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# “We’re all in this together, aren’t we?”: The Role of “The Group” in HIV-positive Adults’ Identity Incorporation and Learning

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**Abstract:** Using data collected from the same individuals *at three points in time*, this qualitative study examined the role of the group in the identity incorporation and learning processes of HIV-positive adults. Members claimed HIV/AIDS as a social identity. Issues of positionality affected membership perception. Group membership enhanced transformational learning.

People experience diseases within a social context. This study examined the role of the group in the identity incorporation and meaning-making processes of HIV-positive adults. A group was defined as people who convened to discuss a common issue. This included various support groups and agencies.

HIV/AIDS identity studies concentrate on *individual* identity development. They briefly mention that groups provide stigma management strategies (Lewis, 1994), support (Bedell, 1998), and acceptance (Jones, 1996). The incorporation of HIV/AIDS into identity occurs within a social context. Therefore, a study that examines the role of the *group* in the identity incorporation process using a psychosocial/ social identity framework could contribute to a more complete understanding of this process.

The researcher also investigated the role of group interaction in individuals’ making sense of their disease. Mezirow (2000) asserts that social interaction is integral to the transformational learning process for the exchange and validation of ideas. Others add that the transformational learning process includes support (Morgan, 1987), and friendship (Taylor, 1994). Investigating the role of group interaction in the transformational learning process could confirm and augment previous findings.

## Theoretical Framework/Relevant Literature

Erikson’s (1968) psychosocial identity theory and Cox and Gallois’s (1996) social identity theory inform this study. Erikson acknowledges the connection between self and society in the identity formation process. He notes that identity formation is “*in the core of the communal individual* and yet also *in the core of the communal culture*” (p. 68, italics in the original). Social identity theory recognizes that social identities and personal identities shape people (Cox and Gallois, 1996). Our multiple social identities are “aspects of oneself which form on the basis of shared group membership” (p. 11). Personal identities are “based on unique aspects of the self” (p. 13). An aspect of one’s social identity may *not* be part of one’s personal identity. For example, sexual orientation can be part of a person’s personal identity but not part of his/her social identity.

Mezirow’s (2000) theory of perspective transformation also informs this study. This theory asserts that learners critically examine their beliefs and assumptions through self-reflection and reflective discourse to arrive at a more inclusive worldview. Trust, empathy, and acceptance are necessary conditions for effective reflective discourse. Mezirow maintains that individual transformation leads to social transformation.

## Methodology

This study used three data sets. Interviews were conducted with the same participants in 1995, 1998, and 1999. A qualitative research design was chosen because the researcher sought to further understand the evolving process of an individual's interaction with the group and its importance in the incorporation of HIV/AIDS into identity. Research questions included: 1) What are the purposes of the group in the incorporation of HIV/AIDS into identity? 2) What are participants' perceptions of group membership? 3) How does the group contribute to the transformational learning process?

All the data sets investigated meaning-making in HIV-positive adults. Questions concerning coping, identity, and faith development comprised the first two studies. The third data set examined identity issues and group membership. Data from the first two studies augmented the third study.

Eleven participants' (7 men and 4 women) transcripts were analyzed. All studies used a semi-structured interview format to collect data. Interviews were tape-recorded and transcribed. Data was analyzed using the constant comparative method. Comparisons within and between transcripts were made until common patterns emerged.

## Findings

The data revealed that the group served two purposes in the identity incorporation process. First, the group *provided a safe haven for self-care*. This assisted in the individual incorporation of HIV/AIDS into identity. Second, the group *provided a place to be others with HIV/AIDS*. Members found a sense of community and belonging. The group provided a place for them to publicly disclose their HIV-positive status. They became empowered and gained a sense of purpose. This, in turn, led to their claiming HIV/AIDS as a social identity. Participants felt simultaneously part of the HIV/AIDS community and apart from it because of various positionalities including economic status, gender, sexual orientation, and age. Last, the group contributed to the transformational learning process by meeting respondents' affective/affiliation needs, providing a place to enact new meaning schemes, and being a catalyst for individual change leading to social change.

### *A Safe Haven for Self-Care (Taking Care of "Me")*

The group was a place to go for self-care. Since many participants were diagnosed in the mid-1980's, often the group was one of the few places people could obtain up-to-date information about treatment and medications. All attended "Operation Survive" (now "Thrive") which was sponsored by an AIDS Service Organization. Joe described the weekend workshop: "Operation Survive... provides everything you ever wanted to know about HIV. They bring in medical experts, legal experts, people from disability [services], people from housing—all kinds of presentations from people [and] they provide you with this huge book of information. He continued, "Four times during the weekend you break into a support group and they have people lead the groups."

Others gleaned valuable medical information from their small support group. Jamie noted that his support group helped him decide whether to take new medications. He said, "In group...you've got 15...different sides to a one story...which I loved...If I decided not to take the drug then I had some good reasons to give to the doctor about why I wasn't wanting to take it and it wasn't just doing something obstinate." Sam said he learned "tricks for dealing with side

effects” from the group. John, diagnosed in the mid-1980’s stated, “[The group] tells you what to expect. What not to expect. Where to go. Who to see.”

Self-care also meant attending to one’s emotional well being. The group helped destigmatize HIV/AIDS which led people to greater self-acceptance. Dawn’s thoughts represented participants’ feelings. She asserted, “[The group] helped me to accept myself...It helped me to accept that—whether or not everybody was going to embrace me in the world there *were* people who were going to embrace me.” Like Dawn, Kenneth, now in his late thirties, also learned self-acceptance. He related, “Like we say in the [Alcoholics Anonymous] program, deal with life on life’s terms. And acceptance plays a big key in everything... I don’t have to be happy with it to accept it. That’s just the way it is.”

The group provided participants with a sense of control. Jamie noted, “[The group] helped me feel like I had control. The more knowledge I got, the more that I felt that I was regaining control of my life. It gave me power over my own disease.” Pat added, “I met this girl in the group. She had a party at her house. A Christmas party. She had a fabulous house—I was—impressed. And the reception was at another friend’s house and I’m saying, ‘Hey, I can live with this thing.’”

#### *A Safe Haven to Be With Others (Appreciating and Taking Care of the “We”)*

A second purpose that the group served was that it provided a safe haven to be with others. It provided a sense of belonging. Pat, now in her early 50’s, stated, “Just being around other people knowing I wasn’t by myself in the beginning [helped]. Kenneth added, “I had the chance to really express honest, true emotion...I didn’t have to mask what I felt.” John simply stated, “There’s a whole group of people who are automatically your brothers.” Jeff added, “You are finally in a room with others with HIV and it’s a really liberating thing...you get to this place where you realize that you are part of the whole.”

Often the group served as a forum for participants’ first public disclosure of their HIV-positive status. This was integral to identity incorporation. Dawn said, “When I went to [a group at an AIDS organization] I started talking within the AIDS community [about my status].... It became real. There was no denying it anymore.” Jamie also recognized the importance of disclosure in the incorporation process. He said, “The first thing I do is encourage people to get involved in a support group to start telling other people that they are HIV-positive.” Elise also revealed her status in a therapy group. She said, “I would have to tell new people in the group about my HIV at some point. At the beginning, I couldn’t say it without...crying... I got to a point where I could say, ‘I’m living with HIV.’”

The group provided a place to develop a sense of personal and social empowerment and a sense of purpose beyond the self. After coming to terms with the disease, participants recognized that HIV/AIDS gave them a larger sense of purpose. Pat noted, “When I walk into these support groups, I give a lot of hope to a lot of people. [My purpose is to] give some people some hope, to be able to educate people, and know that you can get a degree and do what you want to do in life.” Jeffery said, “[The HIV community promoted] self empowerment and not owning the shame...I see the focus of our organization as empowerment and education.” Jamie said, “We are all about empowerment.”

Finding a sense of belonging, publicly disclosing their HIV-positive status, and becoming empowered as a group assisted in the acceptance of HIV/AIDS as a social identity. This acceptance of HIV/AIDS as a social identity was evidenced by disclosure outside the HIV/AIDS group setting. Sam’s words reflected many participants’ sentiments. He stated, “I got to a point

where it was like—you know there is a lot of ignorance out there...I want[ed] to go into the community and educate people... I wanted to be claiming who I was.” Joe’s incorporation of group identity is shown in Joe’s need to lobby for medications. He states, “There’s a definite group identity mainly because...we were forced to band together for survival... If we don’t get out there and lobby for drugs, we are going to die. I’ve seen what the power of a cohesive group of people who have self-identified as HIV-positive can do.”

### *Participants’ Perceptions of Group Membership*

Participants had two perceptions of group membership: 1) “We’re all in this together” and, 2) “We have differences.”

*“We’re all in this together.”* Jamie, a gay White, male relished the togetherness he felt with other group members. He was instrumental in deciding the mission statement for an AIDS Service Organization. He said, “Our first big mission statement we came up with was: ‘We are people living with HIV.’ The universal connectedness I got strength from and that’s what we were. It’s *we*. It’s *we*.” Dawn concurred, “I identify more readily with the community of people living with HIV than I did with White, middle-class, women.” Elise’s story also demonstrates the oneness she feels with those who have HIV. She stated, “I saw an African American man. I remember looking at this man and I had the feeling that he had HIV. I remember thinking, ‘I love him because he has HIV. He is part of my family and we have a connection that I don’t have with...my mother or husband’.” John echoed Elise’s sentiment by saying, “It seems everyone you talk to is HIV. They are just your automatic brothers and sisters.”

*“We have differences.”* While many saw other HIV-positive people as their brothers and sisters, they made some distinctions. Dawn recognized the importance of embracing both similarities and differences. She confided, “We want to say ‘Well, there are some differences but let’s just talk about the similarities.’ No...We have to completely embrace that I’ve had life experiences that you haven’t had.”

Others felt estranged within the group because although they shared being HIV positive, age, gender, sexual orientation, class or race, made them an outsider. Jamie felt alienated because of age. He stated, “[In the support group] I was 23 and the next youngest person was 35... Finally, I just blurted out, ‘All of you... You’re old. It’s time for you to die.’ That’s kind of how I felt because I didn’t identify with the age group.” When Elise started attending an HIV/AIDS support group, there were only gay men. She felt simultaneously embraced and excluded. She said, “I felt embraced...[but] there’s a bit of an identity crisis that I experience being a heterosexual woman in a community with so many gay men in it. These are my people.” Class differences were also apparent in Elise’s comments. She said, “I mean it’s a lot more fun for me to be around gay men who...have good jobs...than it is to deal with people who are maybe in a lower socioeconomic class and have a history of drug abuse. It’s hard for me to relate.” Pat’s comments reflected a resentment of the power gay men had in the HIV community and the lack of resources for women of color. She stated, “I relate better to women. I still have a barrier with gay men...Because I think—I think I have an inner resentment because all of these services are for gay men and women are just one or two of us...There are few Black women.” Tracy also focused and identified with women. She said, “A lot of my interest and a lot of my focus is into women that are infected because we have fallen through the cracks for so long. From the beginning it was a White, male disease. Heterosexual women didn’t think they fit. All the time they didn’t think they fit they were being infected.”

### *The Group's Contributions to the Transformational Learning Process*

The group assisted the process of transformational learning in three ways: 1) It met affiliation/affective needs, 2) It served as a place to enact new meaning perspectives, and 3) It was a catalyst for individual change which led to social change.

*Met affiliation/affective needs.* The group provided a place to meet affective and affiliation needs which aided in the transformational learning process. Tracy, an African American woman in her early forties, indicated, "The biggest strength I got was seeing some [group members] really sick...They still kept coming to the support group. They still kept giving a powerful message...And I didn't feel uncomfortable [telling people] I'm scared." Sam agreed, "We were all there for one another and that gave me a sense of hope—that I wouldn't die alone and unlovable. I realized that these people were not victims and they were working toward a solution." For John and his partner, the group fulfilled affiliation needs. He said, "My partner and I have joined a positive/negative group which is made up of couples where one is positive and the other is negative. It was a way to meet couples who were new to the area and we've made some good friends out of that." Pat simply said, "Groups are necessary. It's imperative that I'm in the right one. I can talk about what I need to talk about...and there are other women who understand. We're friends. We bond." Emotion crept into Dawn's voice when she stated, "[The group] *absolutely* embrace[d] me. They opened their arms and they opened their hearts and they were so...genuinely moved and interested in me."

*Place to enact new meaning perspectives.* Previous research indicated that participants had a transformational learning experience. Their new meaning perspectives included "an opportunity to make a meaningful contribution...A heightened sensitivity to life... and a need to be of service to others (Courtenay, Reeves, Merriam, and Baumgartner 2000, pp. 107-109). The group gave them a forum where they could enact the new meaning perspective. Pat was representative of most participants when she stated, "I've been doing all my service in the field of AIDS. I do [serve as a speaker] at [an AIDS Service Organization]. My job is to help. Elise also felt compelled to serve. She said, "I remember one of the first things I did was to volunteer for ChildPride which is an AIDS organization for children with HIV and then there was the hotline for women." Jeff said, "I have a real sense of drive to work in AIDS Service Organizations because I've gotten so much help from them."

*Catalyst for individual change leading to social change.* Mezirow (2000) mentions that individual change leads to social change. Jeffery lobbied for funds for medications for people with AIDS. He said of the experience:

Here are 17 very green lobbyists to go with the message that we need 2 million for the AIDS Drug Assistance Program or we are going to die...Basically, that was our message...By the end of the session we got \$ 1.2 million dollars and [originally] there was no money in the budget for it.

Joe also realized that he needed to help change society. He said, "Just me bitching about my health situation...that's one thing. If it's a group of standing on the Capitol steps that's different...It's very empowering to be a part of [an ASO] and to have a voice as part of a group because I felt like they were making a difference."

### **Conclusions and Implications for Adult Education Theory and Practice**

There were three conclusions: First, the group is necessary for the incorporation of HIV/AIDS into and individual's identity and for social identity formation. Second, kinship with other HIV-positive individuals is influenced by various positionalities. Third, group interaction is

integral to the transformative learning process. This study confirms Mezirow's (2000) assertion that talking with others is integral to the transformational learning process. It also confirms studies (Morgan, 1987; Taylor, 1994) which indicate the importance of feelings including trust, acceptance, and affiliation in the transformational learning process. Finally, it shows that the group is a place to practice new meaning schemes and that individual transformation can lead to social transformation.

This study contributes to a better understanding of the role of the group in HIV/AIDS and identity incorporation issues. Support group facilitators and agencies should be encouraged that groups are instrumental in the incorporation of HIV/AIDS into an individual's identity and in the formation of a social identity. However, counselors and educators should recognize the impact of various positionalities including race, gender, age, and sexual orientation on the incorporation of HIV/AIDS into identity and on social identity formation. Marginalization can occur *within* an already marginalized group. It is important that these issues be addressed so *all* can benefit from group membership and interaction.

Empirical support for the group as a place to engage in rational discourse and implement new meaning schemes and perspectives is provided. The group also engaged in social transformation. In addition, this study found that trust, support, and a sense of belonging and affiliation was necessary in the perspective transformation process and in continued meaning making. Educators need to foster these to facilitate the affective aspects of learning with individuals and groups.

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