• Appendix C •

A Phenomenological Study—"Cognitive Representations of AIDS"

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Cognitive representations of illness determine behavior. How persons living with AIDS image their disease might be key to understanding medication adherence and other health behaviors. The authors' purpose was to describe AIDS patients' cognitive representations of their illness. A purposive sample of 58 men and women with AIDS were interviewed. Using Colaizzi's (1978) phenomenological method, rigor was established through application of verification, validation, and validity. From 175 significant statements, 11 themes emerged. Cognitive representations included imaging AIDS as death, bodily destruction, and just a disease. Coping focused on wiping AIDS out of the mind, hoping for the right drug, and caring for oneself. Inquiring about a patient's image of AIDS might help nurses assess coping processes and enhance nurse-patient relationships.

A 53-year-old man with a history of intravenous drug use, prison, shelters, and methadone maintenance described AIDS as follows:

> My image of the virus was one of total destruction. It might as well have killed me, because it took just about everything out of my life. It was just as bad as

> being locked up. You have everything taken away from you. The only thing to do is to wait for death. I was afraid and I was mad. Mostly I didn't care about myself anymore. I will start thinking about the disease, and I'll start wondering if these meds are really going to do it for me.

To date, 36 million people worldwide (Centers for Disease Control and Prevention [CDC], 2001b) are infected with Human Immunodeficiency Virus (HIV) that develops into end-stage Acquired Immunodeficiency Syndrome (AIDS). In the United States, 448,060 have died of AIDS-related illnesses, and more than 322,000 persons are living with AIDS, the highest number ever reported (CDC, 2001a). With HIV/AIDS, 95% adherence to antiretroviral (ART) drug regimens is necessary for complete viral suppression and prevention of mutant strains (Bartlett & Gallant, 2001). Adherence to ART regimens can slow the disease process but does not cure HIV or AIDS. Persons with AIDS experience numerous side effects associated with ART drugs, which can lead to missed doses, profound weight loss, and decreased quality of life (Douaihy & Singh, 2001). The incidence of HIV/AIDS is reduced through prevention that is dependent on life-long commitment to the reduction of high-risk drug and sexual behaviors. To achieve maximum individual and public health benefits, it might be helpful to explore patients' lived experience of AIDS within the framework of the self-regulation model of illness.

In the Self-Regulation Model of Illness Representations, patients are active problem solvers whose behavior is a product of their cognitive and emotional responses to a health threat (Leventhal, Leventhal, & Cameron, 2001). In an ongoing process, people transform internal (e.g., symptoms) or external (e.g., laboratory results) stimuli into cognitive representations of threat and/or emotional reactions that they attempt to understand and regulate. The meaning placed on a stimulus (internal or external) will influence the selection and performance of one or more coping procedures (Leventhal, Idler, & Leventhal, 1999). Emotions influence the formation of illness representations and can motivate a person to action or dissuade him or her from it. Appraisal of the consequences of coping efforts is the final step in the model and provides feedback for further information processing.

Although very individual, illness representations are the central cognitive constructs that guide coping and appraisal of outcomes. A patient's theory of illness is based on many factors, including bodily experience, previous illness, and external information. An illness representation has five sets of attributes: (a) identity (i.e., label, symptoms), (b) time line (i.e., onset, duration), (c) perceived cause (i.e., germs, stress, genetics), (d) consequences (i.e., death, disability, social loss), and (e) controllability (i.e., cured, controlled) (Leventhal, Idler, et al., 1999; Leventhal, Leventhal, et al., 2001).

Attributes have both abstract and concrete form. For example, the attribute "identity" can have an abstract disease label (e.g., AIDS) and concrete physical symptoms (e.g., nausea and vomiting). Symptoms are convenient and available cues or suggestions that can shape an illness representation and help a person correctly or incorrectly interpret the experience. Although symptoms are not medically associated with

hypertension, patients who believed medications reduced their symptoms reported greater adherence and better blood pressure control (Leventhal, Leventhal, et al., 2001).

Understanding how individuals cognitively represent AIDS and their emotional responses can facilitate adherence to therapeutic regimens, reduce high-risk behaviors, and enhance quality of life. Phenomenology provides the richest and most descriptive data (Streubert & Carpenter, 1999) and thus is the ideal research process for eliciting cognitive representations. Consequently, the purpose of this study was to explore patients' experience and cognitive representations of AIDS within the context of phenomenology.

Review of the Literature

Vogl et al. (1999), in a study of 504 ambulatory patients with AIDS who were not taking protease inhibitor (PI) drugs, found the most prevalent symptoms were worry, fatigue, sadness, and pain. Both the number of symptoms and the level of symptom distress were associated with psychological distress and poorer quality of life. Persons with a history of intravenous drug use reported more symptoms and greater symptom distress. In contrast, a telephone survey and chart review of 45 men and women with HIV/AIDS suggested that PI therapy was associated with weight gain, improved CD4 counts, decreased HIV RNA viral loads, fewer opportunistic infections, and better quality of life (Echeverria, Jonnalagadda, Hopkins, & Rosenbloom, 1999).

Reporting on pain from patients' perspective, Holzemer, Henry, and Reilly (1998) noted that 249 AIDS patients reported experiencing a moderate level of pain, but only 80% had effective pain control. A higher level of pain was associated with lower quality of life. In a phenomenological study focusing on pain, persons with HIV/AIDS viewed pain as not only physical but also an experience of loss, not knowing, and social (Laschinger & Fothergill-Bourbonnais, 1999).

Turner (2000), in a hermeneutic study of HIV-infected men and women, found that AIDS-related multiple loss was an intense, repetitive process of grief. Two constitutive patterns emerged: Living with Loss and Living beyond Loss. Likewise, Brauhn (1999), in a phenomenological study of 12 men and 5 women, found that although persons with HIV/AIDS experienced their illness as a chronic disease, their illness had a profound and pervasive impact on their identity. Participants planned for their future with cautious optimism but could identify positive aspects about their illness.

McCain and Gramling (1992), in a phenomenological study on coping with HIV disease, reported three processes: Living with Dying, Fighting the Sickness, and Getting Worn Out. Koopman et al. (2000) found that among 147 HIV-positive persons, those with the greatest level of stress in their daily lives had lower incomes, disengaged behaviorally/emotionally in coping with their illness, and approached interpersonal relationships in a less secure or more anxious manner. With somewhat similar results, Farber, Schwartz, Schaper, Moonen, and McDaniel (2000) noted that adaptation to HIV/AIDS was associated with lower psychological distress, higher quality of life, and more positive personal beliefs related to the world, people, and self-worth. Fryback and Reinert (1999), in a qualitative study of women with cancer and men with HIV/AIDS, found spirituality to be an essential component to health and well-being. Respondents who found meaning in their disease reported a better quality of life than before diagnosis.

Dominguez (1996) summarized the essential structure of living with HIV/AIDS for women of Mexican heritage as struggling in despair to endure a fatal, transmittable, and socially stigmatizing illness that threatens a woman's very self and existence. Women were seen as suffering in silence while experiencing shame, blame, and concern for children. In a phenomenological study of five HIV-infected African American women, 12 themes emerged, ranging from violence, shock, and denial to uncertainty and survival (Russell & Smith, 1999). The researchers concluded that women have complex experiences that need to be better understood before effective health care interventions can be designed.

No studies reported AIDS patients' cognitive representations or images of AIDS. Consequently, this study focused on how persons with AIDS cognitively represented and imaged their disease.

Method

Sample

A purposive sample of 41 men and 17 women with a diagnosis of AIDS participated in this phenomenological study. Participants were predominately Black (40%), White (29%), and Hispanic (28%). Average age was 42 years (*SD* = 8.2). The majority had less than a high school education (52%) and were never married (53%), although many reported being in a relationship. Mean CD4 count was 153.4 (*SD* = 162.8) and mean viral load, 138,113 (*SD* = 270,564.9). Average time from HIV diagnosis to interview was 106.4 months (*SD* = 64.2). Inclusion criteria were (a) diagnosis of AIDS, (b) 18 years of age or older, (c) able to communicate in English, and (d) Mini-Mental Status exam score > 22.

Research Design

In phenomenology, the researcher transcends or suspends past knowledge and experience to understand a phenomenon at a deeper level (Merleau-Ponty, 1956). It is an attempt to approach a lived experience with a sense of "newness" to elicit rich and descriptive data. Bracketing is a process of setting aside one's beliefs, feelings, and perceptions to be more open or faithful to the phenomenon (Colaizzi, 1978; Streubert & Carpenter, 1999). As a health care provider for and researcher with persons with HIV/AIDS, it was necessary for the interviewer to acknowledge and attempt to bracket those experiences. No participant had been a patient of the interviewer.

Colaizzi (1978) held that the success of phenomenological research questions depends on the extent to which the questions touch lived experiences distinct from theoretical explanations. Exploring a person's image of AIDS taps into a personal experience not previously studied or shared clinically with health care providers.

Procedure

After approval from the university's Institutional Review Board and a city hospital's Human Subject Review Committee, persons who met inclusion criteria were approached and asked to participate. Interviews were conducted over 18 months at three sites dedicated to persons with HIV/AIDS: a hospital-based clinic, a long-term care facility, and a residence. All interviews were tape-recorded and transcribed verbatim. Participants were involved in multiple life situations and were unavailable for repeated interviews related to personal plans, discharge, returning to life on the street, or progression of the disease. One participant died within 4 weeks of the interview. Interviews lasted between 10 and 40 minutes and proceeded until no new themes emerged. Persons who reported not thinking about AIDS provided the shortest interviews. Consequently, to obtain greater richness of data and variation of images, we interviewed 58 participants (Morse, 2000). The first researcher conducted all 58 interviews.

After obtaining informed consent, each participant was asked to verbally respond to the following: "What is your experience with AIDS? Do you have a mental image of HIV/AIDS, or how would you describe HIV/AIDS? What feelings come to mind? What meaning does it have in your life?" As the richness of cognitive representations emerged, it became apparent that greater depth could be achieved by asking participants to draw their image of AIDS and provide an explanation of their drawing. Eight participants drew their image of AIDS.

Background information was obtained through a paper-and-pencil questionnaire. Most recent CD4 and Viral Load laboratory values were obtained from patient charts. Based on institution policy, participants at the long-term care facility and residence received a $5.00 movie pass. Clinic participants received $20.00.

Data Analysis

Colaizzi's (1978) phenomenological method was employed in analyzing participants' transcripts. In this method, all written transcripts are read several times to obtain an overall feeling for them. From each transcript, significant phrases or sentences that pertain directly to the lived experience of AIDS are identified. Meanings are then formulated from the significant statements and phrases. The formulated meanings are clustered into themes allowing for the emergence of themes common to all of the participants' transcripts. The results are then integrated into an in-depth, exhaustive description of the phenomenon. Once descriptions and themes have been obtained, the researcher in the final step may approach some participants a second time to validate the findings. If new relevant data emerge, they are included in the final description.

Methodological rigor was attained through the application of verification, validation, and validity (Meadows & Morse, 2001). Verification is the first step in achieving validity of a research project. This standard was fulfilled through literature searches, adhering to the phenomenological method, bracketing past experiences, keeping field notes, using an adequate sample, identification of negative cases, and interviewing until saturation of data was achieved (Frankel, 1999; Meadows & Morse, 2001). Validation, a within-project evaluation, was accomplished by multiple methods of data collection (observations, interviews, and drawings), data analysis and coding by the more experienced researcher, member checks by participants and key informants, and audit trails. Validity is the outcome goal of research and is based on trustworthiness and external reviews. Clinical application is suggested through empathy and assessment of coping status (Kearney, 2001).

Results

From 58 verbatim transcripts, 175 significant statements were extracted. Table 1 includes examples of significant statements with their formulated meanings. Arranging the formulated meanings into clusters resulted in 11 themes. Table 2 contains two examples of theme clusters that emerged from their associated meanings.

Theme 1: Inescapable death. Focusing on negative consequences of their disease was the pervading image for many persons with AIDS. Responding quickly and spontaneously, AIDS was described as "death, just death," "leprosy," "a nightmare," "a curse," a "black cloud," and "an evil force getting back at you." The sense of not being able to escape was evident in descriptions of AIDS as "The blob. It's a big Jell-O thing that comes and swallows you up" and "It's like I'm in a hole and I can't get out." Another stated, "AIDS, it's a killer and it will get you at any God-given time."

A sense of defeat was evident in a Hispanic man's explanation that with AIDS you are a "goner." He stated, "With HIV you still have a chance to fight. Once that word 'AIDS' starts coming up in your records, you bought a ticket [to death]."

TABLE 1 ● Selected Examples of Significant Statements of Persons With AIDS and Related Formulated Meanings

Significant Statement	*Formulated Meaning*
In the beginning, I had a sense that I did have it, so it wasn't an unexpected thing although it did bother me. I knew it was a bad thing to let it traumatize so.	AIDS is such a traumatizing reality that people have difficulty verbalizing the word "AIDS."
[AIDS] a disease that has no cure. Meaning of dread and doom and you got to fight it the best way you can. You got to fight it with everything you can to keep going.	AIDS is a dangerous disease that requires every fiber of your being to fight so you can live.
I see people go from somebody being really healthy to just nothing—to skin and bones and deteriorate. I've lost a lot of friends that way. It's nothing pretty. I used to be a diesel mechanic. I can't even carry groceries up a flight of stairs anymore.	As physical changes are experienced, an image of AIDS wasting dominates thoughts.
First image—death. Right away fear and death. That's holocaust. I didn't know any better. Now it's destruction. Pac-man eating all your immune cells up and you have nothing to fight with.	Overwhelming image of AIDS is one of death and destruction with no hope of winning.

TABLE 2 ● Example of Two Theme Clusters With Their Associated Formulated Meanings

Dreaded bodily destruction
Physical changes include dry mouth, weight loss, mental changes
Expects tiredness, loss of vision, marks all over the body
Holocaust victims
Confined to bed with sores all over
Extreme weight loss
Horrible way to die
Changes from being really healthy to skin and bones
Bodily deterioration
Devouring life
Whole perspective on life changed
Never had a chance to have a family
Life has stopped
No longer able to work
Will never have normal relations with women
Uncertain what's going to happen from day to day
Worked hard and lost everything

A 29-year-old woman, diagnosed with HIV and AIDS 9 months before the interview, drew a picture of a grave with delicate red and yellow flowers and wrote on the tombstone "RIP Devoted Sister and Daughter." Over the grave, she drew a black cloud with the sun peeking around the edge, which she described as symbolizing her family's sadness at her death.

Theme 2: Dreaded bodily destruction. In this cluster, respondents focused on physical changes associated with their illness. AIDS was envisioned as people who were skin and bones, extremely weak, in pain, losing their minds, and lying in bed waiting for the end. Descriptions were physically consistent but drawn from a variety of experiences, such as seeing a family member or friend die from AIDS, or from pictures of holocaust victims. It is an ending that is feared and a thought that causes deep pain. Body image became a marker for level of wellness or approach of death.

One woman described her image of AIDS as a skeleton crying. An extremely tall, thin man awaiting a laryngectomy on the eve of his 44th birthday described his image of AIDS by saying, "Look at me." Another recalled Tom Hanks in the movie *Philadelphia* (Saxon & Demme, 1993): "The guy in the hospital and how he aged and how thin he got. You start worrying about . . . you don't want to end like that. I don't

Theme 6: Just a disease. In this cluster of images, people cognitively represented the cause of AIDS as "an unseen virus," "like any infection," "a common cold," and "a little mini bug the size of a mite." Minimizing the external cause, one participant viewed AIDS as an "inconvenience" and another as having been dealt a "bad card."

Some normalized AIDS by imaging it as a chronic disease. Like people with cancer or diabetes, persons with AIDS felt the need to get on with their lives and not focus on their illness. The supposition was that if medications were taken and treatments followed they could control their illness the same as persons do with cancer or diabetes. The physical or psychological consequences that occur with other chronic diseases were not mentioned. The following two excerpts illustrate the disease image:

> It's just a disease. Since I go to support groups and everything, they tell me to look at it as if it were cancer or diabetes and just do what you have to do. Take your medicine, leave the drugs alone, and you will acquire a long life.

And

> [AIDS is] a controllable disease, not a curse. I'm going to control it for the rest of my life. I feel lucky. There is nothing wrong with me. I'm insisting on seeing it that way. It may not be right, but it keeps me going good.

Sometimes, the explanations for AIDS were scientifically incorrect but presented a means for coping. One man described AIDS: "It's just a disease. It's a form of cancer and that's been going on for years and they just come up with the diagnosis."

Theme 7: Holding a wildcat. In this theme, people focused on hypervigilance during battle. While under permanent siege, every fiber of their being was used to fight "a life-altering disease." A 48-year-old man diagnosed 6 months before the interview stated, "I have to pay attention to it. It's serious enough to put me out of work." Another man, diagnosed for 6 years, was firm in his resolve: "I'm a fighter and I'm never going to give up until they come up with a cure for this." These images were essentially positive as can be seen in the following description of AIDS in which a scratch by a wildcat is not "super serious."

> To me HIV is sort of like you've got a wildcat by the head staring you in the face, snapping and snarling. As long as you are attentive, you can keep it at bay. If you lose your grip or don't maintain the attentiveness, it will reach out and scratch you. Which in most cases is not a super serious thing, but it's something of a concern that it will put you in the hospital or something like that. You got to follow the rules quite regimentally and don't let go. If you let go, it will run you over.

Vigilance was used not only to control one's own disease progression but also to protect others. A woman diagnosed for 3 years noted,

> just being conscious of it because when you got kids and when you got family that you live with, you have to be extremely cautious. You got to realize it at all times. It has to just be stuck in your mind that you have it and don't want to share it. Even attending to one of your children's cuts.

Theme 8: Magic of not thinking. Some made a strong effort to forget their disease and, at times, their need for treatment. A few reported no image of AIDS. Thinking about AIDS caused anger, anxiety, sadness, and depression. Not thinking about AIDS seemed to magically erase the reality, and it provided a means for controlling emotions and the disease. A 41-year-old man who has lived with his disease 10 years described AIDS:

> It's a sickness, but in my mind I don't think that I got it. Because if you think about having HIV, it comes down more on you. It's more like a mind game. To try and stay alive is that you don't even think about it. It's not in the mind.

The extent to which some participants tried not to think about AIDS can be seen in the following descriptions in which the word *AIDS* was not spoken and only referred to as "it." A 44-year-old Hispanic woman stated, "It's a painful thing. It's a sad thing. It's an angry thing. I don't think much of it. I try to keep it out of my mind." Another woman asserted, "It's a terrible experience. It's very bad, I can't even explain it. I never think about it. I try not to think about it. I just don't think about it. That's it, just cross it out of my mind."

Theme 9: Accepting AIDS. In this theme, cognitive representations centered on a general acceptance of the diagnosis of AIDS. Accepting the fact of having AIDS was seen as vital to coping well. People with AIDS readily assessed their coping efforts.

A Hispanic woman noted, "I'm not in denial any more." A 39-year-old Hispanic man who has had the disease for 8 years stated, "Like it or not you have to deal with this disease." Another noted, "You have to live with it and deal with it and that's what I'm trying to do." A 56-year-old man who has had the disease for 13 years summarized his coping:

> Either you adjust or you don't adjust. What are you going to do? That's life. It's up to you. I'm happy. I eat well and I take care of myself. I go out. I don't let this put me in a box. Sometimes you don't like it, but you have to accept it because you really can't change it.

Individuals diagnosed more recently struggled to accept their disease. A Black man diagnosed for 2 years vacillated in his acceptance: "I hate that word. I'm still trying to accept it, I think. Yes, I am trying to accept it." However, he stated that he avoids conversation about HIV/AIDS and is not as open with his family. Another man diagnosed 3 years prior noted,

> I still don't believe that it's happen to me and it's taken all this time to get a grip on it or to deal with it. I still haven't got a grip on it, but I'm trying. It's finally sinking in that I do have it and I'm starting to feel lousy about it.

Neither of these last participants mentioned the word "HIV" or "AIDS."

Theme 10: Turning to a higher power. In this theme, cognitive representations of AIDS were associated with "God," "prayer," "church," and "spirituality." Some saw AIDS as a motivation to change their lives and reach for God. An Hispanic man living with HIV/AIDS for 6 years stated, "If I didn't have AIDS, I'd probably still be out there drinking, drugging, and hurting people. I turned my life around. I gave myself over to the Lord and Jesus Christ." Another noted, "It [AIDS] worries me. What I do is a lot of praying. It really makes me reach for God."

Others saw religion as a means to help them cope with AIDS. One person expressed it as "I know I can make it from the grace of God. My Jesus Christ is my Savior and that's what's keeping me going every day." One man reported how his spirituality not only helped him cope but also made him a better person:

> At one point I just wanted to give up. If it wasn't for knowing the love of Jesus I couldn't have the strength to keep going. I feel today that I'm a better person spiritually. Maybe not healthwise, but more understanding of this disease.

In contrast, a man diagnosed in jail attributed AIDS to a punishment from God: "Sometimes God punishes you. It's like I told my wife. I should have cleaned up my act."

Theme 11: Recouping with time. Although the initial fear and shock was overwhelming, time became a healer such that images, feelings, and processes of coping changed. A sense of imminent doom hurled some into constant preoccupation with their illness, despondency, and increased addiction. Living with HIV/AIDS facilitated change. One woman noted, "When I first found out, I wanted to kill myself and just get it over with. But now it's different. I want to live and just live out the rest of my life." Another described her transition as, "At first I thought I was going to be all messed up, all dried up and looking weird and stuff like that, but I don't think of those things anymore. I just keep living life."

As time passed, negative behaviors were replaced with knowledge about their illness, efforts at medication adherence, and a journey of personal growth facilitated by people who believed in them. One man reported that his initial image changed from being in bed with tubes coming out of his nose and Kaposi sarcoma over his body to living a normal life except for not being able to work.

Change was evident in one man's image of AIDS as a time line. He drew a wide vertical line beginning at the top with the first phase, diagnosis, colored red because "it means things are not good, like a red light on a machine." The next phase was shaded blue and labeled "medication, education, and acceptance" to reflect the sky that he could see from his inpatient bed. The final stage was colored bright yellow and labeled "hope."

A 40-year-old Hispanic man drew a chronicle of his life with five addictive substances beginning with alcohol to the injection of heroin. He then sketched four views of himself showing the end stage of his disease: a standing skeleton without face, hair, clothes, or shoes; a sad-faced person without hair lying in a hospital bed; and a grave with flowers. The final picture drawn was of a drug-free person with a well-developed body, smiling face, hair, shoes, shirt, and shorts, symbolizing his readiness for a vacation in Florida. In contrast, a 53-year-old man reported that in 14 years he had no change in his image of AIDS as a "black cloud."

Results were integrated into an essential schema of AIDS. The lived experience of AIDS was initially frightening, with a dread of body wasting and personal loss.

Cognitive representations of AIDS included inescapable death, bodily destruction, fighting a battle, and having a chronic disease. Coping methods included searching for the "right drug," caring for oneself, accepting the diagnosis, wiping AIDS out of their thoughts, turning to God, and using vigilance. With time, most people adjusted to living with AIDS. Feelings ranged from "devastating," "sad," and "angry" to being at "peace" and "not worrying."

Discussion

In this study, persons with AIDS focused on the end stage of wasting, weakness, and mental incapacity as a painful, dreaded, inevitable outcome. An initial response was to ignore the disease, but symptoms pressed in on their reality and forced a seeking of health care. Hope was manifested in waiting for a particular drug to work and holding on until a cure is found. Many participants saw a connection between caring for themselves and the length of their lives.

Some participants focused on the final outcome of death, whereas others spoke of the emotional and social consequences of AIDS in their lives. Efforts were made to regulate mood and disease by increased attentiveness, controlling thoughts, accepting their illness, and turning to spirituality. Some coped by thinking of AIDS as a chronic illness like cancer or diabetes.

As noted earlier, McCain and Gramling (1992) identified three methods of coping with HIV, namely, Living with Dying, Fighting the Sickness, and Getting Worn Out. Images of Dying and Fighting were strong in Themes 1 (Inescapable Death) and 7 (Holding a Wildcat). Participants in this study were well aware of whether they were coping. Many spoke about accepting or dealing with AIDS, whereas others could not stand the word, tried to wipe it out of their minds, or referred to AIDS as "it."

Consistent with Fryback and Reinert's study (1999), Theme 10, Turning to a Higher Power, emerged as a means of coping as participants faced their mortality. Like Turner's (2000) sample, participants in the current study experienced many changes/losses in their lives and reflected on death and dying. Similar to Turner's theme of Lessons Learned, some participants saw AIDS as a turning point in their lives.

Aligned with Brauhn's (1999) study, chronic disease emerged as an image. In contrast to Brauhn's sample, these participants used the nomenclature of chronic illness to minimize the negative aspects of AIDS. It can be posited that the lack of cautious optimism in planning their future was not present in this study because the entire sample had AIDS.

Theoretical Elements

As Diefenbach and Leventhal (1996) noted, cognitive representations were highly individual and not always in accord with medical facts. Consistent with research in other illnesses, persons with AIDS had cognitive representations reflecting attributes of consequences, causes, disease time line, and controllability (Leventhal, Leventhal, et al., 2001). In particular, we identified three themes that centered on anticipated or experienced consequences associated with AIDS. Inescapable Death and Dreaded Bodily Destruction involved negative physical consequences that are understandable at end stage in a disease with no known cure. The theme Devouring Life focused on the far-reaching emotional, social, and economic consequences experienced by participants. The Just a Disease theme reflected cognitive representations of the cause of AIDS and Recouping with Time had elements of a disease time line from diagnosis to burial.

Six themes (Hoping for the Right Drug, Caring for Oneself, Holding a Wildcat, Magic of Not Thinking, Accepting AIDS, and Turning to a Higher Power) were similar to the controllability attribute of illness representations. Previous research centered on controlling a disease or condition through an intervention by the individual or an expert, such as taking a medication or having surgery (Leventhal, Leventhal, et al., 2001). This finding was substantiated in the themes Hoping for the Right Drug and Caring for Oneself. Unique to this study, persons with AIDS attempted to control not only their emotions but also their disease through vigilance, avoidance, acceptance, and spirituality coping methods. This is particularly evident in the statement that "To try and stay alive is that you don't even think about it." This study extends previous research on illness representations to persons with AIDS and contributes to the theory of Self-Regulation by suggesting that in AIDS coping methods function like the attribute controllability. Of note is that eight participants drew and described their dominant image of AIDS. These drawings provide a unique revelation of participants' concerns, fears, and beliefs. Having participants draw images of AIDS provides a new method of assessing a person's dominant illness representation.

Implications for Nursing

Inquiring about a patient's image of AIDS might be an efficient, cost-effective method for nurses to assess a patient's illness representation and coping processes as well as enhance nurse-patient relationships. Patients who respond that AIDS is "death" or "they wipe it out of their minds" might need more psychological support.

Many respondents used their image of AIDS as a starting point to share their illness experiences. As persons with AIDS face their mortality, reminiscing with someone who treasures their stories can be a priceless gift. Asking patients about their image of AIDS might touch feelings not previously shared and facilitate patients' self-discovery and acceptance of their illness.

Future Research

Cognitive representations have been identified with AIDS. From this research, it can be posited that how a person images AIDS might influence medication adherence, high-risk behavior, and quality of life. If persons with AIDS believed that there is no hope for them, would they adhere to a difficult medication regimen or one with noxious side effects? Would a person who experienced emotional and social consequences of AIDS be more likely to protect others from contracting the disease? Would it be reasonable to expect that persons who focus on fighting AIDS or caring for themselves would be more likely to adhere to medication regimens? Do persons who turn to a higher power, accept their diagnosis, or minimize the disease have a better quality of life? Further research combining images of AIDS and objective measures of medication adherence, risk behaviors, and quality of life is needed to determine if there is an association between specific illness representations and adherence, risk behaviors, and/or quality of life.

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