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# The Perceived Effect of Time on HIV/AIDS Identity Incorporation

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## The Perceived Effect of Time on HIV/AIDS Identity Incorporation

### Abstract

Individuals experience disease in a variety of contexts. In this study, I examined how the temporal context (e.g., historical time, social time, chronological age and the passage of time) affected the incorporation of the HIV/AIDS identity into the self. I used semi structured interviews to collect data from 36 individuals living with HIV/AIDS. Historical time did little to influence the initial reaction to the diagnosis. Chronological age shaped the initial reaction to the diagnosis for some participants. 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. The findings add depth to extant studies on the incorporation of the HIV/AIDS identity into the self.

### Keywords

Time, HIV/AIDS, Self, Social Identity, Basic Qualitative Study

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## **The Perceived Effect of Time on HIV/AIDS Identity Incorporation**

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*Individuals experience disease in a variety of contexts. In this study, I examined how the temporal context (e.g., historical time, social time, chronological age and the passage of time) affected the incorporation of the HIV/AIDS identity into the self. I used semi structured interviews to collect data from 36 individuals living with HIV/AIDS. Historical time did little to influence the initial reaction to the diagnosis. Chronological age shaped the initial reaction to the diagnosis for some participants. 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. The findings add depth to extant studies on the incorporation of the HIV/AIDS identity into the self. Key Words: Time, HIV/AIDS, Self, Social Identity, Basic Qualitative Study.*

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Since the widespread use of life-extending medications, human immunodeficiency virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) has been considered a chronic illness for countries where highly active antiretroviral therapy (HAART) is available (Mahungu, Roger, & Johnson, 2009). The number of individuals 13 years or older living with AIDS in the United States grew from approximately 219,000 to 470,000 between 1996 and 2008 (Torian, Chen, Rhodes, & Hall, 2011).

Living with a chronic illness such as HIV/AIDS requires that individuals contemplate the effect of that illness on oneself. Due to medical advances, people living with HIV/AIDS (PLWHAs) face developmental tasks they might not have previously. They might need to consider preparing for retirement, taking care of aging parents while working full time or learning to become a grandparent.

A person's self is also adjusted shaped and changed throughout life. Those that champion identity theory assert that "persons have as many identities as distinct networks of relationships in which they occupy positions and play roles" (Stryker & Burke, 2000, p. 286). Rooted in structural symbolic interactionism, Stryker's strand of identity theory has several points. First, individuals' access to smaller social networks is influenced by "the larger social structure within which the networks are embedded" (Burke & Stets, 2009, p. 45). Hence, different networks are available to different individuals. Second, different roles can be enacted across a variety of networks and these roles are arranged in a salience hierarchy with the more salient identities more likely to be enacted across various contexts (Stryker, 1980). Third, the salience of an identity depends on the commitment to that identity which can be measured by the "number of persons one is related to through that identity" and the depth of ties to others based on that identity (Burke & Stets, 2009, p. 47). "Tom" might have a highly salient Person Living with HIV/AIDS (PLWHA) identity. He might work as a counselor at an AIDS Service Organization (ASO) and talk about his experiences of being HIV-positive with clients. He might volunteer to educate others in his community about HIV/AIDS by speaking to

college students about his HIV-positive status. Most of his friends might be HIV-positive or be living with AIDS. In contrast, “Tom’s” identity as hospice volunteer might be less salient as he does not discuss that identity with many individuals.

With HIV/AIDS considered a chronic disease and since identity development is a lifelong process, a question of interest has concerned how individuals incorporate HIV/AIDS into one’s Self. Although researchers have examined this question to some extent (Awa, & Yamashita, 2009; Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998), they have paid scant attention to the influence of various contexts on the identity 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; Neugarten & Datan, 1973). Although the effect of stigma and/or support (Awa & Yamashita, 2009; Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Tewksbury & McGaughey, 1998; Sandstrom, 1990) on the incorporation of the HIV/AIDS into the self has been mentioned in several studies, the influence of time on the incorporation of the HIV/AIDS identity into the self remains under-researched. An investigation of the effect of historical time on the incorporation process could alert health educators to effectiveness of information campaigns on the availability of life extending medications. Counselors could benefit from knowing whether chronological age or social time issues at diagnosis affects the incorporation process so they could be more sensitive to client’s needs at different ages and stages of life. Therefore, the purpose of this study is to explore the influence of the temporal context, or various types of time, on the identity incorporation process.

## **Literature Review**

### **Types of Time**

The temporal context includes historical time, chronological age, social time, and the passage of time. Hareven (1977) defines historical time as “linear chronological movement of changes in society over decades and centuries” (p. 58). Historical time refers to “long-term processes, such as industrialization and urbanization” and also “economic, political and social events that directly influence the life course of the individuals who experience those events” (Neugarten & Datan, 1973, p. 58). For example, the women’s movement in the United States has had three eras beginning in the mid-19<sup>th</sup> century and continuing today (Krolokke & Sorenson, 2006). Women in each of these eras experienced the feminist movement differently depending on their age and sociocultural circumstances.

Chronological age is part of the segment of time referred to as “lifetime” (Neugarten & Datan, 1973, p. 56). Chronological age is “at best only a rough indicator of an individual’s position on any one of numerous physical or psychological dimensions” (pp. 56-57) and it interacts with social time, or an age-graded system for asserting

cultural norms. A person diagnosed with a chronic or terminal disease as a child might experience it differently than an elderly person.

Social time describes “the dimension that underlies the age-grade system of a society” (Neugarten & Danan, 1973, p. 57). Societies dictate when it is more “on time” to attend school, partner, have a family, and retire. For example, it is usual to retire from work in one’s 60s or 70s (Neugarten, 1976, p. 20). Retiring at age 35 is considered “off time” from the usual pattern in the United States (p. 20). The average age for an American woman to marry for the first time is 26 (Cohen, 2009) which is an increase from age 20 in 1966 (Glick, Heer, & Beresford, 1963 as cited in Neugarten & Danan, 1973, p. 65). Although it appears that social times are more flexible for marrying, having children and retiring than perhaps they were in the past, society still has some age-graded expectations. For example, children typically attend school until age 18 and pursue additional schooling or enter the workforce.

The passage of time affects individuals in different ways. For those living with chronic illness, the passage of time living with the illness might help one integrate it into oneself and adapt to the illness and its demands the best one can (Courtenay, Merriam, & Reeves, 1998). A person might progress from living one day at a time to having a sense of the future if treatments work and symptoms lessen (Charmaz, 1991).

### **Time and Chronic Illness Identity Incorporation**

Context affects the incorporation of an illness into one’s self. Most often, researchers noted the influence of the interpersonal context (e.g., stigma and support) on the identity incorporation of illnesses such as diabetes, depression or chemical sensitivity. Scholars found that support enhanced incorporation whereas stigma prevented disclosure which stymied incorporation (Gibson, Placek, Lane, Brohimer, & Lovelace, 2005; Goldman, 1997; Karp, 1994; Lempp, Scott, & Kingsley, 2006). Likewise, the incorporation of the HIV/AIDS identity was enhanced by support from family, friends and support groups (Baumgartner, 2007; Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990; Tewksbury & McGaughey, 1998), whereas stigma prevented or delayed disclosure, which was integral to the incorporation process (Baumgartner & David, 2009; Dozier, 1997; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990).

The discussion of time as it relates to chronic illness primarily concerned individuals’ perception of time. Charmaz (1991) observed that living one day at a time, mapping the future if a treatment is successful, and trying to recapture one’s past are time-related concepts pertaining to living with a chronic disease (Charmaz, 1991). In addition, the chronically ill sometimes observe “time markers” which are “events in a chronology” (p. 197). People mark their disease by how long they have survived. For example, “It has been one year since I was diagnosed with cancer.” “Turning points” are points in the chronology of the disease where individuals have a shift in meaning about the disease in their lives (Charmaz, 1991, p. 197). A turning point from the shock of being diagnosed with HIV/AIDS was learning that the availability of life-extending medications meant a person could live with the disease for an extended period.

Literature concerning the effects of historical, developmental, and social time on the incorporation of chronic illnesses other than HIV/AIDS into the self was scant.

Scholars explored the effect of the diagnosis of a chronic illness on adolescence, noting that primary tasks of adolescence include identity development and independence (Abraham, Silber, & Lyon, 1999). They concluded that the diagnosis of a chronic illness might curtail the drive toward independence, incite rebellious behavior, or impact interactions with one's peer group (Abraham et al., 1999). Early adolescence is a time when people worry about appearance so a diagnosis of a chronic illness might impact one's body image negatively (Abraham et al., 1999). A diagnosis during late adolescence could disrupt vocational and educational plans and marriage (Abraham et al., 1999). Hence, developmental tasks are affected by the intrusion of a chronic illness.

Merriam, Courtenay and Reeves (2001) investigated the impact of time in relationship to developmental changes on those living with HIV/AIDS. Regarding participants' sense of time, they found that a diagnosis of a critical illness suspended time and people tended to live in the present. They realized they'd have a future after obtaining protease inhibitors. Participants noted that they understood HIV/AIDS over time. In addition, participants noticed the effect of chronological age. They imagined themselves living longer given their success with life extending medications. Some respondents contemplated living a normal life span, celebrating the new millennium and aging normally. Participants recognized that they'd have a future and hence their social time was affected.

Regarding the impact of historical time on the incorporation of the HIV/AIDS identity into one's self, the increased availability of information about HIV/AIDS from a variety of sources and the effect of life-extending medications on identity incorporation was briefly mentioned (Baumgartner & David, 2009; Lewis, 1994). Lewis (1994) found that younger gay men were more upset by an HIV/AIDS diagnosis than older gay men which suggest that a person's developmental stage has an impact on HIV/AIDS identity incorporation.

The passage of time affected the incorporation of chronic illness into one's self. Time allowed for the illness to move from center stage to a place of less prominence as evidenced by studies concerning identity development and cancer (Mathieson & Stam, 1995), HIV/AIDS (Baumgartner & David, 2009) and depression (Karp, 1994). However, a recurrence of the illness or a health-related crisis precipitated the illness becoming central to one's identity or life (Baumgartner & David, 2009; Karp, 1994).

### **Position of the Researcher**

My interest in researching HIV/AIDS might have been influenced somewhat by historical time. I was a junior in high school in April of 1981 when the Centers for Disease Control (CDC) identified the mysterious disease that had been linked to gay men and hemophiliacs (Feldman & Miller, 1998). The perceived lack of response to the disease by the Reagan Administration disturbed me as I progressed through college. I continued to follow news stories on HIV/AIDS through the 1980s and early 1990s, hoping for a cure.

The opportunity to learn more about the lives of those living with HIV/AIDS occurred in 1998 when I was a doctoral student and I was invited on a research team investigating meaning-making in PLWHAs (Courtenay, Merriam, Reeves, & Baumgartner, 2000). I enjoyed the experience immensely and hoped the results of the

research were potentially helpful to HIV/AIDS educators and to PLWHAs. When we presented the results of our research at AIDS Service Organizations (ASOs), individuals seemed genuinely interested in our findings.

I have conducted several studies concerning HIV/AIDS, identity and learning from 1998 to the present. An increasing number of individuals in my life have revealed they are HIV-positive. It is because I have learned so much from conducting this research and because I want to contribute in some small way to the HIV/AIDS community that I continue this research.

## Method

This basic qualitative study emerged from a study on HIV/AIDS and identity incorporation. Qualitative research is especially useful for understanding an in-depth experience such as living with HIV/AIDS and the effect of context on that experience (Bogdan & Biklen, 2007). Further, a qualitative methodology allows the participants and the researcher to delve into the experiences of the participants because the goal of qualitative research is to collect rich, thick descriptive data (Bogdan & Biklen, 2007). Since qualitative research “employs an inductive research strategy” (Merriam, 1998, p. 7), the paradigm values exploration (Patton, 2002) which is an excellent method for an exploratory topic such as the effect of the sociocultural context on HIV/AIDS identity incorporation. Since the researcher is the primary instrument for data collection, the researcher can ask probing questions to have the participant further explain what he/she is thinking. This is advantageous when it comes to looking at how context affects the incorporation of HIV/AIDS into the self. Last, qualitative research is flexible (Patton, 2002). New patterns and directions emerge with each participant. Because I investigated how context affected the HIV/AIDS identity incorporation process, I could tailor my probes to participants’ responses to gain an in-depth look at their particular experiences.

A basic qualitative study was chosen because I wanted “to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved” (Merriam, 1998, p. 11). A basic qualitative study is used when researchers want to know “how people make sense of their lives and experiences” (Merriam, 2009, p. 23). I wanted to know how people made sense of living with HIV/AIDS in a variety of contexts.

Volunteer participants were selected by purposive sampling (Patton, 2002) from an AIDS Service Organization (ASOs) in the Midwestern United States. An AIDS educator at an ASO alerted qualified clients to my study by passing out cards advertising the study and alerting clients via email. Participants had to be age 18 or older and diagnosed HIV-positive or living with AIDS a year or longer because I believed that those diagnosed less than one year might have not had sufficient time to reflect on the HIV/AIDS identity incorporation process. Snowball sampling was also used as participants told their friends about the study.

Thirty-six adults between the ages of 25 and 66 comprised the sample. Twenty-three participants were African American, nine were White, one identified as Latino and three individuals stated that they were biracial. There were 23 men (12 African American, 9 White men, and 1 Latino man and one bi-racial man) and 13 women (11 African American women and two biracial women). Twenty-one participants had

received a diagnosis of AIDS. Participants had lived with HIV or AIDS between two years and 24 years prior to being interviewed. Education levels ranged from eighth grade through master's degree. Sixteen participants had attended college or were college graduates and 8 had not graduated from high school or received a GED. Thirty-two respondents reported a household income of less than \$20,000 or less per year. Participants chose their pseudonym for the purpose of the study.

### **Data Collection and Analysis**

Ethical procedures for data collection and analysis are imperative (Richards & Schwartz, 2002). After I received institutional review board (IRB) approval for the study, I sent cards advertising the study to my contact at the ASO who disseminated the information about the study and contacted me via telephone and email. We arranged to meet at the ASO where I conducted the interviews in a private conference room. Prior to the interview, each participant read a consent form that addressed the purpose of the research, confidentiality issues regarding data collection and the storage, the length of the interview and participants' right to withdraw from the study at any time.

I verbally reiterated aspects of the consent form including the purpose of the research, their need to choose a pseudonym so their information could not be identified, and their right to withdraw from the research process at any time. I pointed out the contact information for the Office of Research Compliance and encouraged respondents to contact that office if they so desired. I encouraged participants to contact me with any questions or concerns they had after the interview. Participants verbally agreed to the terms on the context form since a signature on the form was not allowed per the Institutional Review Board (IRB). Participants were given a \$30 money order at the conclusion of the interview.

I used a semi-structured interview guide to facilitate interviews that lasted between one to two hours. I had to re-interview two participants because of equipment failure during their initial interviews. The interview questions prompted discussion about identity incorporation of the HIV/AIDS identity and the learning that occurred as well as how various contexts influenced identity incorporation and learning. My periodic summaries of participants' responses and their affirmations that I interpreted information correctly served as a member check throughout the interview. I took field notes using Spradley's (1980) four-part method of transcription. First, I took very brief notes during the interview itself. Often, these notes included a physical description of the person and his/her demeanor. Second, after the interview, I made detailed supplemental notes of my impressions during the interview which included observations of body language, attitudes toward self and others, and how individuals appeared to be coping with HIV/AIDS. A third set of notes contained impressions, hunches and tentative findings, such as whether the person appeared to be following a similar incorporation process as delineated in previous research or if their journey appeared especially affected by a particular context such as the interpersonal context (e.g., stigma) or a sociocultural context such as race. A fourth set of notes contained a tentative analysis and explanation of results.

The data were analyzed inductively using the constant comparison method (Glaser & Strauss, 1967). After I conducted and transcribed the interviews, I engaged in incident by incident coding (Charmaz, 2006) where, for example, I compared



participants' thoughts, feelings, and actions and contexts when they were diagnosed with HIV/AIDS. Then I used focused coding to determine which "initial codes make the most analytic sense to categorize your data incisively and completely" (Charmaz, 2006, p. 58). So, "thought she'd die tonight--2003", "fear of death though diagnosed after 1996", "death imminent no hope—2002" and "diagnosed told had five years" became, "Historical time: Post-1996: Fear of death" which evolved into, "Forward to the past" when I realized that participants' fear of death remained consistent at diagnosis even if they were diagnosed after the widespread use of protease inhibitor. I read, reread and coded transcripts looking for themes across and within them. Similar themes were organized into categories and refined. I sent participants their interview transcripts and a summary of final findings that detailed the study's results including the contextual factors that affected the identity incorporation process as well as the implications of the study. Thirty-five of the thirty six participants received the interview transcript. Several participants could not be located to receive the final findings. Respondents were asked to make comments or provide any corrections to the transcripts or discuss any issues or concerns regarding the transcript or findings with me. Several thanked me for sending them their transcripts and findings. None of the participants expressed concerns about their interview transcript or the findings.

## Results

The results of this study are organized according to the effect of the particular aspect of time on the incorporation process. Prior to revealing the effect of various aspects of time on the incorporation process, the process itself must be introduced. Hence, a brief delineation of the components of the incorporation process precedes the results of the study. These components were uncovered in a previous study of individuals living with HIV (Baumgartner & David, 2009) and they were re-confirmed in this study. The process included: a diagnosis, a post-diagnosis turning point, immersion into the HIV/AIDS community and integration. Diagnosis was marked by an initial emotional reaction such as fear or anger and a behavioral reaction such as isolation or drug abuse. The turning point moved people from the reaction to the diagnosis and included entering treatment for HIV/AIDS and drug abuse and attending activities at AIDS Service Organizations. Immersion was shown by consistent and extensive involvement in the HIV/AIDS community. In the integration phase, individuals educated themselves and others about HIV/AIDS and were accepted by other HIV-positive individuals, and 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.

For example, James Brown was diagnosed in 1993 at age 38 with HIV and in 2000 with AIDS. James is a heterosexual, African American man. He was 54 at the time of the interview in October 2009. When he was diagnosed, his initial emotional reaction to the diagnosis was denial and later he went into a depression. His drinking escalated for a time. Then, he entered a treatment program for his drug and alcohol addiction. In the treatment program, he revealed that he was living with AIDS. His counselor in the treatment program told him that there were halfway houses for people living with HIV/AIDS and the turning point from his initial reaction came when he entered the

halfway house and learned more about HIV/AIDS. For a time, James Brown was immersed in the HIV/AIDS community. Most of his friends were in the HIV/AIDS community and he was very actively involved in the community as a peer leader. Although he is still actively involved in the HIV/AIDS community and he works in the community, HIV/AIDS is not his central identity. He considers his central identity to be that of a recovering alcoholic. He believes he has integrated the HIV/AIDS identity into the self. Teaching others about HIV/AIDS, learning more about the disease and the passage of time has helped with integration.

Now that the incorporation process of HIV/AIDS into one's identity has been delineated, the effect of various aspects of time on that process will be explained. First, the effect of historical time on the incorporation process will be explained. This will be followed by an examination of how chronological age affected the incorporation process. The impact of social time and the passage of time on the incorporation process will also be explored.

### **The Effect of Historical Time on the Diagnosis of HIV/AIDS**

Although the widespread availability in 1996 of highly active antiretroviral therapy (HAART) made HIV/AIDS a chronic illness in the United States (Cichocki, 2010), often the initial reaction to the diagnosis was the same for those diagnosed prior to the advent of HAART and those for whom HAART was available at diagnosis. Advancement in medical treatment ultimately affected how individuals lived with the disease. However, the initial reaction to the being diagnosed with HIV or AIDS was similar for most individuals in the sample. Twenty-six of the 36 participants had a fear of a shortened life or imminent death on diagnosis regardless of the year they were diagnosed.

**Pre-1996: Diagnosis equals death.** Seventeen individuals were diagnosed before the widespread use of life-extending medication such as protease inhibitors (PIs) in 1996 when the medical community offered less hope of an extended life (Cichocki, 2010). Gay participants diagnosed before 1996, who were living in large metropolitan areas, saw friends die or knew people in the gay community were dying. Derek suspected he contracted the virus years prior to his HIV/AIDS diagnosis but was in denial. He had seen a roommate die from AIDS and knew he had engaged in risky behavior. He reported, “[The doctor] ran the test and it came back reactive or positive and she said, ‘I think at this point you probably have about three months left.’” He continued, “There were no PIs [protease inhibitors] out there at that point. I just became sicker and sicker and weaker and thinner.” Likewise, Ken had kept up with news about HIV/AIDS through gay newspapers and the mainstream press. When he was diagnosed, he suspected he had AIDS because, like Rock Hudson, he had Kaposi Sarcoma (KS), an opportunistic infection associated with AIDS. He stated, “I remember reading all those articles about poor Rock Hudson and I thought, ‘Gee, I wouldn’t want to find that on my body. And lo and behold [I did].’” He decided against taking azidothymidine [AZT] which was an antiretroviral medication available at the time. He stated, “I was reading all the articles. I knew people were still dying. Their dying was put off for awhile because of the AIDS medications but they were still dying in great numbers, nonetheless and I didn’t want to

prolong my life if I was going to die anyway.” In general, the gay men diagnosed before 1996 who lived in urban areas knew they engaged in behavior that put them at risk for HIV/AIDS. The two gay men diagnosed with HIV or AIDS before 1996 that did not know about HIV/AIDS and risk factors were from rural areas. Regardless of their knowledge about HIV/AIDS transmission and access to AZT, most remained in a state of denial, shock, or sadness about the diagnosis for an extended period because there was little hope of long term survival.

The heterosexual or bisexual participants diagnosed with HIV/AIDS prior to 1996 were less informed than their gay, urban counterparts about how HIV/AIDS was transmitted and what behaviors put them at risk. Some participants believed that HIV/AIDS was limited to gay, White men. Most heterosexual participants were diagnosed in the mid-1990s, when general information about HIV/AIDS was no longer front-page news in the mainstream press (Swain, 2005). Furthermore, many, such as Ed, obtained their misinformation about HIV/AIDS from the streets and thought their race, sexual orientation or sexual practices protected them from contracting HIV/AIDS. Although Ed knew the AIDS virus was killing people, he believed he was safe because he was only practicing oral sex and he did not believe a person could contract HIV/AIDS through oral sex. James Brown believed that the “women [he] messed with were clean”, so he never thought he would contract the disease. He thought that a person could see if another person had HIV/AIDS. Thin did not believe anyone he associated with in his small town could have HIV or AIDS. Furthermore, he thought it was a “gay disease”. Deborah thought AIDS was “some White man’s shit”. She did not believe she was at risk.

In sum, heterosexual participants diagnosed before 1996 reported being surprised or shocked at the diagnosis because they did not believe they were at risk. Both gay urban participants who knew more about risk factors and heterosexual participants who did not tended to remain in denial or another emotional state which prevented them from integrating HIV/AIDS into their identity.

**Post-1996: Forward to the past.** Although there was widespread use of life extending medications by the mid-1990s, individuals diagnosed with the disease from 1996 or later still reacted to their diagnosis as though they were living in the 1980s and early 1990s because they did not have information about current treatments. By the mid-1990s, HIV/AIDS was no longer the media story it had been in the early 1980s (Swain, 2005). Hence, many of those diagnosed with HIV or AIDS after 1996 clung to outdated images and information about 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. Nineteen individuals were first diagnosed in 1996 or later. Despite advances in treatment, 13 of the 19 participants believed that death was near on diagnosis. Kelven had seen friends die in the 1980s and early 1990s and believed he would die from the disease relatively soon. He said, “I still thought about AZT and how sick it made everyone and how they wasted away. The hair. The skin.” He remained unaware of new medications that promised a longer life and sexual practices that put him more at risk for HIV/AIDS. Al, a former nurse, had cared for a sickly AIDS patient several years before Al was diagnosed in 2005 and that image remained in his

mind. Greg, diagnosed after the widespread use of life extending medications, relied on information from the early 1990s about HIV/AIDS when his sister was diagnosed with the disease. Hence, he believed he would “waste away and die”. Octavius stated, “[I knew] it was something bad to have that led up to death...I may die tomorrow or tonight. That is how I was feeling.” His information came from the streets from hearing about rappers dying. Although he knew Magic Johnson was living with HIV, he stated, “I figured, ‘Well, Magic Johnson [has] money. I don’t have his money so therefore I’m not going to [experience the disease] the same.’” Tamara’s impressions of HIV/AIDS were formed in the 1980s. Rock Hudson, Ryan White and a woman who died from HIV/AIDS in her neighborhood were her images of people with HIV/AIDS. She said, “My attitude was: ‘I’m dying.’”

Although most participants had outdated, negative images of HIV/AIDS, some younger participants learned about HIV/AIDS in school and did not fear the disease as much on diagnosis. Joe 2 learned about HIV/AIDS in school. He knew that people lived with the disease and that anyone could contract it. He noted, “I knew there were meds. [I learned about HIV/AIDS] in health class. [There was a] short little chapter on it.” Matthew learned about HIV/AIDS in 7th grade and had HIV-positive friends who educated him on the disease prior to diagnosis. It appears that some younger participants learned about HIV/AIDS in school and those diagnosed after the widespread use of protease inhibitors had friends who were living with the disease and knew a person could live a long time with it. They obtained information from the internet or other social service agencies and also had the support of others who had lived with the disease a long time. Although they experienced the initial reactions of shock, anger and fear, the period in their respective emotional states was several days or weeks compared to an initial reaction period of years for those less educated about HIV/AIDS prior to diagnosis or those who were diagnosed prior to the advent of HAART.

In sum, 26 of the 36 participants had a fear of a shortened life or imminent death on diagnosis regardless of the year they were diagnosed. This strong emotional reaction prevented many from incorporating HIV/AIDS into their identities for years in some cases. Gay men diagnosed before 1996 often suspected they were HIV-positive or had AIDS before they were diagnosed and sometimes knew they had engaged in risky behaviors. Their heterosexual counterparts were not as informed about the disease and the diagnosis came as a shock. Because individuals diagnosed after 1996 relied on friends, family members and outdated media images of HIV/AIDS, they often stayed in their initial emotional reaction of fear, anger, denial, sadness or shock for an extended period which prevented them from integrating HIV/AIDS into their identities.

### **The Effect of Historical Time on the Turning Point**

Historical time had some effect on the turning point in the process of incorporating the HIV/AIDS identity into the self. Individuals diagnosed prior to 1996 were slightly more likely to mention the advent of protease inhibitors as a turning point from the initial reaction to the diagnosis than those participants diagnosed after 1996. However, the majority of respondents, regardless of the year they were diagnosed, stated that learning more about HIV/AIDS either through a drug or alcohol treatment center that served people living with HIV/AIDS or through joining an HIV/AIDS support group

served as turning points from the initial reaction to the diagnosis. Ed's comment was typical:

[My turning point occurred in] the recovery program they had us going to where we talked about different HIV medications and we talked about how people are living longer with HIV and AIDS. That people aren't dying from it and to know that—it gradually started to dawn on me that I wasn't going to die from HIV and AIDS.

In sum, access to correct information about HIV/AIDS and contact with individuals who were hopeful about survival, such as those in support groups, was most often the turning point from the initial reaction to the diagnosis.

### **The Effect of Chronological Age on the HIV/AIDS Diagnosis**

A participant's age at diagnosis affected how he or she dealt with the diagnosis. Although all the participants had an initial emotional reaction including shock, depression and denial, those who were diagnosed in their 30s and 40s thought they would not have handled the diagnosis as well earlier in life. Wene stated, "It was probably easier for me [at my age] because of the 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 20." Teena's teenage son lives with HIV. She stated that had she been diagnosed at his age, she "probably would have killed [herself]". Greg, diagnosed with HIV in his 30s, stated, "I'm glad I wasn't any younger....At least by 30 you are starting to calm down."

Two individuals believed that if they'd been diagnosed later, they would have handled the diagnosis better. Greg's response was typical. He stated, "I think had I gotten it later, I would have been more responsible about going to doctors and making the educated adult decisions as opposed to just keeping going and partying." In sum, in addition to the time in history at which individuals were diagnosed with HIV, the age at which one was diagnosed affected how individuals handled the diagnosis. Participants who were older at the time of diagnosis believed they handled the diagnosis better than younger people did because they had some perspective and life experiences from which to draw.

### **The Effect of Social Time on the Immersion Phase in the HIV/AIDS Identity Incorporation Process**

Although most participants remained healthy enough to pursue employment for a period after diagnosis, several were "off time" regarding being gainfully employed at some point after diagnosis because of illness (Neugarten, 1996, p. 20). In short, they did not follow traditional career paths in part, because of their HIV/AIDS diagnosis. During this time, they often connected with AIDS Service Organizations (ASOs) to learn more about HIV/AIDS and immersed themselves in the HIV/AIDS community which helped integrate the HIV/AIDS identity into the self. Greg immersed himself in the HIV/AIDS community when he had to discontinue his job because of job-related stress which weakened his immune system. He stated,

Not working, I have nothing to do and I like to stay busy so what I've been doing instead now, I go to the [community] board meetings and I [another] board as the enrollment recruiter. I'm in a men's group now [related to HIV]. I'm really outspoken now and I'm going to AIDS day with another client in our group.

James Brown, like several participants in the study, lost his job because of alcohol and drug addiction and attended a treatment facility that addressed chemical dependency issues for those living with HIV. A former patient in that facility, he is now an employee counseling recovering addicts with HIV/AIDS. Although he was "off time" regarding a steady career path, employment at this facility has helped him incorporate his HIV/AIDS status resume a career path.

Al was receiving disability payments for a work-related back injury when he was diagnosed with HIV. He was "off time" regarding his career development, but was afraid to return to his health-care related occupation because he feared that when employers discovered he was HIV-positive, they would not hire him. Because he was not employed at the time of the interview, he focused on educating the newly diagnosed and teens on HIV/AIDS (Neugarten, 1976, p. 20) and this education helped his integration process. He stated,

They've just been diagnosed. They have the attitude, "I don't care. I don't need no [sic] meds." Oh no. You are going about this the wrong way because I try to let them know that at any moment your diagnosis can change. Just like that it can change and if you are still out there having unprotected sex—because there are different forms of HIV. . . I try to educate as many people as I can. Now, in March when I come back from Texas, I am going to speak to the young people in my church.

At times, chronological age interacted with social time in the incorporation of the HIV/AIDS identity into the self. Ken was single when he was diagnosed in his 40s which meant that as a single person, he was "off time" regarding establishing intimate relationships. He believed a diagnosis in his 20s would have meant he would have gotten more support. He said, "I guess I didn't have the support system that I might have had if I was younger." The diagnosis at midlife was less desirable and the initial lack of perceived support initially affected his ability to integrate the HIV/AIDS identity into his self. This finding contradicts earlier findings that indicated individuals either had or thought they would have had an easier time coping with the diagnosis at a later age because of their previous life experiences and maturity level. It also demonstrates the importance of support in the integration process and how various contexts such as the sociocultural context and aspects of time can affect an individual's incorporation process.

### **The Effect of the Passage of Time on Diagnosis and the Turning Point**

The passage of time was a turning point for some participants and assisted in integration of the HIV/AIDS identity into one's self. Upon diagnosis, Steven was

informed that he had 5 years to live. He stated, “And suddenly five turned to six and seven years. Then I started saying, ‘Maybe I’m not going to die and maybe I should stop thinking I’m going to die and start acting and motivating myself to live.’ So that’s when I turned around and said, ‘I’m going to beat this.’” This realization was a turning point from his initial emotional reaction of depression to the diagnosis. Ed had a long history of drug use and eventually entered a recovery program and started talking about his HIV diagnosis. He stated, “Everything was a gradual process. I just kept looking up and I was still alive and getting older. I was still doing drugs and was still healthy....it gradually started to dawn on me that I wasn’t going to die from HIV and AIDS.” Joseph Smith was repeatedly told by his doctors that he was the rare exception that did not need medication. After hearing this for a couple of years, he focused less on dying and more on living one day at a time which was a turning point from his initial emotional reaction to the diagnosis.

Seeing others living with HIV/AIDS for a long time was a turning point from the initial emotional and behavioral reaction. Tamara realized that an HIV-positive child that she had seen on a television talk show years earlier was now a beautiful young woman. Many individuals saw long-term survivors in support groups and that served as a turning point from their initial reaction to the diagnosis. Pearl’s reaction was typical. She stated,

Some of the women are long-term survivors. 20 something years...When I started going to group, I had something like three years with it. There is something so fascinating [about them]. They had their nails done....They were going to be living all right and I wanted to try that. It was my motivation.

For Matthew, time helped him overcome his initial reaction to the diagnosis. He stated,

I guess after I started going to the doctors on a regular basis it started to become normal to me. I guess just over time it just normalized in my head. This is part of my life. This is something that I’m just going to have to do for the rest of my life so it just became a part of my routine.

## **Discussion and Conclusions**

### **Historical Time and Fear at Diagnosis**

Historical time did little to affect the initial reaction to the diagnosis for most participants. Participants diagnosed before 1996 had a more reasonable fear of death given their prognosis prior to protease inhibitors (Cichocki, 2010). Because of their lack of knowledge, participants diagnosed after 1996 experienced unnecessary fear based on the outdated information they possessed about HIV/AIDS. Some individuals stayed in this emotional reaction stage for years. It was only when they learned more about HIV/AIDS that they realized they could live with it. For respondents diagnosed before 1996, the advent of life-extending medications was more often specifically mentioned as

a turning point. For those diagnosed after 1996, the knowledge that they could live with the disease was the turning point from the initial reaction to the diagnosis.

Several factors might have contributed to this lack of current, accurate information about HIV/AIDS and the resulting fear of an imminent death for those diagnosed after 1996. First, HIV/AIDS media coverage waned in the US after 1985 (Brodie, Hamel, Brady, Kates, & Altman, 2004). Considered an epidemic in the 1980s and linked with gay men, by the 1990s the disease became “a routinized news story” and interest piqued only when celebrities such as Arthur Ashe and Magic Johnson announced they were infected (Swain, 2005, p. 259). A survey of HIV/AIDS-related news stories from *The New York Times*, *The Wall Street Journal*, *The Washington Post*, and *USA Today* between 1981 and 2002 revealed that news stories about HIV/AIDS peaked in 1985 and decreased even as the number of new cases of HIV/AIDS increased for the next six years (Brodie et al., 2004). Interest declined after the widespread availability of protease inhibitors and the rise in infection in the African American population (Swain, 2005). In October 1987, 68% of Americans polled named AIDS as the most urgent health problem facing America (Brodie et al., 2004). By June 2009 only 6% said it was the most urgent problem facing the nation (Singh, 2009). In addition, after 1986 fewer news stories “contained information related to consumer education” (Brodie et al., 2004, p. 6).

Second, HIV/AIDS knowledge might be different depending on an individual’s geographic location, and positionalities. This study partially confirms findings from a study of 166 Scottish individuals that noted gay men knew more correct information about HIV/AIDS than their heterosexual single or married counterparts (Ralston, Dow, & Rothwell, 1992). In addition, many participants in the current study were self-described addicts and alcoholics before and after they were diagnosed with HIV/AIDS. At the time of diagnosis, many were in recovery from drugs and alcohol. Some participants admitted that they were feeding their addiction and not gaining information about HIV/AIDS. In addition, many came from lower socioeconomic backgrounds and lower education backgrounds which might have affected their ability to access information. As with some participants living with HIV/AIDS, individuals with less formal education had more fear of breast cancer than those who had higher education levels (Zollinger et al., 2010). Participants who lived in more rural areas also knew less about how the virus was transmitted than their urban counterparts. Like HIV/AIDS, news of medical advances still does not permeate some of the population’s consciousness because no one in their social network knows current information about HIV/AIDS. Some people living in Appalachia were also likely to rely on social networks for cancer information, which meant that some received misinformation about the disease and about the value of preventative measures (Behringer & Friedell, 2006).

Third, adults often seek information about a new topic on a need-to-know basis (Knowles, 1980). Gay men diagnosed in the 1980s and early 1990s saw people in their community dying. They feared for their lives. Many sought whatever information they could on the disease believing they might be next. Many heterosexual participants did not believe they could be infected because they believed only gay men contracted HIV/AIDS so they were not concerned about getting the disease and did not seek updated information on it until they were diagnosed.



## **Historical Time and Turning Point**

In a previous study, my co-author and I discovered that those diagnosed with HIV after the widespread use of life-extending medications reached the turning point from the initial reaction more quickly than those diagnosed with HIV/AIDS prior to the availability of life-extending medications (Baumgartner & David, 2009). We reasoned that access to life extending medications at diagnosis or easier access to information about HIV/AIDS through AIDS Service Organizations (ASOs), friends and the internet assisted participants in reaching the turning point more quickly (Baumgartner & David, 2009). The findings from the current study suggest that although access to life extending medications is important, the key to a shorter period between the emotional reaction to the diagnosis and the turning point is getting education about HIV/AIDS prior to being diagnosed or immediately after being diagnosed regardless of the type of diagnosis (HIV or AIDS). Another study confirms that education on breast cancer immediately after diagnosis reduces anxiety and helps physical functioning (Helgeson, Cohen, Schultz, & Yasko, 2001).

## **Chronological Age and Diagnosis**

Some participants believed their chronological age influenced their reaction to the HIV/AIDS diagnosis. Several participants indicated that had they been diagnosed at a younger age, they would not have handled the diagnosis as well. They maintained their prior hardships made them better able to cope with their HIV/AIDS diagnosis. The idea that older individuals handle their diagnosis and subsequent adjustment to a chronic disease better than younger individuals has partial support from one study concerning women and breast cancer. Researchers measured women's reported emotions and coping strategies at diagnosis and then at three and six months after diagnosis and found that younger women were more emotional and evidenced more distress immediately following diagnosis than older women (Compas et al., 1999). However, results at the 3- and 6-month mark revealed that younger and older women's distress were similar. Younger women were more likely to engage in "emotional ventilation" than older women immediately after diagnosis which increased distress (Compas et al., 1999, p. 201). Other researchers found that younger women were more distressed about their cancer diagnosis than older women and reasoned that younger women were more prone to depression and anxiety than older women in general, had less life experience with chronic disease and therefore less resilience than older women (Politi, Enright, & Weihs, 2007).

Most participants in this study did not mention chronological age as a factor in reaction to the diagnosis or did not believe it would have made a difference if they were older or younger at diagnosis. This is perhaps because many of the respondents used drugs and alcohol to cope with their diagnosis and believed that being substance dependent was integral to their initial reaction regardless of age.

## **Social Time and Incorporation**

Some of the participants were "off time" regarding pursuing a career or being employed either at or after their HIV/AIDS diagnosis. (Neugarten, 1976, p. 20). This

allowed respondents time to immerse themselves in the HIV/AIDS community and to teach others about the disease which assisted in the integration of the HIV/AIDS identity into one's self. Individuals living with some chronic diseases such as multiple sclerosis (MS) face higher unemployment rates over time than those not affected by MS (Rumrill, 2009). However, it is unknown whether being unemployed necessarily means that people use their time to immerse themselves in their respective disease communities. Research has shown that those living with HIV/AIDS when it was considered a terminal illness, some of whom were unemployed, immersed themselves in the HIV/AIDS community because they felt less stigmatized among others with the disease and they wanted to learn more about the disease (Baumgartner, 2007; Gurevich, 1996; Lewis, 1994; Sandstrom, 1990). Support groups for those living with other chronic illnesses help normalize the disease also (Gallant, 2003; King et al., 2003).

Additional research on the effects of being "off time" regarding forming intimate relationships, having children, and retiring because of an HIV/AIDS diagnosis and the resulting effects on the incorporation of HIV/AIDS into one's self is warranted. How does having HIV/AIDS affect marriage and childbearing? In turn, how does marriage and childbearing affect HIV/AIDS identity integration? How does retirement affect the incorporation of HIV/AIDS?

### **Passage of Time and its Effect on Diagnosis and Turning Point from the Diagnosis**

The passage of time helped the HIV/AIDS identity incorporation process. Charmaz (1991) discussed individuals creating time markers in the course of their illness narrative. Charmaz stated, "A timemarker places an event in a chronology" (p. 197). A physician gave Steven a timemarker when the physician noted that the participant had five years to live after his HIV/AIDS diagnosis. When the participant lived past that point, it became a turning point which goes beyond benchmarking time and "a shift in self follows" (Charmaz, 1991, p. 197). Steven believed that the doctor had been incorrect in his diagnosis and that the participant could live well with the disease. This event caused a turning point from the participants' initial reaction of depression to his HIV diagnosis. Similarly, doctors told Thin he was a healthy exception to the rule when he was diagnosed and after a couple of years, he started thinking he could live with the disease. Timemakers and turning points can be diagnoses, surgeries or treatments, or a family history of the disease such as a family history of cancer (Charmaz, 1991).

Another turning point for participants from their initial emotional reaction to diagnosis involved seeing others who had lived with the disease a long time. Participants were encouraged that individuals could survive with the disease for decades. This was especially helpful for those diagnosed before 1996. Studies concerning the role of support groups and chronic illness note 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 from this (Peterson, 2009; Wiener, 1998).

The passage of time allowed for adjustment to the illness. This is confirmed by studies that discuss other chronic illnesses. For example, women who received a cancer diagnosis reported declines in "physical and social function, vitality, and the ability to perform emotional and physical roles compared to women who did not receive a cancer diagnosis" (Michael et al., 2000, as cited in Stanton, Revenson, & Tennan, 2007, p. 569).

Likewise, depressive symptoms of those diagnosed with cancer increased the first two years following diagnosis but decreased thereafter (Polsky, Doshi, Marcus, Oslin, & Rothbard, 2005).

Time allowed respondents to gain more knowledge about the disease which helped them have a sense of control over it. Numerous participants' repeated refrain was, "I have HIV but it doesn't have me." This finding was also true for other chronic diseases. Increased patient control and self-efficacy was related to decreased distress for individuals living with cancer (Fife et al., 2000; Stiegelis et al., 2003, as cited in Stanton, Revenson, & Tennan, 2007) and better adjustment for those living with rheumatoid arthritis (Schiaffino & Revenson, 1992). In addition, an increased sense of control predicted better adjustment to chronic pain (Esteve, Ramirez-Maestre, & Lopez-Martinez, 2007).

Although the results from this study make practical contribution to the literature, there are limitations. First, most participants were associated with an AIDS Service Organization (ASO). Their responses might differ from participants not associated with an ASO. Second, participants volunteered for the study and their responses from non-participants might differ. Third, 32 of the 36 participants reported that they earned \$20,000 or less per year. A wealthier population might have different experiences. For example, wealthier individuals might have greater access to resources and information about HIV/AIDS than poorer individuals. Fourth, only six of the 36 individuals lived in a rural area, so their experiences are not well-represented in this study. Future studies should more closely examine the interaction of the temporal context and the sociocultural context (race, class, gender and sexual orientation) on the HIV/AIDS identity incorporation process. Last, readers should note that participants gave retrospective reports of their experiences. Scholars have noted that retrospective reports might contain inaccuracies and participants might try to present themselves in a socially desirable manner (Golden, 1992).

In conclusion, the findings from this study add depth and nuance to the HIV/AIDS identity incorporation literature. The findings show the importance of historical time and chronological age on the experience of the diagnosis of HIV/AIDS. This study confirms a previous study that suggested that chronological age affects diagnosis (Karp, 1994). Unlike previous studies on HIV/AIDS identity incorporation, the results from this study provide reasons as to why those diagnosed before and after 1996 had the same emotional reactions to the diagnosis. In addition, this study uncovered the impact of social time; namely, how being "off time" regarding one's career provided time for immersion into the HIV/AIDS community (Neugarten & Datan, 1973, p. 20). Third, the study suggests that gay men living in urban areas who were diagnosed before 1996 might have had access to information about HIV/AIDS that their heterosexual counterparts or those living in rural areas did not. Last, the impact of seeing long-term survivors helped integration.

This study not only makes theoretical contributions but has practical implications. Clearly, HIV/AIDS education is a necessary component of the HIV/AIDS integration process. This study's findings shows how individuals diagnosed after the widespread use of life-extending medications lived in fear of imminent death because they did not have correct information. More HIV/AIDS education targeted at chemically dependent, low income individuals is needed. Second, the importance of newly diagnosed individuals

seeing long-term survivors and hearing their stories cannot be underestimated. HIV/AIDS educators need to continue to provide opportunities for the newly diagnosed to meet long-term survivors in order to enhance the incorporation of the HIV/AIDS identity into the self. Last, HIV/AIDS educators and counselors need to recognize that younger participants, who know less about HIV/AIDS, might have more difficulty dealing with an HIV-positive diagnosis than older participants who are equally misinformed about HIV/AIDS, because younger participants have less life experience from which to draw. In addition, health educators might want to note that single individuals could need additional support because they might not have the support system of friend that they did earlier in life. It is encouraging that some younger individuals are learning about HIV/AIDS before they are diagnosed and this prior knowledge helps them cope more readily with the disease.

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