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PoZitively Transformative: The Transformative Learning of People Living with HIV

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Abstract: The purpose of this study was to investigate meaning making in People Living with HIV (PLWH) as a *chronic* illness. Findings confirm those of Courtenay, Merriam and Reeves (1998) who examined meaning making in PLWHAs when HIV/AIDS was a terminal illness. Contextual factors that mediate meaning making were uncovered.

HIV is considered a manageable chronic disease in the United States because people have access to life-extending medications (Teague, 2007). The number of people living with HIV in the United States was estimated at 1.2 million in 2005 (UNAIDS, 2006) which is an increase from 850,000-950,000 in 2002 (Centers for Disease Control, 2004).

Individuals have to make sense of living with HIV as a chronic disease. Researchers explored the meaning making process of those diagnosed with HIV/AIDS when it was considered a terminal illness. Guided by Mezirow's (1991) theory of transformative learning, Courtenay et al. (1998) interviewed 18 participants and concluded that for them meaning making was a five-step process. First, they experienced an initial reaction that included "cognitive, affective, and behavioral responses" (§ 17). Next, a catalytic experience "helped the respondents begin to view their diagnosis in a new way and make decisions about how to live" (§ 24). Third, they took stock of their lives, critically examined their priorities, and modified their activities in accordance with their new priority of helping others. Fourth, in a phase called the "consolidation of new meaning" (§ 40), they "help[ed] other HIV-positive individuals" (§ 40). Fifth was the stabilization of their new perspective, which included a heightened their sensitivity to life and the need to make meaningful contributions in the service of others.

Follow-up studies with 14 of the original 18 participants concluded that participants' perspective transformation held over time and there were new changes in meaning schemes (beliefs and attitudes), but not new changes in perspective (worldview) (Mezirow and Associates, 2000). The new meaning schemes included a future-oriented perspective, a greater attention of care to the self, and a greater integration of HIV/AIDS into who they were. (Courtenay, Merriam, Reeves, and Baumgartner, 2000). A third study with 11 of the original 18 participants confirmed the stability of the perspective transformation. The previous meaning-schemes were also evident. New meaning schemes included an increased appreciation for the human condition and an expanded view of intimacy (Baumgartner, 2002).

It is possible that the meaning making process could differ for people currently diagnosed with HIV since it is not the death sentence that it was prior to the advent of protease inhibitors. Therefore, the purpose of this study is to investigate the meaning making process of people diagnosed HIV-positive 1996 or later when the disease was considered *chronic* in the US because access to life-extending medications was widespread.

Theoretical Framework

Mezirow and Associates' (2000) conception of transformative learning is the theoretical framework for this study. Mezirow (1991) delineates a 10-step process, which begins with a

“disorienting dilemma” such as a divorce, the death of a loved one, or the diagnosis of an illness (p. 168). Such a dilemma might cause individuals to reflect critically on their assumptions about the world. This critical reflection can lead to a “perspective transformation,” or changes in “habits of mind,” or modifications in one’s worldview, leading to a “more inclusive, discriminating, permeable and integrative perspective” (Mezirow, 1990, p. 14). People talk to others about their new perspective and eventually integrate it into their lives. They also might experience changes in meaning schemes or “sets of immediate beliefs and expectations, beliefs, feelings, and attitudes” (Mezirow and Associates, 2000, p. 18).

Methodology

Fourteen volunteer participants were selected by criterion sampling (Patton, 2002) from AIDS Service Organizations (ASOs) in the Midwestern U.S. The criteria were: (a) age 18 or older, (b) HIV-positive for a year or longer, (c) diagnosed HIV-positive in 1996 or later and with access to life-extending medications, and (d) no AIDS diagnosis. Those diagnosed HIV-positive for less than a year were excluded, as they might not have had adequate time to make sense of their HIV-positive diagnosis. As it was imperative that all participants had experienced HIV as a chronic illness, only those diagnosed after life-extending medications were widely available in the U.S. were included. Last, we suspected that those diagnosed with AIDS might have incorporated the diagnosis differently than those diagnosed with HIV because those living with AIDS have a more compromised immune system.

The sample consisted of 14 adults. Respondents ranged in age from 25 to 52 years old. There were 3 African American men, 3 African American women, 5 White men, 1 White woman, 1 Latino man and 1 African American male-to-female transgender. Participants’ education level extended from high school graduate to some graduate coursework.

Data collection consisted of 14 1 ½ to 2 hour interviews using a semi-structured interview guide. Areas investigated included the process of identity incorporation, the nature of learning that occurred during that process, and questions concerning how other identities were affected by HIV.

Data were analyzed inductively using the constant comparative method (Glaser and Strauss, 1967; Strauss and Corbin, 1990). Interviews were conducted and transcribed and we read, re-read, and coded the transcripts and looked for themes within and across transcripts. As a result, themes emerged. These themes addressed the questions about identity incorporation, the nature of learning, and how HIV affects other identities.

Findings

The nature of learning was transformational. The process of transformative learning largely replicated the findings in Courtenay, Merriam and Reeves’s (1998) study that examined the centrality of meaning-making in the lives of People Living with HIV/AIDS (PLWHAs).

Initial Reaction

Namely, participants had an initial reaction to diagnosis that included cognitive, affective, and behavioral reactions. Shock, numbness, and believing that death was near were cognitive responses participants experienced. This replicates the reactions of participants in Courtney et al.’s (1998) study. Enrique thought he was going to die. He stated, “The first thing that [came] to mind was ‘I’m going to die. I’m going to die.’ [That] was in my mind 24 hours.” This fear of death occurred although most participants knew that there were life extending medications.

Anger, sadness/depression, and fatalism emerged as affective reactions to the diagnosis. Brian showed depression. Brian stated, “I was very sad. I was sedated for about a week. I didn’t

go to work. I sat in bed. My partner had to bathe me, clean me, feed me. I didn't do anything." Last, two participants had a rather fatalistic attitude toward what they thought was their impending death. Jason said, "When I was finally diagnosed there was part of me saying, 'This was kind of what you wanted all along. An easy way out.'" Behavior included using drugs, seeking information about HIV and talking to others.

Turning Point/Catalytic Experience

Eleven participants remained in the initial reaction phase from several days to a year. The time spent in this phase was generally shorter for participants in this study than for those studied by Courtenay et al. (1998), who stayed in the initial phase from 6 months to 5 years. This phase was followed by a turning point, or catalytic experience, which forced respondents to start making sense of the disease. The turning point fit into one of three categories: (a) learning about HIV, (b) support from others, and (c) medical intervention.

Observing others with HIV and talking with medical personnel served as a turning point and precipitated a need to get educated about HIV. Terry, as with many others, thought he was going to die from HIV until he went to his doctor. He related his turning point, "I go in and see the doctor ...and he tells me that he can keep my alive for ten years.... I decided then I was going to live and just live my life to the fullest." When Clinton started taking medication for HIV it was a "real slap in the face."

Phase 1: Exploration and Experimentation

Just like participants in Courtenay et al.'s (1998) study, participants in the current study took stock of their lives and made adjustments in activities. Taking stock meant questioning priorities and re-creating their identities. Rich "became [his] own man." Eleven of the 14 respondents felt a connection to others they had not experienced before. They became more empathic and felt closer to others.

Phase 2: Consolidation of New Meaning

All the participants realized that people were the top priority in their life. Unlike in Courtenay et al.'s (1998) study, HIV was not the central identity of most respondents, nor were they immersed in the HIV/AIDS community. However, many fulfilled a need to give back to the community through HIV/AIDS-related service work. Randy co-chaired a group for those living with HIV and recovering from chemical dependency. Christina attended health department advisory meetings and lobbied her senators for funding of HIV/AIDS medications. Clinton worked at a local ASO where he did "an array of things from testing to counseling to case management to prevention to education and outreach."

Phase 3: Stabilization of the New Perspective

Like the participants in Courtenay et al.'s (1998) study, the participants in this study made meaning of the disease by gaining new worldviews. Participants saw HIV as a way to make a meaningful contribution and all of them wanted to be of service to others.

Service to others. Twelve of 14 respondents made sense of their HIV diagnosis by reaching out to help others. This was the most common perspective change for the group. Niecy lobbied at her state capitol for money for HIV-related causes. She said, "My state representative, H___. [We] sit up there. You would think we were buddies. I sit up there and cross my legs and talk to him. When I go to [the capitol city] he's like, "This is my favorite person." Enrique recognized a need to provide current information about HIV to those who speak Spanish. He noticed that much of the information written in Spanish was outdated so he is translating information at his ASO into Spanish.

Heightened sensitivity to life. Several people appreciated what life had to offer.

Linda's change in attitude and her sensitivity to life is apparent. She confessed, "I have a chair... In the beginning it was my 'Looking at my life pass me by' chair because I have a garden apartment and it faces right out to [a street] and over to the park and it's beautiful... I didn't think it was pretty for the first part of my illness... Now I call [that chair] my 'inspiration chair' because now I see all the beauty out there. I kind of see the things that are out there and I didn't see before."

Increased self-esteem. Blackberriz is a male-to-female transgender individual. Her acceptance of her gender identity and HIV went hand-in-hand. She stated, "What got me out of denial was at the time accepting myself for who I was. Once I accepted me for being me and started to love myself more then I think that's what it was." Terry, Blackberriz, and Clinton came to terms with being gay and with being HIV-positive around the same time. Acceptance of themselves and their sexuality helped them begin to make sense of their HIV.

Changes in Meaning Schemes

In addition to changes in perspective regarding the value of people and relationships and the subsequent need to be of service to others, participants experienced changes in meaning-schemes including an increased appreciation of the human condition, reevaluation of work, increased spirituality, growth of an advocate identity, and integration of HIV into the self-concept.

Appreciation for the human condition. Lee recognized that people were on their own journeys and had their own battles. He was less bothered by homophobic people than he used to be. He stated, "There are good and bad people... some of whom are homophobic... those that are homophobic—they don't bother me... I don't let them get to me the way I used to. I realize they have their own issues to deal with. Many of the most rancid homophobics are usually closet cases." Blackberriz stated, "I just learned to accept people for who they are."

Reevaluation of work. Nine of 14 participants reevaluated the importance of work in their lives and sought personally fulfilling work. Brian's comments were typical. "Living in New York, you identify yourself with your job I needed a wake-up call. This is not real. *It's* what you *do*, it's not who you are!" Brian found the fashion industry unfulfilling and found he needed to "do something that is going to make me happy at the end of the day."

Increased spirituality. Half the participants claimed spiritual growth. Clinton's journey to spirituality was typical. Clinton, who was spiritually "absent" prior to contracting HIV said, "I'm in a 12-step program now. It's a spiritual program basically. It led me back to church I didn't talk about God, but I can do that now."

Growth of advocate identity. Eleven of the 14 participants became HIV/AIDS advocates. Brian, a fundraiser for HIV/AIDS-related causes, stated, "I think [my job] has helped me grow. And be more passionate about what I'm doing and actually go back to the political I'm a big social advocate."

Integration of the HIV identity into the self-concept. The prominence of the HIV identity depended on context. It was integrated well into the self-concept but it became more prominent in dating situations.

Mediating Factors in the Meaning-Making Process

Meaning-making does not occur in isolation. It is influenced by participants' sociocultural context.

Social Interaction. Whether one-on-one or in a group setting, social interaction was a necessary part of meaning making, because it occurred when they saw others in the same situation. Information they received from others about living with the disease was a turning point for some participants. ASOs and support groups provided a place to enact their new meaning

perspectives and give back to the HIV/AIDS community. A *lack* of social interaction, represented by the inability to find an appropriate support group, impeded meaning making. The education and support that people received in the group provided the turning point from the initial reaction to the diagnosis, and participants started to make meaning.

Stigmatization. Although much has been learned about how HIV is transmitted, people still have inaccurate information and it is still a stigmatized disease. This stigma affected the meaning-making process because it delayed entrance into a support group that served as a turning point for some from dealing with emotions to beginning to make sense of the disease. Further, it prevented disclosure to others who could have been a part of the meaning-making process. People also avoided information seeking about the disease because of stigma. Had people received accurate information about the disease sooner, they could have moved from their initial reaction to meaning-making more quickly.

Contextual factors affecting incorporation of an HIV identity. Time, health, and economics affected the incorporation of HIV into the participants' identities. With the passage of time HIV became more a part of participants' self-definition. Health scares made HIV/AIDS more prominent and economics, namely concerns about affording HIV medication kept HIV in the minds of many.

Discussion

The results of this study confirm that participants' meaning making process is similar to those diagnosed with HIV/AIDS when it was a terminal illness (Courtney et al., 1998). The initial reaction, emotions and a catalytic event are important in the meaning making process. In addition, participants experienced a change in meaning perspective and meaning schemes.

Unlike previous research, participants reevaluated the role of work in their lives. They sought work more personally meaningful to them and considered work a less salient identity. In addition, few ever held HIV as a primary identity. Because HIV is a chronic illness and people are living longer, participants have the privilege of engaging in full-time employment. However, the HIV diagnosis precipitated a change in the value of work in people's lives.

This study adds depth to the importance of context in transformative learning. The interpersonal context (e.g. social support or lack thereof) affected meaning making. In addition, the sociocultural context (e.g. stigmatization and economics) affected information seeking about HIV and the salience of the HIV identity. Likewise, the situational context, living in a large city, meant increased access to HIV/AIDS resources and social networks. Likewise, the fact that the HIV/AIDS identity was never a central identity for most participants is due to the temporal factors. HIV is a chronic disease in the US, and although people initially feared death, they quickly realized that they could live with the disease.

HIV/AIDS educators need to recognize that HIV is still a stigmatized disease. Because it is stigmatized, people might not seek the information they need. In addition, assigning people to appropriate support groups based on a person's developmental stage in life (e.g. childrearing stage vs. retirement) and stage of living with the disease (1 year vs. 12 years) is important for meaning making to occur.

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