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HIV/AIDS Identity Incorporation and the Temporal Context

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Abstract: The purpose of this study was to examine how the temporal context affected the incorporation of the HIV/AIDS identity into the self. In-depth interviews were conducted with 36 individuals living with HIV/AIDS. Chronological age shaped the initial reaction to the diagnosis whereas historical time did not. Social time affected immersion in the HIV/AIDS community and the passage of time influenced the integration of the HIV/AIDS identity into the self. These findings have implications for health educators.

HIV/AIDS is considered a manageable chronic disease in the United States because people have access to life-extending medications (Mahungu, Rodger & Johnson, 2009). The number of people living with HIV in the North America has risen from 1.2 million in 2001 to 1.5 million in 2009 (UNAIDS, 2010). In the United States, AIDS-related deaths decreased 69% between 1994 and 2007 (UNAIDS, 2009).

Because HIV/AIDS is a chronic illness, individuals need to incorporate the HIV/AIDS identity into the self. Identity theorists maintain that people possess multiple identities that form a stable self (Serpe, 1987). The self is formed through interaction with others and remains stable. Identities are “parts of the Self—internalized positional designations that represent the person’s participation in structured role relationships” (Stryker & Serpe, 1982, p. 206). Identities are synonymous with role relationships. For example, a woman could have the identities of sister, lawyer, tennis player, and ovarian cancer survivor. These identities make up a stable self. The salience of the identity depends on the number and strength of role relationships with which it is associated (Serpe, 1987). “Andrew” might have a highly salient professor identity. He might talk about being a professor to his friends, colleagues, and casual acquaintances. His identity as a hospice volunteer is less well-known since he does not talk about that identity publicly.

Several researchers have investigated the incorporation process of HIV/AIDS into one’s identity (Awa & Yamashita, 2009; Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstorm, 1990; Tewksbury & McGaughey, 1998). However, researchers have paid scant attention to the influence of various contexts on the incorporation process. These contexts include the sociocultural (e.g. race, class, gender, and culture), interpersonal (e.g. support and stigma), temporal (e.g. developmental stage in a person’s life or social time, historical time, chronological time and the passage of time), and situational (e.g. contexts specific to that person’s experience such as pregnancy) (Ichovics, Thayaparan, & Ethier, 2001). In particular, the impact of the temporal context *on the identity incorporation process* has been under-researched. The purpose of this study is to investigate the impact of historical time, social time, chronological age, and the passage of time on the HIV/AIDS identity incorporation process (Neugarten & Datan, 1973).

Neugarten and Datan (1973) discuss various aspects of time. Historical time refers to “long-term processes, such as industrialization and urbanization” and to “economic, political and social events that directly influence the life course of . . . individuals” (p. 58). Social time refers to “the dimension that underlies the age-grade system of a society” (p. 57). Societies dictate when it is customary to start formal education, marry, have children, and retire for example. Chronological age is one’s age as measured by years after birth. The passage of time refers to the passage of chronological time. For example, those living with a chronic illness might adapt to it after living with it for several years (Courtenay, Merriam & Reeves, 1998). Likewise, a person might progress from living day-to-day with an illness to having a sense of a future if treatments work and symptoms lessen (Charmaz, 1991).

Literature Review

Context affects the incorporation of an illness into one’s identity. Most often, researchers noted the influence of the interpersonal context, (e.g. stigma and support), on the identity incorporation of an illness. Support from friends and family helped the identity incorporation process of individuals with diabetes, chemical sensitivity, epilepsy, depression, and HIV/AIDS because participants disclosed their illness and received support whereas stigma prevented disclosure which inhibited the incorporation process (Allotay & Reidpath, 2007; Awa & Yamashita, 2008; Baumgartner & David, 2009; Dozier, 1997; Gibson, Placek, Lane, Brohimer & Lovelace, 2005; Gurevich, 1996; Karp, 1994; Lempp, Scott & Kingsley, 2006; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998).

A few scholars discussed the impact of time on the identity incorporation process. The passage of time allowed for the illness to move from the foreground to the background in individuals living with cancer (Mathieson & Stam, 1995), and depression (Karp, 1994). A relapse precipitated the illness returning to the foreground in people’s lives (Karp, 1994). In addition, a cancer diagnosis in adolescence could disrupt educational or marriage plans (Abraham, Silber & Lyon, 1999) and cause individuals to be “off time” regarding societal expectations (Neugarten, 1976, p. 20). Regarding historical time, the increased availability of information about HIV/AIDS and the effect of life-extending medications on identity incorporation were briefly mentioned (Baumgartner & David, 2009; Lewis, 1994). Lewis (1994) found that older gay men were less upset by an HIV/AIDS diagnosis than those who were younger suggesting that developmental stage in life affected the HIV/AIDS identity incorporation process.

Merriam, Courtenay and Reeves (2001) investigated the impact of time in relationship to developmental changes on those living with HIV/AIDS. Those participants with an HIV/AIDS diagnosis lived in the present. Their sense of a future returned with the advent of life-extending medications. In addition, participants noticed the effect of chronological age. They imagined themselves living longer given their success with life extending medications. Last, the researchers discovered that participants’ social time was also affected. After the advent of protease inhibitors, a participant realized he needed to start saving for retirement and some women considered having children.

Method

Sample selection occurred through purposive sampling (Patton, 2002). Volunteers were sought from AIDS Service Organizations (ASOs) located in the midwestern United States. Selection criteria included: (1) Age 18 or older, (2) HIV-positive or living with AIDS for a year or longer. The sample consisted of 36 adults ranging in age from 25 to 66 years old. Participants self-identified their demographic characteristics. There were 11 African American men, 11 African American women, 10 White men, 1 Latino man, 2 biracial women, and one biracial man. Education levels ranged from 8th grade through master's degree. Twenty-two participants reported an income of less than \$10,000 a year.

An in-depth investigation of a process warranted a qualitative methodology. Data collection consisted of 36 one to two hour interviews using a semi-structured interview guide. Data were analyzed inductively using the constant comparative method (Glaser & Strauss, 1967). Interviews were conducted and transcribed and I read, re-read and coded the transcripts and looked for themes within and across transcripts. Similar themes were organized into categories and refined. Strategies used to increase the reliability and validity of the findings included member checks, an audit trail, and adequate engagement in data collection to achieve saturation.

Findings

To discuss the influence of context on the incorporation of HIV/AIDS into one's identity, a brief overview of the components of the incorporation process is necessary. The four-component process included diagnosis, a post-diagnosis turning point, immersion into the HIV/AIDS community, and integration. Diagnosis consisted of an initial emotional reaction (fear, anger, sadness, denial, shock, and relief), and a behavioral reaction (e.g. increased drug/alcohol use and/or isolation from others). The turning point jarred people from their initial reactions and included entering a treatment center that dealt with alcohol/drug addicts living with HIV/AIDS, learning about HIV, and attending HIV/AIDS support groups. Immersion consisted of involvement in the HIV/AIDS community and making the HIV/AIDS identity central. In the integration phase, individuals educated themselves and others about HIV/AIDS and were accepted by HIV-negative individuals. The passage of time also helped integration. HIV-positive individuals were somewhat less likely than participants living with AIDS, to become immersed in the HIV community or have HIV as a central identity.

Historical Time

Twenty-six individuals feared that they were going to die soon after being diagnosed with HIV or AIDS before and *after* the widespread use of life-extending medications including protease inhibitors in 1996. Historical time and medical advances had little impact on the emotional reaction for those diagnosed after 1996 because most relied on old media images and misinformation from their neighbors concerning HIV/AIDS. This meant that people experienced unnecessary fear at diagnosis which slowed disclosure to others. This lack of disclosure prevented participants from gaining support from others which was integral to incorporation of the HIV/AIDS identity.

Chronological Age

Ten participants mentioned that age affected how they handled the diagnosis. Several respondents diagnosed in their 30s and 40s said they would not have handled the diagnosis as well earlier in life. Wene, diagnosed HIV-positive at age 41 stated, “It was probably easier for me [at my age] because of things I’d been through in life. I was in Vietnam when I was 18...I saw stuff over there...I don’t think I could have dealt with [an HIV diagnosis] at age 20.” Joe 2 was diagnosed with HIV at 31 thought he would have been more responsible about “going to doctors” rather than “going out and partying” had he been diagnosed at a later age.

Social Time

Women, who had married or had children “on time” and were raising small children when they were diagnosed, tended to not disclose this information to their children, families, and larger community as readily as those with older or grown children (Neugarten, 1976, p. 20). This lack of disclosure to others meant these women generally took longer to integrate the HIV/AIDS identity into themselves and they had a smaller support system than others in the study.

Twenty-eight participants were unemployed at the time of the interview. Many received social security supplemental income for disability. They were “off time” as regards retirement from paid work (Neugarten, 1976, p. 20). Therefore when health permitted, they had time to volunteer at the AIDS Service Organizations and learn more about HIV/AIDS and teach others about HIV/AIDS which helped in integration.

Passage of Time

The passage of time was the turning point for the emotional reaction for some participants. Steve, age 57, was told he had five years to live when he was diagnosed in 1995. After five years, he realized he was going to live long-term with HIV/AIDS. Ed said he just kept “looking up and getting older” and he realized he was not going to die from getting HIV/AIDS. Seeing others living with HIV/AIDS was also a turning point from the initial reaction. Most participants attended support groups and saw long-term survivors. Michael’s reaction was typical, “What made me come to terms was when I saw people with 20-25 years that had the disease and were still living.”

Conclusions and Implications

Historical time had little effect on the diagnosis. Several factors might have contributed to the lack of current information about HIV/AIDS and the resulting fear for those diagnosed after the widespread use of life-extending medications. First, media coverage wanted in the US after 1985 (Brodie, Hamel, Brady, Kates & Altman, 2004). Media coverage of HIV/AIDS declined after the widespread use of protease inhibitors and the rise in infection in the African American population (Swain, 2005). Second, HIV/AIDS knowledge might vary according to a person’s location, sexual orientation and demographics. Research has shown that individuals with less education feared breast cancer more than those with more education (Zollinger et al., 2010). Third, individuals seek information on a need-to-know basis (Knowles, 1980). Gay men diagnosed in the 1980s saw people in their community dying and thought they might be next.

Heterosexual participants did not believe they could be infected and did not seek information about the disease.

The passage of time encouraged the incorporation of the HIV/AIDS identity into the self. When Steven lived past the five year mark after his diagnosis, he believed he could live a long time with the disease. This event was a turning point from his initial reaction to the diagnosis. Another turning point from the initial emotional reaction to diagnosis involved seeing others who had lived with the disease a long time. Studies that concern the role of support groups and chronic illness not that support groups provide hope and a forum in which individuals can know of others living with the same disease or condition and gain strength and comfort in this (e.g. Peterson, 2009).

There are several implications for health educators. Despite advances in treatment, individuals still fear imminent death when diagnosed with HIV/AIDS. Culturally relevant AIDS education is especially necessary in poor, underserved urban and rural communities. Younger participants might need more emotional support than older participants because of their lack of life experiences. Women with young children face additional issues when they receive a diagnosis of HIV/AIDS. Learning how, when, why and where to disclose their status to others is vital for their health. Newly diagnosed individuals need to see and talk to long-term survivors as they provide hope, information, and coping strategies for the newly diagnosed.

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