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HIV as a Chronic Illness: Identity Incorporation and Learning

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Keywords: HIV, chronic illness, identity, learning

Abstract: The purpose of this session is twofold: (1) to review tentative findings of a study-in-progress concerning the identity incorporation process and learning of people living with HIV as a chronic illness and (2) to explore issues encountered in conducting research with the chronically ill.

Although HIV/AIDS continues to be a worldwide problem, it is now considered a chronic disease in the United States due to the widespread access to highly active antiretroviral therapy (HAART) (Schmitt & Stuckey, 2004). The number of individuals living with HIV in the United States is estimated at between 1.04-1.2 million in 2003 which was an increase from 850,000-950,000 in 2002 (Centers for Disease Control, 2004).

Living with a chronic illness requires adjustments in thinking about one's sense of Self. The Self refers to the whole person. The Self is a collection of identities or "multiple selves" that interact with society and are changed by that interaction (Serpe, 1987). People have multiple identities (e.g. mother, Person's Living with HIV). While scholars have explored the effect of chronic illness identities such as arthritis (Rosenfelt & Faircloth, 2003) and asthma (Radtke & Van Mens-Verhust, 2001), the process may differ amongst people with HIV/AIDS.

Learning drives identity development and is a lifelong process. Few studies examine the nature of learning in those diagnosed with chronic illnesses. Studies explored the transformative learning of those diagnosed with HIV/AIDS when it was considered a terminal illness but not as a chronic illness (Baumgartner, 2002). Therefore, the purpose of this study is to explore the incorporation of HIV as a chronic illness into the Self. The research questions include: (1) What is the process by which HIV is incorporated into the Self? (2) What effect does being HIV-positive have on other identities? (3) What is the nature of learning that occurs?

Methodology

A basic qualitative design was chosen for this study-in-progress. A non-random, purposeful sample of HIV-positive adults was selected to be interviewed for this study. They were solicited from HIV/AIDS Service Organizations in the Midwest. All participants were diagnosed with HIV after 1996 and had access to life extending medications. All had been diagnosed HIV-positive for at least one year. Each participant was given \$30. Thus far, six one to two-hour semi-structured interviews were completed, transcribed and analyzed using a critical framework. Participants range in age from 25-50 years old. Three participants are gay, White men. One participant is a heterosexual, African American woman, one participant is a heterosexual White woman, and one is a gay, African American man. Their education level ranges from some college to master's level coursework. Data were analyzed inductively using the constant comparative method where data analysis proceeds simultaneously with data collection. By comparing data and interpretations within and between transcripts, a process of incorporation, effects on other identities, and the nature of learning emerged.

Tentative Findings

The incorporation process includes: (1) initial reaction: shock, fear with sense of a future, denial, depression; (2) Turning point: HIV is not a death sentence. Education and time were factors that influenced this turning point. (3) HIV identity one amongst more salient identities. Mediating factors in the incorporation process include: (1) Time/health, (2) stigma, (3) economics/ resources, (4) positionalities and (5) support systems. The identities affected by the incorporation of the HIV identity include the work, physical, intimate/social, spiritual, advocate, and survivor identities. The nature of learning is transformative. Participants wanted to be of service to others and wanted to make a meaningful contribution to the world. They believed that HIV was a positive change agent in their lives. The nature of learning is also self-directed. Participants used books, the internet, caseworkers, friends, and HIV/AIDS Service Organization-sponsored workshops to learn more about their illness. Learning is affected by stigma and resources.

Questions for Discussion

This study-in-progress has provided surprises and caused critical reflection. The purposes of this roundtable are to share experiences with others who have conducted research with those living with chronic illness and to reflect on the following questions: (1) What are some challenges in researching the chronically ill? (2) What effect do sociocultural factors such as stigma, positionalities, and the health care system in the United States have on HIV identity incorporation and learning? (3) How are multiple identities affected by chronic illness? (4) What implications does this study have for self directed and transformative learning? (5) What are some implications for adult educators?

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