

PERSPECTIVE TRANSFORMATION OVER TIME: A 2-YEAR FOLLOW-UP STUDY OF HIV-POSITIVE ADULTS

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The purpose of this study was to find out whether HIV-positive adults who had participated in a study of the centrality of meaning-making in transformational learning had maintained 2 years later their perspectives of making meaningful contributions through service to others, or if the advent of protease inhibitors would have resulted in their reverting to previously held, self-oriented, and materialistic views of the world. Fourteen of the original 18 participants were interviewed. Two major findings emerged: First, for all 14 participants, the perspective transformations that they had undergone 2 years previously had held. Second, there were changes in meaning schemes that included the adoption of a future-oriented perspective, greater attention to care of the self, and an integration of the HIV-positive status into their self-definition. The life-changing nature of transformational learning, the stability of its outcomes, and ongoing changes in meaning schemes suggest implications for adult educators.

Most people would agree that a considerable amount of learning takes place in adulthood. Much of this learning is additive in nature; that is, we add on to what we already know and what we already can do. Less common but more significant is transformational learning, which involves a fundamental change in the way we see ourselves and the world in which we live. As presented by Mezirow (1981, 1990a, 1991), a chief theorist of transformational learning, this type of learning involves critically reflecting upon our lives and becoming aware of “*why* we attach the meanings we do to reality, especially to our roles and relationships” (1981, p. 11, emphasis in original). The process of transformational learning is developmental:

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ADULT EDUCATION QUARTERLY, Vol. 50 No. 2, February 2000 102-119
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Seeing how “our presuppositions have come to constrain the way we perceive, understand, and feel about our world” leads to “reformulating these assumptions to permit a more inclusive, discriminating, permeable, and integrative perspective” (Mezirow, 1990b, p. 14).

The past decade has witnessed a burgeoning of both empirical research and philosophical critique in regard to Mezirow’s theory. Recently, Taylor (1997) reviewed some 39 empirical studies using Mezirow’s transformative learning as the theoretical framework. The focus of most of these 39 studies was on the process of transformational learning, either in its entirety or with respect to a particular component of the process. Taylor notes that whereas there is “much support for Mezirow’s theory,” there is also a need

... to recognize to a greater degree the significant influence of context, the varying nature of the catalyst of the process, the minimization of the role of critical reflection, and increased role of other ways of knowing and relationships, and overall broadening of the definitional outcome of a perspective transformation. (Taylor, 1997, abstract)

It is the outcome of a perspective transformation that most interests us, not in terms of what might be an outcome, but rather what happens to the perspective transformation over time. The purpose of this study was to explore just that question by reinterviewing, 2 years later, the 18 HIV-positive adults who were participants in our original study of the centrality of meaning-making in transformational learning (Courtenay, Merriam, & Reeves, 1998).

THE ORIGINAL STUDY

In the fall of 1995, we interviewed 18 HIV-positive adults, all of whom (with one exception) were 23 to 45 years of age. We purposely chose young adults because we assumed that the prospect of death at an unnaturally early age challenges assumptions and values about the meaning of life. Participants’ T-cell counts were 500 or less, indicating a compromised immune system that renders medical intervention likely. To our knowledge, none were on protease inhibitors. The purpose of the study was to understand how HIV-positive adults made sense of their lives in the face of a potentially life-threatening illness.

Qualitative analysis of the interview data revealed a five-stage process of meaning-making. The initial reaction to the diagnosis lasted from 6 months to 5 years and consisted of affective, cognitive, and behavioral responses. A catalytic experience initiated movement from initial reaction to the three phases of meaning-making: exploration of other ways of thinking, feeling, acting, and perceiving their situation; consolidation of new ways of being; and stabilization of the new perspective. This new perspective was characterized by the opportunity to make a meaningful contribution, by a heightened sensitivity to life and other people, and by service to others.

Two years later, we wondered about the stability of these perspectives. Were they maintained over time? Did participants undergo further transformation(s)? If so, what was the nature of these transformations? For those using protease inhibitors, what effect has the remission/suppression of HIV had on their perspectives?

WHAT THE LITERATURE SUGGESTS

Although no empirical studies focusing on the stability of perspective transformations could be found, based on Mezirow's and others' writings, we first speculated that participants would not have regressed to a less-inclusive, integrated, or discriminating perspective, and second, that they would have continued making meaning.

Mezirow (1991) is quite clear that once a transformation has taken place, there is no going back to an earlier position: "The transformative learning process is irreversible . . . we do not regress to levels of less understanding" (p. 152). Kegan (1994) similarly characterizes cognitive development, noting that "each successive principle subsumes or encompasses the prior principle. . . . The new principle is a higher order principle (more complex, more inclusive) that makes the prior principle into an element or tool of its system" (p. 33). We found only one study that included a follow-up of perspective transformation. Williams (1986) examined the role of transformational learning in changing the behavior of male spousal abusers. Using an evaluation form and exit interview, he assessed the degree of perspective transformation at the end of a 12-week intervention. In follow-up interviews with 6 of the 19 participants 3 months later, Williams found that four ratings for perspective transformations were slightly higher and two were lower. Little information was given about the nature of these perspective transformations or how they were measured.

A veteran researcher who has studied traumatic life events suggests that although survivors usually retain the "newfound appreciation for life," that it might be "more apparent at certain moments rather than functioning as a general 'glaze' over all of one's experience" (R. Janoff-Bulman, personal communication, March 17, 1998). She also indicated that she knew of no work addressing the stability of a changed perspective over time.

It seems that once a perspective transformation has occurred, reversion to a less-developed state is not possible. However, one has not necessarily reached an end state. Development is continuous and is more than change over time; it is change in a positive direction, toward a more complex, integrated, inclusive, and tolerant perspective (Brew, 1993; Daloz, 1986; Kegan, 1994; Mezirow, 1990a, 1991; Tennant, 1993). Indeed, Mezirow (1990a) equates changes in meaning perspectives with stages of moral, ethical, and ego development: "Each stage . . . involves a developmentally advanced and progressively more functional meaning perspective"

(p. 359). Daloz (1986) concurs, stating that the “later stages are by definition more conceptually inclusive and discriminating, are ‘better’ in some sense than earlier ones” (p. 137).

Although we could speculate that participants would have maintained their transformed perspectives, we could also surmise that there would be continual changes in meaning-making. Mezirow (1990b) differentiates between *meaning schemes* and *meaning perspectives*. Meaning schemes are the specific beliefs, assumptions, values, feelings, and concepts, our “habitual, implicit *rules* for interpreting [experience]” (Mezirow, 1990b, p. 2, emphasis in original). They change through content, process, or premise reflection. Premise reflection can lead to changes in the meaning perspective, whereas content and process reflection result in changes in meaning. According to Cranton (1994), “as soon as the learner asks *why*, her reflection begins taking place on the level of a meaning perspective rather than a meaning scheme. Asking *why* takes account of the larger framework within which an assumption exists” (p. 67, emphasis in original). Mezirow (1990b) defines meaning perspectives as the overarching “structure of assumptions within which new experience is assimilated and transformed” (p. 2). Changes in meaning perspectives “may occur through an accretion of such transformed meaning schemes” (Mezirow, 1990b, p. 13).

That the process of a perspective transformation is recursive and ongoing has been supported in both the research and theoretical literature (Coffman, 1991; Laswell, 1994; Pope, 1996; Saavedra, 1995). Usher (1993), for example, notes that “at any one point in time, a meaning has to be fixed, but that’s not the only meaning possible for all time” (p. 172). Furthermore, meaning-making is highly contextual. “When we interpret ‘our’ experience, we do so from a particular context or standpoint” (Usher, 1993, p. 170). Thus, we anticipated that individuals in our follow-up study may have adjusted, modified, or changed particular meaning schemes, and that the accumulation of these changed meaning schemes may have led to perspective transformations. Similar to the way an HIV-positive diagnosis functioned as the “disorienting dilemma” precipitating a perspective transformation that we documented in the original study, protease inhibitors may have served as a disorienting dilemma effecting yet another perspective transformation.

In summary, the literature on transformational learning suggests that it is not possible to regress to less-developed perspectives. Whether set in motion by the accumulation of changed meaning schemes or by a disorienting dilemma with the passage of time, perspective transformations lead to more inclusive, mature, complex, integrative perspectives that are not constricted by old ways of thinking. However, meaning-making or making sense of our experiences is an ongoing process, evidenced over time in changes in meaning schemes and possibly meaning perspectives.

DATA COLLECTION AND ANALYSIS

The basic question of how participants' perspectives had changed over time framed this follow-up study of HIV-positive adults. Specifically, we were interested in the stability of a perspective transformation and the nature of ongoing meaning-making. As with the original study, a qualitative approach was deemed most appropriate to discover how participants' perspectives may have changed over time. However, although the design was qualitative and thus primarily inductive in nature, one aspect of our study was an implicit test of Mezirow's 1991 contention that perspective transformations are stable and irreversible. As Glaser and Strauss (1967) note,

there is no fundamental clash between the purposes and capacities of qualitative and quantitative methods or data. . . . We believe that *each form of data is useful for both verification and generation of theory*, whatever the primacy of emphasis. Primacy depends only on the circumstances of research. (pp. 17-18, emphasis in original)

The final sample consisted of 14 (8 men and 6 women) of the original 18 participants. All respondents, except one 59-year-old male, ranged in age from 25 to 47. Eight of the 14 participants were Caucasian, five were African American, and one was Hispanic. The level of educational attainment spanned Grade 10 to master's degree. Ten were currently employed and 10 of the 14 reported being on protease inhibitors. Respondents were given \$30 to participate in interviews of approximately 90 minutes in length.

Data were collected through semistructured interviews. In preparation for the follow-up interviews, each transcript from the November/December 1995 round of interviews was read, studied, and discussed by two members of the research team. This procedure served two purposes: First, it reacquainted the researchers with each respondent's particular story and the nature of his or her perspective transformation; second, phrases or statements were occasionally read back to the participants during the second interviews as memory prompts, or for their comments. The interview schedule contained open-ended questions regarding how participants were making sense of their lives today, the impact of protease inhibitors, current physical and emotional health, the extent to which they were still involved in service-oriented activities, the spiritual/faith dimension of their lives, how they were coping with the infection, and so on.

Interviews were held in January and February of 1998, more than 2 years after the 1995 interviews. All were tape-recorded and transcribed. For 10 of the 14 interviews, two of the team's four researchers were present for the interview itself. This proved advantageous during our data analysis, as two people were able to confirm each other's recollection of contextual, affective, and nonverbal factors; this helped to illuminate the team's understanding of particular comments.

With regard to the question of the stability of perspective transformations, we considered each participant's responses in light of the three components of their perspective transformation found in the earlier study. These were whether they continued to (a) make meaningful contributions, (b) maintain a heightened sensitivity to life, and (c) be of service to others. Each participant's responses were analyzed in reference to the three components of the transformed perspective reported 2 years prior. Interview data from all 14 participants verified the maintenance of the perspective transformation; no "negative cases" were found that would have led us to conclude otherwise (Bogdan & Biklen, 1998; Merriam, 1998).

To address the question of the nature of ongoing meaning-making, data from the transcripts were analyzed inductively using the constant comparative method (Glaser & Strauss, 1967). In this method, data analysis proceeds simultaneously with data collection. Each member of the research team individually read, reread, and coded the transcripts for key points regarding our questions. The research team met on a regular schedule to compare each member's analysis of individual transcripts and to compare analyses across transcripts. Intensive analysis involved moving between the data and the interpretations within the same transcript and across different transcripts. Eventually a common pattern of responses across the 14 interviews with regard to the stability of perspective transformation, continued meaning-making, and the effect of protease inhibitors was identified.

FINDINGS

Two major findings emerged from the data. First, as speculated, the perspective transformation proved irreversible. People continued to make meaningful contributions and to appreciate their lives and the lives of others. They maintained the more integrated, inclusive, and discriminating perspective that they had attained earlier. Second, there were changes in meaning schemes, which included the adoption of a future-oriented perspective on life, greater attention to issues pertaining to care of the self, and integration of one's HIV-positive status into self-definition.

Irreversibility of the Perspective Transformation

Over time, the perspective transformation was neither lost, rejected, nor reversed. Maintenance of the perspective transformation was evidenced in three ways: Participants continued (a) to view their HIV status as an opportunity to make a meaningful contribution, (b) to maintain a heightened sensitivity to life, and (c) to be of service to others.

Opportunity to make a meaningful contribution. In the first study, the new perspective was evidenced by the participants' beliefs that their HIV-positive status served as an opportunity to make a meaningful contribution. Infection with HIV

facilitated the use of their lives in a purposeful way. Two years ago, Steve, then 39, noted,

I'm real grateful to be here . . . I think there's a reason and I don't really have to know what the reason is. I have a hunch that if there's, you know if anything can come from this to help anybody else, that's reason [enough].

Pat, when first interviewed, recognized that being HIV-positive was a "blessing" because she could "touch a lot of people." She added, "My job is to help. . . . That's my journey." When we first spoke to Jeffrey, he also had a "great need to [contribute]" and "want[ed] to pass along [his] knowledge . . . and skills."

During the second interviews, it was evident that respondents retained the desire to make a meaningful contribution. Steve, for instance, said he was pleased to "be able to be on this planet and have an impact," whether it meant helping friends or family. Pat reiterated her sense of purpose by saying, "I have a mission . . . this is my path, this is my road in life and my road in life could not go this way unless I was positive." Jeffrey's continued desire to make a meaningful contribution led to AIDS education work, which he found "rewarding and fulfilling." He added, "I know I'm doing something that's worthwhile."

Often this sense of purpose was expressed in terms of spirituality, as with Jamie, who said during the initial interview that his HIV status was "part of God's plan" because God knew "good could come out of it . . . not only for me but for others." Two years later, Jamie underscored this connection to spirituality:

I'm not gonna die until God's through with me, until I've accomplished whatever goal or whatnot that He put me here to do . . . I still think there's a plan, and I still think that I'm an active participant in it whether I don't always understand it or not.

A continued heightened sensitivity to life. When respondents were interviewed 2 years ago, they expressed gratitude for their lives and evidenced a newfound appreciation for nature and people. Sam, who works as a handyman, described his life as "heavenly" and said, "I feel like I'm on the verge of crying tears of gratitude." Dawn commented on "how fragile life is," and Tracy concluded that she had previously taken life and people for granted. She said, "Today I don't, I take each second, each hour, each minute and try to make somebody else happy just for that day or just for that moment." Steve and Myrna recognized the value of nature. Myrna said, "I'm more self-conscious even when it gets cloudy out there and the clouds and the sun shining at certain points . . . I value life a little bit different." Steve found happiness in "driving these streets again and seeing these trees and seeing the seasons and seeing the leaves turn."

In the second interviews, the heightened sensitivity to life was shown in participants' continued appreciation for their lives, the lives of others, and nature. John, a former Episcopalian priest, spoke of his gratitude by saying, "I am a very blessed person and I don't take that for granted. I am really grateful to the supreme being, to

my doctor, to [my partner], to my family, to my profession.” Kenneth remarked, “I acknowledge my blessings and I acknowledge who they come from. They’re not just for me only. They are for me to share.” Nicole, a customer service supervisor, stated, “When the New Year rolled in I was like, ‘Thank you Jesus for letting me see another year.’” Jeffrey, age 41, “continue[d] to feel very blessed and merry.”

A continued need to be of service to others. The importance of the participants’ relationships with others drove their need to be of service. During the first interviews, most worked for or volunteered at AIDS service organizations (ASOs) and engaged in activities such as peer counseling or educational speaking. Steve’s eloquent quote captured his desire to help:

I just want to hold a candle to where maybe somebody two steps behind me can make it to that point and then perhaps go a couple more steps if I can’t go. I just feel like we’re all helping each other walk through this.

The strong desire to be of service to others continued to be apparent in the second interviews. Many were still working or volunteering at ASOs, serving in a variety of roles. Pat, diagnosed HIV-positive more than 12 years ago, discussed her continued service to others:

I volunteer for Outreach . . . I sit on a board . . . I’m a patient advocate for [a local AIDS group] . . . I sponsor a lot of women in . . . in recovery that are struggling to stay clean, but the ones that have HIV, you know, I work with their minds and try to keep them on a . . . positive plane about the disease.

Likewise, Joe continued editorship of a newsletter for HIV-positive readers:

If I know I can touch somebody in [the] rural [area of the state] somewhere and get that feedback that ‘you touched my life’, that’s a significant job to me, not how much money I get from it, or how much fame I get from it or anything like that. Is it gonna make some kind of significant change in society that will benefit other people, even if it’s just one person at a time, and it’s just one guy who helps?

Jamie also continued to reach out to “everybody from teenagers to nurses and doctors; this past week I spoke to a group of pharmacists, a group of first year medical physicians’ assistants, then spoke to an AIDS 101 class.” Jeffrey maintained his service to others by serving on the board of a local ASO. In the first interview, he talked about a “circle of giving,” and in the follow-up interview noted, “I affirm the circle of giving. It’s so true. Once you begin to give things away, it comes back and if you stop that, then you become stagnant.”

Interestingly, participants themselves recognized the irreversibility of their perspective transformation. Jamie realized that the way he viewed the world had changed and he expressed concern about reverting to his previous worldview:

I'm afraid of somebody snatching me away to become somebody that I never wanted to be and never would have been probably . . . HIV did hit me and it taught me a whole lot . . . I don't [want to] lose what I've learned and I don't [want to] lose what I've got . . . I don't want to become less, I wanna become more.

Similarly, Steve recognized the permanence of his new perspective. In the first interview, he asserted, "My world has been shattered . . . I think it had to be shattered in order to fall back together." During the second interview he said,

Well, I don't feel like my world is shattered at all. I feel like it's in a constant state of healing, almost . . . I really don't think I would have as much fear if things were to shatter again. If things were to . . . I don't think the shattering would be as deafening.

When Joe rekindled his interest in a comic book collection because he realized that he would continue to live, he recognized how his worldview had changed:

And it was like, "Oh cool, you know, I'm gonna be around another 20 years to enjoy this maybe." So, uh, I did go through a short time where I was buying things and felt kind of materialistic but it didn't last. You know, it was like, I hadn't forgotten all the lessons I'd learned—I was kind of indulging in it for a little while, just to get that feeling back I used to have. But I'd changed too much. . . . Ultimately, I realized these are just things. If I'm collecting it to have just number 1 through 20 or something, you know, why am I doing it? It didn't have the same meaning anymore as that, it was one of those unimportant things, ultimately.

In summary, there was ample evidence for the irreversibility of the perspective transformation. The desire to make a meaningful contribution continued and was manifested in a wide variety of ongoing service activities. Additionally, respondents' continued heightened sensitivity to life was evidenced in their appreciation for nature, their families, and friends. Participants also recognized the irreversibility of their perspective transformation.

Changes in Meaning Schemes

Over time, the participants in this study evidenced changes in their meaning schemes. These changes can be characterized in three ways: (a) adoption of a future-oriented perspective to life, (b) greater attention to issues pertaining to care of the self, and (c) integration of one's HIV-positive status into self-definition.

Adoption of a future-oriented perspective. When last interviewed, the focus of the participants in this study was on living in the present. Many eloquently spoke of the "uncertainties of tomorrow" and how "living for today" provided the freedom to do what they felt was really important in life. Dawn, for instance, said that she had "watched people all my life around me who 'someday they're gonna do this and someday they're gonna do that' and I try really hard to make my someday today."

John's need to "really enjoy today" was representative of the positions of others. In short, the participants expressed gratitude for having survived as long as they had and committed their energies to living in the here and now. Rarely did they project a future for themselves.

The orientation of the participants was noticeably different in the follow-up interviews. Protease inhibitors, still in clinical trials during the first round of interviews, were now included as part of the medication regimens of most of the participants and with dramatic results. T-cell counts soared as viral loads dropped to nearly undetectable levels for many. Experiencing a level of health and vitality believed to be outside of the realm of possibility 2 years ago produced a new outlook on life, an outlook of hope for a future. Participants spoke of this new perspective in various ways, including having a "positive outlook," "making long-range plans," and "looking forward" to benchmark events in life, such as a 30th birthday or retirement. Nicole, one of the youngest participants in the study, said simply and frankly, "I'm not thinking I'm going to die any time soon." Because she no longer believed that her life would be cut short by HIV, Tracy stated that she would now "make plans . . . I set goals, things that I would like to do."

Dawn, too, could see new possibilities for her life:

I haven't planted an herb garden and I want to take a pottery class and I want to get back to reading books for fun and some things like that. And, I think those are some of the things that somebody who thinks they have a future talks about.

Sam, who had just turned 40, also remarked that his life now held promise of a future he had not believed possible: "Suddenly, I have a future again. . . . I and a lot of my friends are like, 'Oh my God, you know, I'm not going to die now. I need to start saving for retirement and stuff like that.'"

The thrill that the hope for a future brings, however, is not without its own trepidation and challenge, as Sam's remark illustrates. Also, whether the effect of protease inhibitors can be sustained is unknown, leading several of the participants in this study to be what Steve calls "cautiously optimistic" in thinking ahead and planning for a future. Jeffrey, for example, was quick to note that the prospect of living is precipitating "a kind of metamorphosis," and that others are experiencing the same things:

Do I put my energy into living or do I still be safe and keep all the safeguards that I have? Do I go out and get the mortgage or do I just stay. . . . These life choices are scary and yet we never thought we'd have to deal with them.

Joe, too, used the word *scary* in describing the new mindset toward life created by the promise of protease inhibitors:

I've spent my retirement money that was in my 401K for medicine and I don't have any kind of savings account. . . . And so everything I had set up in my life for a

long-term future I've had to cut short. And it's kinda like starting all over again and that's really scary.

Jamie, who had been living with HIV for 11 years since being diagnosed in his early twenties, voiced similar concerns, stating that "now, suddenly, things are different. . . . I mean, it's much easier to plan to die than it is to plan to live." He noted that his heretofore practice of considering his longevity in "2-year increments" had allowed him to live with intensity and focus. In fact, he jokingly stated, "I mean, I think I could have lived until I was 60 as long as they kept telling me you're gonna be dead in 2 years [*laughter*]." He added that "knowing you might live . . . that's thrown a whole monkey wrench into things. . . . You've got to consider consequences way down the road. I've never done that before."

Greater attention to care of the self. During the first round of interviews, the participants reported that the meaning they had made of their HIV status centered largely on being of service to others. Although serving others has continued to be a hallmark in the lives of all the participants in this study, data from the second interviews reveal that they evidence an awareness of the need to care for themselves as well, an awareness rarely articulated 2 years ago. For some, like Dawn, caring for others had often been in lieu of caring for herself, not in conjunction with it. She explained it like this:

Over the years, I've had the privilege of meeting . . . tens of thousands of HIV-positive people . . . I started running back into them [*laughter*] and, you know, they say, "You were such an inspiration" . . . I shamefully stand there and say to myself I haven't done any of those things. It's time for me to do that too.

She added, "Actually, I think, finally, I am starting to be fairly important to me for the first time." She also noted that "what I have found in my efforts to take care of everyone else is that, in fact, if I don't take care of myself at all, then I fail at taking care of other people that I care about." Elise, likewise, observed that in addition to that "blessed feeling of being of service to other people," there "always has to be a part of me that's taking care of me. Otherwise, I'm of no service to anyone else."

Several of the participants reinforced this new awareness of attending to their own needs with comments pertaining to an emphasis on ways to improve their health. Pat, for example, stated,

I don't go buy clothes any more, you know, to fix up the outside. But what I do is that I fix up my body, you know. Or I make sure that I get more rest or just pump up on some juices or make sure I eat good.

Integration of HIV-positive status into self-definition. There was also a notable difference in the centrality of HIV in the lives of the participants in the second interviews. Most participants, 2 years earlier, had defined themselves primarily in terms

of their HIV status. In the intervening 2-year period, however, the prominence of HIV in their lives had receded. Elise, for instance, noted that “I’m more integrated with HIV. It’s . . . as opposed to being as big as I am, it’s just a part of who I am now.” Sam similarly remarked that “[HIV] is just a part of me now.”

That HIV has ceased to occupy a dominant role in terms of self-definition is further exemplified by John’s comment:

And I would say 2 years ago if you said tell me about yourself, one of the first things I would say is that I’m HIV. Now, I would talk more about my job, my house, my relationship [with my partner] . . . all of which certainly involves HIV, but it’s not the leading characteristic of my life.

The level of comfort that John now feels with his HIV status was evident in his reference to the virus as more of a “companion” that he didn’t particularly want to have, but one that is with him nevertheless. He noted, with a bit of amusement, that “actually we’re old friends. I kind of understand the virus and know that it’s here and it lives with me.” Kenneth shared a similar perception of his HIV-positive status, calling it “more like a pet—you have to take care of it. You don’t take care of it, it start[s] whining and scratching and doing all sorts of annoying things [*laughs*].”

Infection with HIV occupied an even less conspicuous presence in the lives of two of the participants in this study. Mirna, who had remarried her husband of almost 30 years, stated rather nonchalantly that “I don’t ignore it [HIV]; I just don’t put any emphasis on it.” Ben similarly noted, “I really don’t even think about being HIV positive today, I really don’t.” He added, “I don’t deny myself that I’m HIV anymore, but it’s not something I’m gonna worry about. After 13 years of everybody saying you’re gonna die in a year or two, and then you’re still around,” his HIV status no longer dictates his life or his perception of himself. In fact, for both Mirna and Ben, definitions of the self more closely reflect their histories of substance abuse.

In summary, there were clear indications of changes in meaning schemes for the participants in this study since the first round of interviews. Specifically, participants had become less focused on the present and adopted more of a future-oriented perspective to life. Also, they evidenced a greater awareness of the need to care for the self, striking a healthy balance between attending to their own needs and caring for the needs of others. Finally, their definitions of self no longer centered on their HIV status. Being HIV-positive was just one of many descriptors that characterized their lives.

DISCUSSION

For all 14 participants in this study, there is evidence of the enduring nature of a perspective transformation. Our study thus provides empirical evidence that perspective transformations are irreversible, confirming the thinking of Mezirow (1991)

and Kegan (1994). However, the perspective transformations of our participants were triggered by the highly emotional and traumatic impact of a life-threatening diagnosis. We wonder about the staying power of perspective transformations that emerge from non-life-threatening events and encourage subsequent research in this area as a means of illuminating our understanding of the key ingredients of an enduring perspective transformation.

The second major finding of this study confirmed the expectation that over time meaning schemes do change. Our data indicate that the adults in this study experienced changes in some of their basic beliefs and assumptions. For example, most participants had become more future oriented. Two years ago, we found that most of these HIV-positive adults were largely focused on living in the present and if thinking about the future at all, they were planning for the short term. In the past 2 years, they had moved from being present centered to future oriented. Thus, they had revised the assumption that they would only live for maybe 2 more years to the assumption that they might live a life of normal longevity.

In our earlier study, however, one individual claimed to be focused on the present but also looking to the future, as evidenced by her plans to enroll in college and complete her degree. The comments of two other individuals reflected a stronger future-orientation. One participant described her plans for completing a college degree and another spoke of starting a business. The other 15 participants were clearly focused on the present. The first set of findings is consistent with those of a study focusing on time and positive HIV status (Davies, 1997). From an examination of interviews with 38 HIV-positive individuals who had been living with their diagnosis for 5 years or more, Davies (1997) concluded that three views about time are present in adults with this diagnosis. One group lives with a philosophy of the present, freed from the responsibilities normally associated with adulthood and enabled to enjoy the present as long as is possible. Some individuals in our first study exhibited this temporal orientation. The second group, like the two individuals in our study, lives in the future, refusing to accept the possibility of imminent death and maintaining an orientation of life in the future. The third group, like some participants in our first study, were "living in the empty present." This group is similar to the first except that they are so focused on the possibility of an early death that they are unable to enjoy the present.

Our second set of interviews indicate that all members of our sample shifted their temporal perspective to living in the future, unlike those adults interviewed by Davies (1997). We would speculate that the difference in these findings is due to the widespread use of protease inhibitors and their positive effects on our sample. It is not clear from Davies's study whether any participants in her sample were using protease inhibitors.

Our sample of participants also spoke of how they had changed their beliefs about the self. Two years ago, data from the first interviews with these individuals reflected an "other" orientation, especially with respect to what is important in life. What we found 2 years later are individuals who have realized that concern for the

self is also important. In the past 24 months, the majority of adults in this study had integrated their beliefs about the self and others, realizing that both are vital for fulfilling their purpose in life.

Participants' views of their HIV-positive diagnosis is the third area where we uncovered changes in meaning schemes. Whereas 2 years ago, being HIV-positive produced anxiety about dying, it has currently been integrated into their everyday lives. Although the potential for HIV to end life is still imminent, it no longer controls the thoughts and actions of its hosts. Thus, the previous assumption that one's thinking and behaving are subservient to being HIV-positive has evolved to the belief that the person is greater than the diagnosis.

These three changes in perspectives about the future, self, and HIV uphold the expectation that we would find alterations in meaning schemes after 2 years. What the data do not reflect are subsequent perspective transformations. When asked whether they had experienced a situation or event as influential as their HIV-diagnosis, most of the adults in this study answered that they had not. And, in those few instances where individuals described an experience that affected them as much as their diagnosis, they did not evidence having had another perspective transformation.

This finding is explained by Mezirow's (1990b) distinction between content and process reflection. Unlike the HIV-positive diagnosis that was the disorienting dilemma (Mezirow, 1990b) that raised such basic questions as, "Why am I still alive?" or "Now, what is my purpose in life?" the events over the past 2 years have prompted what Mezirow refers to as "content reflection" (description/facts) of an experience or "process reflection," the strategies one might employ in an experience. A different view of the self illustrates this distinction. Two years ago, the adults in this study explained how an HIV-positive diagnosis forced them to come to grips with what was really important in life and what would be their role in life with HIV, and they concluded that they should devote their remaining time helping other people. Thus, they shifted their meaning perspective from being self- to other-oriented. The nature of their reflection on those two questions was premise reflection because they were assessing the reasons for their existence and their future.

Two years later, the majority of the sample gave evidence that their thinking had gone from one extreme to a more balanced view, that concern for the self is equally important to concern for others. By reflecting on their decision to help others and its consequences for their own lives, they realized that they could not effectively serve others if they did not care for themselves as well. Rather than asking the important question about the purpose of life, in the past 2 years, the participants in this study discovered that their strategies (process reflection) for fulfilling their purpose needed adjustment.

Although protease inhibitors did not prompt additional perspective transformations, their positive effects do appear to explain at least one of the changes in meaning schemes. The knowledge that T-cell counts rose dramatically and that viral

loads became undetectable, accompanied by such physical manifestations as less-frequent illnesses and weight gain, provided hope for a longer life. Consequently, the individuals in this study shifted to a more futuristic outlook for their lives and reported that instead of planning for death, they were now preparing for life.

Another question that guided this study was the impact of time on a perspective transformation. As indicated by our findings, there has not been a reversion in the perspective transformations of the sample during the past 2 years. However, meaning schemes, the specific beliefs and assumptions of the individuals in this study, have changed, and time appears to be a contributing factor. First, the passage of 2 years provided an opportunity to reflect further about being HIV-positive. Without the time to act on their new perspectives and to observe the effects of their actions, the adults in this study would obviously not have had the "space" to examine their meaning schemes.

Second, the findings reveal how some members of the sample attributed their revised perspectives to the fact that in the past 2 years they had turned 30 or 40 years of age, ages that are important adult life transitions (Bee, 1996; Merriam & Caffarella, 1998). Could it be that these new levels of maturity have facilitated the changes in meaning schemes for some adults in this study? For example, did our sample realize that care of self is equally as important as serving the needs of others because they had reached a stage in life where this awareness would ordinarily emerge?

The third way in which time appears to be related to changes in meaning schemes is the perception by the HIV-positive adults that they have more time to live. This aspect of the importance of time in altering meaning schemes may be unique to this sample or to other individuals who have had a perspective transformation as a result of a tragic experience. In those instances when a perspective transformation isn't effected by a life-threatening event, the perception of having more time to live is likely to be irrelevant to revisions in meaning schemes. A question for further study would be about the perception of time in relation to perspective transformations.

In addition to our interest in knowing whether the participants in this study had experienced further transformations, we were curious to learn the directions of those changes. Were they progressive? Were they regressive? The three changes in meaning schemes all appear to be developmentally positive. Rather than living only in the present and planning for death, the adults in this study have renewed their concerns for the future and are making plans well beyond 2 to 3 years of life. Furthermore, the members of the sample had reached a more integrated view of the relationship between themselves and other individuals by realizing that they could most effectively reach out to help others by taking care of themselves as well. The views of the participants in this study also evolved with respect to the centrality of

HIV in their lives. They no longer felt oppressed and controlled by their diagnosis, but had integrated it as part of their daily routine. Although they recognized that it still had the potential to end their lives, they were not paralyzed to move forward with future plans as they had been 2 years ago.

IMPLICATIONS FOR ADULT EDUCATION

On one hand, the fact that we found perspective transformations hold over time is encouraging to those concerned about transfer and stability of learning. Transformational learning, acknowledged by some as an appropriate goal for adult education (Robertson, 1996), may endure because it effects a dramatic change in the learner. Thus, adult educators who purposefully configure adult learning experiences to bring about a perspective transformation have one empirical indicator that learners experiencing perspective transformations are likely to maintain the change.

On the other hand, that a perspective transformation is stable over time reflects serious concerns for the adult educator. Ethical issues regarding the right of the adult educator to intentionally plan for perspective transformation, as well as his or her responsibility for the subsequent impact of the perspective transformation in the lives of learners, are important to consider. Robertson (1996) provides a helpful observation about this dilemma when he argues that although transformational learning is an appropriate goal for adult education, “the field neither adequately prepares nor supports adult educators to manage the dynamics of helping relationships or the dynamics of transformative learning within the context of those relationships” (pp. 43-44). Thus, whereas the first finding of this study offers hope to those who are interested in long-term change, it also raises concern over the moral and ethical implications of deliberately effecting change in the lives of adult learners.

The second major finding of this study, that meaning schemes do change over time and in a developmentally positive direction as indicated by our data, also has implications for adult education. This evidence offers assurances that fundamental beliefs and assumptions of learners are continuously changing; therefore, our efforts to configure learning experiences that help learners examine their meaning schemes may be productive for them. However, that conclusion assumes that changes in meaning schemes are always developmentally positive, as was true for our sample. The findings of this study do not counter that assumption, but neither do they confirm it as a universal experience. Thus, although we have found that alterations in meaning schemes are favorable, they may not change or change negatively in other situations. We encourage future investigations that focus on the direction of change in meaning schemes.

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