interviews occurred between October 2009 and April 2010, and they lasted from one to two hours. The final sample size consisted of thirty-six adults between the ages of 25 and 66. Twenty-three African Americans, nine Whites, one Latino, and three participants identifying as biracial comprised the racial composition of the sample size. Further, twelve African American, nine Whites, one Latino, and one biracial participant identified as men; eleven African American and two biracial participants identified as women. Participants had lived with HIV or AIDS for a period of time of two years to twenty-four years prior to the interview. The education level ranged from an eighth grade education through master's level education. Sixteen of the participant graduated college, and eight participants did not graduate from high school or receive their GED. Last,, thirty-two participants reported less than \$20,000 or less as their household income. All participants chose their own pseudonym for this study.

To maintain the utmost ethical standards for data collection and analysis, the first author of this study received institutional review board approval (IRB). Cards advertising the study were sent to my contact at the ASO who informed people about the study. Potential interviewees contacted me using telephone and email, and 30 interviews were conducted at the metropolitan ASO in their private conference rooms. Six interviews were conducted in a hotel room in a mid-size city. Consent forms addressing the purpose of the study and its related confidentiality issues were read before for the interview, and participants were informed they had the right to withdraw from the study at any time for any reason. Additionally, I offered to refer participants to a social service agency in the event of any psychological discomfort. Along with the written communication, these aspects were provided orally, and I provided contact information for the Office of Research Compliance in case participants had questions or concerns. Due to an IRB policy, participants could not sign documents, but they agreed orally to the terms. Participants chose their own pseudonym; and, at the conclusion of the interview, they received a \$30 money order.

The interviews were conducted using a semi-structured approach to allow for consistency across the participants, but to still allow the necessary flexibility to probe and discern individuals' particular stories. Participants' interviews contained some very poignant stories. Because most participants had shared their stories in support groups and in larger public venues prior to being interviewed, they generally related their experiences in a matter-of-fact manner. On occasion, some respondents teared up especially when discussing their children or relationships with nephews or nieces. Due to equipment failure, two interviews were rescheduled. The questions encouraged discussion regarding how they incorporated their HIV/AIDS identity, and what learning occurred in the various contexts influenced by this incorporation. Questions concerning the effect of HIV/AIDS on other identities were created, in part, from a review of the literature. This review indicated that work and relationships were usually affected when a person contracted HIV or AIDS (e.g., Conyers, 2004). Participants were first asked, "How has living with HIV/AIDS affected other aspects of your life?" This often resulted in discussions concerning their work lives and relationships and spirituality. If respondents indicated that no other aspects of their lives had been affected, I sometimes asked a follow-up question such as, "How has HIV/AIDS affected your work, if at all?" or "What differences, if any, have occurred in your dating/romantic life after you were diagnosed with HIV/AIDS?" Other questions included "What aspects of who you are have you given up



because of HIV/AIDS, if any?” and “What other parts of yourself have you gained as a result of having HIV/AIDS, if any?” After the interview, I provided periodic summaries of their responses and sought affirmation, and this served as a member check for the interview.

I used a series of grounded theory procedures to conduct my study. After conducting and transcribing the interviews, I used a constant comparison method (Glaser & Strauss, 1967) to provide the initial inductive analysis. This analysis was then supplemented by incident by incident coding (Charmaz, 2006). Focused coding then determined which “initial codes make the most analytic sense to categorize [the] data incisively and completely” (Charmaz, 2006, p. 58). These focused codes provided reoccurring themes that I used to structure and analyze the data. Transcripts were read, re-read, and coded to discover themes occurring both in them and across them. These themes were then categorized and refined. Finally, participants received copies of the transcripts and initial summaries of study findings. They were asked to document changes, comments, or corrections and several thanked me for the interview and my findings. No participants expressed negative comments or concerns about the transcripts or findings; although, several participants could not be located to receive them.

I used Spradley’s (1980) four part method of transcription because I considered it a very useful method to use in the field that ultimately helps during the initial coding process. Namely, I took field notes, and these were complimented by brief notes taken during the interview. Frequently, these notes focused on the physical appearance of the participants and any notable aspects of their demeanor and/or posture. Following the interview, I wrote detailed supplemental notes that summarized thoughts and observations about body language, my initial analysis about attitudes towards themselves and others, and how they displayed an ability to cope with this HIV/AIDS identity. Notes were also taken about her reactions, impression, hunches, and thoughts during the interview, and these notes further contained my observations about whether this participant’s incorporation process contained similarities or dissimilarities to other participants’ incorporation process.

In 2011, I invited the second author, Eric, to participate in a second analysis of transcripts to provide him an opportunity to learn qualitative data analysis and to perhaps unearth additional findings. We re-analyzed each transcript and unearthed a couple of additional themes from my original findings. This peer review of the transcripts strengthened the validity of the study.

## **Findings**

### *Identity*

Identity has been conceptualized in numerous ways. The theoretical framework used for this study centers on identity theory. This theory posits that individuals possess many identities that comprise a stable self (Stryker, 2007). These identities are shaped by individuals and by society (Stryker, 2007). The salience of an identity is defined as “the likelihood that a given identity will be invoked . . . in a variety of situations [or]... the differential likelihood across persons that a given identity will be invoked in a given situation” (p. 1092).

The salience of an identity depends on how committed individuals are to that identity. Commitment is measured by how many relationships are affected by enacting an identity and how emotionally attached in the person to that identity (Stryker, 2007). A higher commitment to an identity means that individuals enact that identity across different groups of people (Stryker, 2007). For example, Sandra used to have a highly salient identity as a vegan. At one point, most of her friends were vegans and she was very emotionally committed to being a

vegan to the point of trying to convince others to become vegan. After encountering resistance from individuals in some of her other social groups to her vegan identity, these days, she is less likely to enact that identity across different groups of people although she remains emotionally committed to remaining vegan. Hence, the salience of her vegan identity has lessened somewhat.

The next portion of the findings section shows how the salience of various identities has changed or emerged since contracting HIV or AIDS.

### *Work Identity*

Studies on work and HIV/AIDS have shown that early in the HIV/AIDS epidemic individuals had to leave the workforce with little hope of returning (e.g., Bedell, 1997). After the advent of life-extending medications, scholars' research focused on issues related to individuals returning to work (e.g., Hergenrather, Rhodes & Clark, 2005). In our study, most participants' work identities remained strong in that they were emotionally committed to that identity but the ability to work in paid employment changed for many. Thirty participants were not part of the paid workforce at the time of the interview. Of the thirty, one person was a retired teacher and another was a full-time student. Some respondents were receiving disability checks for issues unrelated to HIV/AIDS. Others were full-time homemakers. A few respondents remained in paid employment but changed fields after being diagnosed with HIV or AIDS. Several participants reported lower energy levels but continued to work. Some participants wanted to work but feared stigma in the workplace or they saw benefits to remaining unemployed. Others pursued volunteer positions to fulfill their work identity.

Of those respondents that mentioned a change in work identity, four indicated that they found paid work in the HIV/AIDS service field after being diagnosed with HIV or AIDS and work remained important to them. Debonaire noted that after diagnosis, he now has to "find more meaningful work." Although he received disability payments, he created his own HIV/AIDS education consulting firm. He stated, "Whatever I'm going to do and get paid for, I've got to want to do it and it has to mean more. . . My ultimate goal is to be this advocate/entertainer/peer counselor/motivational speaker." Likewise, Kelvin left the banking industry and was a peer educator at an AIDS service organization. At the time of the interview, Derek, a former actor, worked full-time at an AIDS Service Organization.

A change in one's employment field was not only precipitated by the desire to find more meaningful work but also by physical limitations. Eight participants mentioned that their energy level was lower because of reactions to HIV/AIDS medications and complications from other chronic illnesses such as depression, Hepatitis C, diabetes, and high blood pressure. Some participants continued to work and others sought less stressful positions. Gerald's response was typical: "I had to listen to my body and say, 'Look you need to go home and get rest.' Before HIV I was sleeping six hours a night. Now there's time like now I have not been feeling well. . . I'll come through the door, come home and just be worn out. . . Some days I just want something that is low stress." Derek added that after being diagnosed with HIV he "feels like less of a go-getter." However, he was employed full-time at an AIDS Service Organization but had given up acting and life on the road. It appeared work was important to participants but they needed to listen to their bodies and accommodate their lack of energy.

Whereas some participants left stressful work situations to pursue less taxing employment, others *wanted* to work but feared that they would be stigmatized in the workplace. Al wanted to pursue a degree in nursing after being a certified nursing assistant but physical challenges and his fear of being accepted in the nursing profession as an HIV-positive individual prevented him from pursuing that goal. He now receives disability for an

injury received at work. Likewise, Joe Smith did not pursue a career in the restaurant business because he was afraid others would find out he was HIV-positive.

Those who were unable to seek paid employment because of physical or mental disabilities related or unrelated to HIV/AIDS or who were retired from other paid employment pursued volunteer employment to fulfill their work identity. Booker volunteered at an AIDS Service Organization after a career in education. Sherry received disability and she volunteered to write a church newsletter. Greg was actively involved in many HIV/AIDS related activities in the community. Ken received disability due to neuropathy and volunteered at an AIDS Service Organization.

In sum, although many individuals were not employed at the time of the interview, their commitment to their work identity remained strong despite physical challenges, a decrease in energy level due to medications or other chronic illnesses. Many respondents volunteered in the HIV/AIDS community. Several participants sought more meaningful work after being diagnosed with HIV/AIDS and found employment in an HIV-related field. A few individuals wanted to pursue other careers but were afraid to do so because they had HIV/AIDS and were afraid to tell potential employers.

### *Sexuality Identity*

In addition to changes in the work identity, there were changes in the sexuality identity for some individuals but not for others. There were three findings: no change in the salience of the sexuality identity, an initial decrease in the salience of the sexuality identity and then a resumption of activity after a period, and a complete discontinuation of sexual activity with a partner. Twelve of 25 individuals who mentioned a sexuality identity reported no decrease in the salience of the sexuality identity although individuals acknowledged increased attention to safe sex practices and dealing with rejection. Joe dated regularly and said, "I've had a couple rejections—people accepted [my HIV-positive status] and later they said they couldn't accept it anymore... [Rejection] gets easier." Mother said her sexuality identity did not change. She noted that her partner was not HIV-positive and said, "We use protection. . . It's a good relationship because we keep each other safe."

The second most common reaction to an HIV/AIDS diagnosis was an initial decrease in the salience of the sexuality identity with an increase after a period with nine of the 25 respondents reporting this reaction. Greg's reaction was typical:[When I was diagnosed] I didn't want to touch anybody. I didn't want anybody to touch me. I felt dirty... for six months to a year...[Then] I started looking for people who said they were positive [on the computer]. Matthew concurred and indicated that being accepted by a non-positive partner was integral to the integration of HIV/AIDS into his self.

At first I didn't want anybody. Not because I didn't *want* anybody but because I was scared I'd give it to somebody. I was afraid of infection. Slowly, I met people here and there who had HIV that I would be intimate with but I was still really, really nervous about it. Slowly, over time I started meeting other people in the area who didn't have HIV but who were familiar with it and they were educated and I think that would be like the biggest turning point where I started really, really accepting it and internalizing that I had HIV when I started meeting guys who *didn't* have HIV and still wanted me. They made me feel normal in a sense.

A few individuals indicated that their sexuality identity decreased significantly in its salience. Thin had not engaged in sexual relationships since his diagnosis. Thin's physical health was also complicated by a stomach condition. He stated:

I have none [no romantic relationships]. . . I don't want to give [HIV] to somebody else. Condoms break, you know. I'd have a tough time dealing with that one. I'm better off leaving it alone. I don't need it that much anyway. . . I want a girlfriend bad, but it's just not that feasible. They've got to fix this stomach thing first.

Sherry did not have any romantic relationships because she did not know how to disclose her status to prospective partners. She stated, "I don't know how to tell a person. That's why I have avoided relationships. . . I don't want to get too close to anybody and then have to say that I have HIV because I don't want to hear what [they] might have to say."

To summarize, participants' sexuality identity remained the same, decreased for a period and returned to normal or decreased significantly. It should be noted that support from others and education about HIV/AIDS helped some respondents resume intimate relationships with others. The ability and desire to be intimate was complicated by other factors besides HIV/AIDS.

### *Spiritual Identity*

Like sexuality, the HIV/AIDS identity affected the spiritual identity differently. Of the 19 participants who discussed their spiritual identity, 15 indicated an increase in the salience of the spiritual identity. Ed's comment was typical:

[Being diagnosed with HIV] has enhanced [my spirituality]. I do try to pray every night. I pray a lot at any moment. I'm not a religious person but I am a spiritual person. I try to pray while walking or riding the train or whatever. In my daily life, I just pray. I want to try to pray to thank God for what He's done for me and ask God to help me to accept what He has for me and others and that's it.

Although many participants noted an increase in the salience of their spiritual identity, two individuals described a decrease. Juan stated:

Yeah, [my spirituality has] gotten worse. I mean what Father do you know would give you ten rules that if you didn't follow [and] he'd send you to the worse place imaginable forever? But he loves you. That don't make sense.

Tina's spirituality initially decreased and she is still struggling with her relationship with God. She remarked:

In the beginning I was further away [after being diagnosed with HIV]. I felt like, "Why would He let me...He [God] knows how I lived my life. What could I have done that was so bad by Him allowing me to get this disease?" At one point, I had denounced him. [Now] I know there is a God and I know I love God but it's hard for me. Because it's like we live on this earth and they say He knows what we are going to do and what we're not going to do and

how we are going to live our lives. But I've wondered if he's such a humble or gracious God, why would there be so much pain and turmoil in the world?

Although many respondents reported an increase in the salience of their spiritual identity, individuals working with PLHWAs should note that spirituality can decrease or respondents can have a crisis of faith after diagnosis.

### *Advocate Identity*

More respondents reported an increase in the salience of the advocate identity than in spirituality. Twenty-one of the 36 individuals indicated that they had gained an advocate or activist identity after contracting HIV or AIDS. Booker "sent letters out to congressmen" concerning HIV/AIDS issues. Others chose to join community groups to advocate for HIV/AIDS causes. Greg's response was typical of those newly involved in HIV/AIDS activism:

I go to the community action board meetings and I joined the health connect HIV board as the enrollment recruiter. I just joined that last week and I joined the community action board two weeks ago. I'm in a men's group now [related to HIV]. I'm really outspoken now and I'm going to AIDS day with another client in our group. . . Of everybody on the Health Connect Board--I'm the only one who said I'm a client and I USE your services. All you have to do is be a member and live or work in the area. . . I'm starting to become an activist after all this—going from not caring at all, wandering around, having to go to different areas.

Unlike Greg, who was a recent convert to advocacy work, Deborah was diagnosed with AIDS in 1985. She has been involved in advocacy work for some time. Her most recent advocacy work concerns working with "affected but not infected." She explained:

I just want this group because I see a lot of people that are affected but not infected and they don't have nowhere to go and they don't know who to talk to. Some of them are in these programs because of their spouse. If they have to deal with their spouse, where are they going to go?

Advocacy was a new identity that emerged after the HIV/AIDS diagnosis. All individuals connected to AIDS Service Organizations and had opportunities to do advocacy work. It is possible that participants not associated with AIDS Service Organizations might be less likely to develop this identity after receiving an HIV/AIDS diagnosis.

### *Self-esteem/Self-worth*

Changes in self-esteem were mentioned less often than the emergence of an advocate identity although it is likely that other identities besides HIV/AIDS affected participants' self-esteem. Ten of the 36 individuals mentioned changes to self-esteem. Four respondents stated that their self-esteem was lower after contracting HIV or AIDS and six participants remarked that their self-esteem was initially lower but now it had rebounded. For some participants, a lower self-esteem affected their ability to approach potential romantic partners. Ed noted, "[HIV] has lowered my self-esteem. Yeah. To a certain extent where I'm not as apt to approach women." Gloria said she felt "damaged" after being diagnosed. She added, "I still

feel damaged because I haven't found someone who loves me for me or who understands me."

Six respondents suffered a decrease in self-esteem initially after diagnosis and then their self-esteem rebounded. Greg's response was typical:

At first I was dirty. Felt like things were crawling inside me and I was worthless and never going to be touched and loved again. Never going to find happiness to dealing with it, breaking down occasionally. Like if I cut myself, I'd freak out [and then I went to] accepting [HIV] and finding humor. . . I am not embarrassed of who I am or what I am.

To summarize, self-esteem initially decreased and was sometimes related to a respondent's sexuality identity. Participants felt "damaged" and "dirty" after diagnosis but some individuals eventually accepted themselves and their self-esteem rebounded.

### *Addict/Recovering Addict Identity*

It might be argued that self-esteem was also affected by the addict/recovering addict identity although this assertion is speculative. Twenty individuals reported being addicted to drugs or alcohol prior to being diagnosed with HIV or AIDS and this identity was primary for a period after diagnosis. Linda had "been a drug addict for 30-some years." Linda's substance abuse escalated after diagnosis and despite difficulty walking as the result of a car accident, Linda explained,

I had a body brace. . . Since I was going to die anyway, let's do this. I'm going out with a bang. Now I know how embarrassing it was and how ridiculous I looked trying to walk to the drug spot. . . All I wanted was my drugs. . . At this point, it didn't matter. Nothing mattered. Nobody mattered. I wouldn't take my HIV meds because they were making me sick. I had bad side effects. . . My medication became crack and my alcohol.

Typically, individuals' drug and alcohol use escalated after their HIV/AIDS diagnosis and many sought substance abuse treatment and relapsed before and after their HIV or AIDS diagnosis. Mother's journey was representative of others. She had been a drug addict "for 20-some years" and was diagnosed with HIV/AIDS in 2003. She kicked her drug habit in 2004 through treatment but she "relapsed in 2006 [and] went to [a treatment center]." She added, "Then I went to another [treatment center] to another one last year. I graduated from that one in 90 days."

All 20 individuals considered themselves recovering alcoholics and addicts at the time they were interviewed although five of the 20 reported using alcohol or marijuana in moderation. Some respondents were in programs that focused on recovering addicts living with HIV. Other participants attended Alcoholics Anonymous or Narcotics Anonymous meetings. Pearl's story was typical. She was addicted to drugs and alcohol prior to diagnosis and used substances for a period after diagnosis. At the time of the interview she was a recovering addict. She stated

I don't want to repeat those things I have done so I must maintain my sobriety at all costs. So, I do meetings. Service work. Work with other people. That is all consuming. . . So, I do the AA [Alcoholics Anonymous] . . . meetings. . . Mostly, during the week I go to AA-related activities.

In sum, drugs and alcohol were used to cope with life before and after diagnosis. The addict/recovering addict identities were quite salient for many participants throughout their lives. For many addicts, the HIV diagnosis resulted in an initial increase in drug and alcohol use followed by participants seeking treatment and becoming sober. Occasionally, relapses occurred and respondents returned to treatment several times. Therefore, the addict identity/recovering addict identity was fairly salient before and after an HIV/AIDS diagnosis.

### *Parent Identity*

Some of the participants struggling with addictions were also parents. Seventeen individuals mentioned referred to parenting or engaging in parenting behavior such as guiding a younger generation in their interview. Seven mentioned that they were not responsible for their children at the time of their HIV/AIDS diagnosis. This was primarily because they were chemically dependent at the time of diagnosis and others were caring for their children. After being diagnosed HIV-positive and coping with their addictions, they were in the process of repairing their relationships with their children or parented others' children. Deborah's response typified others:

[My children] were babies [when I was diagnosed with HIV/AIDS]. My daughter was 10 [and my other children] were 8 and 9. . . [Social services] took them from me because of the drugs. . . [Now] I have an eight-year-old. . . She's a friend of mine's daughter. Her mother died so I took over. . . I teach her too. I got a book on HIV and I let her read about STDs and everything. Every question she asks me I answer to the best of my knowledge. . . I want to live a happy life. To raise this child and keep God in our lives.

When Linda was diagnosed with HIV, only "the drugs mattered." She said, "I was treating my kids like crap." The death of Linda's grandson was a turning point from Linda's addictions. At the time of the interview she was "clean for 2 years and a couple of months" and she said, "I'm not 'that lady' today. I'm mother. I'm mom. . . My daughter calls me over to spend the night . . . I've got my children back in my life."

The HIV/AIDS diagnosis compelled several individuals to education their children and younger relatives about HIV. Kelvin noted that HIV made him a "better uncle." He "schools" his nephews on "HIV and relationships." He said, "I'm straight up with them. Sex. Condoms. Abstinence. Sexual health. Mental health. Gay health."

Four individuals wanted to have children and talked about the effect of an HIV/AIDS diagnosis on achieving that goal. Octavius did not have children at the time of the interview and wanted to be a father. He stated, "I never thought I'd be able to have kids [when I was diagnosed]. But once I started educating myself I learned I could have kids. Cool." In contrast, Ed wanted to be married and have children but he saw his diagnosis as a potential barrier to meeting women. He said, "It would have been easier to have the motivation to meet women. . . I don't bother [women] because I really don't want to have to get into telling someone I'm HIV-positive and them not being able to accept it."

## **Discussion and Conclusions**

Returning to the thesis, there is a clear indication that contracting HIV/AIDS produces an effect on other identities. Based on the data, the development of an HIV/AIDS identity constitutes a nexus that affects the development and salience of other identities. Other identities are connected with the HIV/AIDS identity and function symbiotically—one cannot

be separated from the other. Other identities depend upon the HIV/AIDS identity for meaning and definition.

A possible effect of this centering is the evolution of the work identity. Consistent with the research, there seems to be a renegotiation of this work identity (Alsaker & Josephsson, 2003). This new development blurs the line between work and advocacy because many of the participants noted how their work identity became related to and dependent upon their advocacy identity. Debonaire, Booker, Sherry, Greg, and Ken show this relationship by their transitioning into new roles focusing on HIV/AIDS advocacy and community service. In part, this development occurs because of the reported growth in an advocacy identity after the diagnosis, such as Booker suggests. Given the impact of this HIV/AIDS identity, participants appear to align the work identity and advocacy identity; however, the HIV/AIDS identity seems to remain centered and appears to affect the development of this work identity. Without the HIV/AIDS identity, it is possible there would be no merging of a work and advocacy identities.

Also consistent with the research is the reported change in work and change in fields. Asbring (2001) and Thornhill et al. (2008) discuss a loss of work identity and Allen and Carlson (2003) note a fear of being discovered by coworkers and stigmatization. Participants' testimony suggests these conclusions: eight participants noted a lack of energy because of the HIV/AIDS medication, which caused them to renegotiate their work conditions. Despite their work identity being important to them, changes brought about by the HIV/AIDS identity dictate a new direction and development. Further, respondents noted a change in fields based on fear of the HIV/AIDS diagnosis. Al discussed how he was no longer able to maintain the demands of his work—despite his desire; Joseph Smith had to change jobs because he feared being discovered as HIV-positive. More so, this development marks another instance of the work identity being dependent on the HIV/AIDS identity. Because of the centering of the HIV/AIDS identity, the work identity seems to change and evolve in relationship to it. The work identity, then, strikes one as being dependent on the HIV/AIDS identity.

This interdependence of identities also occurs in the changes of participants' sexual identity. The HIV/AIDS identity influences the development of how they conduct themselves in terms of sex and relationships. As noted, the most common reaction is a shift in sexual habits. There is an increase in safe sex practices, and participants noted a change in dealing with rejection. The HIV/AIDS identity seems centered in this development, too, because the fear of spreading the disease or being infected with a new strand of it influences the decision to change sexual practices. More so, the temporary decrease in sexual activity or relationships is based on the development of the HIV/AIDS identity. Whether or not the participants noted an increase or decrease in these activities, the findings suggest that their relationship to the HIV/AIDS identity affects the development of the sexual and relationship identity. Future actions concerning sexual encounters or relationships seem to be based upon this new identity, which is representative of the centering of the HIV/AIDS identity.

The effect of the illness on one's intimate relationships or sexuality identity affirmed findings from the literature. Interest in sexual activity decreased for some participants and not others (Keegan & Lambert, 2005). For many, there was no decrease in sexual activity but an increased attention to safer sex. The same level of sexual activity has been shown in other studies (e.g., Anwar & Khan, 2010; Bova & Durante, 2003). However, our study participants seem to report more of an increase in safer sex practices compared to some literature (Anwar & Khan, 2010; Bova & Durante, 2003). The continuation of sexual activity for many can be seen, perhaps, as a positive sign for individuals and for the larger HIV/AIDS community because individuals do not have to abandon their sexuality identity after being diagnosed with a sexually transmitted disease. However, it is clear that continued safer sex education is



needed so PLWHAs can maintain intimacy with their respective partner(s) and engage in safer sex.

Unlike other studies that reported a loss of libido with decreased sexual activity (El Fane et al., 2011; Keegan & Lambert, 2005; Maticka-Tyndale, Adam, & Cohen, 2002) few participants in this study mentioned a loss of libido as the reason for decreased activity but instead were dealing with other health issues such as Thin's stomach problems or they feared disclosure of their status for fear of rejection as mentioned in previous studies (Maticka-Tyndale, Adam, & Cohen, 2002; Relf et al., 2009). These findings point to perhaps larger issues. First, individuals are coping with other chronic illnesses in addition to HIV/AIDS. The other chronic illnesses might be more salient than the HIV/AIDS. Hence, knowing PLWHAs' medical history and current status of other chronic illnesses is important.

The development of an HIV/AIDS identity seems to affect the development of their spiritual identity. Much like the work and relationship identity, the saliency of their spiritual identity increased for many because of their HIV/AIDS identity. Many participants noted a growth in prayer, religious activities, and some even noted this was a new identity that developed from the creation of the HIV/AIDS identity. Even when participants denounced their spirituality they did not renounce a belief in their spirituality, but rather they expressed confusion at the plan or reason for why they would be infected with the disease. For many, their spiritual identity grew stronger, despite disbelief in the plan or reasoning for their diagnosis. In alignment with the other selves, the HIV/AIDS identity seems to have influenced the positive or negative development of their spirituality identity. The findings suggest that this new HIV/AIDS identity affects the salience of a previously held identity—the spiritual identity.

The results of this study partially confirm the results of other studies. Of those mentioning spirituality, there was an increase in salience of this identity for many and a decrease in salience for fewer (Ironson et al., 2006). Further, spirituality served as a support for individuals (Peterson et al., 2010). An interesting facet of this research that is discussed less in the studies we found concerning HIV/AIDS and spirituality is participants' struggle with spirituality as expressed by Tina, "He [God] knows how I lived my life. What could I have done that was so bad by Him allowing me to get this disease? At one point, I had denounced Him. [Now] I know there is a God and I know I love God but it's hard for me." This struggle with spirituality seems a less trumpeted finding than spirituality being used as a way of coping (Peterson, Johnson, & Tenzek, 2010). However, this crisis of faith and anger at God has been mentioned in a dissertation concerning breast cancer survivors (Sadler-Gerhardt, 2007) so the results of this study confirm this finding. This crisis of faith perhaps is more prevalent than we found both in our sample and in the literature. At any rate, it is an area that might deserve more investigation as regards individuals living with HIV/AIDS and other chronic illnesses. How do people resolve this crisis of faith? What effect does it have on their physical well-being as PLWHAs?

Just as an HIV/AIDS diagnosis prompted individuals to change the salience of their spiritual identity, many individuals became advocates after their HIV or AIDS diagnosis. This finding confirmed findings in prior research concerning the role of advocacy in the lives of PLWHAs in that their advocacy identity blossomed after diagnosis (Baumgartner, 2007). Participants, such as Booker, took a less visible approach to advocacy and wrote his congressional representatives about HIV/AIDS concerns, whereas Greg was involved in community and state activities concerning HIV/AIDS funding and services. Advocacy and community involvement occurred after the HIV/AIDS diagnosis for many and centered on HIV/AIDS-related initiatives.

Although we know that there was a growth in the advocacy identity for many, the reasons for its growth is less known for participants in this study. Individual characteristics

such as being a member of an AIDS Service Organization or a support group at an AIDS Service Organization might have contributed to the growth of the activist identity (Brashers, Haas, Neidig, & Rintamaki, 2002; DeMarco, Miller, Pastdaughter, Chisholm, & Grindel, 1998). Participants reported that the AIDS Service Organizations they were associated with provided information about opportunities for activism such as Lobby Days where individuals journeyed to the state capitol to lobby for HIV/AIDS-related services. Alternatively, an HIV or AIDS diagnosis alone might have prompted individuals to advocate for themselves (DeMarco et al., 1998).

One area in which this development clearly can be noticed is the impact of the HIV/AIDS identity on the participants' self-esteem. While it appears that more articles discuss the effect of self-esteem on sexual behavior as it applies to HIV prevention (e.g., Martin & Knox, 1997; Sterk, Klein, & Elifson, 2004), self-esteem has also been discussed in relation to individuals living with HIV. Researchers found that social comparison between women living with HIV increased self-esteem (Dibb & Kamalesh, 2012). As with the participants in this study, researchers discovered that the stigma felt by participants as a result of contracting HIV or AIDS decreased self-esteem although the negative effect on self-esteem was less if subjects engaged in problem-solving or cognitive restructuring (Varni, Miller, McCuin, & Solomon, 2012). Since participants spoke about the positive effect of HIV/AIDS education and HIV/AIDS support groups as helping to destigmatize the disease, it is possible that participants' increase in self-esteem was in part due to HIV/AIDS education and support group attendance that might have helped participants engage in cognitive restructuring and view their illness more positively.

Different from the development of these other identities, the impact upon the participants' self-esteem perhaps resulted in a systemic change. Participants noted their entire view changes because of the creation and inclusion of this HIV/AIDS identity. Be it a lowering or raising of self-esteem, the participants view of themselves appears to have changed as a result of contracting HIV or AIDS and that change seems to have affected the salience of their other identities. Most noticeably this effect appeared in the development of the relationship identity because participants noted trouble or decreased desire in approaching others. If there is a symbiotic relationship, the connection between the HIV/AIDS identity and the other identities is connected.

An identity that existed for many prior to their HIV/AIDS diagnosis was that of addict. This finding is consistent with the literature since roughly 25% of those living with HIV in 2009 reported seeking treatment for alcohol or drugs (National Institute of Drug Abuse, 2011). Twenty participants admitted they had been addicted to drugs or alcohol in their past. Nineteen of 20 reportedly had chemical dependency issues prior to being diagnosed with HIV/AIDS. One person started using drugs after diagnosis. The addict identity was very salient for many prior to diagnosis and remained salient for a while after diagnosis as many individuals initially increased their drug and alcohol use to cope with the HIV/AIDS diagnosis. All 20 participants eventually sought treatment. Some individuals relapsed and sought treatment for addiction several times after being diagnosed with HIV/AIDS. The HIV/AIDS diagnosis prompted many to eventually examine their addiction and to assume a recovering addict identity.

The recovering addict identity seemed to be as important as or more important to participants than the HIV/AIDS identity. Remaining sober was important to participants because periods of relapse put participants at risk for irresponsible sexual behavior and it also lowered their immune system making them more likely to contract opportunistic infections. Many reported still struggling with remaining sober but they expressed a commitment to their sobriety because they knew they needed to remain healthy to live.

Another identity affected by the HIV/AIDS identity and the addict identity was the parenting identity. Some respondents contracted HIV/AIDS, received treatment for chemical dependency, were in recovery from drug or alcohol addiction, and then began to focus on taking care of their HIV/AIDS and reclaiming their role as a parent. This confirms researchers' findings that children were sometimes the impetus to live after the HIV/AIDS diagnosis and remain sober for HIV-positive mothers (Sandelowski & Barroso, 2003; Wilson, 2007). What is of particular interest in our study is that the HIV/AIDS diagnosis often eventually prompted chemically dependent parents to seek treatment and then participants started to re-build the relationship with their children. The parent-child relationship was previously strained by parents' drug use but it could be argued that for some, participants' HIV/AIDS diagnosis led them deal with their alcoholism or drug use which eventually resulted in their reclaiming their parenting role.

This study accentuates a couple of areas regarding parenting. Most research on parenting and HIV/AIDS did not target or explicitly include chemically dependent parents. Given the findings of this study, it might be important to investigate the special needs of families coping with HIV-positive addicts and recovering addicts. Another finding that was more evident in this study was the parenting behavior of non-parents in their need to educate relatives about HIV/AIDS. Although not all HIV-positive individuals have biological children, their need to engage in parenting behavior, such as educating their younger relatives is interesting to note. This need to engage in what Erikson calls "generativity" or guiding the next generation (Erikson, 1980) by educating them about safer sex and HIV/AIDS is not generally part of the HIV/AIDS and parenting literature. Yet, it can be argued that these participants are, in a broader sense, engaging in parenting behavior.

The traditional definition of parenting involves having children. Our findings confirm results from other studies which suggest that individuals have a variety of reactions when asked if they want to become parents from being very interested about the prospect to fearing the risks of having children (Finocchiaro-Kessler, Sweat, & Dariotis, 2009; Rutenberg, Biddlecom, & Kaona, 2000). Clearly, counselors and HIV/AIDS educators need to be aware of the various issues involved in becoming a parent for PLWHAs and that individuals with HIV/AIDS can fill parenting roles although they might not be biological parents.

In sum our research affirms Burke's assertion that "identities that share common meanings" can be activated and verified together (Burke, 2003, p. 197). Burke notes that if two identities (e.g., parent and spouse) have as an expectation that "providing material support" is important then "getting a well-paying job will help verify both identities" (p. 200). Contracting HIV or AIDS caused some individuals to re-evaluate their priorities. They needed to find more meaning in their lives beyond their jobs or obtaining drugs to get high. After being diagnosed with HIV/AIDS, many concluded that helping others was important. Helping others became a standard for their work identity, an apparent mandate from their spiritual identity, and seemingly a part of their advocate identity, recovering addict identity and parenting identity. For example, Debonaire needed to find "more meaningful work" and became an advocate and HIV/AIDS educator. As an HIV-positive individual and recovering addict, he helped those struggling with alcohol addiction and HIV. Derek discontinued his acting career to become an HIV/AIDS educator and advocate as a result of becoming HIV-positive.

Our research also confirms the effect of the stigma of HIV on other identities (e.g., Bogart et al., 2008; Liu, Canada, Shi, & Corrigan, 2012). Individuals did not pursue work for fear of being stigmatized in the workplace. Some participants curtailed their sexual activity because they feared rejection from partners, felt "dirty," or were afraid to disclose their HIV-positive status. As parents, participants needed to negotiate the disclosure of their HIV-identity or their child's HIV-identity carefully.

Because of the continued stigma of HIV/AIDS, HIV/AIDS education for all is necessary so individuals do not have to live in fear. It is clear from previous findings from this study (Baumgartner, 2012) that those living with addictions and in poverty need education about HIV/AIDS. HIV/AIDS education needs to occur in prisons and in poor neighborhoods. Culturally sensitive education is imperative. Ideally, community members should spearhead these efforts so their peers see this education as relevant to their lives.

Future research should target several areas. First, 30 of the 36 individuals interviewed for this study lived in a large metropolitan area. The voices of PLWHAs living in rural areas are underrepresented in the HIV/AIDS identity literature and in this study. Therefore, it is important to see how HIV/AIDS affects rural residents' identities. Second, a more thorough and nuanced investigation of how individuals' identities as patients is warranted. Although we found that all of our participants were involved in the healthcare system, the interviews only provided the most rudimentary information about their healthcare experience. Third, more than half of the participants in this study were lower-income individuals with a history of chemical dependency. Whereas the sexual risk and medication compliance literature has focused on this population (e.g., Barnett, Sorensen, Wong, & Haug, 2009; Hagen, Perlman, & Des Jarlais, 2011), there needs to be more attention paid to the challenges of this population in examining how they negotiate employment, relationships with others, and how to best approach this population regarding HIV/AIDS education. Fourth, participants mentioned they lived with several chronic illnesses in addition to HIV/AIDS. Participants briefly discussed how interactions between chronic illnesses affected their HIV/AIDS identity. For example, many were worried more about their Hepatitis C diagnosis or diabetes than HIV/AIDS. Further, more research on the salience of other chronic illnesses and their interaction with HIV/AIDS should be conducted. Not only would it provide evidence and analysis on this marginalized interaction, it would also bring attention to chronic illnesses in addition to HIV/AIDS. Last, any of these topics could be approached using a grounded theory approach in order to arrive at a larger overarching theory.

## References

- Adams, B. D., Maticka-Tyndale, E., & Cohen, J. J. (2001). *Living with combination therapies*. Windsor, Canada: University of Windsor.
- Alcano, M. C. (2009). Living and working in spite of antiretroviral therapies: Strength in chronicity. *Anthropology & Medicine, 16*(2), 119-130. doi: 10.1080/13648470902940630
- Allen, S., & Carlson, G. (2003). Psychosocial themes in durable employment transitions. *Work, 20*, 185-197.
- Alsaker, S., & Josephsson, S. (2003). Negotiating occupational identities while living with chronic rheumatic disease. *Scandinavian Journal of Occupational Therapy, 10*, 167-176. doi:10.1080/11038120310017525
- Ambs, A. H., Miller, M. F., Smith, A. W., Goldstein, M. S., Hsiao, A. F., & Ballard-Barbash, R. (2007). Religious and spiritual practices and identification among individuals living with cancer and other chronic disease. *Journal of the Society for Integrative Oncology, 5*(2), 53-60.
- Anwar, N., & Khan, S. I. (2010). Sexual life after HIV infection: An exploratory study among HIV positive adult males and females in Dhaka, Bangladesh. *International Journal of Interdisciplinary Social Sciences, 5*(2), 589-602.
- Asbring, P. (2001). Chronic illness—a disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing, 34*(3), 312-319 doi: 10.1046/j.1365-2648.2001.01767.x.

- Barnett, P. G., Sorensen, J. L., Wong, W., & Haug, N. A. (2009). Effect of incentives for medication adherence in health care use and costs in methadone patients with HIV. *Drug and Alcohol Dependence, 100*(1-2), 115-121.
- Baumgartner, L. M. (2007). The incorporation of the HIV/AIDS identity into the self over time. *Qualitative Health Research, 17*, 919-931. doi: 10.1177/1049732307305881
- Baumgartner, L. M. (2012). The perceived effect of the sociocultural context on HIV/AIDS identity incorporation. *The Qualitative Report, 17*(Art. 45), 1-21. Retrieved from <http://www.nova.edu/ssss/QR/QR17/baumgartner45.pdf>
- Bedell, G. (1997). *Finding balance: The daily lives of eight gay men with HIV/AIDS*. Retrieved from Proquest Dissertations (UMI No. 9819847).
- Bogart, L. M., Cowgill, B. O., Kennedy, D., Ryan, G., Murphy, D. A., Elijah, J., & Schuster, M. A. (2008). HIV-Related stigma among people with HIV and their families: A qualitative analysis. *AIDS and Behavior, 12*(2), 244-254. doi: 10.1007/s10461-007-9231-x.
- Brashers, D. E., Haas, S. M., Neidig, J. L. & Rintamaki, L. S. (2002). Social activism, self-advocacy and coping with HIV illness. *Journal of Social and Personal Relationships, 19*, 113-133. doi: 10.1177/0265407502191006
- Braveman, B., Kielhofner, G., Albrecht, G. & Helfrich, C. (2006). Occupational identity, occupational competence and occupational settings (environment): Influences on return to work in men living with HIV/AIDS. *Work, 27*, 267-276.
- Brooks, R. A. & Klosinski, L. E. (1999). Assisting persons living with HIV/IDS to return to work: Programmatic steps for AIDS service organizations. *AIDS Education and Prevention, 11*(3), 212-223.
- Bova, C., & Durante, A. (2003). Sexual functioning among HIV-infected women. *AIDS Patient Care and STDs, 17*(2), 75-83.
- Burke, P. J. (2003). Relationships among multiple identities. In P. J. Burke, T. J. Owens, R. T. Serpe & P. A. Thoits (Eds.), *Advances in identity theory and research* (pp. 195-216). New York, NY: Kluwer Academic/Plenum Publishers.
- Centers for Disease Control. (2010). Chronic Disease Health and Promotion. Available from: <http://www.cdc.gov/chronicdisease/overview/>
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London, England: Sage.
- Conyers, L. M. (2004, Fall). Expanding understanding of HIV/AIDS and employment: Perspectives of focus groups. *Rehabilitation Counseling Bulletin, 48*(1), 5-18. doi: 10.1177/00343552040480010201.
- Cotton, S., Tsevat, J., Szaflarski, M., Kudel, I., Sherman S. N., Feinberg, J., Leonard, A. C., & Holmes, W. C. (2006). Changes in religiousness and spirituality attributed to HIV/AIDS: Are there sex differences? *Journal of General Internal Medicine, 21*, S 14-20. doi: 10.1111/j. 1525-1497.2006.00641.x
- Courtenay, B. C., Merriam, S., & Reeves, P. M. (1999). Faith development in the lives of HIV-positive adults. *Journal of Religion and Health, 38*(3), 203-218. doi: 10.1023/A:1022928601047
- Cuevas, J. E., Vance, D. E., Viamonte, S. M., Lee, S. K., & South, J. L. (2010). A comparison of spirituality and religiousness in older and younger adults with and without HIV. *12*(4), 273-287. doi: 10.1080/19349637.2010.518828.
- DeMarco, R. F., Miller, K. H., Patsdaughter, C. A., Chisholm, M., & Grindel, C. G. (1998). From silencing the self to action: Experiences of women living with HIV/AIDS.

- Health Care for Women International*, 19(6), 539-552. doi: 10.1080/073993398246106
- Dibb, B., & Kamalesh, T. (2012). Exploring positive adjustment in HIV positive African women living in the UK. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 24(2), 143-148. doi:10.1080/09540121.2011.597710
- El Fane, M., Bensghir, R., Sbai, S., Chakib, A., Kadiri, N., Ayouch, A., & Himmich, H., (2011). Quality of sexual life for people living with HIV (PLWHA). *Sexologies: European Journal of Sexology and Sexual Health*, 20(3), 158-162.
- Erikson, E. H. (1980). *Identity and the life cycle*. New York, NY: W. W. Norton & Company.
- Finocchiaro-Kessler, S., Sweat, M. D., Dariotis, J. K., Trent, M. E., Kerrigan, D. L., Keller, J. M., & Anderson, J. R. (2010). Understanding high fertility desires and intentions among a sample of urban women living with HIV in the United States. *AIDS and Behavior*, 14(5), 1106-1114. doi: 10.1007/s10461-009-9637-8.
- Ghaziani, A. (2004). Anticipatory and actualized identities: A cultural analysis of the transition from AIDS disability to work. *The Sociology Quarterly*, 45, 273-301. doi: 10.1111/j.1533-8525.2004.tb00013.x
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Harrison, K. M., Song, R., & Zhang, X. (2010). Life expectancy after HIV diagnosis based on national HIV surveillance data from 25 states, United States. *Journal of Acquired Immune Deficiency Syndromes*, 53(1), 124-130.
- Hagen, H., Perlman, D. C., Des Jarlais, D. C. (2011). Sexual risk and HIV infection among drug users in New York City: A pilot study. *Substance Use and Misuse*, 46(2-3), 201-207.
- Hergenrather, K. C., Rhodes, S. D., & Clark, G. (2005). The employment perspectives study: Identifying factors influencing the job-seeking behavior of persons living with HIV/AIDS. *AIDS Education and Prevention*, 17(2), 131-142. doi: 10.1521/aeap.17.3.131.62905
- Ironson, G., Stuetzle, R., & Fletcher, M. A. (2006). An increase in religiousness/spirituality occurs after HIV diagnosis and predicts slower disease progression over 4 years. *Journal of General Internal Medicine*, 21, S 62-68. doi: 10.1111/j.1525-1497.2006.00648.x
- Jakobsen, K. (2001). Employment and the reconstruction of self: A model of space for maintenance of identity by occupation. *Scandinavian Journal of Occupational Therapy*, 8, 40-48. doi:10.1080/11038120120825
- Keegan, A., & Lambert, S. (2005). Sex and relationships for HIV-positive women since HAART: A qualitative study. *AIDS Patient Care and STDs*, 19, 645-654. doi:10.1089/apc.2005.19.645.
- Kirton, C. A. (2011). The changing epidemic of HIV. *Nursing*, 41(1), 36-44. doi: 10.1097/01.NURSE.0000391398.13322.18
- Liu, Y., Canada, K., Shi, K., & Corrigan, P. (2012). HIV-related stigma acting as predictors of unemployment of people living with HIV/AIDS. *AIDS Care*, 24(1), 129-135.
- Martin D. J., Brooks R. A., Ortiz D. J., & Veniegas R. C. (2003). Perceived employment barriers and their relation to workforce-entry intent among people with HIV/AIDS. *Journal of Occupational Health Psychology*, 8, 181-194.
- Martin, J. I., & Knox, J. (1997). Self-esteem instability and its implications for HIV prevention among gay men. *Health & Social Work*, 22, 264-273. doi: 10.1037/1076-8998.8.3.181

- Maticka-Tyndale, E., Adam, B. D., & Cohen, J. (2002). Sexual desire and practice among people living with HIV and using combination anti-retroviral therapies. *The Canadian Journal of Human Sexuality, 11*(1), 33-40.
- McCall, G. J., & Simmons, J. L. (1978). *Identities and interactions*. New York, NY: Free Press.
- MedicineNet. (2011). Definition of chronic disease. Retrieved from <http://www.medterms.com/script/main/art.asp?articlekey=33490>
- Merriam, S. B., (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- Murphy, D. A., Roberts, K. J., & Herbeck, D. M. (2011). HIV disease impact on mothers: What they miss during their children's developmental years. *Journal of Child and Family Studies, 20*, 361-369. doi: 10.1007/s10826-010-9400-9.
- National Institute of Drug Abuse (2011). Drug abuse and the link to HIV and other infections. Retrieved from <http://www.drugabuse.gov/publications/infofacts/drug-abuse-link-to-hiv-aids-other-infectious-diseases>
- Nixon, S., & Renwick, R. (2003). Experiences of contemplating returning to work for people living with HIV/AIDS. *Qualitative Health Research, 13*, 1272-1290. doi: 10.1177/1049732303257190
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3<sup>rd</sup> ed). San Francisco, CA: Jossey-Bass.
- Peterson, J. L., Johnson, M. A., & Tenzek, K. E. (2010). Spirituality as a life line: Women living with HIV/AIDS and the role of spirituality in their support systems. *Journal of Interdisciplinary Feminist Thought, 4*(1), Article 3. Retrieved from: <http://escholar.salve.edu/jift/vol4/iss1/3>
- Relf, M. V., Bishop, T. L., Lachat, M. F., Schiavone, D. B., Pawlowski, L., Bialko, M. F., Boozer, D. L., & Dekker, D. (2009). A qualitative analysis of partner selection, HIV serostatus disclosure and sexual behaviors among HIV-positive urban men. *AIDS Education and Prevention, 21*(3), 280-297.
- Ridge, D., Williams, I., Anderson, J., & Elford, J. (2008). Like a prayer: The role of spirituality and religion for people living with HIV in the UK. *Sociology of Health and Illness, 30*(3), 413-428. doi: 10.1111/j.1467-9566.2007.01062.x
- Rutenberg, N., Biddlecom, A. E., & Kaona, F. A. D. (2000). Reproductive decision-making in the context of HIV and AIDS: A qualitative study in Ndola, Zambia. *International Family Planning Perspective, 26*(3), 124-130.
- Sadler-Gerhardt, C., (2007) "And then what happened?": The lived experiences of breast cancer survivors and their stories of change and meaning. Retrieved from ProQuest Dissertations database. UMI No. 3293820. University of Akron, Akron, OH.
- Sandelowski, M., & Barroso, J. (2003). Toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Research in Nursing and Health, 26*, 153-170.
- Sherr, L. (2010). Fathers and HIV: Considerations for families. *Journal of the International AIDS Society, 13*(Supplement 2): S 4, 1-10. Retrieved from <http://www.jiasociety.org/contetn/13/S2/S4>.
- Spradley, J. (1980). *Participant observation*. New York, NY: Rinehart and Winston.
- Stanley-Hermanns, M. & Engebretson, J. (2010). Sailing the stormy seas: The illness experience of persons with Parkinson's disease. *The Qualitative Report, 15*(2), 340-369. Retrieved from <http://www.nova.edu/ssss/QR/QR15-2/stanley-hermanns.pdf>
- Sterk, C. E., Klein, H., & Elifson, K. W. (2004). Self-esteem and "at risk" women: Determinants and relevance to sexual and HIV-related risk behaviors. *Women and Health, 40*(4), 75-92. doi:10.1089/jwh.2004.13.676.

- Stryker, S. (2007). Identity theory and personality theory: Mutual relevance. *Journal of Personality, 75*, 1083-1102. doi: 10.1111/j.1467-6494.2007.00468.x
- Stryker, S., & Burke, P. J. (2000). The past, present and future of an identity theory. *Social Psychology Quarterly, 63*, 284-297
- Stryker, S., & Serpe, R. T. (1994). Identity salience and psychological centrality: Equivalent, overlapping or complementary concepts. *Social Psychology Quarterly, 57*, 16-35.
- Tanyi, R. A., & Werner, J. S. (2008). Women's experience of spirituality within end-stage renal disease and hemodialysis. *Clinical Nursing Research, 17*(1), 32-49. doi: 10.1177/1054773807311691
- Thornhill, K., Lyons, A. C., Nouwen, A., & Lip, G. Y. H. (2008). Experiences of living with congestive heart failure: A qualitative study. *British Journal of Health Psychology, 13*, 155-175. doi: 10.1348/135910706X170983
- Tompkins, T. L. (2007). Parentification and maternal HIV infection: Beneficial role or pathological burden. *Journal of Child and Family Studies, 16*, 113-123. doi: 10.1007/s10826-006-9072-7.
- Tuck, I., McCain, N. L., & Elswick, R. K. (2001). Spirituality and psychosocial factors in persons living with HIV. *Journal of Advanced Nursing, 33*, 776-783.
- Varni, S. E., Miller, C. T., McQuin, T., & Solomon, S. (2012). Disengagement and engagement: Coping with HIV/AIDS stigma and psychological well-being of people living with AIDS. *Journal of Social Change and Clinical Psychology, 31*(2), 123-150. doi: 10.1521/jscp.2012.31.2.123
- Verschuren, J. E. A., Enzlin, P., Dijkstra, P. U., Geertzen, J. H. B., & Dekker, R. (2010). Chronic disease and sexuality: A generic conceptual framework. *Journal of Sex Research, 47*(2-3), 153-170. doi: 10.1080/00224491003658227
- UNAIDS World AIDS Day Report. (2011). Joint United National Programme on HIV/AIDS (UNAIDS). Retrieved from [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2216\\_WorldAIDSday\\_report\\_2011\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2216_WorldAIDSday_report_2011_en.pdf)
- Walker, C. (2010). Ruptured identities: Learning work because of chronic illness. *International Journal of Health Services, 40*(4), 629-643.
- Wilson, S. (2007). 'When you have children, you're obliged to live.' Motherhood, chronic illness and biographical disruption. *Sociology of Health & Illness, 29*, 610-626. doi: 10.1111/j.1467-9566.2007.01008.x
- Wilson, T. E., Feldman, J., Vega, M. Y., Gandi, M., Richardson, J., Cohen, M. H., McKaig, R., Ostrow, D., Robinson, E. & Gange, S. J. (2007). Acquisition of new sexual partners among women with HIV infection: Patterns of disclosure and sexual behavior within new partnerships. *AIDS Education and Prevention, 19*(2), 151-159. doi: 10.1111/j.1467-9566.2007.01008.x

### Author Note

Lisa M. Baumgartner is a professor in the Adult and Higher Education Program at Northern Illinois University, DeKalb, IL. Her research and writing concern adult development, adult learning and chronic illness. She can be contacted at Northern Illinois University, Counseling, Adult and Higher Education Department, 200 Gabel Hall, Northern Illinois University, DeKalb, IL 60115; Phone: (815) 753-8168 (work); Fax: (815) 753-9309; or E-mail: Lbaumgartner@niu.edu

Eric Niemi is currently a developmental writing instructor at Chippewa Valley Technical College in Eau Claire, WI. He is a former graduate assistant and current doctoral candidate in the Adult and Higher Education Program at Northern Illinois University,



DeKalb, IL. He can be contacted at 847-361-6696; or E-mail: ericniemi@hotmail.com

Copyright 2013: Lisa M. Baumgartner, Eric Niemi, and Nova Southeastern University.

#### **Article Citation**

Baumgartner, L. M., & Niemi, E. (2013). The perceived effect of HIV/AIDS on other identities. *The Qualitative Report*, 18(Art. 15), 1-23. Retrieved from <http://www.nova.edu/ssss/QR/QR18/.pdf>

---