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The Incorporation of the HIV/AIDS Identity Into the Self Over Time

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In the mid-1990s HIV/AIDS transitioned from a terminal illness to a chronic disease because of medical advances. In this qualitative study the author examines how people incorporate the HIV/AIDS identity into their selves at three points in time. Findings demonstrate a five-component process, including diagnosis, postdiagnosis turning point, immersion, post-immersion turning point, and integration. In addition, the disclosure process corresponds to a particular component of incorporation. The author makes comparisons with the incorporation process of other chronic illness. Findings augment the literature on HIV/AIDS, chronic illness, and identity and have practical implications for HIV/AIDS educators.

Keywords: *HIV/AIDS; identity; longitudinal study; disclosure*

AIDS, once considered a plague because its onset appeared to be rapid and people lived only a few months after diagnosis, is now viewed as a chronic disease in the United States, where access to life-extending medications is widely available (Schmitt & Stuckey, 2004). As a result, an increasing number of individuals are living with HIV or AIDS in the United States each year. The number of people living with HIV in the United States surpassed a million and was estimated at between 1.04 and 1.2 million in 2003, which was an increase from between 850,000 and 950,000 in 2002 (Centers for Disease Control, 2004).

The possibility of living a longer life with HIV/AIDS means that people living with HIV/AIDS (PLWHAs) might ask themselves, Who am I now that I have HIV/AIDS? Identity theorists have posited that people have multiple identities that combine to form a self (Serpe, 1987). The self develops through interaction with others in society and remains relatively stable. Identities are "parts of the Self—internalized positional designations that represent the person's participation in structured role relationships" (Stryker & Serpe, 1982, p. 206). The number of identities is limited only to the number of role relationships that a person holds. For example, a person can have the identities of a surgeon, mother, friend, and breast cancer survivor that all comprise a stable self.

The salience of these identities depends on the number and strength of social relationships associated with that identity (Roberts & Donahue, 1987; Serpe, 1987; Stryker & Serpe, 1982). The more likely the identity will be invoked, the higher its salience (Serpe, 1987). For example, "Ann" has a highly salient student identity. She talks about her studies to other students, friends who do not attend college, her coworkers, and her relatives (Stryker & Serpe, 1994). In contrast, Ann's cancer survivor identity is less salient than her student identity because few people beyond her immediate family know that she is a cancer survivor. Social expectations and tolerance might affect identity salience. For example, socially stigmatized identities might affect their salience.

Because people are living longer with HIV/AIDS, they have time to incorporate the HIV/AIDS identity into themselves. Therefore, the purpose of this study is to explore the incorporation of HIV/AIDS into identity over time. Specifically, I investigate the incorporation of HIV/AIDS into identity over a period of time when the disease transitioned from being classified as an acute, terminal illness to a chronic disease. What is the incorporation process? How does it compare with and contrast to other chronic diseases?

Literature Review

The Effect of Chronic Illness on the Self and Identity

In the chronic illness literature self and identity, although coconstituted, were defined separately. The self was described as composed of many identities.

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Kralik, Koch, and Eastwood (2003) stated, “The ‘self’ reflects international thinking of what it is ‘being a person,’ whereas ‘identity’ is shaped by social interaction” (p. 13). Literature concerned with identity change used Kelly and Field’s (1996) crisis model. The identity change framework “is concerned with potential labeling, felt stigma, status passage and experience of power relations in social institutions. The analytic focus is on status passage” (Kralik, Koch, et al., 2003, p. 13). This was exemplified by studies where the person needed to come to terms with the social identity of having a chronic illness such as HIV/AIDS (Lewis, 1994; Sandstrom, 1990) or asthma (Adams, Pill, & Jones, 1996) and works through status passages.

The negotiation model is used to shape literature on the effect of chronic illness on the self, discussed as the loss of the normal self and the struggle to be normal (Kralik, Koch, et al., 2003). The disruption of a chronic illness causes disruptions in relationships and work, and there is a loss of self (Charmaz, 1987; 1994a, 1994b). Chronic illness is viewed as a “biographical disruption” of the self (Bury, 1982, p. 167), and this literature described the coping mechanisms used to return to a more normal state.

In sum, the literature on chronic illness and self and/or identity concerned the effect of an illness identity on the self (e.g., Charmaz, 1987, 1994a, 1994b; Kralik, 2002; Whitehead, 2006); on another identity, such as the effect of multiple sclerosis on a person’s sexual self-identity (Koch, Kralik, & Eastwood, 2002; Kralik, Koch, et al., 2003); or on role changes, such as loss of a work role or changes in the role as a mother (Driedger, Crooks, & Bennett, 2004; Gibson, Placek, Lane, Brohimer, & Lovelace, 2005).

The themes of loss, transition, and living with the disease pervaded the literature on the effect of a chronic illness on one’s self. The loss of being seen as a healthy, independent person was primary (Gibson et al., 2005). Responses to this loss included changed identity goals. Some tried to keep other identities such a mother, wife, and teacher primary (Charmaz, 1994a), whereas others changed their “professional aspirations, intellectual pursuits, and the evolution of a planned life” (Gibson et al., 2005, p. 512). They learned the new limits of their bodies and created a new identity by not letting the chronic illness control them but by living with it (Adams et al., 1997; Michael, 1996). Others simply denied their chronic illness identity or minimized its impact on their lives (Adams et al., 1997; Charmaz, 1994b; Goldman & Maclean, 1998).

Although many scholars do not delineate particular phases or recursive stages in the process of incorporation of a chronic illness, one author’s investigation might be of interest. Kralik (2002) discussed a period of extraordinariness and a transition to ordinariness after the diagnosis of a chronic illness. The feeling of extraordinariness occurred when people were first confronted with a chronic illness. During this period they realized how quickly life changed, and they felt “alienated from familiar life” and “out of touch with their bodies” (p. 149). This loss of control over their daily activities and bodies damaged their self-esteem. The transition to “ordinariness” occurred when women recognized the illness as life transforming, and they experienced a sense of progress and felt empowered, enlightened, and more in control of their lives. They “found a place for the illness in their lives” (p. 151).

HIV/AIDS and Identity Incorporation

Although numerous studies have examined the lived experience of PLWHAs (Barroso & Powell-Cope, 2000), only a few researchers have explored the incorporation process of HIV/AIDS into identity. All studies could be classified as crisis model studies, in that they spoke about observed status passages. In short, they spoke to the incorporation of a stigmatized identity into the self. Two of the four studies presented a linear model of incorporation (Dozier, 1997; Sandstrom, 1990), whereas two believed (Gurevich, 1996; Lewis, 1994) that the process could be recursive. In general, people experienced shock and disbelief on diagnosis, spent some time in denial, struggled with the stigma of the disease, and eventually embraced the HIV/AIDS identity (Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). For some the HIV/AIDS identity became primary (Sandstrom, 1990), whereas for others it became one of many identities (Gurevich, 1996). In two studies teaching others about HIV/AIDS was important for incorporation of the identity (Dozier, 1997; Gurevich, 1996). In all cases finding a community of HIV-positive people aided greatly in the incorporation process.

Although the studies on HIV/AIDS and identity incorporation have uncovered somewhat similar findings, what remains to be investigated is an examination of identity incorporation over time. None of the aforementioned studies were conducted when there was widespread use of highly antiretroviral therapy (HAART). Furthermore, no study was found that compared the incorporation of HIV/AIDS into identity as a chronic illness with other chronic illnesses. An investigation of the incorporation of HIV/AIDS into identity at three points in time would add depth to the extant literature.

This study might have practical implications as well. HIV/AIDS educators, who have historically disseminated information concerning transmission and prevention (M. Swick, personal communication, October 10, 2004), might increasingly be asked to assist PLWHAs who are grappling with identity issues. This study's findings augment results found before the widespread use of HAART.

Method

In this study I examined HIV/AIDS identity incorporation at three points in time. The sample consisted of participants previously selected for research on meaning making in HIV-positive adults (Courtenay, Merriam, & Reeves, 1998; Courtenay, Merriam, Reeves, & Baumgartner, 2000). Selection of the original sample occurred via criterion sampling (Patton, 2002). Volunteer participants were sought from four AIDS service organizations (ASOs) located in a large metropolitan area in the southeastern United States (Courtenay, Merriam, & Reeves, 1998). All participants (with the exception of one), were under age 45, as "it was assumed that the possibility of encountering death at an age earlier than normally expected carries with it a sense of urgency that drives the meaning-making process" (p. 68). Another criterion for selection was having a CD4 (T cell) count of 500 or less "because it . . . marks the point of medical intervention [at the time of the first study]" (p. 68).

The original sample, interviewed in 1995, consisted of 18 adults (10 men and 8 women) ranging in age from 23 to 45 (with one man, aged 57, who slipped through the screening process). For the second set of interviews, conducted in early 1998, all 18 participants were contacted, and 14 of the original 18 participants consented to be interviewed (8 men and 6 women). For this study, 12 of the 14 people were located and 11 consented to an interview. Respondents ranged in age from 31 to 61 years old. Participants were interviewed between October 1999 and December 1999. There were 6 White men, 2 White women, 2 African American women, and 1 African American man. Participants' education level extended from high school graduate through a master's degree. Ten of the 11 had either attended college or were college graduates. One person had a graduate degree. Eight were employed at the time of the interview, 2 were unemployed but did extensive volunteer work for ASOs, and 1 person was retired.

When the research team conducted the initial study in 1995, it was not anticipated that the original inquiry would evolve into a study over time. In 1995 many of the participants had severely compromised immune systems. During the first round of interviews many participants questioned how long they would live. However, members of the research team maintained contact with participants by conducting member checks, sending published articles, and sending members a copy of their respective transcripts. When the research team decided to conduct a second study on meaning making after the widespread use of life-extending HIV/AIDS medications such as protease inhibitors, 14 of the 18 participants agreed to be interviewed. After the second study members of the research team again conducted member checks, provided participants transcripts, and sent participants published articles. When I decided to conduct a third study with the same participants almost 2 years after the second study, I found participants receptive to a third interview because of my previous contact with many of them when I was part of the research team.

Data Collection and Analysis

The study was approved by the institutional review board of the university with which I was affiliated at the time of the research. Before the interview commenced, participants signed a consent form that addressed the purpose of the research, explained confidentiality issues, and discussed participants' rights to withdraw their data at any time. In addition, the consent form informed participants that the interviews would be tape recorded and transcribed and that if participants experienced psychological discomfort, they could terminate the interview and, with the participant's permission, I would make a referral to a social service agency. Participants were compensated $35 for their time. Most respondents donated the money to a local ASO.

Data collection consisted of 11 1½- to 3-hour interviews using a semistructured interview guide. Areas investigated included the process of identity incorporation and the nature of learning that occurred during that process. These interviews were added to the previous two sets collected from the same participants in the fall of 1995 (18 interviews) and the early spring of 1998 (14 interviews). In all, 33 interviews were analyzed. The 1995 and 1998 data sets contained information on the meaning-making process, faith development, general identity issues, and coping. Although not exclusively concerning an identity incorporation process, they contained data germane to this process, such as how people felt at the time of diagnosis and how they thought of themselves before diagnosis, after diagnosis, and at the time of the interview. It is important to note that participants' recollections, for example, of being diagnosed did not change between the 1995 and 1999 interviews. However, additional components were evident in the 1998 and 1999 interviews.

I took field notes using Spradley's (1980) four-part method of transcription. (a) Notes were taken during the interview. (b) After the interview supplemental notes were taken that detailed observations and impressions attained during the interview, such as body language and overall impressions. (c) A third section of notes contained impressions, hunches, and findings. (d) The fourth set of notes contained tentative analysis and explanations. This assisted in recall of interview details, including the person's gestures, eye contact, and tone of voice.

Follow-up telephone calls were made to clarify information collected or to ask additional questions. Participants were provided the transcripts of the 1999 interviews as well as a summary of tentative findings. They were asked to make any comments and either return the transcript or discuss any concerns or changes they wanted. No one contacted the researcher. A final summary of the findings and implications was provided to the participants. In addition, the findings were peer reviewed.

Before imposing the three approaches to narrative analysis on the data, I summarized the "story" of each person's incorporation process. This storying process provided a general impression of the incorporation process. Next, data were analyzed inductively involving use of psychological (Alexander, 1988; McAdams, 1988), biographical (Denzin, 1989), and linguistic (Gee, 1990) methods of narrative analysis. Alexander's nine "principal identifiers of salience" (p. 269) were used to assist me in identifying what is important to the respondent. These identifiers of salience include such things as primacy (the participant's first response to a query), frequency (how often a theme is mentioned), uniqueness (which is generally marked by words such as "This never happened before"), negation, emphasis, omission, error, isolation, and incompletion. A second psychological method of analysis included using McAdams's concepts of nuclear episodes (high points, low points, and turning points) in the incorporation process.

Denzin's (1989) biographical approach and Gee's (1990) sociolinguistic methods were also used. I was especially interested in uncovering what Denzin has called epiphanies, or turning points, in the HIV/AIDS incorporation process. In addition, Denzin recognized the influence of gender and class on lives. I used Gee's idea of the prosody of the text, which refers to the speaker's intonation, emphasis on words, rate of speech, and hesitations and pauses, to recognize emphasis and omission in a narrative. Data analysis and collection proceeded simultaneously (Glaser & Strauss, 1967). Comparison within each interview and between interviews resulted in categories that reflected an impression of the identity incorporation process.

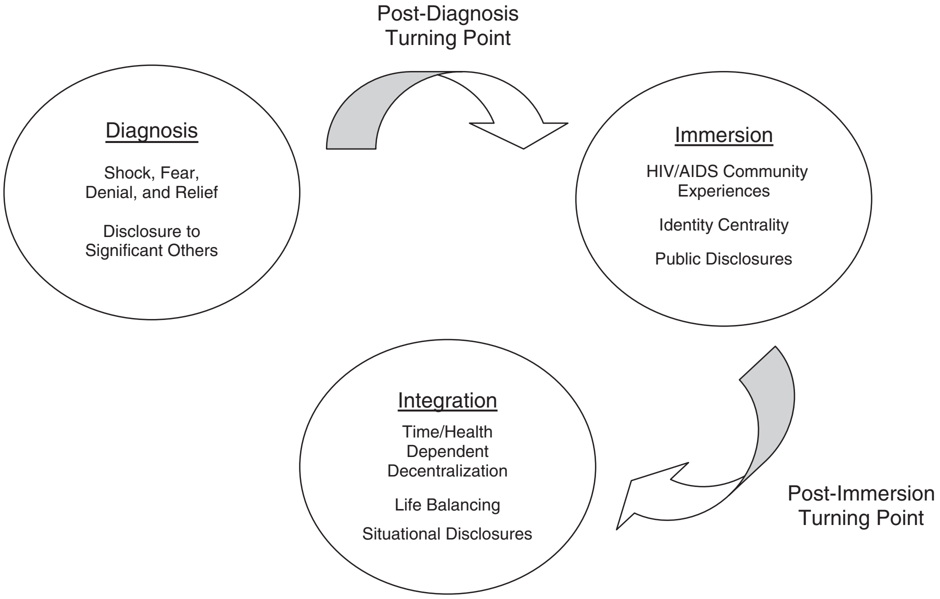
Results

The incorporation of HIV/AIDS into a person's identity, in most cases, began on diagnosis. The initial reaction to the diagnosis included shock, fear, denial, and relief. Next, a postdiagnosis turning point, such as needing medical intervention for an HIV/AIDS-related opportunistic infection, jarred respondents from their reaction to the diagnosis and propelled them toward immersion. During the immersion stage participants joined the HIV/AIDS community, HIV/AIDS became a central identity, and individuals engaged in learning about and teaching others about HIV/AIDS. A postimmersion turning point, often precipitated by the success of life-extending medications, served as the impetus for a life reevaluation. This reappraisal led to increased integration of the HIV/AIDS identity. This identity became decentralized, and respondents strove for a more balanced existence. Finally, disclosure was a component interwoven throughout the process. Participants moved from telling significant others to public disclosure to situational disclosure. In short, people revealed their HIV/AIDS status to a larger audience over time. Later, they selectively disclosed their HIV-positive status. Figure 1 delineates the principal components of the identity incorporation process.

Stage 1: Diagnosis

For most participants diagnosis was the beginning of incorporating HIV/AIDS into identity. All participants were diagnosed between the early 1980s through 1991, before the use of HAART. The diagnosis challenged respondents' identity as healthy individuals.

Figure 1
Model of the HIV/AIDS Identity Incorporation Process



They grappled with a new idea of themselves. Others' impressions affected how they saw themselves. They began to incorporate a new personal identity as a person living with HIV/AIDS within the context of a society that stigmatizes the disease. Ten of the 11 participants did not expect an HIV-positive diagnosis and reacted with shock, fear, and denial. The person who expected to contract the disease was relieved.

Shock. Shock was the most frequent reaction to HIV-positive diagnosis. This participant's reaction was common:

> Seven days later . . . [The doctor called] and said, "Your HIV test came back positive. You should come back right away so we can test you again." . . . I flew back and that afternoon got tested again and spent seven days in a complete trance walking around the house.

Another respondent took the HIV test to put his family's mind at ease. He said,

> I went in [to the doctor's office] not expecting what I heard. I was shocked. Real shocked. I mean I literally went out on the sidewalk afterwards and stood while people were just walking around me.

Fear. Another common reaction to receiving an HIV-positive diagnosis was fear: "When I was first diagnosed, I was scared . . . I would . . . be in a state of terror. Complete soul shock." Others mentioned hopeless and lack of control along with fear. "[I felt] hopeless. Terrified." "Fear . . . and anxiety—feeling that I wasn't in control anymore." Part of the fear was related to the stigma of the disease for respondents. "The initial feeling was just like the whole world closed in on me. . . . The paranoia was enormous. I was worried about contacting past partners and fearing they may find out."

Denial. Most participants experienced some level of denial for a period lasting from 6 months to 5 years (Courtenay, Merriam, & Reeves, 1998). Some escaped the reality of the diagnosis through alcohol and drug use, whereas others pursued their daily lives not fully appreciating the seriousness of having HIV/AIDS. A respondent remarked, "I wasn't dealing with any part [of being HIV positive], I was just feeding my addiction." Several participants manifested their denial through trying to lead a normal sex life:

> I wanted to go out and I wanted to still have sex with people. I just didn't deal with the HIV at all. I knew I was HIV-positive. I didn't go out of my way to have unsafe sex . . . I didn't talk about the HIV unless I had to.

Relief. One participant was relieved because he assumed that he would contract the disease. He stated that on diagnosis no longer did the "dragon . . . follow me around all the time." Although this person was the only one in the study who stated that he was relieved on diagnosis, he believed that others had a similar reaction.

Postdiagnosis Turning Point

Six months to 5 years after being diagnosed as HIV positive, respondents experienced a turning point event that forced them to deal with their diagnosis. The event helped people advance to the next component in the process. Respondents indicated that the postdiagnosis turning point involved interaction with others. For some, it meant joining others who discussed the possibility of miracles. For others, the event was as simple as a chance encounter with another HIV-positive man:

> We sat down on the curb and I began to share with him what I had been told and what my thoughts were. And I started crying and he was sharing with me that he was also HIV-positive and had been living with the virus for like six years . . . I said, "I don't know if I believe you or not, but . . . I want to live."

Medical interventions served as a turning point for some:

> I remember standing in front of the doctor and he said, "That's the third time your T-cells have dropped. We have to put you on this drug." And I looked at him like a child who had just been scolded and I said, "Well, if I get my T-cells back, can I go off?" And he said, "No, you will be on this for the rest of your life." At that moment, he made your life finite. And . . . that was the line . . . That's when it became really real.

Stage 2: Immersion

The second stage (third component) of the incorporation process was immersion. The immersion component consisted of (a) the HIV community experience, (b) identity centrality, and (c) education.

The HIV community experience. Joining an HIV/AIDS support group and being accepted as a person with HIV or AIDS was integral to identity incorporation. One participant noted, "They opened their arms and they opened their hearts and they were so . . . genuinely moved and interested in me . . . I started to want to claim [HIV] and talk about it." The sense of group unity helped others in the incorporation process:

> Being able to go from the individual to the group is what helped me. I didn't have to claim this thing by myself . . . [It helped] just being around other people knowing that I wasn't by myself in the beginning . . . I started volunteering at AIDS organizations. Group membership was a major factor [in incorporation].

Finally, others felt the group helped them gain control over the disease. "[The group] . . . helped me feel like I had control because the more information I got and the more knowledge I got, the more that I felt I was regaining control of my life."

Identity centrality. Two gay identity development models (Cass, 1979; Troiden, 1989) include a stage at which individuals are immersed in the subculture where they associate almost exclusively with other gays and their gay identity is in the forefront. A similar phenomenon occurred for HIV-positive individuals. All participants indicated that the HIV/AIDS identity had been central to the immersion component during the incorporation process.

One participant described herself as a "poster child" for the disease. "I went to the far end of the spectrum. . . . Everything was AIDS. I couldn't have a conversation that didn't include AIDS. . . . I became this poster child. . . . It was all-consuming." Another reflected, "At a certain point, that was my whole life. I went to work, but it was about volunteering, and going to doctor's appointments, and living, reading, and being HIV-positive." A third respondent stated, "I got to this place where HIV became everything. . . . All my friends were HIV-positive. I swam around in it for a long time."

Education. Initially participants devoured information on HIV/AIDS. This learning was followed by a strong desire to teach:

> Once I became educated, it kind of freed me because I knew that I could live. I guess from that point on . . . I just felt that I needed to do something. I needed to get involved and get busy and try to get this message out. . . . So . . . that's my mission.

Teaching helped participants claim the illness as well:

> There's a lot of ignorance out there and I can do something about that. And so wanting to go out into the community and educate people about HIV, but also understanding that I wanted to be claiming who I was . . . that would be empowering.

Most participants used stigmatizing situations as an opportunity to educate. One participant stated that when she revealed she was an AIDS educator, a man she was dating stated, “You work with THOSE people?” After several dates the man asked for a kiss. At this point she said, “I don’t think you want to do that . . . I’m one of those people.” She stated, “I think he changed his attitude about THOSE people. It was a process, because [later] he would call to ask questions.”

Postimmersion Turning Point

Respondents spent several years in the immersion component of the incorporation process. Eventually a specific event or series of events caused them to reexamine their immersion in the HIV/AIDS world. For many the advent of HAART served as a postimmersion turning point. New medications brought new hope: “Protease inhibitors signaled the beginning of . . . this being a chronic illness. . . . Everyone had this sense of ‘The struggle is over. Let’s try to live a semi-normal life.’ ” New medications also brought new questions: “All of a sudden, this big cause [is gone]. People are going, ‘Get on with your life.’ And you’re like, ‘Easy for you to say!’ ”

Others cited “burn out” as a factor in helping them past the immersion point:

> After being the Tasmanian Devil of HIV . . . I was wearing myself out. . . . I realized that just like in anything else, any extreme is too much. . . . It took a lot of wake-up calls. It took a lot of people saying, “You aren’t doing anybody any favors if you kill yourself.”

One participant felt less connected to the HIV community. She reflected, “When I started, it was so beautiful . . . And we would bond. I don’t know, maybe like anything, it just lost its sparkle a little bit.”

Stage 3: Integration

Similar to those negotiating the incorporation of a gay identity (see Cass, 1979; Troiden, 1989), those grappling with HIV/AIDS moved away from immersion in the HIV/AIDS subculture and work on increased integration. Integration was composed of (a) time- and health-dependent decentralizing and (b) balancing. The prominence of the HIV/AIDS identity receded. Participants engaged in non–HIV/AIDS-related activities. They reevaluated other aspects of their lives, such as the work life they had abandoned.

Time- and health-dependent decentralizing. Decentralizing was an internal process. Respondents realized that they were more than their HIV/AIDS identities. The passage of time allowed decentralization to occur. A participant who referred several times to HIV/AIDS as a “dragon” illustrated the progression of decentralization, saying,

> I went from being in its shadow and being overwhelmed by it and my life completely controlled by it . . . to acceptance. . . . The dragon doesn’t tower over me anymore. It’s kind of like the story of the three pigs. The wolf has been blowing at the door for so long. He finally came down the chimney and I cooked him and I ate him, so he’s a part of me.

Naming an illness gives it a sense of the “other” (Lal, 1999). The progression from naming the illness to not giving it a name shows the virus’s decreasing emphasis. For many, HIV moved from being “more like a pet . . . [If] you don’t take care of it, it starts whining and scratching and doing all sorts of annoying things” or a “partner” to “just part of what I do . . . It’s just part of my life” and “more integrated into who I am . . . It’s something that is, but I don’t really think about it all the time.” In addition, health status affected the centrality of the HIV/AIDS identity:

> I’ve struck a balance with HIV in my life and there are days when you feel a little consumed. . . . Health stuff is the stuff that tips that balance where you’ve incorporated HIV to where you feel consumed by HIV.

Balancing. Whereas decentralizing refers to the internal experience of the HIV/AIDS identity, balancing was the external manifestation of this change. An orientation toward the future precipitated by the success of HAART had respondents trying to balance their lives by taking care of themselves: “When I feel too overworked . . . I evaluate what needs to go and I let it go . . . I let my support group go because you have to go every week.”

Others concerned themselves with activities outside the HIV/AIDS community. A participant stated, “I took a sabbatical from [HIV/AIDS] work to re-do the house.” Similarly, a person “joined Overeaters Anonymous for about a year.” She explained that the energy she used “just surviving” could be used in other ways. Pursuing goals previously thought unattainable was a facet of the balancing.

Several respondents in this study spoke of returning to work. One “made a plan” that included gradually reclaiming a work identity that he had abandoned several years earlier because of poor health. One person began working “15 hours a week as a receptionist [and thought] ‘Maybe, I can work part-time.’ ” He is now a workshop manager at an ASO.

Others renegotiated their sexual selves and relationship with others. A participant noted that his improved health was allowing his “sexual [self] to wake back up again” and that he “felt more flirtatious.” Others were “reassessing their relationship” in light of improved health. “Both of us look at each other . . . and go ‘What now? . . . Did we stay together the last fifteen years because [I] was sick?’ We’re reassessing.”

Disclosure

Disclosure, a component of the identity incorporation process, was the thread that wove itself through the other components. There were three types of disclosure: (a) telling significant others, (b) public disclosure, and (c) situational disclosure. Each type of disclosure corresponded with a component of the incorporation process. For example, during the diagnosis stage participants informed significant others, such as close family and friends. During the immersion stage of incorporation all publicly revealed their HIV-positive status. After greater integration of the HIV/AIDS identity several realized that telling everyone about their status was not necessary and that situational disclosure was more appropriate.

Telling significant others. Most participants were diagnosed in the mid-to-late 1980s, when discrimination against PLWHAs was significant and medical options were few. The disease was highly stigmatized. Doctors often advised newly diagnosed patients to tell few outside the family. A respondent stated,

> The psychiatrists and psychologists told me over and over . . . “Absolutely, you cannot tell anyone about your status. If you do you are going to be hurt. . . . You can tell your wife, but that’s it.”

Telling the public. Most respondents publicly declared their HIV-positive status when they were immersed in the HIV/AIDS community. Typically, this occurred in a support group: “I was in this therapy group and would have to tell new people . . . about my HIV at some point. . . . I got to a point where I could say, ‘I’m living with HIV.’ ” After disclosing their status to a group, many felt compelled to tell the public about being HIV-positive. One person “went on the national news . . . because [he] felt obligated to do it.” Others proclaimed their HIV-positive status in the local newspaper.

Situational disclosure. Situational disclosure occurred after people had integrated HIV/AIDS more fully into their lives:

> I know today that I don’t have to tell everybody.
>
> I don’t wear this big sign that says I’m HIV . . . but when somebody comes in who doesn’t know anyone who is HIV, who assume that they’re going to be dead in a month, I can kind of shock them in saying, “Well, I really do know because I’m HIV-positive.”

Discussion

The purpose of this article was to explore how people incorporate HIV/AIDS into their identities over time. A six-component process of incorporation was uncovered. Turning points or transitions appeared. In addition, I found a process of disclosure that correlated with the level of incorporation of the HIV/AIDS identity. In the following discussion I situate these findings in the HIV/AIDS literature and compare and contrast them with other literature on the incorporation of other chronic illnesses.

The Diagnosis

For 10 of the 11 participants the incorporation of HIV/AIDS into identity began with diagnosis. Only one person anticipated an HIV/AIDS identity before he was officially diagnosed. This might indicate that the question of when does incorporation begin needs further study. Previous researchers of the incorporation of HIV/AIDS into identity disagree on this topic. Dozier (1997) maintained that incorporation began after diagnosis, whereas Gurevich (1996), Lewis (1994), and Sandstrom (1990) found that incorporation began when people suspected that they were HIV positive.

It could be hypothesized that if a person suspects that he or she is HIV positive, confirmation of this fact would be less dramatic, and there might be a shorter period of shock and denial than for those who were not expecting an HIV-positive diagnosis. However, other studies do not support this hypothesis, noting that those who suspected that they were HIV positive experienced shock, denial, and depression just as those who did not anticipate their HIV-positive diagnosis did (Gurevich, 1996; Lewis, 1994; Sandstrom, 1990).

The diagnosis experiences of others with a chronic illness have been examined (Kralik, Brown, & Koch, 2001; Salik & Auerback, 2006). Reactions to being diagnosed with diabetes and multiple sclerosis included shock and fear at not being able to care for oneself properly (Kralik, Brown, et al., 2001). Shock, fear, and relief were experienced by those diagnosed with cancer and leukemia. Relief was mingled with fear for one participant diagnosed with leukemia because her illness now had a name but there was no known cure for it. Although some in the HIV/AIDS community might have the same relief and/or fear reaction on diagnosis, the person in this study expressed relief at diagnosis because he always thought he would contract the disease. A similar reaction might occur for some people diagnosed with diseases that have a known genetic component, such as Lou Gehrig's disease (ALS) or perhaps Alzheimer's disease. However, this reaction was not found in the chronic illness literature. Perhaps being relieved at receiving a diagnosis for a disease that "haunted" at least one participant in this study is somewhat unique. Participants in this study were diagnosed when HIV/AIDS was considered a terminal illness and when it was decimating the gay community, which might explain the reaction. On the other hand, this reaction might still be common.

Turning Points/Transitions

I uncovered explicit turning points in the incorporation process. The postdiagnostic turning point served as a wake-up call. Previous studies concerning the incorporation of HIV/AIDS into identity do not pay explicit attention to turning points. No other HIV/AIDS identity studies uncovered a postimmersion turning point. Perhaps the lack of a postimmersion turning point in other studies can be attributed to their completion before the widespread use of HAART and the dearth of longitudinal studies.

The importance of turning points has been mentioned in other chronic illnesses' incorporation (Kralik, 2002; Martin-McDonald & Biernoff, 2002). Kralik's model of transitioning from extraordinariness to ordinariness while living with a chronic illness might have some application to HIV/AIDS participants. Like Kralik's participants, respondents in this study felt a sense of extraordinariness on diagnosis. They, too, knew that life would never be the same and felt "alienated from familiar life, and a loss of control over life circumstances" (p. 149). As with Kralik's participants, a sense of ordinariness occurred when they "embraced the illness experience as an opportunity to learn and expand" (p. 150), and they began to reconstruct their life with the illness. However, my model is more specific in that it shows two particular turning points in a process of incorporation rather than a more general sense of movement, as Kralik's model indicates. This specificity might be important in helping with the incorporation process in that it shows that a turning point is necessary after diagnosis and after immersion into the HIV/AIDS community.

In a literature review exploring how the word *transition* has been used in the health literature, Kralik, Visentin, and van Loon (2006) noted that in all studies, "Researchers concluded that it is through understanding the transition process that health care professionals will be better equipped to aid clients through the process of adaptation" (p. 325). Certainly, this incorporation model can help HIV/AIDS educators know when intervention is necessary and they can perhaps help to move HIV-positive individuals along the path toward integration.

Immersion

Immersion consisted of three components: (a) the HIV community experience, (b) the centrality of the HIV identity, and (c) education. Each subcomponent will be discussed.

Joining an HIV/AIDS community to promote integration was mentioned in several studies (Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). Likewise, literature on other chronic illnesses shows the importance of a community or support group in the psychosocial adjustment and management of chronic illness or disabilities (Gallant, 2003; King et al., 2003). Like those with HIV/AIDS, the group helped normalize the disease. However, there was a greater sense of immersion in the culture in this study compared to other studies. Perhaps this can be explained by differences in the sample. All of the participants in this study were solicited through ASOs. Perhaps those not as closely connected to ASOs would be less likely to become immersed in the HIV/AIDS culture. In addition, participants in this study were diagnosed when HIV/AIDS was a terminal illness and people came together in an effort to survive. Perhaps this sense of complete immersion in the HIV/AIDS culture would be less intense now that those diagnosed with HIV/AIDS consider it a chronic illness.

The centrality of the HIV/AIDS identity was confirmed, although it was not necessarily tied to a particular time in the process of incorporation. Lewis (1994) believed that the HIV-positive identity became a primary identity on diagnosis until it was usurped by the HIV/AIDS identity. Gurevich (1996) did not associate the centrality of the HIV/AIDS identity to a particular point in the incorporation process, instead noting that it shifted continuously. This identity centrality was not located in other chronic illness literature. However, the immersion component of the identity incorporation process was found in models where people incorporated other stigmatized identities such as gay or lesbian identities or an African American identity. Troiden (1989) noted that people might "immerse themselves completely in a homosexual [sic] subculture" (p. 62) during the identity confusion and acceptance stages to avoid a heterosexual setting that reminds them of their stigma. Likewise, Cross described a four stage process of the incorporation of a Black identity (Cross & Vandiver, 2001). The third stage is called Immersion/Emersion, where the person immerses him- or herself in the African American community. During this stage the person is typically "simplistic, romantic, oceanic, and obsessively dedicated to all things Black" (p. 376). Therefore, it is possible that the need to make the HIV/AIDS identity central during incorporation is related to its particularly stigmatized state.

Education was a subcomponent of the immersion stage and was found in four of the five studies but was not necessarily prominent during a particular stage in the process, although it always occurred after people had accepted that they were HIV positive (Dozier, 1997; Gurevich, 1996; Sandstrom, 1990). Both learning and teaching others were important parts of the process of incorporation (Dozier, 1997; Gurevich, 1996; Sandstrom, 1990). Just as this study's participants felt a sense of responsibility toward teaching others, so did Gurevich's (1996) participants. As was evident in this study, educating others was a way to claim HIV/AIDS and to destigmatize the disease (Dozier, 1997; Gurevich, 1996).

Integration

The level of integration of the HIV/AIDS identity appears to be greater in this study than in other studies, partly because there seems to be an increased orientation toward the future. New medications and the passage of time have allowed participants in this study to move beyond the acceptance of an HIV/AIDS identity, the focal point previous studies (Dozier, 1997; Lewis, 1994; Sandstrom, 1990).

Several studies mention a reevaluation of roles, such as a person's career role or role as an intimate partner (Gurevich, 1996; Lewis, 1994; Sandstrom, 1990), but there is no mention of reclamation of these roles as is evidenced in the balance subcomponent of integration. For example, one participant rejoined the workforce at age 34 after receiving disability checks since age 22. Another respondent admitted to reclaiming his "sexual self." Participants in the aforementioned studies did not experience the Lazarus syndrome, wherein they felt that they have been given a second chance at life (Henderson, 2000). However, Trainor and Ezer's (2003) research on the lived experiences of PLWHAs who responded to protease inhibitors after facing death found that participants reclaimed the role of student and worker to reintegrate into society. Like participants in my study, Trainor and Ezer's participants wondered how far they should plan into the future.

A reevaluation of relationships in light of a chronic illness is common (Lyons, Sullivan, Ritvo, & Coyne, 1995). Chronic illness interrupts activities that a couple might have enjoyed. Lyons and colleagues asserted that chronic illness means that the healthy partner must assume an increasing burden of responsibility as the condition of the chronically ill person worsens. Findings from this investigation add a new twist. Like Trainor and Ezer (2003), I found that participants reevaluated their relationships. Participants also reclaimed relationship responsibilities that they had previously abandoned. In addition, the attention given to the HIV/AIDS identity was both health dependent and time dependent. In general, the longer participants lived with their diagnosis, the more incorporated the HIV/AIDS identity became, and the less attention was paid to it. At diagnosis it consumed respondents' thoughts, but after 7 to 16 years of living with HIV/AIDS, they adapted and integrated it into their lives. This general truism, however, was mediated by health. When participants were feeling well, often the only daily reminder that they had HIV/AIDS was their medication. When their health worsened, their HIV/AIDS identity became more prominent.

The impact of time on adaptation to disease is evident in the chronic disease literature and the AIDS and identity literature (Corbin & Strauss, 1988; Dozier, 1997; Gurevich, 1996; Sandstrom, 1990). The longer a person had an illness, the more that person can integrate that illness into his or her identity. New medications gave people more time and the sense of a future. Time allowed people to recover from the shock of the diagnosis and work at accommodating the illness in their lives (Pollin & Golant, 1994). Participants had a chance to learn more about the disease, feel more in control, and take measures that might help extend their life span. On the other hand, time can also be considered the enemy, just waiting to pounce on those with HIV/AIDS. A participant summed up this tension best when she said,

> There are days when you think . . . "I gotta take this one day at a time. I gotta live well. I've got to live a full life and I'm gonna live until I've got a retirement account." And then there are days when you're like, "Whoa, I made it this far. Sand through the hour glass."

In addition to time, health is an inextricable component in the experience of a chronic disease. Charmaz (1991) noted that for individuals who are chronically ill, good days give a larger temporal perspective. People feel "normal," and their whole life is ahead of them. On bad days the illness comes to the fore, and people live in a painful present. Charmaz contrasted good days and bad days. She says that on good days, "Illness remains in the background of their lives. . . . Like ex-convicts just released from jail, they may wish to make up all at once for lost time" (p. 50). Charmaz contrasted this image of freedom with the frustration of a bad day. She stated, "Illness and regimen take center stage. . . . Bad days elicit anger and frustration" (pp. 51-52). In this study several participants spoke about bad days, when their health consumed their thoughts. A participant echoed others' sentiments: "Health stuff is the stuff that tips the balance where you've incorporated HIV to where you feel like you're consumed by HIV . . . consumed is a little out of control."

Disclosure

Disclosure to a trusted few as a method of stigma management was mentioned in several HIV/AIDS incorporation studies (Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). This type of disclosure was done early in the incorporation process. People initially told a select few because they were ashamed of their diagnosis and were afraid what others would think of them. Similarly, individuals' public admission of their status in a public setting was noted (Dozier, 1996; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). I found that there is another level of disclosure beyond telling the public; namely, the more integrated the HIV/AIDS identity became, the less people discussed it. This situational disclosure was further evidence of integration. These participants lived long enough to realize that they do not have to talk about their illness to everyone. Situational disclosure is not because of fear but because, as one participant stated, "I think I had a real need to tell people before. Now, if it comes up it's just like—'I've got a nose.' "

Literature concerning disclosure of chronic illness seems centered on disclosure of the chronic illness in the workplace (Munir, Leka, & Griffiths, 2005) or on the relationship between living with a stigmatized disease and disclosure (Charmaz, 1991; Cline & McKenzie, 2000; Joachim & Acorn, 2003). If the process of disclosure is discussed, people seem to tell relatively few people for fear of negative reactions (Adams et al., 1997; Joachim & Acorn, 2003) or to accept the disease and tell everyone (Adams et al., 1997). Unlike previous studies, this study revealed a third alternative, selective disclosure, after people traversed the public disclosure stage.

The disclosure process hints at the salience of the HIV/AIDS identity in the larger self. Initially the stigma of the disease and the shock of being diagnosed with HIV/AIDS meant that the identity was hidden from all but a few close friends and relatives. After the postdiagnosis turning point, people began to join HIV/AIDS support groups, and the HIV/AIDS identity became more public. In the immersion stage of the incorporation process, the HIV/AIDS identity assumed a master status. People claimed publicly that they were HIV positive. Participants' social activities centered on being HIV positive. After the postimmersion turning point the HIV/AIDS identity became less prominent as people started reclaiming other identities.

Although this study contributes to the literature on HIV/AIDS as a chronic illness, it has limitations. First, participants were solicited from ASOs. It is possible that this population would have a different incorporation process than those not associated with ASOs. Guarino (2003) suggested that PLWHAs associated with ASOs tend to see their diagnosis as a turning point and an opportunity to live a better life. This self-transformation is promoted by the narrative discourse of the ASO. Hence, participants not affiliated with an ASO might have a different identity incorporation process. Second, the participants responded to flyers distributed at ASOs. They self-selected to be part of these studies. Those who volunteer to participate for studies might be different from those who chose not to participate. Perhaps study participants were more outgoing, mentally and physically more healthy, and coping better than those who did not volunteer. Third, 7 of the 11 study participants are White, gay men who reside in a large southeastern metropolitan area. Fourth, all but one participant attended college. Future studies should examine the incorporation process of those from rural areas, people of color, and heterosexual men and women to see if there is a different process. Another study should examine the incorporation process of HIV-positive individuals who were diagnosed after the widespread use of HAART to explore how that process might differ from the one presented in this manuscript. Furthermore, because support group dynamics were so prominent in the incorporation process, it might further research on group process and chronic illness to study the various functions of the group in the incorporation process more closely.

In conclusion, the findings from this study demonstrate the importance of transitions/turning points in the incorporation process and corroborate the findings of other studies that indicate stigma influences the incorporation process (Alonzo & Reynolds, 1995; McCormack, 1997; Page, 1999; Tewksbury & McGaughy, 1997). Unlike in other HIV/AIDS and identity investigations, results from this study suggest that disclosure is integral to the incorporation process and that it might be indicative of the level of incorporation. A particular level of disclosure (situational disclosure) might indicate a level of integration beyond that experienced by telling the public. Finally, this study adds to the HIV/AIDS identity literature by identifying components of the HIV/AIDS process after the widespread use of life-extending medications and confirms that time is a factor in the incorporation process. Furthermore, time can be considered from a positive light and a negative light by PLWHAs. Time allows people to incorporate HIV/AIDS into their identities, but poor health brings the HIV/AIDS identity to center stage.

The value of research resides not only in its theoretical contributions but also in its practical implications. The identification of turning points in the incorporation process can help HIV/AIDS counselors identify these turning points in clients and ultimately assist clients in further incorporation. Finally, acknowledgement of the importance of disclosure and its link to particular stages in incorporation might alert HIV/AIDS counselors to the need to provide safe opportunities to reveal their diagnosis, knowing that it will help in the incorporation process.

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