Adult Education Research Conference

1998 Conference Proceedings (San Antonio, TX)

"Dancing As Gracefully As I Can": A Developmental Model Of Coping Strategies In Successfully Adapting To Hiv Infection

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Abstract. The purpose of this study was to understand the use of coping strategies in successfully adapting to HIV infection. Data analyzed from 18 interviews revealed that coping strategies employed immediately after diagnosis differed from those used later. An underlying developmental process in the use of coping strategies was also uncovered.

Introduction

Since the 1970s, there has been an upsurge of interest in research that explores the ways humans deal with and adapt to the internal and external stresses of life. From a Broadway play entitled "Don't Bother Me I Can't Cope," to the commonplace use of expressions about being "in denial," to shelves of reading material on "coping" that can be found in any bookstore, there is ubiquitous evidence by researchers and lay persons alike of engagement with "the mental demands of modern life" (Kegan, 1994).

A review of the coping literature reveals two trends that have gained momentum within recent years: movement toward an interactional approach to coping, and a change in the way stress is viewed as well as the role it plays in the adaptive process. An interactional approach to coping incorporates the complementary strengths of two opposing perspectives -- transactional and ego psychology. A transactional perspective emphasizes the importance of factors *external* to the individual (e.g., support networks), whereas the psychoanalytically-rooted ego psychology perspective is concerned with how an individual's *internal*, psychological processes govern attempts to cope through the use of defense mechanisms. It has been suggested that the study of coping could best be served by promoting an interactional approach -- a "third generation of coping theory and research" that "acknowledges the importance of both situational and individual determinants of coping" (Suls, David, & Harvey, 1996, p. 720).

There is also evidence of a second, more subtle trend in the coping literature -- one that reflects a change in the way stress is viewed and its role in the adaptive process. Use of the word "stress," has been associated most often with unhealthy manifestations (e.g., depression). This depiction, however, may offer a limited view of the range of outcomes that are possible. Aldwin (1994), for one, maintains that "stress is so ubiquitous that it seems intuitively unlikely that its effects on adaptation are solely negative" (p. 241). She suggests that coping can foster change, or transformation, rather than promote homeostasis. And when viewed as an impetus for growth, stress may provide a catalyst for adult development.

The literature is replete with anecdotal accounts of individuals who report richer, more meaningful lives as a result of encountering stressful situations, including potentially life-threatening illnesses. Such individuals have been able to confront the prospect of death in healthy, satisfying, and life-affirming ways. That is, they have evidenced a positive adaptation to news that has shattered their basic assumptions about themselves and their place in the world. Looking at a specific population, such as those coping with an HIV-positive diagnosis, provides the keenest insight into how the process of successful adaptation unfolds.

The purpose of this study was to understand the use of coping strategies in effecting a successful adaptation to an HIV-positive diagnosis. Specifically, what are the coping strategies that are used? Is there an underlying developmental process in the sense of movement from less adaptive to more adaptive strategies?

Relevant Literature

The literature in psychology, counseling, social work, nursing, and adult development was reviewed to inform this study. Much of the research on coping with a life-threatening illness, including HIV/AIDS, has focused on the impact of coping on psychological distress. The most consistent finding in these studies has been that emotion-focused behaviors (e.g., denial) are associated with increased distress. The relationship between problem-focused behaviors and psychological distress is not as clearly defined, although many studies have associated problem-focused or "active-coping" with a higher quality of life and less depression (Adam & Sears, 1996).

Few studies have identified specific coping strategies, delineated their change over time, and explored the transformational effects of dealing with stressful events. Two studies outlining specific coping strategies used by individuals with HIV were uncovered. Leserman, Perkins, and Evans (1992) delineated four coping strategies: adopting a fighting spirit, reframing stress to maximize personal growth, planning a course of action, and seeking social support. Barroso (1997) found that the prospect of long-term survival is embedded in five dimensions that allow individuals to reconstruct their lives within the context of HIV/AIDS: normalizing, focusing on living, taking care of oneself, being in relation to others, and triumphing.

A few studies have proposed conceptual frameworks that contextualize HIV-related changes. Siegel and Krauss (1991) noted the emergence of three major challenges in coping with HIV: dealing with the possibility of a curtailed life span, dealing with reactions to a stigmatizing illness, and developing strategies for maintaining physical and emotional health. Chidwick and Borrill (1996) discovered that individuals who managed their lives successfully after an HIV-positive diagnosis shared the following characteristics: They were able to cope more effectively after at least two years had elapsed since diagnosis, had a perception of good physical health, and felt they had appropriate and sufficient social support. O'Brien (1992) constructed a data-based typology of coping behaviors for persons living with HIV that consisted of five core categories: negotiating, collaborating, participating, distancing, and free-lancing.

Even fewer studies have addressed how adult development may be fostered by the struggle to cope with a life-threatening illness. Schwartzberg (1993) uncovered ten ways 19 HIV-positive gay men conceptualized the meaning they had made from being infected with HIV (e.g., "HIV as Punishment," "HIV as Irreparable Loss"). "HIV as a Catalyst for Personal Growth" was the one most frequently mentioned.

Method

This study employed a qualitative design to understand the use of coping strategies that effect a successful adaptation to HIV infection. Eighteen respondents were located through four AIDS service organizations in Atlanta, Georgia. They were 45 years or younger in age because it was assumed that the possibility of dying at an unnaturally early age would allow all coping strategies within one's repertoire to be tapped. Respondents also had a CD4 (T-cell) count of 500 or less. This count signifies a compromised immune system, rendering it difficult to remain in denial about the presence of HIV. The final sample consisted of ten men and eight women ranging in age from 23 to 47 (one male was age 57). Eleven are Caucasian, six are African-American, and one is Hispanic. The amount of time since diagnosis ranged from 18 months to 13 years. Level of educational attainment spanned Grade 10 to Masters Degree. Nine of the participants are currently employed. A semistructured interview format was used and areas explored included coping, psychosocial development, faith development, and meaning-making. Data were analyzed inductively using the constant comparative method.

Findings

The model (Figure 1) below addresses both the coping strategies used and the developmental progression of these strategies from the time an HIV-positive diagnosis is received until the present. The period we call "in transition" spans the time between "immediately after diagnosis" and "currently," and functions as a "testing ground" for the coping strategies currently being used. A developmental movement over time, from coping strategies that are more reactive, evidence less control, and are more self-centered to those that are more proactive, evidence more control, and are more other-centered is also depicted.

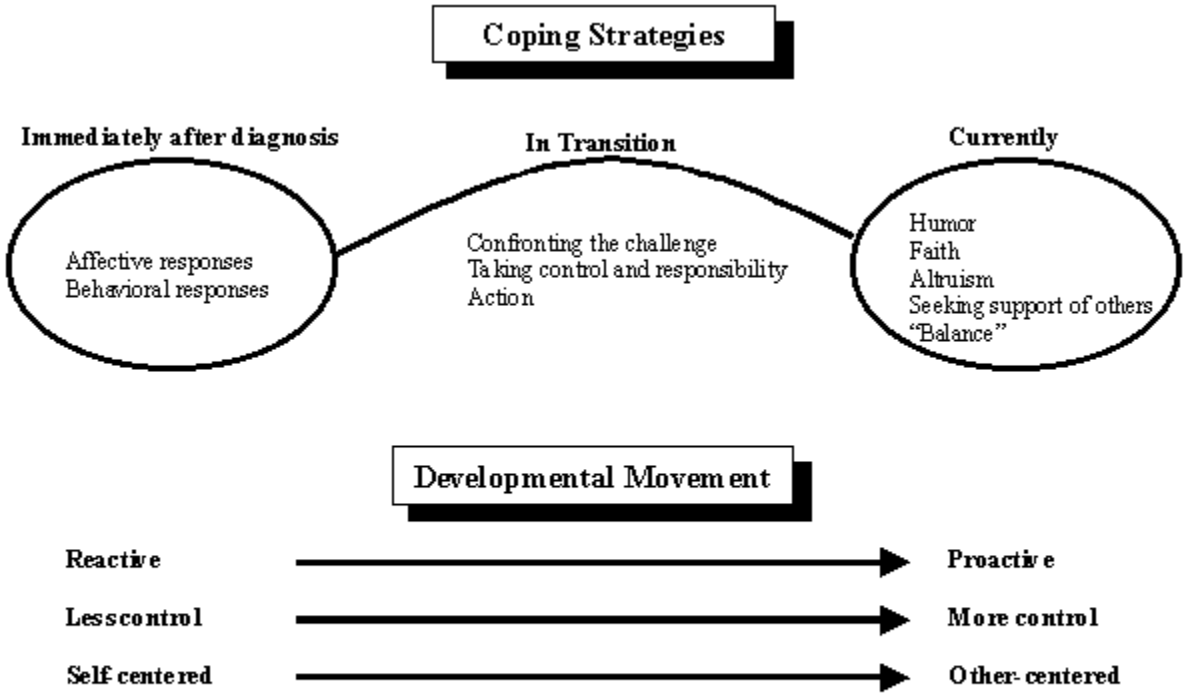

Figure 1. Coping Strategies and Developmental Movement

Coping strategies utilized immediately after diagnosis were primarily of two kinds: affective and behavioral. The scope of affective responses was broad, ranging from complete denial to intense anger. The simple response, "It couldn't be," by John, a former priest, elegantly captured the denial reported by many respondents. Dawn identified a period of denial which she described as being the product of "core fear." Anger was another commonly reported affective response. Steve recalled going to the bathroom and "wishing I had a meat locker or some place that was soundproof so I could really scream . . . . Why have I got this? . . . Angry, so angry!" Coping strategies post diagnosis also revealed numerous behavioral responses, including excessive use of drugs/alcohol and "automatic pilot" reactions -- behaviors commonly employed during other stressful times. Sam, a recovering alcoholic, stated: "I pretty much stayed drunk for another three years." Pat, whose life journey was particularly colorful, revealed, "I just used drugs day-in and day-out . . . . [they] helped keep me in denial." Not all behavioral responses were so self-destructive. "Automatic, survival mode" strategies, while not especially purposeful, were used by several participants. For example, Mirna, the one Hispanic participant, stated that immediately after diagnosis, she "just went on with the flow." Similarly, Elise, who was 29 when diagnosed, indicated, "I just did my life."

The period, in transition, is best understood as a time of change. An individual realizes that many coping strategies employed immediately after diagnosis are without long-term utility and are

ineffective in assimilating the diagnosis. "In transition" serves as a launching pad for successful coping strategies and is characterized by three particularly salient occurrences: *confronting the challenge*, *taking control and responsibility*, and *action*. Jeffrey, in *confronting the challenge* of an HIV-positive diagnosis, was "forced to focus on what is there . . . then I began to process the information and began to look at myself with different eyes." *Taking control and responsibility*, a cognitive process reflecting empowerment, was poignantly described by Joe: "You realize that there are still a lot of factors despite the HIV that you have under your control . . . . it [HIV] made me realize that my time is limited . . . and I better get off my butt and do something if I'm going to stay alive." *Action* also serves to facilitate the development of successful coping strategies. Tracy, after becoming involved in a support group and "getting educated," realized that her "mission, and I ain't talking about as far as a paycheck, just as a person living with this virus" was to "get out and get involved."

Currently, five coping strategies are being used: *humor*, *faith*, *altruism*, *seeking the support of others*, and *"balance." Humor* liberally punctuated all of the interviews. Sam, for example, revealed, "Before, when I was drunk, I was very judging . . . . I was very critical, very uptight, very paranoid (laughter). I come from an upper middle class Republican family, and I used to be very Republican. I sobered up . . . I'm no longer a Republican!" Leeza, the youngest participant, indicated how *faith* is a primary coping strategy in her life: "I'll get the Bible and I'll look at myself in the mirror as a way of talking to God . . . . and tell Him how I feel."

Altruism is the coping strategy most widely employed. From Tim's humble statement, "I just want to make a difference," to Steve's more eloquent, "I want to just 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," there is ubiquitous evidence of the desire to help others. *Seeking support*, a strategy rarely employed immediately after diagnosis, is often accompanied by relinquishing "control." Participants articulated a deep appreciation for reciprocal relationships -- where help can be sought as well as given. *"Balance,"* the fifth coping strategy, is defined as the conscious act of weighing and dealing with competing life demands. Steve, in juggling the need to live a life not ruled by HIV with the awareness that long-term survival is dependent on *not* forgetting his status, illustrated the concept of balance: ". . . for this weekend let's go away and this weekend I won't think about it [being HIV positive]. This weekend I'm going to live as if this weren't a part of my life . . . . I think it really helps me get by."

Clearly, participants exhibited healthier, more adaptive coping strategies over time, with developmental movement being characterized in three ways: reactive to proactive, less control to more control, and self-centered to other-centered. The coping strategies used immediately after diagnosis were primarily reactive in nature. However, coping strategies currently in use, such as altruism and balance, are much more evolved, requiring awareness and conscious effort. They also reflect a greater sense of empowerment and a shift in focus from oneself to others.

Discussion

Immediately after receiving an HIV-positive diagnosis, respondents used both affective and behavioral strategies. Affective responses are emotion-focused and are employed when one perceives s/he has little control over a situation. Utilizing emotion-focused strategies immediately after diagnosis was a logical action for these respondents, since many were diagnosed in the 1980s when infection with HIV was equated with certain death.

The findings of this study also revealed an interim period, "in transition," that is unique to this study. "In transition" is the time when individuals realize their earlier coping strategies are not successful in dealing with HIV. Consequently, they become more self-directed in their coping efforts by confronting the challenge of their diagnosis, taking control and responsibility for their lives, and putting their new-found attitudinal changes into action.

The five coping strategies currently being used by respondents -- humor, faith, altruism, seeking the support of others, and balance -- are considered healthy and adaptive responses by any measure. Humor is situated among the most mature strategies in Vaillant's (1977) developmental hierarchy. The use of faith in coping with HIV supports the findings of Kaplan, Marks, and Mertens (1997), who discovered that prayer was among the most frequent and effective coping responses in a multiethnic sample of 53 women with HIV/AIDS.

Altruism, the most prevalent coping strategy, is reflected in respondents' statements about the beneficial effects of helping others; most often, those helped were also HIV-positive. Barroso (1997) similarly found that reconstructing one's life within the context of AIDS involves "helping others with HIV" (p. 67). Leserman et al. (1992) also emphasized the value of altruism and linked participation in the AIDS community with the utilization of healthy coping strategies.

Seeking the support of others is a finding that adds to the emerging body of literature underscoring the relationship between social support and positive adaptation in persons with HIV. Finally, balance resembles Vaillant's (1977) depiction of suppression, which entails temporarily putting aside unacceptable or inappropriate thoughts or impulses. Vaillant found, in fact, that suppression was the defense most closely associated with "positive mental health, warm human relationships, and successful careers" (p. 126).

Over time, participants evidenced a clear developmental progression in the use of coping strategies: from reactive to proactive, from less control to more control, and from self-centered to other-centered. This movement paralleled the progession of coping strategies that occur within the three unfolding stages of HIV infection (Living with Dying, Fighting the Sickness, and Getting Worn Out) delineated by McCain and Gramling (1992), and underscored Chidwick and Borrill's (1996) finding that coping abilities develop over time.

That change was in a positive, growth-oriented direction suggests that coping with HIV may foster adult development, defined by Bee (1996) as "those changes that arguably reflect the emergence of some more complex or more integrated system or structure" (p. 16). Healthy, successful strategies for dealing with a life-threatening illness can be learned, and coping, like adult learning and development, is a complex phenomenon. While some of the coping strategies that we uncovered (e.g., humor) clearly fall within the province of an ego psychology perspective on coping, others (e.g., seeking support) are not similarly linked. Thus, we must

support an interactional approach to coping since its vision "seems most compatible with the complexity of coping processes in everyday life" (Suls et al., 1996, p. 731).

The ultimate value of research in applied fields like adult education, social work, and nursing resides in its ability to understand and improve practice for "what we do affects the lives of real people" (Merriam, 1995, p. 51). An interactional approach to coping affords a broader lens for identifying adaptive strategies in coping with an HIV-positive diagnosis, and thus provides the best hope for assisting individuals stuggling with life-threatening situations.

References

Adam, B., & Sears, A. (1996). *Experiencing HIV: Personal, family, and work relationships.* New York: Columbia University Press.

Aldwin, C. M. (1994*). Stress, coping, and development: An integrative perspective*. New York: The Guilford Press.

Barroso, J. (1997). Reconstructing my life: Becoming a long-term survivor of AIDS. *Qualitative Health Research, 7*(1), 57-74.

Bee, H. D. (1996). *The journey of adulthood.* (3rd ed.). Upper Saddle River, NJ: Prentice Hall.

Chidwick, A., & Borrill, J. (1996). Dealing with a life-threatening diagnosis: The experience of people with the human immunodeficiency virus. *AIDS Care, 8*(3), 271-284.

Kaplan, M. S., Marks, G., & Mertens, S. B. (1997). Distress and coping among women with HIV infection: Preliminary findings from a multiethnic sample. *American Journal of Orthopsychiatry, 6*(1), 80-91.

Kegan, R. (1994). *In over our heads: The mental demands of modern life*. Cambridge, MA: Harvard University Press.

Leserman, J., Perkins, D. O., & Evans, D. L. (1992). Coping with the threat of AIDS: The role of social support. *American Journal of Psychiatry, 149*(11), 1514-1520.

McCain, N. L., & Gramling, L. F. (1992). Living with dying: coping with HIV disease. *Issues in Mental Health Nursing, 13,* 271-284.

Merriam, S. B. (1995). What can you tell from an N of 1?: Issues of validity and reliability in qualitative research. *PAACE Journal of Lifelong Learning, 4,* 51-60.

O'Brien, M. E. (1992). *Living with HIV: Experiment in courage.* New York: Auburn House.

Schwartzberg, S. S. (1993). Struggling for meaning: How HIV-positive gay men make sense of AIDS. *Professional Psychology: Research and Practice, 24*(4), 483-490.

Siegel, K., & Krauss, B. J. (1991). Living with HIV infection: Adaptive tasks of seropositive gay men. *Journal of Health and Social Behavior, 32,* 17-32.

Suls, J., David, J. P., & Harvey, J. H. (1996). Personality and coping: Three generations of research. *Journal of Personality, 64*(4), 711-735.

Vaillant, G. L. (1977). *Adaptation to life.* Boston: Little, Brown.