

# **“It Made Me a More Self-Directed Learner”: The Non-Formal, Informal and Transformative Learning of People Living with HIV/AIDS**

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**Abstract:** The nature of learning for those living with HIV/AIDS was explored. Learning occurred in non-formal settings. Informal learning occurred including self-directed, incidental and tacit learning. Prior learning affected current learning. The transformative learning that happened confirmed previous studies’ findings. Findings have implications for HIV/AIDS educators.

The widespread availability of life-extending medications in the United States for People Living with HIV/AIDS (PLWHAs) means HIV/AIDS is considered a chronic illness (ElZarrad, Eckstein, & Glasgow, 2013). Approximately 1.14 million individuals ages 13 and older are living with HIV/AIDS in the United States (Centers for Disease Control and Prevention (CDC), 2013). In the last decade, this number has increased although the annual rate of newly infected individuals has remained stable (CDC, 2013).

Learning to live with a chronic illness is a lifelong endeavor. Learning can occur in formal contexts (e.g. community colleges) or non-formal contexts (e.g. libraries). Individuals can learn in a variety of ways. Informal learning “occurs without the presence of externally imposed curricular criteria” (Livingstone, 2001, p. 4) and includes self-directed, incidental, and tacit learning. Self-directed learning occurs when individuals consciously take the initiative and decide what to learn, how to learn it and how to evaluate the learning experience (Knowles, 1975). For example, a woman decides to learn how to cross country ski. She reads books on the subject, consults with other cross-country skiers and joins a cross country ski club. She successfully completes a 5 kilometer cross-country ski trail and considers herself a competent skier. Incidental learning is the “unintended outcome of a learning experience” (Keeping & English, 2001, p. 313). For example, a person might attend a dog obedience course and incidentally learn about temperament differences between dog breeds. Tacit learning is not conscious or intentional but awareness of this type of learning can occur later (Marsick & Watkins, 1990). Transformative learning occurs when one’s worldview changes (Mezirow, Taylor & Associates, 2009).

## **Literature Review**

Researchers have investigated the learning of those living with chronic illness through various lenses. The self-directed learning of individuals living with breast and prostate cancer (Rager, 2004; 2006) and multiple sclerosis (Holland, 1992) has been discussed. Rager (2004) discovered that women with breast cancer felt empowered and connected to others as a result of their self-directed learning. They engaged in very selective learning related to their breast cancer diagnosis and made sense of their breast cancer diagnosis. In contrast, men with prostate cancer were reluctant to talk with others about their illness and had difficulty dealing with the emotions associated with diagnosis. Men learned about the side effects of prostate cancer treatment but this did not prepare them for the actual experience. Men learned that the process of dealing with a prostate cancer diagnosis is never over as “watchful waiting” is part of the process (Rager,

2006, p. 447). Holland (1992) discovered that the kinds of information individuals wanted about multiple sclerosis differed as they learned to live with the disease. Those diagnosed five years or less sought information on typical symptoms, treatment, coping strategies and disease progression whereas individuals diagnosed over six years desired information about stopping disease progression.

Incidental learning and informal learning has been unearthed in individuals who use continuous ambulatory peritoneal dialysis (CAPD) (Keeping & English, 2001). Participants studied the medical language associated with their condition, how to manage their treatment, and the liminal nature of their existence as they recognized how close they were to death. They also felt a sense of depersonalization as their bodies changed.

Transformative learning has been used as a framework for those living with chronic illness. In one recent example, researchers conducted a metasynthesis of articles that focused on “transformation in primary care” (Dubouloz, King, Paterson, Ashe, Chevrier & Moldoveanu, 2010, p. 282) of those living with chronic illness such as HIV and diabetes. They created a model of the transformative process based on five studies with three main phases including “initial response, embracing the challenge and integration of new ways of being” (p. 289).

The purpose of this study is to explore the nature of learning for those living with HIV/AIDS. Although researchers have examined self-directed, and/or incidental learning in those living with cancer (Rager, 2004, 2006) multiple sclerosis and PID (Keeping & English, 2001), these diseases are not as stigmatized in society as HIV/AIDS remains and so learning to live with HIV/AIDS might differ from learning to live with other diseases. Last, very little attention has been paid to the incidental and tacit learning that occurs while living with a chronic illness.

### **Method**

For this study, I sought participants from an AIDS Service Organization (ASO) in a large metropolitan area. Additionally, a key informant referred individuals who lived in a smaller town. Snowball sampling occurred as respondents referred friends and acquaintances to me. The criteria for participation included (1) being 18 years old or older and (2) having HIV or AIDS for a year or longer. It was reasoned that individuals needed a year to come to terms with their diagnosis.

Thirty-six individuals participated in the study. There were 23 self-identified African American participants, one Latino man, nine White participants, and three biracial participants. Participants ranged in age from 25 to 66. Respondents had been diagnosed with HIV or AIDS between 1985 and 2007. The education level ranged from 8<sup>th</sup> grade to master’s degree.

Respondents were interviewed from 1.5-2 hours. Participants received a \$ 30 money order for their time. The constant comparative method was used to analyze data (Glaser & Strauss, 1967). I used open and axial coding and looked within and between transcripts to derive themes (Glaser & Strauss, 1967). Consistency and trustworthiness of the data was ensured through member checks, triangulation, using an audit trail and rich thick description (Merriam, 2009).

### **Findings**

Participants learned about HIV/AIDS in non-formal contexts such as AIDS Service Organizations and health agencies. Respondents’ informal learning included self-directed and incidental learning. Transformative learning was also evident in their responses. Last, prior learning about HIV/AIDS enhanced and inhibited present learning.

**Non-formal learning contexts.** Non-formal learning contexts included education groups at AIDS Service Organizations (ASOs), health agencies, and church. Individuals learned about medications, how HIV/AIDS is transmitted, and self-care techniques. Joe's experience was typical of participants involved with an AIDS Service Organization. He stated,

By going to training class, though [an ASO], and taking the [names specific group] training I learned about everything else. So, when it was time to take meds, I told the doctor this is what I wanted. She knew I was taking the class and it made it so much easier for me to talk to her. So she goes, 'That's a good one but we have to do a resistance test on you first.'

Peer and professionally led support groups were also sites for non-formal education. Greg's comment regarding support groups was indicative of others' responses:

But I went to the support group . . . the best way to find out about care and help is through . . . other people because the health places will tell you what they think you need but other clients will tell you what they've been through. . . You get more information from 5-6 people sitting around talking about, "I've tried that med. I've done this. I've done that. What do you use for diarrhea? What do you do for night sweats?" Simple things that doctors don't think about.

**Prior learning.** An unexpected finding was the discussion of learning about HIV/AIDS prior to diagnosis. Outdated or incorrect information about HIV/AIDS learned from peers or the media meant individuals believed HIV/AIDS was a death sentence even when life-extending medications were available. This misinformation impeded learning after diagnosis in part because clients had to cope with emotions before they could process current information about HIV/AIDS. When Kelven was diagnosed in 1999, he only remembered how his friends suffered on AZT and died. He noted,

Yeah. I'm going to die. I maxed out my credit. I gave up on life. . . I didn't know anybody that was—... Yeah, [protease inhibitors] were out because they gave me a prescription right away. I still had the images of AZT and wasting away. That's what I had and that's what I thought was coming because protease inhibitors weren't out long enough for me at that point. I still thought about AZT and how sick it made everyone and how they wasted away. The hair. The skin.

It took Kelven time and encouragement from his mother to attend a retreat sponsored by an ASO where he learned he could truly live with the disease.

Learning current information prior to diagnosis made coping with the disease much easier. Joe 2 learned about HIV/AIDS in school and immediately went to the internet for information when he was diagnosed. Role models with the disease also eased participants' minds when diagnosed. Chanel stated,

OK, when I found out I had it Magic Johnson had it and he was doing well. . . I knew that there [were] going to be some drugs maybe sooner or later. When I found out that Magic Johnson had it, then I knew I was going to be OK.

Part of the issue in the learning process was participants *believing* the correct information. Respondents who received the correct information and believed it had an easier time than those who received the correct information and still thought they were going to die.

***Informal learning.*** Informal learning includes self-directed learning, incidental learning and tacit learning. Participants' self-directed learning was shown when they sought information from the internet, books, television programs, pamphlets and they asked others for advice. Respondents utilized health professionals for information. They believed that they learned best through conversation with others who were knowledgeable about HIV/AIDS or who lived with it themselves.

Regarding incidental learning, after learning about HIV/AIDS in education groups, individuals recognized that they could live long-term with the disease. Second, they realized that they were not alone in their experiences when they saw long-term survivors in support groups. Last, respondents understood how emotional support was integral to learning about and living with HIV/AIDS.

With respect to tacit learning, some participants recognized the effect of stigma on their lives as part of another learning experience (incidental learning) whereas others later realized stigma's effect on their learning. Stigma affected some participants' learning because they were afraid to look up information about HIV/AIDS. Second, some realized, in retrospect, that race, class, and sexual orientation influenced how they were treated while living with HIV/AIDS. Some African Americans indicated that race affected how they were treated in their community. Others said White gay men had advantages when it came to getting correct information about HIV/AIDS.

***Transformative learning.*** As with previous studies (e.g. Courtenay, Merriam & Reeves, 1998), participants' worldviews changed. First, they felt the need to give back to others and had a greater appreciation for life. They experienced changes in meaning-schemes or beliefs and attitudes (Mezirow, Taylor & Associates, 2009). They engaged in greater self-care, were more accepting of others, recognized the power of banding together to support each other, and needed to help others. Greg's comment was typical,

The community needs to get together with men and women. That is a definite source that is not being met. It's like—just like with people of color—it's time we put aside our petty differences, economic, race, gender—all of it from cross dressers to gay to straight—all of it. Anybody with this disease needs to band together.

### **Conclusions and Implications**

This study concerning the learning of PLWHAs yielded several findings. First, prior learning about HIV/AIDS affected how individuals coped with the HIV/AIDS diagnosis. Misinformation created fear about HIV/AIDS that impeded learning for some at diagnosis whereas correct knowledge made coping with the disease easier. Second, findings revealed the importance of informal learning in PLWHA's lives. In particular, the value and variety of learning that occurred in support groups was shown. The support group serves as a one-stop shop for self-directed, incidental and tacit learning. Third, the importance of incidental and tacit learning in the lives of PLWHAs was evident. Last, participants recognized the effect of stigma,

race, class, and sexual orientation on their experience of living with HIV/AIDS, and in some cases, on their seeking knowledge about HIV/AIDS.

In light of these findings, HIV/AIDS educators and ASOs should recognize that newly diagnosed individuals with incorrect information might be less able to cope with the diagnosis whereas individuals with current information assimilate additional information more readily. Second, newly diagnosed people especially benefited from seeing long-term survivors in support groups and from trading helpful tips regarding side effects from medications. Health educators and support group leaders need to create space for such learning to occur. Last, positionalities such as race, class, and sexual orientation affect access to HIV/AIDS information in some cases and may lead to disparities in treatment in the HIV/AIDS community. Continued efforts to rectify disparate treatment of PLWHAs are needed.

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