To the Graduate Council:

I am submitting herewith a dissertation written by Jeannie Vaughan Gillian entitled "The Nature of Hope Among Men and Women Living with HIV-AIDS." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Psychology.

Ronald E. Hopson, Major Professor

We have read this dissertation
and recommend its acceptance:

Accepted for the Council:

Associate Vice Chancellor and Dean
of The Graduate School

THE NATURE OF HOPE AMONG MEN AND WOMEN LIVING WITH HIV-AIDS

A Dissertation

Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

Jeannie Vaughan Gillian

August 1996

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DEDICATION

It is an honor and a privilege to dedicate this dissertation to my mentor, Dr. Richard C. Rose, III, M.D., and to the women and men who shared their personal stories of hope. My respect and admiration for each of them is immeasurable.

A SPECIAL THANK-YOU

It is with love and appreciation that I offer this special thank-you to my family. I am profoundly grateful to my husband, Vernon, for his endless patience and love during this endeavor. His strength, understanding, and compassionate attention has been a model of encouragement. Vernon's thoughtful contribution of the poetry in this dissertation emerged from his awareness and validation of the participants' experiences.

I am also deeply grateful to my son Bobby for his courageous example and for teaching me how to live with hope in spite of everything. I am thankful for my son Paul, whose sense of humor provided encouragement.

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Lastly, I cherish the memories of my friends, Dr. Donna Bentley, Bill Fossett, and Dr. Bob Goetzman, whose love and unwavering support inspired me throughout this long journey. I shall always miss them.

ABSTRACT

The goal of this qualitative study was to discover how individuals living with the human immunodeficiency virus (HIV) experience hope. Still considered a life-threatening illness, the acquired immune deficiency syndrome (AIDS) continues to challenge those who are affected by it. In an attempt to enhance understanding of the nature and role of hope in HIV-related illness, repeated in-depth conversational interviews were conducted over 24 months in naturalistic settings.

Participants in this longitudinal study originally included 5 women and 30 men; 15 deaths have occurred since the onset of the study. Of the 28 participants who completed the study, all but 7 were diagnosed with AIDS. Many lived with a positive HIV status for 8 years or more. Ages of the participants ranged from 22 to 60 years; the average age for men and women was 34.7 years.

Individuals were invited to respond to the questions, "Please tell me what it has been like for you living with HIV or AIDS," and "Can you tell me about some times when you have been aware of hope?" Twelve themes of the experience of hope were determined through the process of phenomenological analysis of personal narratives. The following portrait of the nature of hope emerged from the discovery process: Hope is the belief in possibilities; it is believing in the possibility of living a meaningful, purposeful life; of having physical comfort; and belonging and connecting with others. Hope is the belief in the possibility of managing the illness, holding on to one's independence, living a "normal" life with humor and love, and doing good deeds. It is the belief in the

possibility of acceptance, living *with* HIV-AIDS, dying with some life left, and being at peace.

An unexpected finding of this study was the lasting quality of hope over time, regardless of illness progression or severity of symptoms. This finding suggests that fatalistic perceptions of an HIV or AIDS diagnosis are not shared by those who live with the virus and that a context for hope should be considered an important aspect of caring for HIV-affected individuals. Thematic descriptions of the experience of hope were discussed in relation to social support, stigma and stereotypes, and Erikson's stage theory of psychosocial development. A notable finding was the participants' complaint of "becoming old." Fatigue and pain were the physical symptoms cited most frequently by both men and women as being difficult to live with. The notion of *hopeful dying* was relevant to many participants. A *hope model* for HIV-AIDS caregivers is discussed.

PREFACE

Due to the involvement of sensitive human issues and distinctive terminology in this study, some statements about general semantics are needed. First, since the qualitative method nudges us toward dialogue and reflection (Spiegelberg, 1976), the first-person style of writing will be utilized whenever possible. This style necessarily flows from the more literary point of view of writer as speaker. Thus, I will avoid the impersonal third-person language in favor of a qualitative stance that seeks to reduce the distance between the writer and reader (Creswell, 1994, p. 43).

Second, due to my ongoing relationship with research participants, the literary distance between the writer and the participants also will be narrowed by design. As one example, the popular (and perhaps worn out) colloquialism "PWA" (persons with AIDS) will be replaced by people with AIDS when speaking about a large uncountable group, and persons with AIDS when speaking about a small countable group of usually four persons or less (Bernstein, 1979, p. 330; Heacock, 1989, p. 156). Both of the above grammatical approaches are compatible with the humanistic paradigm guiding this investigation.

Third, the names of all research collaborators have been changed to protect their privacy. It should be noted, however, that with one exception, all who wished to be a part of the study wanted to use their real names as a means to emphasize the universality and *humanness* of AIDS. Ironically, the one exception was a man who wanted to use his true

name, but feared the loss of his employee health insurance even more than the potential loss of his job if his HIV status became known.

Fourth, I agree with social psychologist Ellen Langer (1989, p. 155) who objects to the label of "patient" both in its noun and adjectival forms, for the reason that labeling has a tendency to negatively affect judgments or reactions toward the people who have been so labeled. Whether we label ourselves patient or are assigned the label by others in the mental health field, for example, it implies something abnormal. Of course, it is understandably a matter of confidentiality that prevents our arbitrary identification of clients or patients by their given names. At the other extreme, however, is the frequent utilization of a person's physical ailment as their means of identification in a medical context. We have heard in radiology departments, for instance, statements such as "Your BE with air is ready in room 3," or "Your L-S spine needs a CT," when referring to a *patient* who is having a barium enema study with air contrast and a *patient* who has had x-rays of the lower spine and needs to have a Computerized Tomography scan. Although not an ideal choice, the familiar word patient will relate to medical contexts in this study with the caveat that it implies positive rather than negative descriptors.

Fifth, unusual concepts, phrases, or words will be defined whenever possible at the time they appear in an effort to facilitate comprehension and preserve the original experiential context.

Finally, the differentiation between HIV and AIDS continues to elicit controversy in a small segment of the scientific population (Price, 1995). The purpose of this study was to hear the voices of people with HIV-AIDS as they described hope in an illness

context; therefore, the debate is of little import for this study. It is generally accepted, however, that the human immunodeficiency virus is the causative agent of the acquired immune deficiency syndrome, although other factors may also be involved. AIDS does not occur in the absence of HIV (Pinsky & Douglas, 1992, p. x), so one cannot "catch" AIDS. AIDS is a variety of diseases and conditions that can result from the breakdown of the immune system (Nuland, 1993). To avoid confusion, I will generally refer to "HIV-AIDS," except for specific instances where only HIV or AIDS is appropriate.

A positive antibody test means that a person has been exposed to HIV and is now infected with the virus. A diagnosis of testing HIV-positive does not carry an automatic diagnosis of AIDS. Specific criteria set by the Centers for Disease Control and Prevention (CDC) must be met. Therefore, the nonscientific (and redundant) phrase "full-blown AIDS" generally refers to those situations where a person has progressed from a HIV-positive status to AIDS, based on the CDC's (1992) revised case definition. Infected people who have less than 200 CD4 T-lymphocytes or a CD4 T-lymphocyte percentage of total lymphocytes less than 14 are now classified as having AIDS (Andrews & Novick, 1995, p. 38). Normal values for CD4 counts are generally 500 to 1600 in adults (Bartlett, 1995; Saag, 1992). The CDC added three clinical conditions (i.e., invasive cervical cancer, recurrent bacterial pneumonia, and pulmonary *mycobacterium tuberculosis*) to their AIDS surveillance definition for adolescents and adults, effective January 1993 (CDC, 1992). Kloser and Craig (1994) note the significance of invasive cervical cancer as an AIDS-defining diagnosis exclusive to women. This addition occurred "a full twelve years into the epidemic" (p. 31), after the

deaths of many HIV-infected women. The other 21 clinical conditions required by the CDC for an AIDS diagnosis are cited by Bartlett (1995, p. 10):

- Candidiasis of esophagus, trachea, bronchi, or lungs
- Coccidioidomycosis, extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis with diarrhea more than 1 month
- Cytomegalovirus of any organ other than liver, spleen, or lymph nodes
- Herpes simplex with mucocutaneous ulcer over 1 month or bronchitis pneumonitis, esophagitis
- Histoplasmosis, extrapulmonary
- HIV-associated dementia; disabling cognitive and/or motor dysfunction interfering with occupation or activities of daily living
- HIV-associated wasting; involuntary weight loss of more than 10 percent of baseline plus chronic diarrhea or chronic weakness and documented enigmatic fever for 30 days or more
- Isosporosis with diarrhea one month or more
- Kaposi's sarcoma in patient younger than 60 (requires positive HIV serology in patient older than 60)
- Lymphoma, non-Hodgkin's of B cell or unknown immunologic phenotype and histology showing small, noncleaved lymphoma or immunoblastic sarcoma
- Lymphoma of brain in patient younger than 60 (or older than 60)
- *Mycobacterium avium* or *M. kansasii*, disseminated

- *Mycobacterium tuberculosis*, disseminated
- Nocardiosis
- *Pneumocystis carinii* pneumonia
- Progressive multifocal leukoencephalopathy
- *Salmonella* septicemia (nontyphoid), recurrent
- Strongyloidosis, extraintestinal
- Toxoplasmosis of internal organ

An Introduction to the Participants in the Study

Alec*
Allyn
Amie
Andy
Ben
Douglas
Elliott
Erik*
Frank*
Garrett
Hal
Julian
Kate
Lawrence
Les*
Lorraine
Lydia*
Mark*
Matt
Max*
Nathan*
Nick
Peter
Phil
Randy*
Raymond*
Russell*
Ryan
Sarah*
Stuart*
Ted
Theo*
Victor
Walt
Webb*

(*Deceased)

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CHAPTER 1

I approached Room 735 with dread and profound sadness, expecting the grotesque indignities that often befall sufferers of Pneumocystis carinii pneumonia. The response to my timid knock on the door was the command from someone inside to "Come!" With heightened senses I was pulled into the room's fragrances of apples, melons, scented candles, and flowering plants. Flashes of color everywhere demanded immediate inspection of various religious icons, a rosary, photographs, and a wall covered with cards, letters, and poetry. A funny character on the front of a get-well card caught my eye (did I suppress a smile?) while my finger found its way across the spine of a treasured book.

The bubbling oxygen machine drew me, albeit hesitantly, to the bed where Lawrence lay smiling under his mask. His fingers closed around my extended hand. He asked, "Have you heard how bad it is?" I answered his direct question with an equally direct "Yes." Fighting back unwanted tears, I grinned instead at the teddy bear keeping a vigil under his right arm. One of the doctors had reported that Lawrence had one foot in his grave and the other on a banana peel. He had been given the Last Rites by a bishop. The expectation of his survival was frail at best.

But something about this room and the people in it felt different from other rooms I had visited. It was curiously comfortable and nearly reverential--not at all an atmosphere of dread or grotesqueness. Where was the gloom and doom? Hadn't I come to the hospital, after all, to say goodbye? Instead, I found myself questioning these feelings, wondering what was actually going on here. There was an absence of hopelessness despite the ominous prognosis. Plus, there were around-the-clock caregivers engaged in their specific roles with obvious competence and compassion. There was a medical advocate who greeted the physicians and discussed each health protocol as though it were his own. Other caregivers served as spiritual guide, keeper of the always-ringing telephone, massage therapist, and even deliverer of homemade treats.

Ten days later, Lawrence and his friends were discussing this healing. He claimed his doctors, nurses, caregivers, and his family "yanked him back from death." He was fascinated by the "massive pyramid of creative energy" that everyone had who was seriously involved in his care. He and his caregivers identified this energy as hope. They were aware that hope could influence the outcome of his life-threatening illness and were

determined to keep it even in the worst of times. Their sense of hope was not a denial of the possible fatal consequences of the pneumonia. They openly talked about their private moments of sorrow. Still the dominating mood was remarkably positive. More than that, there was an inextinguishable presence of hope.

[Researcher notes]

Phenomenon of Interest

This recovery exemplifies a passionate, organized assault against fatalistic beliefs in the treatment of HIV-related pneumonia. Given the lack of any known cure for the human immunodeficiency virus (HIV) that can lead to the acquired immune deficiency syndrome (AIDS), the still-prevalent "myth of 100 percent mortality" (Callen, 1990, p. 65) predicts that *Lawrence*'s survival of this grim opportunistic infection should not have occurred. Indeed, men, women, and children living with HIV-AIDS are still held captive by the formidable tenet that AIDS is inevitably fatal. Remarkably, these predictions of death failed to deter the hope among this mobilized group of caregivers.

According to Karl Menninger, we should not be surprised to witness unexpected healings. In his 1959 address to the American Psychiatric Association, he invited scientists to speak up about "this ancient but rediscovered truth, the validity of Hope in human development" (p. 491). Menninger further suggested we ask ourselves these questions: "If we dare to hope, should we not dare to look at ourselves hoping? Should we not adhere to our professional habit of self-examination and contemplation?" (1959, p. 482). Heeding this invitation, two preliminary questions emerged about hope relating to health care. First, how do men and women describe their experience of hope in the

lived context of HIV-AIDS? Second, how is the experience of hope revealed over time for individuals living with a terminal disease?

In her work with people living with terminal illnesses, Elisabeth Kubler-Ross (1969, p. 138) tells us that hope persists to the end and even in the worst situation it is hope that "sneaks in" to help patients cope a little longer. If this is so, where does hope come from? What is it? How is it sustained? Do people with AIDS who are not expected to live have hope sneaking in to help them? And what, after all, are the unique or shared meanings of hope from their perspectives?

It is clear from the early writings that a uniform meaning of hope does not exist (Farran, Herth, and Popovich, 1995), although hope certainly is a universal phenomenon. Hope's perceived elusiveness was succinctly confirmed by *Garrett*, a research participant, who remarked that trying to describe hope is "a little like trying to dissect a sneeze." A reportedly multidimensional concept, hope has been touted as future oriented and energizing (Hickey, 1989; Vaillot, 1970), the best resource of mankind (Lynch, 1974), constantly changing (Nowotny, 1991), a shorthand term for an expectation about goal attainment (Snyder and Forsyth, 1991; Stotland, 1969), and an essential component in human development (Erikson, 1982).

Godfrey (1987), Kierkegaard (1968), and Obayuwana and Carter (1982) wrote that hope is the feeling or passion that what is desired *must* also be possible. Korner (1970) agrees with this dependence on outcome and stresses its role as the *central* characteristic of hope for the person who feels that the "hoped-for events must occur for the sake of his well-being" (p. 135). However, this description lacks congruency for

Lawrence and others living with HIV-AIDS, because having the desire and passion to survive may not be possible without a cure for this disease. In fact, survival was not possible for 15 of the original participants who asked to be a part of this study.

On the other hand, what is it like for those who are long-term survivors? Is hope their constant companion as they endure HIV-AIDS over many years? For example, what is the nature of hope for *Peter*, who has outlived his entire circle of friends, which also made up his social support network? Little is understood about the meaning of hope in a longitudinal context where men and women are challenged by existential issues. Some are abandoned by family during their most fragile moments. Others survive long enough to experience the constant loss of friends and lovers, while struggling to hang on to their own lives, work, productivity, and health. For some individuals, having AIDS means the loss of one's children or grandchildren. *Les*, for example, was not allowed to see his small children. *Russell's* grandson was removed from the home by court order for the reason that the child's life "was in jeopardy because his grandfather, who lives in the same house, has AIDS." All are continually grieving their many losses, both real and anticipated. As *Raymond* explained, "My greatest fear is losing my ability to think; the next fear is losing my ability to use the bathroom by myself."

The purpose, then, of this research was to gain an understanding of what hope means to people who are living with the challenges of HIV-AIDS. Because the nature of hope was the focus of the study, it was identified as the *Hope Project*. This abbreviated title facilitated immediate recognition of the study by referring physicians and other health care professionals. Distinct from the American Psychological Association's *HIV*

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Office for Psychology Education (HOPE), which conducts AIDS training programs, the Hope Project was designed for the longitudinal study of hope among adults in a specific southeastern community.

Using a phenomenological approach, this study attempted to uncover the experiential meanings of hope as it unfolded along a retrospective-prospective continuum. Throughout 24 months of participatory research, detailed narratives were given by 28 adults during serial conversational interviews. The process of inquiry was facilitated by the context-bound nature of experience for these participants whose stories were revealed in their own words across time. From transcribed audiotapes, and from informal communications and personal documents, thematic descriptions of the phenomenon of human hope were elucidated. Interpretive guidelines adapted from the qualitative intuitive-inductive perspective of van Manen (1990) enhanced the development of a meaningful gestalt of hope. Heuristic inquiry (Moustakas, 1990) and the examination of creative and artistic sources relating to hope also contributed to the thematic structure.

Perceived Justification for Studying the Phenomenon

To create a context for hope that supports adults in their effort to survive HIV-AIDS, we first must strive to understand the nature of hope in the daily lives of those who exist with this infectious disease. That goal created the impetus for this inquiry. Marshall and Rossman (1995, p. 26) suggest that a study's justification may also

be addressed by demonstrating its relevance to four domains. These domains are particularized in the following questions:

1. Who has an interest in this inquiry?
2. What do we already know about this phenomenon?
3. What has not been answered in previous research and in health care practice?
4. How will this new research contribute to the existing literature and to applied health care practices.

Interest in the Phenomenon

The perceived interest and concern for this work stems from the discrepancy between how people with HIV-related disease talk about and assign meanings to hope, and how others (e.g., caregivers, family, friends, and health care providers) think about hope. For instance, as this study of hope progressed, more than one person asked incredulously, "You mean there's really hope for these people?" That the question is still asked, however, reveals a need for exploration and discovery. Each of us, whether we are clinicians, educators, students, or patients, will have a first-hand connection or experience with HIV disease and the nature of hope.

Perceptions of hope may be subtle or obvious. Carol Alter (1994) described an incident several years ago in which a physician stated that he saw no point in aggressively treating hospitalized AIDS patients because, as he said, "They will die anyway" (p. 2). In relating his experience of living with the ubiquitous notion of a death sentence, *Garrett* emphasized this point:

> *The minute I told people [I am HIV-positive] they got this strange look--and it wasn't shock. There's something else right under the surface. They were looking at me because they wanted to see what it looks like to find out you're going to die. It's a more civilized version of executioners looking into the eyes of people they guillotine. People want to know what it's like.*

Insensitivity to the power of hope can dramatically affect the psychological and physical well-being of patients, particularly at the time of initial HIV diagnosis. An example of insensitivity can be illustrated by my recent visit to a hospitalized young man who had just learned of his HIV status and he was diagnosed with AIDS at the same time. What he thought was bronchitis resulting from a common cold turned out to be Pneumocystis pneumonia. Openly sobbing, he related how a physician came into his hospital room, informed him that he might be able to live two more years, and then promptly left the room. With tears falling on his oxygen mask, this young man cried out repeatedly, "I'm going to die, I'm really going to die!" His panic was palpable. His friends in the room were crying. It was an atmosphere of total and utter doom.

We began to talk at length about how beliefs and emotion influence the immune system and how mind-body interactions can profoundly affect the healing process. We tried to imagine how it must feel to survive pneumonia and live many years with the virus. Referrals for psychosocial support within the community were given. Embedded in the conversation was hope. As it surfaced and became real for him, he was able to recognize the importance of his personal beliefs, choices, and coping strategies. Admitting he previously "fell apart" in any crisis he experienced, he was nevertheless able to work out a plan for survival. The crucial first part of the plan was to focus on

being able to breathe and relax; the second part was to conclude that the physician's opinion might be flawed, and the patient would, as he said, "prove it!" by surviving.

One of the remarkable characteristics about hope according to Andrews and Novick (1995) is that it "provides the basis on which patients can act in their own self-interest" (p. 29). That is, hope is empowering and enabling. For this patient, hope seemed to enhance his ability to breathe more gently and provided the needed energy for healing. So far, he continues to enjoy relatively stable health and a renewed sense of humor. Rather than being a person dying with AIDS, he is now a person living with AIDS.

It is unfortunate that the offering of unsolicited timetables regarding life expectancy has increasingly been reported by research participants. For example, *Alec*'s physician was brutally specific; she claimed he would live 18 months. In fairness to health care providers, however, the expectation of imminent death following an AIDS diagnosis is consistent with how the epidemic is perceived, and it continues to be a belief held by most people. Several factors contribute to perpetuation of this belief. One factor is the exposure to the early tragic media images of emaciated young men with skeletal faces gazing into nothingness through blackened, deep-set eyes as they awaited death.

As the public became aware of the epidemic and its gruesome physical assaults, the existence of survivors was of little importance to the media. Ironically, an initial focus on survivorship would have threatened the epidemic's life-and-death significance, perhaps resulting in an even greater delay in grants for research, education, and treatment than those that actually occurred (see Shilts, 1987). Given this unfortunate dilemma,

death from AIDS became a self-fulfilling prophecy as evidenced by the numbers of people with AIDS who gave up and "obediently died on schedule" (Callen, 1994, p. 69).

AIDS has already killed 311,381 men, women, and children. It is the leading cause of death among adults aged 25 to 44 in the United States (followed by unintentional injuries, cancer, heart disease, suicide/homicide, liver disease, stroke, and diabetes). Another one million Americans are estimated to be HIV-infected (CDC, 1995a). Furthermore, the World Health Organization (WHO) predicts that most of those Americans who have the virus will develop AIDS by the year 2000 (Stine, 1993; WHO, 1994). This ominous data surely punctuates the death-sentence myth and the accompanying ambivalent beliefs about the efficacy of treatment. In other words, why bother treating a person who is assumed to be dying? These attitudes diminish the worth of human life and a person's need to live life with AIDS as it happens--maybe even to survive. A malignant doom has threatened personal dignity, choices, and decision making. An example of this was revealed by a mother of a person with AIDS. The mother was asked by a friend why she was "letting" her child take the antiviral drug zidovudine (AZT). The presumed well-intentioned rationale for the question was that it would be kinder to let the child die than to prolong the illness and the suffering. It is shocking to realize how quickly and easily life can be discarded when perceptions of hope are lacking. For patients and their families who are struggling to survive with the virus, misguided notions can be tantamount to despair. Once again *Garrett* reflects on his own experiences:

When you tell [them], when you say, I'm HIV positive, their brain is picking out which tie they're going to wear at the funeral. And they're wondering, will I have to carry the body or will you cremate it? And who is going to get his record collection? I hear them think, Who's going to get all the CDs? I wonder if they're already spoken for?

There is indeed sufficient concern to support Alter's (1994) appeal for an awareness of hope in the second decade of AIDS and to support her call to "redefine" hope for patients, families, and those working on the front lines in AIDS care. As the audience of this study, whether we are directly or indirectly involved, we have a role in this epidemic and in hope phenomena. While the epidemic continues to puncture lives, we are, as Matousek (1995) eloquently proclaimed, "howling in the nineties, not just because of this virus, but [because of] an epidemic of godlessness [and] a hunger for light, and meaning, and home" (p. 308).

Knowledge of the Phenomenon

Despite sobering HIV-AIDS statistics, this epidemic has challenged health care professionals trained in the Western model of medicine. Historically, the medical milieu has been dominated by a biomedical paradigm, focusing on the prevention, diagnosis, treatment, and cure of disease. Powerless either to predict or effect a cure for people with AIDS, however, it is no wonder that death as the only outcome has been a pervasive belief and prediction.

In contrast, we now know that many people will survive ten or more years with HIV before significant damage to the immune system puts them at risk for multiple infections (Price, 1995). We also know that new treatment protocols have contributed to survival in spite of recurrent infections and drastic T-cell depression (Callen, 1990). Just

hearing that a pharmaceutical company has released a new HIV drug therapy allows patients and families to feel hopeful. For instance, as he lay in the hospital, *Russell* asserted that the morning news on television could be interrupted with a news flash about a cure for AIDS. And although the cure might not save him, he hoped it would save others.

What, then, accounts for survival when people are told that AIDS is not survivable? How important is the role of hope? In the traditional medical view of illness, descriptions of hope would easily be dismissed as "soft" nonscientific data (Illich, 1976) as opposed to "hard" data, which refers to the assignment of numbers to a phenomenon that is statistically investigated (Maguire, 1987, p. 27). Even in this decade the possible interaction of positive or negative psychological factors (e.g., optimism, humor, and hope, or depression, guilt, and anxiety) with immune function and disease progression still elicits debate within the scientific community (Kemeny, 1994). Nonetheless, we are reminded by Cousins (1989a) and Dossey (1991) that relationships exist which link physiological changes with psychological constructs, including hope. That hope can affect health outcomes was documented by Dr. Bruno Klopfer (1957) in his now-classic anecdote of the hospitalized patient, Mr. Wright, who suffered from cancer of the lymph nodes. The failure of treatments to diminish his tumors (reportedly the size of oranges) prompted the physician to administer an experimental cancer drug called Krebiozen. Within ten days after the injections, Mr. Wright's tumors shrunk and he was apparently disease free for two months.

Coincident with a report he read that the cancer drug was ineffectual, Mr. Wright had a relapse and was rehospitalized. Although not expected to live, he pleaded for more treatments in the hope his life would be spared. Having nothing more to offer, Dr. Klopfer used his patient as a control in a drug study testing the supposedly "new, improved" version of Krebiozen. This was actually a placebo drug of sterile water injections. Once again Mr. Wright was symptom free and enjoying good health, which he attributed to the new injections. Just as before, however, the patient heard an announcement from the American Medical Association clearly warning that Krebiozen was a worthless drug in cancer treatment. His tumors returned and he died within two days of being hospitalized. Dr. Klopfer associated his patient's death to a loss of faith, claiming that his patient's last hopes had vanished. Although it is not reasonable to assume that this patient's death was *caused* by hopelessness rather than the effects of cancer, neither can we discount the influence of psychological factors in health and well-being.

Both Mr. Wright's death from cancer and *Lawrence*'s recovery from pneumonia speak to the influence of hope on complex negative and positive emotions surrounding mortality. If viewed from the interdisciplinary perspective of psychoneuroimmunology (PNI) whereby the mindbody dichotomy is abandoned, both death and recovery are linked with the interaction of psychic and biological processes involved in the body's defenses. Empirical and anecdotal evidence for this interaction exists (see Weil, 1995, for a review). PNI links learned emotional patterns with illness through the disciplines of psychology, neurophysiology, immunology, and endocrinology (Siegel, 1989). A

striking recent example was the report of a young woman whose HIV-positive diagnosis immediately thrust her into physical and emotional decline. After enduring three years of HIV drug therapy and its resultant side effects, along with severe depression, physiological deterioration, and a loss of hope, she consulted a different physician who propitiously ordered a repeat HIV antibody test. It was negative. He learned that the original test results were erroneous--she had never tested positive for HIV antibodies. This woman's health improved quickly and dramatically when she heard the new test results.

In the same way that Cannon (1942) described death by voodoo and Klopfer described his patient's placebo response, this woman's perception of HIV-AIDS illustrates how, to use the words of Cousins (1989b, p. 229) "belief becomes biology." What happens in the brain affects the body, and what happens in the body affects the brain. This intimate melding of mind and body ultimately and directly affects health and disease processes (Dienstfrey, 1991). In support of an interactional, biopsychosocial approach to AIDS research, Solomon (1985), Talal (1983), and Solomon and Temoshok (1987) demonstrated in their early studies that there is a relationship between psychological and immunologic variables and disease outcome variables (e.g., CD4 T-cell counts). Based on his postulates elucidating the intimacy of this relationship, Solomon (1985, p. 16) stressed the need for further study of the possible role for psychological intervention in immune enhancement for HIV-infected patients. Nurse researchers Lovejoy and Sisson (1989, p. 12) presented five of Solomon's postulates, listing those factors which might enhance or decrease immunocompetence:

1. Are individuals who are out of touch with, unaware of, or unable to express emotions [specifically negative emotions] most at risk for increased AIDS progression rates?
2. Do personality characteristics influence the incidence, severity, or course of immunologically resisted and autoimmune diseases, including AIDS?
3. Is the onset of AIDS [following HIV infection] preceded by emotional distress or failure of coping mechanisms or psychological defenses?
4. Are happiness, security, sense of control, relaxation, and other positive emotions [e.g., hope] accompanied by immune enhancement?
5. Is longevity among persons with AIDS associated with superior psychological defenses, interpersonal skills, and coping mechanisms?

Solomon's (1987) postulates generated considerable support for the psychoneuroimmunological study of HIV-AIDS. The notion of longevity as hypothesized by Solomon (see No. 5 above) is rapidly becoming the nexus for AIDS research in the 1990s. In fact, Price (1995) contends that studying psychological processes in large groups of people who are living longer and doing well with HIV should be "the single most important area for study...more so than any pharmaceutical drug trial" (p. 12).

Also advocating the suitability of AIDS research under the umbrella of psychoneuroimmunology, Locke and Colligan (1986) claim that one specific goal of PNI research is the discovery of a way both to summon and to measure the hope phenomenon:

> Part of its quest is to call forth the biology of hope through an appreciation of the healing powers of the human spirit and a deeper understanding of the intimate neuronal and hormonal bonds between the mind and body. In the remainder of this century and in the one to come, the art of healing and the science of medicine will be transformed by that quest. (p. 221)

Previously, Solomon and Temoshok (1987) reported that because "AIDS is under an epidemiologic, clinical, and psychosocial cloud of such uncertainty and bleakness, it is difficult to see a silver lining" (p. 287). With the foundation for further study having been erected by Solomon and his colleagues, however, this bleakness has waned somewhat. Due to their pioneering work in the study of HIV-AIDS, we now know more about AIDS as a multifactorial disease. Much has since been learned about the effects of HIV on psychosocial aspects; however, the importance of mental states on progression of HIV is still in need of investigation (Folkman, 1993; Stern, 1994). Reviews by Antoni et al. (1990) and Coates et al. (1987) highlight research endorsing the benefits of early behavioral interventions on psychological and immunological functioning, and how these interventions may reduce or prevent AIDS-related deterioration.

Indeterminate Research Findings

In a selected chronology of research of hope and hopelessness, Farran et al. (1995) listed over 50 quantitative (i.e., deductive and statistical) studies conducted primarily in adult populations over a 20-year period. The initial conceptualization of hope from which standardized scales for measurement were designed viewed hope as unidimensional, action-oriented, and future oriented. This cognitive appraisal tied hope to expectations of a better future and goal achievement (Snyder, Irving, & Anderson, 1991, p. 286).

Generally, in psychiatric and psychotherapeutic settings, the absence of hope was reported in levels of hopelessness as measured by specific instruments. When clinical research on hope progressed to the health-illness domain, the earlier conceptualization of hope based on goal attainment was disputed by clinical nurse researchers who were able to describe many different dimensions of hope in their patients' lives. As Owen (1989) pointed out, patients' qualitative (inductive and descriptive) experiences of being hopeful in spite of a grim prognosis contradicted the unidimensional view of hope. There is more to hope, therefore, than the quantitative scales revealed. In the opinion of Owen (1989, p. 75), hope has indeed been recognized as a unique human experience, but its uniqueness has not been preserved in quantitative studies of hope done in medical settings. To learn more about hope, researchers began to explore its qualitative aspects outside the rigid boundaries of cognitive and affective goal expectations.

In today's health science literature on hope, there is still a gap concerning the existence and role of hope for individuals living specifically with HIV-AIDS. Since the AIDS epidemic is a recent phenomenon, instruments previously utilized for measuring relationships between such variables as hope and depression or hope and locus of control may necessarily be inadequate for people who are HIV-infected. In considering this research, the following questions should be addressed:

1. Is it useful to assume that an instrument developed in one culture will be applicable to all cultures?

2. Is the purpose of a hope scale for people with arthritis or alcoholism the same as for people with HIV-AIDS?
3. Will the findings of a hope scale for one population be generalizable to all others?
4. If a research goal is the discovery of personal meanings of hope throughout the lived course of HIV-AIDS, will standardized measurements enhance this discovery?

In their study addressing levels of hope in the context of HIV, Rabkin, Williams, Neugebauer, Remien, and Goetz (1990) reported baseline assessment data for 124 HIV-positive and 84 HIV-negative homosexual men who were to be followed for 5 years. Participants were mostly well-educated, financially successful men who had neither a diagnosis of AIDS nor a neurological disorder. Rabkin and her colleagues had as their long-term goal the identification of both risk factors and protective factors in the progression of HIV. Variables measured were social support, health locus of control, commitment, stressful life events, depression, and physical symptoms. These were correlated with hope, as measured by the Hopelessness Scale (Beck, Weissman, Lester, and Trexler, 1974). The Beck Hopelessness Scale evaluates negative attitudes and goal expectations based on three types of hopelessness (i.e., lack of enthusiasm, lack of motivation, and lack of future expectations).

The results indicated that hope was positively associated with perceived social support and negatively associated with depressive symptoms (Rabkin et al., 1990, p. 1326). Less hopelessness was found among those having a higher internal locus of

control. No relationship was discovered between level of hopelessness and physical symptoms, HIV status, or CD4 T-cell counts. (Generally, the assumption is that as the number of T-cells decline, there is a higher risk for various infections.)

These initial findings imply that higher levels of hope were found in men, independent of their HIV status, who had a strong sense of control, few depressive symptoms, and adequate social support; all of which validates Solomon's (1985) hypotheses mentioned previously. The authors of this study ask us to recall that the results pertain only to this group of well-educated, financially secure men who receive care at a major AIDS epicenter. Aside from the generalization problem, however, questions remain: What *is* hope for this group of men? Can hope in HIV disease be validated by an instrument originally designed to quantify hopelessness in psychopathological conditions? (Beck et al., 1974, p. 864). What does it mean to have "levels" of hope? More important, if the findings had revealed that the HIV group demonstrated higher levels of hopelessness than the HIV-negative group, could we presume that they had less hope (or no hope)? To discuss these questions further, let us consider a sample of the 20 true-false items (scored 0 or 1) appearing on the Hopelessness Scale (Beck et al., 1974, p. 862). Six questions were answered by *Allyn*, a person with AIDS, during the initial preparation of this research:

1. I can't imagine what my life would be like in 10 years. (*Allyn* checked *true*.)
2. My future seems vague and uncertain to me. (*Allyn* checked *true*.)
3. I don't expect to get what I really want. (*True*)
4. I expect to get more of the good things in life than the average person. (*False*)

5. I can look forward to more good times than bad times. (*False*)

6. I have enough time to accomplish the things I most want to do. (*False*)

The first three items are keyed *true* and are reversed scored, resulting in higher levels of overall objective hopelessness when combined with the final three items which are keyed *false*. *Allyn*'s score was six, an indication of marked hopelessness. I asked him to describe his thoughts as he checked true or false responses. He revealed an acceptance of a shortened life span threatened with uncertainty, illness, and losses (e.g., friends, health, work). He did *not* expect to receive more good things than any other person, and he was certain there would be insufficient time for accomplishments. Questioned further as to his perception of hope, he replied, "Yeah, I have hope, lots of hope--at least today--tomorrow I might not feel like I have it. You never can tell." Responses are typically positive, although not always. The point is that *Allyn*'s responses reflected his realistic assessment of living with HIV. Although the quantitative survey suggested hopelessness, his own perception was quite hopeful, at least for that moment in time.

I concur with Owen (1989) that a serious disparity exists between empirical studies and real-world clinical experience relating to perceptions of hope. Equally disturbing are forced-choice responses resulting in low levels of hopelessness (more hope?) on the Hopelessness Scale. It is not uncommon for people diagnosed with HIV to continue living as they did before diagnosis. For example, after receiving his diagnosis by mail, *Victor* carried on as usual as if he only had experienced, in his words, a "bad dream." This protective denial could easily transfer to objective hope measures such as the Hopelessness Scale. It would be difficult to ascertain if high levels of objectified

hope were accurate in this instance, or indicative instead of anxiety manifested in using denial. Both situations magnify the need for qualitative evaluations of hope in conjunction with quantitative surveys (where applicable), both in research and in clinical practice.

AIDS is a nondiscriminating infectious disease that affects a culturally diverse population of all ages and lifestyles; thus, its unique characteristics are not easily studied. Regardless of transmission route, for instance, all people diagnosed with HIV or AIDS are at risk for experiencing profound shame, guilt, isolation, discrimination, or anger. We only have to imagine ourselves hearing the words, "Your HIV test is positive," to appreciate the blow to one's well-being. The consequences of infection separate HIV-AIDS from other serious illnesses and cannot be catalogued according to statistical hypotheses or a priori assumptions. Parents who unknowingly infect their child have qualitatively different circumstances than parents who conceive a Downs syndrome child. Young HIV-positive adults may be cast out of their homes, or they may be required to use a separate bathroom. Others are asked to use separate eating utensils. These patterns are not issues in illnesses such as leukemia or spinal trauma, or even sexually transmitted diseases such as herpes or gonorrhea. People with AIDS have been asked not to attend their church or participate in religious rituals. Others have lost jobs, and still others have been refused medical or dental care.

Somewhere within this experiential territory lies hope. Its uncharted role, meaning, and influence ripples through the lives of people living with HIV-AIDS. Lonely and frustrated, many people have little social support. *Garrett* explained how relationships can change after HIV exposure:

> *After this happened, I really lost hope in ever finding anyone again. And that is the part--if there is a part that really destroys people--that's the part that does it. I think that if you really talk to people you'll find that it's the abandonment and the loneliness that destroys--that this disease does to people--because suddenly you are different from everybody around you in ways that have nothing to do with the clinical progression of this disease.*

One person with AIDS-related skin cancer mentioned the irony of losing what he valued the most--human touch--which played a significant role in his acquiring the virus. Others have all the comfort and care they need yet they suffer inexorable personal anguish because of their fear of death.

Cultural diversity also increases the need for alternative exploratory styles in HIV-AIDS research. Personal narratives are particularly well suited to studying subjective meanings of hope throughout the course of any illness. This naturalistic, nonpresumptive style allows for the preservation of a person's unique experience in his or her own unique voice and language (Sarbin, 1986). Bevan (1991) endorses this approach in his statement, "To insist on the objectivity of a science in terms of its separateness from the life experiences, intentions, values, and world views of the persons who create that science is to deny its fundamental character as a human activity" (p. 477). Therefore, to dehumanize the experience of HIV-AIDS by objectifying its characteristics is akin to turning a deaf ear and avoiding understanding that which is unmistakably human.

Contribution to Literature and Practice

Narrative research with HIV-affected people has value for several reasons. For one, it allows patients to tell their own stories without having researchers speaking for them. Who knows the experience better than the person whose life has been pierced by disease and can describe it as it is lived? Narrative research is respectful and acknowledges the participant's unique expertise in the research collaboration (Viney and Bousfield, 1991). Also important is the often-reported catharsis that occurs as a result of hearing one's own story told to an active listener. As *Ryan* said after a conversation, "I feel much better now!" Or *Matt*, who came to a changed understanding of something he was describing and said, "I guess I never realized that before." Traveling this pathway enables many participants to experience self-knowledge, empowerment, and emotional release (Kleinman, 1988; Stivers, 1993). Sometimes a family member may share in these insights. For example, after *Russell* and his wife Shirley shared a conversation with me in which they discussed the topic of dying for the first time, they both remarked how a burden had been lifted by addressing what they both had been avoiding. After finally saying what needed to be said, they were able to get past the silence and make plans for his funeral and for his family's future. Mishler (1986) supports this type of empowerment through personal narratives because it points the person toward the possibility of action. In other words, "to be empowered is not only to speak in one's own voice to tell one's own story, but to apply the understanding arrived at to action in accord with one's own interests" (p. 119).

In the realm of chronic and terminal HIV-AIDS illness, narrative research contributes to the discovery of how people cope and make sense of the absurd or disruptive situation, the disappointments, and the physical destruction occurring over time (Pickrel, 1989; Riessman, 1990). It has also provided an opportunity for reciprocity--a giving back to others--via the contribution of shared experiences. Finally, Viney and Bousfield (1991) found that qualitative narrative analysis used in conjunction with other methods of research reveals a synthesis of psychosocial phenomena within the studied population. In the Hope Project, for example, one outcome was the synthesis, or "cultural portrait" (Creswell, 1994) of hope as revealed by gay men living with the virus, which differed from the portrait of nongay men. Viney and Bousfield encourage the future use of narrative strategies for the purpose of informing policy makers on AIDS issues by "going beyond head counts to reveal a little of the complex experiences in those heads" (1991, p. 764).

Given the deficiency of narrative data in describing the awareness and meaning of hope among people living with HIV-AIDS, this study attempted to augment the literature by collecting data obtained in face-to-face conversations. This method contributed to the shared understanding of significant experiences of hope gleaned from personal narratives. Consider, for example, what *Garrett* had to say about the role of hope in HIV disease:

> *Hope is a real malleable thing. It is circumstantial. There's a possibility that somebody at the Sherwin Williams plant will accidentally drop the peach paint into something and produce the wonder drug. The mold growing in somebody's coffee cup will be the big answer. Who knows? If we're going backwards, cats and dogs will get their own checking accounts...It's just not reasonable to expect that things will remain the same.*

Garrett makes a salient point. Nothing stays the same. Changes are constant, and science is constantly propelled by change and by new possibilities for hope. The history of cancer care is an apt example.

Like AIDS, cancer was once viewed by most people as abhorrent, and its implications unthinkable. As one woman exclaimed, "When I heard the diagnosis and the word cancer, I nearly stopped breathing." One's life unfolds in slow motion and then bends back upon itself in defense of the contemplation of death. With the association of cancer and death came the construction of the phrase *terminal illness*, which further perpetuated the isolation of people with cancer into dark cubbyholes juxtaposed with hospitals, terminal wards, and death. The horror and the stigmatization of cancer splattered onto anyone who was near or dear to the cancer patient. (Ironically, in the early days of cancer care, even nurses who elected to care for the terminal patients were sometimes labeled weird or morbid by their peers.)

Suffering physical debility, surgical mutilation, and drug experimentation, cancer patients accepted (or welcomed) death as an escape from the unbearable captivity of pain and hopelessness. With the sophistication of diagnostic procedures and chemotherapy protocols, however, survival rates improved over time and hopelessness gave way to hope (R. Blum and D. Blum, 1988). Public awareness of cancer as a treatable disease encouraged the active participation of both patients and caregivers in the treatment process (Blumberg, Kerns, and Lewis, 1983). Today we seldom witness the rejection or fear of cancer patients that was seen 25 years ago. In many cases, although not all, cancer is now linked with hope.

Coupled with the changes in the technology guiding cancer therapy were the new questions being addressed about the awareness of hope among the seriously ill (Miller, 1989; Owen, 1989). Coping responses, in particular, were associated with hope in the early studies of cancer patients (Buehler, 1975; Hickey, 1989; Laney, 1969; Limandri and Boyle, 1978). The quantitative measurement of hope in chronic illness among diverse groups was the concern of nurse researchers studying patients with adolescent cancer (Hinds and Martin, 1988), multiple sclerosis (Foote, Piazza, Holcombe, Paul, and Daffin, 1990), traumatic spinal cord injuries (Elliot, Witty, Herrick, and Hoffman, 1991), and chronic heart failure (Rideout and Montemuro, 1986).

As the multidimensionality of hope was discovered, its conceptualization became broader. While quantitative methods had identified correlations between hope and hopelessness and other variables (e.g., social support, depression), qualitative methods were used to identify meanings of hope and reveal those circumstances that appear to hinder or foster it (Artinian, 1984; Herth, 1990).

Social science researchers are credited with the continuation of hope-related research in diverse clinical settings using varied qualitative methods (Ersek, 1992; Herth, 1993; Raleigh, 1992). For example, Ersek (1992) used grounded theory analysis (Glaser and Strauss, 1967; Strauss, 1987) in her qualitative study of adults coping with bone marrow transplantation. Interviews were conducted at three intervals during the transplantation process. The maintenance of hope for these 20 patients was uncovered in the strategies they used to sustain it. Ersek's report of the two categories used to maintain hope (e.g., dealing with it; keeping it in its place) clearly illustrates the "contradictory

nature of a treatment...[bone marrow transplantation] that both gives and threatens hope" (p. 889).

Farran et al. (1995, p. 25) stress the importance of designing research methods that specifically measure hope or hopelessness. Although interrelated, hope and hopelessness create different questions about different experiences. It is the process of confronting these questions that leads to a deeper understanding of both experiences as they are positioned at opposite ends of a spectrum. Farran et al. (1995) suggest that a blending of quantitative and qualitative studies will contribute to our understanding of the attributes and expressions of hope in various illness situations (p. 196).

Just as new questions guided research on hope among cancer patients, new questions are now guiding AIDS-related research on hope. Recently, studies utilizing qualitative methods in the investigation of HIV-AIDS and hope began to emerge in the literature (Hall, 1990; Herth, 1990; Shelby, 1995). Inquiries into the nature of hope in the context of HIV-AIDS may contribute to the way we think about AIDS, about hope, about the people who are infected by the virus, and about its perceived fatality. By extension, it may also contribute to health care practices and the manner in which we provide support and care for people with HIV-AIDS. Although as yet unexplored, this research has potential relevance to the application of health care resources, especially in light of recent health reforms. Thomasma (1995) suggests a "new kind of health care" that restrains traditional biomedical models and embraces alternative therapies and interventions that may contribute to the better care of the whole person. While conceding that the successes of the biomedical perspective are numerous, a mechanistic approach to health will

nonetheless advance medical technology to the point of excluding the important interdependence of physical, psychological, and social factors. According to Weil (1995) holistic medicine is needed, but it is obstructed by a lack of viewing humans as more than their physical bodies. What is needed is an exploration of hope that engages the mind-body condition, which emphasizes the broad context of humans struggling with a disease. As Capra wrote, "any illness...can be understood only in relation to the whole network of interactions in which that person is embedded (1982, p. 152).

Since we are now aware that people with HIV-AIDS are living longer, their care necessarily involves many dimensions of expertise over time, but in an unpredictable fashion. Similarly, as greater numbers of people develop AIDS, biotechnical capacities will be reduced during health care reform making alternative interventions figural during the next decade. The unveiling of hope phenomena could enhance the pragmatic, holistic, and successful treatment of HIV-AIDS. For Lawlis (1995), an understanding of the role of hope in medical care is "unchallenged as the most critical of all psychological attributes of healing" (p. 41). Ultimately, of course, what we learn about hope will be relevant, given the estimated worldwide population of 20,025,000 adults and 2,175,000 children who are now HIV-infected (Global AIDS Policy Coalition, 1995), and the one million adults and half-million children who are now in a late stage of AIDS (CDC, 1995a). By the turn of the century an estimated 10 million people worldwide will have progressed from HIV infection to a diagnosis of AIDS (WHO, 1995).

In sum, the following concerns directed the goals of the Hope Project and afforded its justification:

1. Hope phenomena have not been explored or described within the longitudinal context of HIV-AIDS specifically, nor among women and men who live many years with HIV illnesses.
2. Because other people have a crucial role in all human experiences, understanding the meanings of hope for HIV-affected people should help formal and informal caregivers be more vigilant and sensitive to the ways that their thoughts and actions affect health and well-being.
3. There is a need to foster an understanding of the nature of hope for each person who is trying to live a meaningful, normal life. Being treated as a dying person (often for ten or more years), while living with hope, undermines this effort.
4. An examination of the role of hope across the illness continuum from diagnosis to death could influence quality of life issues and intensify individual life meanings.
5. An awareness of hope could enhance and promote holistic treatment practices. Such collaborative efforts may prompt the development of hope patterns that view humans who live with HIV-AIDS as whole people, rather than as infected or diseased parts of a whole.
6. An inquiry into hope phenomena may contribute to insights regarding women's issues concerning HIV-AIDS and cross-cultural experiences among people with AIDS, and enrich the ways in which we respond to the special needs of a diverse group of patients. Of the 501,310 cumulative AIDS cases

reported to the CDC, over 60,000 are women; 80% are of child-bearing age. The proportion of AIDS cases among women has increased from 7% in 1985 to 18% in 1994; 52% are Black, 26% are White, and 21% are Hispanic (CDC, 1994).

7. From the perspectives of psychoneuroimmunology, and the current reforms in health care, knowledge of hope as a psychological construct may shape strategies for coping and stress reduction that could expressly affect the newly diagnosed and HIV-AIDS-affected people who are asymptomatic nonprogressors. An understanding that hope is a positive psychological construct linked to health outcomes may be especially important in the prevention of AIDS onset for those who are now HIV-infected, including 15,000 children and 140,000 women (CDC, 1995b).
8. Awareness of hope experiences can shape intervention efforts to halt the spread of infection. A recent example of this concern occurred in the classroom after a discussion of AIDS. When asked how students might respond to a positive HIV test, many replied that they would probably "just give up," or "go right into denial," for the reason that "there's no hope." With this conviction comes the risk for continued unprotected sexual practices, the possibility of exposure to the virus, and the biopsychosocial challenges that emerge with a diagnosis of HIV exposure. In contrast to this, when students met people with AIDS who visited the class and learned that hope exists, the result was a fostering of self-efficacy and confidence, with subsequent HIV

Historically, the quantitative (or positivist) paradigm has been the dominant perspective in research. This is the approach most students of psychology, anthropology, sociology, nursing, and other disciplines are exposed to in their early academic years. As Kuhn pointed out, however, new ways of thinking and perceiving reality evolve over time, leading to revolutionary frameworks for discovering, understanding, and explaining knowledge. When this occurs it is known as a "paradigm shift," that is, where scientific advancement is borne from the transition of a paradigm in crisis to a completely new pattern, or paradigm, of scientific beliefs (Kuhn, 1970, p. 84).

The notion of a paradigm shift has frequently been used to describe new perspectives in the ways we conduct research. It accounts for some of the decision-making process when selecting the quantitative "model" over the qualitative model, or both. Kuhn makes it clear, however, that a new paradigm is not merely an extension of an old one:

> Rather it is a reconstruction of the field from new fundamentals, a reconstruction that changes some of the field's most elementary theoretical generalizations as well as many of its paradigm methods and applications. During the transition period there will be a large but never complete overlap between the problems that can be solved by the old and by the new paradigm. But there will also be a decisive difference in the modes of the solutions. When the transition is complete, the profession will have changed its views of the field, its methods, and its goals. (p. 85)

This transition is now evident, in my view, in the social sciences and medicine, where paradigm shifts seem to explain new approaches to research and health care practices. For example, an emphasis on exploration and description has advanced the qualitative model along a continuum through generations of cultural anthropologists and

American sociologists (for reviews, see Kirk & Miller, 1986; and Penniman, 1974). The studies of pioneering fieldworkers (e.g., Evans-Pritchard, 1937; Malinowski, 1935; Mead, 1928; Shaw, 1938; Whyte, 1943) were grounded in the method of ethnography, defined as the descriptive analysis of a culture (Geertz, 1973; Glittenberg, 1981), typically achieved through participatory research (Agar, 1986). Ethnography has since been adopted by researchers in education, law, political science, social work, and philosophy (Jacob, 1987; Robertson & Boyle, 1984; Spradley, 1980; Stocking, 1983; Zaner, 1988).

Recent interest in critical ethnography shows promise for AIDS-related research, both as an independent method and in conjunction with other methods (Bolton, 1992). Critical ethnography moves beyond the objective of invoking and challenging social consciousness and societal change (Thomas, 1993). Since AIDS is an unprecedented disease, ethnography is a necessary means to gain access to health and illness cognitions, representations, behaviors, and practices not revealed in surveys or other more cognitive measures (Herdt & Boxer, 1991). As Kuhn suggested, it is often a challenge to be able to *see* the change as worthwhile or applicable to one's own worldview. As an analogy, we might consider the student who is looking for the "old woman" in Boring's (1930) ambiguous figure. The figure is described as ambiguous because it may be perceived as either an old woman or a pretty, young woman. No matter how hard she struggles to see the old woman, the student's blinking, squinting, or wide-eyed maneuvers fail; she only sees the pretty woman. Later, a casual glance at the ambiguous figure results in the immediate recognition of the old woman. The student has made the transition and now

finds it difficult to "switch back and forth" (Kuhn, 1970, p. 85) between figures. The point, for this discussion, is that students also engage in paradigm shifts along the course of their academic careers. Having been trained in the behavioristic philosophy, I, like others, was unable to "see" the old woman because I perceived the younger one. Over time, my perception changed, and I adopted new views of the field. This transition reflected a paradigm shift.

The transition to a new paradigm also has been associated with feminist studies (e.g., Lawless, 1991, on women's life stories; and Maquire, 1987, on battered women), and with phenomenological studies in nursing (for reviews, see Morse, 1991; Munhall, 1994a). The new paradigm recognizes the importance of the culture, the active participation of the interviewer in the study, and the need for giving research collaborators a voice (Rubin & Rubin, 1995, p. 31).

Changes in mental health and medical treatment perspectives have been explained in terms of a paradigm shift (Capra, 1982, p. 265; Ferguson, 1987, p. 26). With the challenge of the mainstream biomedical paradigm came cries for health care reform, managed care, and complementary (alternative) medicine. The "remodeling" (Dossey, 1995) of the medical sciences can be illustrated by new practices in which seven in ten users of alternative therapies fail to mention these activities to their primary physicians (Eisenberg et al., 1993). Because they are often controversial, new paradigms are met with skepticism and debate. Such has been the case with the qualitative phenomenological paradigm. For this reason, I will outline the characteristics of

qualitative research and discuss the ways in which they are exceptionally suited to the purpose of exploring hope in HIV-related illness.

A Human Science Approach

The justification for selecting a particular research design over another lies in its congruency with the research question and purpose of the study. As this issue relates to the Hope Project, no current description of the nature of hope exists for men and women in the longitudinal experience of HIV-AIDS. Furthermore, previously developed measures for hope and hopelessness had their origin in populations other than the HIV-AIDS population. As such, these measures and their outcomes have little in common with HIV disease--a recent phenomenon in civilization--or with the people who are living with the virus. For these reasons, research into HIV-AIDS must necessarily invoke a human science perspective in which it becomes possible to ask the questions that will provide insights into the quality of hope.

Human science research gives priority to the phenomenon of the person, with the choice of method following from the phenomenon (Crothers & Dokecki, 1989, p. 446). Having a person-centered focus, human science research is an activity of explicating human meanings, feelings, emotions, beliefs, and purposes (van Manen, 1990). The goal of human science study is to understand phenomena through meaningful interpretation. According to Lincoln and Guba (1985), Polkinghorne (1983), and van Manen (1990), this interpretation should be communicable, trustworthy, credible, reasonable, and persuasive, and its generalizability should be explored. Of course, as Miles and Huberman (1994) rightly point out, included in this activity is the challenge to find "coherent

descriptions...that still include all of the gaps, inconsistencies, and contradictions inherent in social life" (pp. 14-15).

By contrast, the natural sciences give priority to the formal observation and study of objects, things, and natural events (Dilthey, 1987). The research variables are typically predetermined and operationalized (that is, identified and clearly defined before data collection). Traditional (experimental) methodological conventions surrounding data collection in natural sciences are usually systematic, rigorous, and quantitative. Deductive, statistical analyses lead to the goal of natural science research, which is to obtain the truth--objective facts--determined in a value free, transhistorical, epistemological framework. The extent to which objective facts are inescapably interlaced with subjective reality is another matter (Woolfolk, Sass, & Messer, 1988, pp. 24-25). The purpose of this discussion is not to provide an argumentative stance for the superiority of one design over another; instead, the purpose is to point out why one approach is better suited to the task of discovery. McCracken (1988) makes this point in his words:

> It is time for the field of qualitative methods [human science research] to make itself a full citizen of the social sciences. If the field fails to move from defensive postures to constructive ones, and if it fails to begin to systematize and routinize qualitative methods, it can expect to lose the constituency in the social scientific community that now looks to it with interest. It is time to stop proclaiming, and to start demonstrating, the value of qualitative methods. (p. 13)

Characteristics of Qualitative Inquiry

Creswell (1994) defines qualitative exploration as "an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting" (p. 1). With the emphasis on "process" this definition has an appropriate relation to the exploration of hope over time among people living in an extraordinary, multifaceted, and temporally significant environment. It is the beneficial match between the *humanness* of this type of inquiry and the Hope Project that influences the nonarbitrary selection of the research design.

Consistent with Creswell's definition of qualitative inquiry, I have chosen to focus on the following characteristics of qualitative inquiry: holism, naturalism, induction, and description. This discussion may also serve as a pathway to the informative works of several authors who have outlined multiple characteristics in qualitative studies relating to education, psychology, sociology, anthropology, and nursing (Burns, 1989; Cobb & Hagemaster, 1987; Knaack, 1984; Knafl & Howard, 1984; Leininger, 1985; Merriam, 1988; Moorse, 1991; Munhall & Boyd, 1993; Patton, 1980, 1990; Sandelowski, Davis, & Harris, 1989; Smith & Debus, 1992). These authors, and others, highlight the congruency of discovery and exploration vis-a-vis qualitative research, which, by extension, provides an organizing framework for conducting research with the human science model.

Holism. Inherent in the qualitative design is a holistic perspective which promotes an understanding of the complete situation or experience. Holistic research

gives detailed attention to nuance, context, complexities, and idiosyncrasies (Patton, 1987, p. 17). This has important implications in health-oriented research where the meanings of illness and psychological constructs (such as hope) may be embedded in nonverbal behavior. An appreciation of the holistic view has been addressed by Capra (1982) who discussed a "new psychology" which "sees the human organism as an integrated whole involving interdependent physical and psychological patterns...that cannot be comprehended by reducing them to isolated elements" (p. 368).

Ferguson (1987) cites a touching example of how the totality of a particular context in medicine is experienced holistically. The example is an account of a surgeon describing the physician to the Dalai Lama as he made rounds in an American hospital:

> For the next half hour he remains thus, suspended above the patient like some exotic golden bird with folded wings, holding the pulse of the woman beneath his fingers, cradling her hand in his. All the power of the man seems to have been drawn down into this one purpose....And I know that I, who have palpated a hundred thousand pulses, have not truly felt a single one. (p. 243)

The surgeon goes on to report that the Tibetan physician accurately diagnosed a congenital heart ailment based solely on his taking the patient's pulse.

The holistic perspective, by embracing the complex "whole" of the experience, takes into account the subtle expressions of hope that might be offered to the vigilant researcher. *Lydia*, for example, whose listless days in the hospital fell on each other like a long line of dominoes, whispered repeatedly, "It will be over soon." Suddenly one day she was alert, agitated, and verbally demonstrative. Ready to go home, she had packed her belongings and sat in the chair waiting for a ride. What could account for the drastic change in her AIDS-related illness and behavior? Had we witnessed a miracle? Perhaps.

But with further inquiry, *Lydia's* mysterious behavior became clear. It was time for school to begin again and her children "had to get ready!" School clothes and supplies needed to be purchased. *Lydia* had things to do to fulfill her role as a single parent. Her children needed their mother at home with them as they began the new school term. For *Lydia*, this need shaped the structure of her dying experience, my awareness of it, and her hope.

Because human conditions are undeniably complex, there also tends to be a holistic approach in the formation of questions in qualitative research. Questions are typically broad and are framed around a daily human life experience without concern for causal explanations (Merleau-Ponty, 1956, p. 59; Oiler, 1982). The two-year Hope Project was grounded in dialogue and the broad questions, "Could you describe what it has been like for you, living with HIV?" and, "Can you tell me about when you have been aware of hope?" These questions facilitated the initial shape of what was to come over time: a picture of the total process of experiencing this phenomena. According to Miles and Huberman (1994), the advantage of data being collected over a sustained period is that the result is more than a "snapshot" of the experience. In HIV-related studies, where cultural diversity and gender differences prevail, going beyond a snapshot to an understanding of the totality of an experience can be extremely valuable. Smith and Debus (1992) make this point in their discussion of women's HIV issues in AIDS prevention. To understand women (with HIV) requires knowing the other facets of their lives, including how their roles as professionals, mothers, wives, or students fit within varied cultural situations (p. 59).

An ability to avoid dividing the whole into parts in scientific inquiry is a strength of the qualitative paradigm. I agree with Harmon (1988) who suggested, "Perhaps the time has come to tiptoe no longer, but to quietly, firmly, and self-confidently insist on the need for a restructuring of science to accommodate all, rather than just part, of human experience" (p. 21).

Naturalism. Naturalistic designs are often useful when little is known about a phenomenon or when there is a lack of formal investigation of the natural setting in which it occurs (Sandelowski et al., 1989). Naturalistic designs invite direct and personal contact through observation and participation, which affords first-hand discovery and knowledge. After all, for the most part, researchers have no personal experience in surviving a life-threatening infectious epidemic. Being included in the everyday life in close proximity with research collaborators differs from the sterile, detached experience of nonqualitative work. Since naturalistic research is context bound, there is also an opportunity to follow the temporal aspect of hope as it influences, and is influenced by, daily situations in the home, hospital, or elsewhere.

A naturalistic design is important in the applied social sciences and for those who are working in the "caring" professions. Their work can be enriched by first-person narratives about what it means to be ill. For this reason, the natural environment, or personal context, of the person with HIV-AIDS would seem to offer a more complete portrait of what might never be known if the research were conducted only in a laboratory or other "controlled" setting.

For example, when *Mark* phoned to cancel our follow-up interview due to "problems breathing," he invited me instead to join him at his physician's office. While waiting for the doctor, he described explicitly some of the physical symptoms which he felt were threatening his life, and then asked, "What do you think, is there still hope?" Knowing from previous situations and conversations that *Mark* had a reliable intuitive sense about his mortality, my reply was to remind him of those previous circumstances and their outcomes. After thinking for a moment, he remarked, "It doesn't *feel* like it is time to die," which was, ultimately, the answer to his question about hope. As this example illustrates, a benefit of the natural setting in longitudinal research is that the temporal aspect, with its antecedents and consequences (Sandelowski et al., 1989) becomes figural for both the researcher and the collaborator. Moreover, having continuous contact begets careful attention to the ways in which people cope with illness challenges in their individual surroundings. Observing these events helps us to understand what "real life is like" (Miles & Huberman, 1994, p. 10) for the participant, like *Mark*, whose breathing problems were quite serious and required that he be hospitalized.

Induction. Qualitative researchers strive to understand the commonalities, patterns, and themes that originate from the data. To a great extent, this process is artistic (Eisner, 1981), intuitive (van Manen, 1984a), and creative, since careful judgments must be made about what is meaningful in the data. This decision-making activity requires experience, humility, and the capacity for context flexibility (Burns, 1989; Munhall, 1994c; Patton, 1987). The latter requirement points to the researcher's role as learner,

observer, and communicator, all of which are congruent with the goal of understanding social reality from the perspective of the research collaborators (Cobb & Hagemaster, 1987).

Aligned with an emergent design, there are no prior hypotheses, fixed theoretical frameworks, or experimental variables to be determined before data collection begins. The goal of inductive research is not statistical significance. Instead, the goal is to faithfully describe from the text those meanings and experiences revealed by the participants. Sandelowski (1986) maintains that qualitative inquiry is most credible "when it presents such faithful descriptions or interpretations of a human experience that the people having that experience would immediately recognize it...as their own" (p. 30).

In the Hope Project, no prior cause-effect relationship or conceptualization (theory) of hope in the context of HIV was identified. Nevertheless, qualitative inquiry often enhances conceptualization through description of experiences (Munhall & Boyd, 1993). As Knafl and Howard (1986) state, qualitative findings can be a "sensitizing device...in and of themselves" since the depth of the descriptions provide powerful insights into the world of the participants. With discovery and illustration come the possibility that future researchers may translate the raw data from qualitative studies into useful and revealing conceptualizations of hope. Qualitative data also have the potential to supplement, validate, explain, illuminate, or reinterpret quantitative data collected from the same context (Miles & Huberman, 1994, p. 10).

Description. Qualitative data are typically in the form of words, and direct quotations are used to capture the participants' personal lives. The descriptive focus has

as its aim disclosure rather than explanation or prediction (Patton, 1990; Van Maanen, 1988). Qualitative data are generally nonnumerical, although numerical data may complement the investigation.

When there is insufficient information available about a phenomenon, a prospective study must begin with those who personally experience the topic being studied (Giorgi, 1967). The suitability and strength of a qualitative design for the Hope Project evolved from a need to describe the totality of hope phenomena from the person's frame of reference (Leininger, 1985, p. 5). It is difficult to imagine an investigation of hope administered by a machine, based on surveys, scales, or questionnaires developed by noninfected social scientists who are not ensconced in the daily biopsychosocial exigencies of HIV-AIDS. From what experiential foundation might the questions be formed?

To paraphrase Kubler-Ross, if we wish to understand dying and death experiences, we should ask the people who are engaged in those realities. To do otherwise is to miss the point. Similarly, if we wish to understand meanings of hope among HIV-affected people, we should ask *them* to describe those meanings. The qualitative paradigm is a canopy under which the questions may be discovered. Marshall and Rossman (1995) cite four primary ways in which descriptive data are collected when applying the qualitative design to research: (a) direct observation, (b) participation in the setting, (c) in-depth, phenomenological interviewing, and (d) document review (p. 78). Each of these modes, or methods, have been utilized in the Hope Project and will be articulated in Chapter Three.

This section is not the forum for an exhaustive listing of methods consistent with the qualitative paradigm. Still, it is useful to know that multiple labels exist for the varied techniques used by qualitative researchers. In her survey of labels relating to qualitative studies, Tesch (1990) cited 46 terms which she reduced to 26 approaches used by social scientists. Other authors have described the methods of grounded theory, case study, life history review, fieldwork, videotaping, ethnonursing, dramaturgic analysis, and archival data analysis (for reviews, see Creswell, 1994; Hunt, 1989; Stern, 1985; Wenger, 1985; Van Maanen, 1982).

Summary of Qualitative Research

The value, then, of qualitative research is that it starts with an exploration of the depth of experience from the person's own viewpoint. Bogdan and Biklen (1982) cite an anecdote that clarifies the importance of first-person descriptions. They call their story "Forever." At a university faculty dinner, a diverse group of professors, all distinguished in their fields, discussed the concept of "forever." Each professor had a unique notion of the concept, depending on the way it related to his or her profession of law, geology, or physics. For example, while the law professor grounded "forever" in legal complexities, the physics professor stated that in his view, forever was quite simply forever, and nothing more. (To accentuate this point, what is *your* notion of "forever"?) Rather than resolving the ambiguity between their views, a qualitative, human science researcher would seek to study the concept as it is understood in the context of the various people who experience it (Bogdan & Biklen, 1982, p. 38). That is, the concern is not to establish

a confining, standard definition of a concept. Instead, the purpose is to expand its realm of understanding.

As Lofland (1971) emphasized, the first principle to be recognized in qualitative work is the participant's vantage point. In Lofland's words, "In order to capture participants in their own terms one must learn their categories for rendering explicable and coherent the flux of raw reality" (1971, p. 7). A potential outcome of this emphasis is that the "raw reality" may eventually contribute to existing social science literature in the way that Munhall (1994c) described as "feeling like coming home to oneself or knowing the home of another in everyday life" (p. 31). Another potential outcome is the possibility of combining the qualitative findings with epidemiological, survey, psychometric, or other quantitative measures used to explore and comprehend hope phenomena, or to develop new measures and interventions (Kleinman, 1992). The benefit of this outcome underlines how one approach to research can inform and guide other approaches (Creswell, 1994; Salomon, 1991).

Qualitative inquiry is a means to "do justice" to the study of human psychological phenomena by including the subjective, experiential qualities that make up this human science (Koning, 1986, p. ix). It can also be a means to augment textbooks which provide a thorough account of the theoretical and procedural aspects of health care, but exclude the experiential facets. Students and clinicians eventually become sensitized to terminology without ever having learned how the experience is played out in real life. For example, *Allyn*'s ordeal with the procedure of having several arterial blood gases (ABG) drawn is an apt illustration. (Elliott, Phillip, and Stuart have reported nearly

identical events.) ABG analysis is done to evaluate the oxygen delivery to the blood and the elimination of carbon dioxide. It requires a painful, deep arterial puncture. Patients are told to breathe normally and that they will feel "a stick." This sounds fairly benign. It is a textbook description of an experience that many people with AIDS eventually undergo, especially if they develop pneumonia. After years of enduring this procedure, however, it becomes a recurring nightmare for some people. In his own words, *Allyn*'s reality becomes precise for readers who may have out-of-context knowledge of this test:

> *I still have problems with my hands and arms [points to the painful areas]. In the emergency room the nurses tried twice in each hand to get blood, but they couldn't get it. The last time this guy came in to try again. And he numbed the place, but it didn't work. And he wouldn't pull the needle out when he hit the nerve. I said, "You're hitting the nerve again!" But he just kept digging, moving it around. It felt like...I mean, the throbbing, it felt like it was going to blow up, my arm did. I can't explain what it feels like to hit a nerve. You just know it; your whole body knows it. And I was sitting there and my friend was like "Calm down." My pulse went sky high. He said it got to 200, my pulse rate. I was so tense. I started crying. I said, You're hurting me!" He said, "Relax." I said, "I can't relax." So he finally pulled it out because he couldn't get it. He said they'd try again in the morning. And I said, "Oh, no, they're not coming near me again. You did it for the <u>last</u> time. I will <u>never</u> have this done again, ever. And he came in the next morning wanting to do it, took my hand and was feeling for the artery. I said, "No, no more!" And you know they have a cup of ice that they use to put the glass syringe and needle in when they're done, and he <u>threw</u> it across the room toward the sink and it hit the wall. Ice just went flying everywhere, and I was like, well, this is it.*

<u>Assumptions and Biases.</u>

A critical feature in qualitative research is the identification of assumptions and biases held by the researcher. Certain beliefs, intuitions, and perceptions about the realities of everyday life are naturally brought to the study and need to be attended to

early on (Lauterbach, 1994; Munhall, 1988). The extent to which we know, or know about, the studied phenomenon may be problematic during the investigation. As van Manen (1990) cautioned:

> The problem is that our 'commonsense' pre-understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question. (p. 46)

Van Manen clearly does not suggest that we try to forget or ignore our beliefs, but that we try to hold them deliberately at bay until we learn the nature of the phenomenon in the first place (p. 47). (I have more to say about this concept of "bracketing" in the chapter introducing phenomenology.)

Since the previous sections have explicated *general* assumptions and biases about hope in the context of HIV-AIDS, the purpose of this section is to make my personal beliefs known as they relate to my role as a human science researcher.

1. The informant-teacher, researcher-learner roles are congruent with my goal of understanding the participants' view of social reality as it is constructed in their daily lives (Burger & Luckmann, 1967; Cobb & Hagemaster, 1987).
2. Meanings are constructed within a complex interactive context of history, knowledge, and culture, all changing over time. Therefore, neither hope nor HIV-AIDS can be understood outside of this meaning context.
3. I should not assume that the intentional use of language has the same meaning for each individual in the study. Comprehension of word usage depends on careful attending, listening, questioning, and clarifying.

4. Worldviews are multidimensional across cultures and subcultures. Opinions are as varied and unique as the people who have them. This study, consistent with traditional qualitative research, does not endorse the pigeon-holing of people into standardized categories according to preconceived notions (Patton, 1987, p. 15).
5. My role as a researcher is to learn what things "feel like" to the participant. This implies "feeling with" in order to understand (Zaner, 1988). In this longitudinal study, my role involved sustaining relationships and long-term commitments as well.
6. I should not assume that human behavior is similar or predictable. People differ. Gender assumptions are not applicable, nor are there preconceived behaviors attributed to coping, or surviving.
7. There must be flexibility in the research process. Nothing may be taken for granted, including hope. Questions may be altered over time; adjustments may be made. There is a need to go with the flow and not become rigid about methods or let them take precedence over the participants' welfare. Research methods must take a position off stage, in the unpredictable moments when the participants' health and well-being is a concern.
8. As the primary human agent for data collection and analysis, my responsibility is to protect the research participants at all times from harm and exploitation, and to also be respectful of their autonomy. This differs from studies which utilize machines or papers as instruments. Participants are not

cases, subjects, or objects to be used as the means to an end in an investigation. They are human research partners who enter into a relationship based on trust and informed consent. The consent is mutual and dynamic. It may be renegotiated over time, depending on the circumstances (Estroff, 1995). Illustrations pertaining to these assumptions may be useful:

The first time I met Alec he was sitting in his hospital room looking out the window in such a way that I was immediately touched by the poignancy of his demeanor. Intuitively, I knew that he was "visiting" a place in his mind and that I would not be able "to go there" with him. My presence seemed almost an invasion of his privacy and I nearly tip-toed away. This push-pull feeling was quickly replaced by the establishment of a relationship through easy, comfortable conversation. Alec was eager to share his thoughts and feelings about being ill and having AIDS. His aim was to open the private windows of his world in order to help others. Informed consent was completed and we talked briefly about ordinary things. And then I asked him if he could share what he was thinking about when I approached the room. He said he was watching "out there" [pointing to the city streets] because that was the direction his friend would be coming from when he visited. My first thought was that his friend must be very dear to him, and I anticipated learning more about this friendship. As John Donne wrote in his Devotions Upon Emergent Occasions, "No man is an island entire of itself; every man is a piece of the continent, a part of the main." Before we could begin our "formal" conversation, however, [with the tape recorder on] Alec became extremely fatigued and returned to his bed. He asked if I could return another time.

Lorraine was ambivalent about participating in the Hope Project. The greatest concern was for her children, not herself. Her diagnosis of HIV infection was concurrent with other medical care. The news was both a shock and a mystery, which she explained during our initial telephone conversation. Sadness, depression, fear, anxiety, uncertainty, and intense anger were interwoven with expressions of hope. Lorraine was very interested in participating and wanted "to help with the study," she said, as she listened to the signed consent requirement. But she would not meet face-to-face. She asked if we could "just talk on the telephone for now?"

Randy wanted me to push him in a wheelchair to the patio outside the hospital where he could "get some fresh air." His nurse agreed, but only with the warning that Randy should not be smoking. Settled in a chair,

safe and secure, we set off on our jaunt through corridors and elevators until we reached, in Randy's words, "Freedom at last!" Even with a severely swollen abdomen resulting from liver failure, Randy nevertheless attempted to reach his ankle and sock where he had "stashed" a cigarette and lighter. "An old Navy trick," he commented. His reach was about two inches shy of the cigarette. Would I please help, he asked? My hesitant look must have been the catalyst for one last try. He stretched and moaned, but, victorious, he laughed as he blew smoke rings in the summer air.

[Researcher notes]

As these examples demonstrate, context flexibility must become a part of the qualitative research paradigm. Yet, when we learn about this paradigm, there tends to be a misleading concreteness that ultimately is not applicable to every research setting. Based on established guidelines and criteria, we set our goals and requisite boundaries in order to stay focused on the task at hand. And then night turns into day and things change. If we are to be present with those whose lives we explore, our assumptions about reality must be recalled again and again during the research process. Sometimes meanings of hope can be discovered in perfectly formed smoke rings.

Precise criteria for conducting and evaluating qualitative research can be found in the literature on hermeneutic phenomenology in education (Marshall & Rossman, 1995; van Manen, 1990), nursing science (Burns, 1989; Cobb & Hagemaster, 1987), and psychology (Giorgi, 1983; Kvale, 1983; Polkinghorne, 1983). This necessity evolved over time from the quest to establish the qualitative paradigm as a worthy alternative or complement to traditional research methods. Although extremely valuable, these criteria should be viewed within a human context so we do not lose the opportunity to discover

that which we thought was "lost" according to our research agenda. The interactions with *Alec*, *Lorraine*, and *Randy*, for example, did not "fit" my definitive research plan; nevertheless, lived meanings were there all along. Had my assumptions not been acknowledged beforehand, I might have missed them all.

Summary

This chapter focused on the introduction, aim, and organization of an investigative inquiry into the phenomena of human hope for the purpose of understanding how HIV-affected men and women experience hope in their lives. An explication of the study's justification was framed in the questions: (a) Who has an interest in hope? (b) What is known about hope? (c) What has not been addressed in previous research? (d) How will this study contribute to existing literature and to health care practices? These questions help to locate the present study within a larger framework that explores the "whatness" of hope for people who (at this moment) are told they are living with an incurable illness, and to ask the broader question, "What *in the world* might this study be relevant to or benefit?"

Underlying ontological and epistemological assumptions were gleaned from tracing the historical roots of the qualitative research paradigm. Paramount to qualitative inquiry is its emergent design; that is, the study is not "fixed" prior to data collection such that preconceived notions guide the research process. Illness narratives give voice to research participants who are often spoken *about* in nonqualitative work, and they describe experiences that only participants can *truly* know or give meaning to. Consistent with a paradigm that seeks exploration and discovery, awareness and understanding,

participant narratives are not data destined for abstraction and statistical analysis. A human science approach to research promotes the uniqueness of human existence.

The role of the researcher as both research collaborator and analyst is grounded in the recognition of preconceived notions, intuitions, and values. Tantamount to this work was the duty to protect participants from harm as they allowed me to witness and share their uncertainty, pain, hope, joyfulness, and their experiences of dying and death.

CHAPTER 2

Evolution of the Study

A computerized tomography (CT) scan was ordered STAT (now) on the young man whose admitting diagnosis was "pneumonia." In my role as clinical coordinator, I explained procedures to patients as a means of reassurance and confirming informed consent. Because his respiratory distress was acute, however, this patient was uncommunicative. Still, there was something tragic about the way he looked back and forth at us--the darkness about his eyes was haunting. When I assisted the technologist in the patient's transfer from the gurney to the CT table, I noticed that he was incontinent. As soon as he was secure on the table, I rushed to wash my hands. Later that day we heard that he was "shipped off" to a metropolitan county hospital when an AIDS diagnosis was confirmed. Someone standing nearby said, "Good! We don't need some queer giving us all AIDS." I stood there looking at my hands, as though some trace of "AIDS" might still be on them. A frightening doom welled up inside me like an elevator rushing to the top floor. A warning? What kind of virus could elicit such a primitive, visceral feeling? I washed again, both concerned and embarrassed about my behavior this day. I remember thinking that I must be vigilant and informed about this virus, because it was the enemy. That was in 1982. Ten years later, the memory of that young man returned when a physician informed us that our son was infected with the AIDS virus. It was then that I recognized the eyes.

[Researcher notes]

Background of the Study

During what is now described as the first decade of AIDS (Berridge, 1992; Herdt, 1992), I watched the epidemic take shape over time as if it were a huge puzzle with thousands of parts yet to be identified and placed within the whole. Then, as an undergraduate in 1988, I conducted a survey of adults' opinions about children with AIDS

and whether or not they should attend school with their peers. That the opinions were nearly evenly divided was not as striking to me as the *manner* in which the respondents answered the question, "Do you think children with HIV or AIDS should be allowed to attend school?" Although only yes-or-no responses were required, most of the respondents insisted on elaborating about their opinions. For example, one person argued loudly and passionately that *all* people with AIDS should be taken to an island to live out their lives in isolation. Another suggested that people with AIDS should be tatooed or "marked" in some way that designates they have the virus. On the other hand, a young mother apologized for her answer (No), stating that her duty as a mother was to protect her children from harm.

The range of emotions about contagion was disconcerting, especially in light of such a simple yes-no question format. This fear of contagion contributed in a significant way to the prejudice, discrimination, anger, and violence that characterized the first decade. Investigative reporter Randy Shilts (1987) chronicled the political events of the decade, including the violence. In Seattle, for example,

> Gangs of youths roved Volunteer Park, a local gay cruising spot, and beat up gay men with baseball bats, shouting invectives about "plague-carrying faggots" and "diseased queers." One gang raped two men with a crowbar. Once arrested, one attacker told police, "If we don't kill these fags, they'll kill us with their fucking AIDS disease." (p. 353)

Social psychologist Gregory Herek investigated violent behavior, beliefs, and attitudes, and conceptualized the psychological structure that leads to AIDS stigmatization (Herek, 1990; Herek & Glunt, 1988, 1991). One of the suggestions

resulting from his work is the development of educational programs that present factual information about AIDS in a context that reduces hysteria and anxiety. And of course, the underlying factor regarding fear of exposure to the AIDS virus is the human understanding of death. Herek and Glunt's call to action stresses awareness on the part of psychologists who should acknowldege their *own* attitudes, fears, and prejudices in order to educate others. Further, psychologists should become educated about the epidemic so that they will "understand how their reactions to AIDS might unintentionally stigmatize HIV-infected people" (p. 890). It was with this caveat that I entered into the second decade of the AIDS epidemic.

This chapter places the Hope Project in the historical, experiential, and philosophical contexts from which it originated (Munhall, 1994b, p. 15). The historical context is what I, the researcher, already know about both HIV-related illness and hope, and how this knowing was based on personal experiences and professional involvement (the experiential contexts). In a more philosophical context hope phenomena include its epistemological, psychological, and metaphysical dimensions as they are played out in everyday life for those living with a serious illness. These seem to be natural starting points from which the phenomenon can be discussed and brought together to form a holistic portrait of how the study evolved.

Historical Context

An important feature of phenomenological inquiry is that it often begins with personal concerns, interests, and involvement (Munhall & Boyd, 1993). In reality, it would be a struggle to sustain a longitudinal commitment to some degree without having substantial personal investment. Lofland and Lofland (1984) include a temporal and emotional readiness to the commitment:

> Starting where you are provides the necessary meaningful linkages between the personal and the emotional, on the one hand, and the stringent intellectual operations to come, on the other hand. Without a foundation in personal sentiment all the rest easily becomes so much ritualistic, hollow cant. (p. 10)

This statement speaks unquestionably to the researcher, the person who builds the study from *where he or she is* and from a foundation made of perseverance, readiness, and (to borrow a popular cliché) passion. This was the foundation supporting the creation of the Hope Project.

As the mother of a person with AIDS, I came to realize that general assumptions about hope (including my own) in the context of AIDS were mostly ambiguous and often downright pessimistic. The experience of reading about cultural violence and hysteria was even more figural for me when I listened to my own son's ordeal of being assaulted by men who perceived him as being "one of those faggots." The horror of the physical and emotional pain for him was ameliorated only by the realization that he *could* have been murdered.

In the second decade, we have seen a reduction in overt accounts of violence and discrimination, but a substantial bias against groups associated with HIV infection

persists. Hope cannot be separated from the reality that people have religious beliefs, cultural and gender differences, and perceived threats to their survival. These factors contribute to the way their behavior affects or stigmatizes people who are infected. For example, physicians at a large university hospital conducted an in-patient survey about patients' objections to rooming with other patients with HIV infection. They found that over one-half *would* object, and over one-third would get their health care elsewhere rather than share a room (Seltzer, Schulman, Brennan, & Lynn, 1993, p. 566).

Both fear of the virus and bias may have played a role in the story that *Stuart* told about his experience with paramedic personnel who were called to his home when he had his first heart attack:

> *It [the situation] scared the hell out of me. I didn't want to die. The paramedics said it was heartburn. I think they were afraid of me, or they didn't like me. They were more rude than cautious. [In the ambulance] they never turned the lights on. They took their time. I'm sorry, but heartburn doesn't make me stop breathing. And so at the signal out here at about three in the morning, at the red light, instead of putting the lights on and going on through, they waited. But Christopher [his spouse] went on through the red light and he beat <u>me</u> to the hospital....My life did flash before my eyes, and I knew I was having a heart attack. I knew I didn't want to leave Christopher at all.*

As a result of this event and the heart muscle damage that occurred, *Stuart* filed a formal complaint against the paramedics. They were both fired from their positions. *Stuart* and Christopher decided to avoid 911 calls altogether. On the occasion of *Stuart's* next attack, Christopher took him to the hospital in the car. They did not want to take the chance that fear or bias or "an attitude" would jeopardize *Stuart's* life again.

Experiential Context

How hope is linked with the initial diagnosis of HIV or AIDS was discussed in Chapter One. When hospitalization is necessary, the patient (and all who are close to him or her) become *tuned in* to the atmosphere very quickly. There is an immediate recognition of the personnel who care and are educated about HIV and those who care but are not educated or who are biased in some way.

Something needs to be said about how important medical care providers are to the patient and family. For example, during my son's first hospitalization, he found it distressing that everyone "came in the room dressed in some type of space suit." A special stethoscope was obtained only for his room which the nurses used to take his blood pressure. The door was kept shut even if he asked that it be opened. When his IV monitor signaled that the medication had been completely administered, he said the incessant beeping prompted him to learn what needed to be done to stop the noise. Because his treatment of HIV-related infections was complicated by other longstanding medical conditions, it was frightening for him (and his parents) when important medications were not administered when needed. A significant experience occurred one day, however, when he was the recipient of a human touch--the first touch--by a nurse who came in the room without gloves. After she had completed the blood pressure reading (using her *own* stethoscope), my son said, "Did you see that, Mom? She actually touched me without gloves on!" Until that moment, he (and I) had been feeling very hopeless.

Hopelessness is a destructive force that threatens the physical and psychological well-being of the ill person. For example, the beliefs of the people who surround a child or adult who has HIV-AIDS can be absorbed by the ill person regardless of his or her age. Therefore, if all who surround this individual believe (overtly or covertly) that AIDS is an automatic death sentence, their behavior will reveal this belief. Such a mind-set and alters the structure of hope in the person's lifeworld.

The curiousness and unpredictability of hope has been apparent in my involvement with community activities and with support groups where people with HIV-AIDS and their families discuss their fears and their experiences. It has been puzzling to realize that many of us need permission to hope. I believe this is an extension of the term, *false hope*, which has become attached to the fatalism of AIDS. Although attention has been given to the study of social support needs for people who have HIV-AIDS (Hays, Chauncey, & Tobey, 1990; Nott, Vedhara, & Power, 1995), less is known about the social support needs or outcomes among parents, siblings, co-workers, or medical care providers. And how any of these people perceive or are influenced by hope remains to be explored. As facilitator of a support group for mothers whose child has or had AIDS, I am increasingly aware of the pronounced role of hope in family relationships.

A final contribution to the creation of the Hope Project has been my professional involvement as an intern observing the practice of Dr. Rose, an infectious disease specialist, over a 12-month period. These observations made the importance of hope phenomena discernable rather than dubious. Additionally, it was this experience that

outlined the primacy of hope in the ways it affects the totality of a person's health as the illness is being lived over time. As a parent dealing with AIDS, I had vowed to march into the second decade with the passion and determination of a lioness protecting her young, without the faintest notion that a study of hope would eventually unfold. Working with Dr. Rose in his medical practice, then, was the turning point that cemented the significance of hope. Taken together, these personal and professional experiences make up the whole that includes all the assumptions, biases, expertise, and dedication relevant to this research. These experiences also explain the necessity of my commitment to the time frame required in this prospective, qualitative exploration.

The purpose of the following section is to trace the philosophical language of hope over time, and to illustrate the application of traditional (quantitative) research findings as they contrast with human science (qualitative) procedures. This discussion is intended to provide a backdrop to a clarification of the essential role of hope in the human condition. The next section will review research on hope in health care so that a medical background can be established within the philosophical underpinnings of hope.

Philosophical Context

Language of hope. Philosophical interpretations of hope are found in the writings of Aristotle, Aquinas, Descartes, and Hume, who equate hope with *emotion* (for reviews, see Muyskens, 1979; Pieper, 1969). This relationship is interesting etymologically because the word *hope* derives from *desperado*, the past participle of the Old Spanish *desperar* (to despair) and from the Latin *desperare* (a desperate one), which is formed from *de* (without) combined with *sper* (hope). Historically, then, it appears that to be

without hope means that one is also desperate. Shipley (1945) has made the point that it is a "sad reflection on human hopes that the word *sper* has come to us only in its negative forms; hope itself is a late word from the Anglo-Saxon *hopian* (to hope)" (p. 114).

That hope exists in an emotional symbiotic relationship with despair is the opinion of Mills (1979) who believes that hope is a force that comes to birth out of the pain of despair. He argues that hope would not "arise" without the antecedent state of despair (p. 50). In sorting out the early philosophical writings on hope phenomena, interpretations appear to focus on antecedent conditions. Despite this, it is reasonable to wonder if we must *necessarily* experience despair in order to experience hope?

For the existentialists, particularly the French existentialists, despair is indisputably linked to hope. This view is strengthened by Marcel's (1962, 1967) philosophy of hope which mandates the importance of hope in order to survive despair. His metaphysic of hope states that "there can strictly speaking be no hope except when the temptation to despair exists. Hope is the act by which this temptation is actively or victoriously overcome" (p. 36). Marcel contends that human existence is generally a state of *captivity* subject to hope when the inevitability of despair is realized.

The relationship between hope and despair is also described by Kast (1991). She suggests that hope is the ultimate foundation of our basic source of *Geborgenheit* (safety, security, protectedness) upon which our higher feelings and psychic strength are nourished. She further implies that without hope as a foundation, the "good" emotions of joy, inspiration, and creativity will not prevail as a means for self-transcendence during

times of despair. On the other hand, hope may be perceived as an acquiescent "easy way out" which tempts us to live in an illusion of what *might* occur instead of living in the here and now of our personal worlds--no matter how miserable the circumstances. By taking the easy way out we invalidate our lives, and they slowly slip away in the fog of hope without our having fully experienced the joy or insightfulness of the present (Kast, 1991).

We wonder, then, if joy and happiness are at all possible for those who live with an illusion of hope. Frankl (1984) explored this notion in his narrative about the war prisoners in Auschwitz, whose hope was, in his words, "naive hope" (p. 84). He wrote, for example, that the majority of prisoners who had devoted all their energy to the hope that they would be liberated and home by Christmas, 1944, were dead by New Year's, 1945, just a week later.

Frankl proposed that his friends' despair was attributed to their unrealized hopes and expectations. In his opinion, his friends would have known less pain had they understood that suffering provides opportunities to realize the capacity to rise above one's fate. He wrote:

> When a man finds that it is his destiny to suffer, he will have to accept his suffering as his task; his single and unique task. He will have to acknowledge the fact that even in suffering he is unique and alone in the universe. No one can relieve him of his suffering or suffer in his place. His unique opportunity lies in the way in which he bears his burden. (p. 86)

The "burden" is also described by Camus (1955) in *The Myth of Sisyphus* which clarifies this perspective. Camus' hero is condemned to rolling a rock to the top of a

mountain, whereby it falls back of its own weight. Were Sisyphus never to recognize the extent of his absurd life and then engage only in the illusion of hope, what might his pain be like? Camus expresses this thought by asking, "Where would his torture be, indeed, if at every step the hope of succeeding upheld him?" (p. 90). Returning to his rock again and again, Sisyphus owns his burden and his fate, knowing that there cannot be a sun without a shadow. His understanding makes him stronger than his rock. Camus suggests a contemplation: "One must imagine Sisyphus happy" (p. 91).

The phenomenon of hope, whether born from despair or causing despair, has a clear and continuing affiliation with emotion. The emotion of hope, or the *feelings* of hope, can be traced along varied continuums in the works of theologians, philosophers, psychiatrists, and psychologists. Most of the early theological works on hope emerged from the war era. A significant contribution comes from the Jewish Marxist, Bloch (1959) who is considered by some to be the philosopher of the theology of hope (White, 1970). In my view, the writings of Bloch are reminiscent of Socrates in that Bloch, too, seems a gadfly goading the (Christian) conscience to heed the serious social, economic, and political issues of the day. Bloch's hope is positioned right in the middle of the present world with all its flaws, where hope can creatively stimulate a disdain for the status quo. This is the first step in Bloch's hope, which assumes a "knowing" disenchantment of the past's deficiencies. The second step is to apply this knowledge. Bloch recommends taking action for future change.

What is unusual about Bloch's recommendation, however, is that he endorses the need for *learning* how to hope. The advantage is not only being able to envision a better

world, but also to be able to extinguish anxiety and dissatisfaction about the present lifeworld. He writes:

> What matters is learning to hope. Hope does not abandon its post. It is in love with success rather than failure. Hope, superior to fear, is neither passive...nor imprisoned in nothingness. Hope reaches out; it broadens rather than narrows. This affect summons persons who actively throw themselves into the process of becoming...it does not tolerate the life of a dog that allows itself to be passively flung into the would-be, the inscrutable, and the grudgingly accepted. (p. 1)

Of all the books on hope during the 1950s and 1960s, it was Bloch's treatise that introduced the possibility of learning how to hope. This is an intriguing idea because it affirms efficacy while reducing anxiety during troubled times. Individuals who are experiencing the darkness and challenge of despair may, as a consequence of learning how to hope, be able to reflect on the necessary realistic changes needed for an improved quality of life. Bloch's notion is especially compelling in the context of HIV-related illness because of the potential for self-empowerment.

In Schachtel's analysis of affect, hope is seen as both a passive and active emotion, depending upon the context. At the passive end of the spectrum is the wishful expectation that things are going to become better, somehow. We may have no idea how the change will occur, or exactly what the change should involve. We simply believe that something external to us, perhaps something "magical," will facilitate our wished-for ideal without our active participation (Schachtel, 1959). For instance, *Nathan*, a research participant, hoped that at his death his guardian angels would arrive and "wrap their

loving arms around him." Magical hope may also be an imagined "better life" after death (Schachtel, 1959, p. 38).

At the opposite end of the hope spectrum, in Schachtel's model, the affect of hope is based on realistic activity. There is no magical transformation expected. Instead, an active role is taken in the desired change by the engagement of "thoughtful actions" which will ultimately cause the improvement. Here, however, there is an assumption that we already know what those thoughtful actions are supposed to be. For the person who feels confident that change is truly possible, a greater degree of energy will be expended toward the goal. In other words, if a person has hope, there will necessarily be more sustained action.

This affect is not based on wishful thinking, but on a pragmatic, genuine effort to effect the hoped-for transformation. In considering *Lawrence*'s recovery, for example, the degree of hope and confidence felt by his caregivers may have contributed to their sustained efforts. Schachtel believes, however, that most people wax and wane between hope based on passive expectation and hope based on realistic effort. There is a middle ground for hope, although the passive or active affects often predominate (p. 38).

Lynch's psychology of hope. In a psychological analysis of hope, Lynch (1974) identified antecedent conditions that are required aspects of hoping. First there must be a sense of the possible. Along with possibility, there must be confidence. In his view, hope is realistic and relative because there is a "fundamental knowledge and feeling that there is a way out of difficulty, that things can work out, that we as human persons can somehow handle and manage internal and external reality" (p. 32). The solution, or the

"way out," may be discovered by way of the outside world, through help from others, and by waiting, wishing, and imagining.

Lynch also makes the provocative statement that to consider hope an exclusively inward trait, an "interior thing," is nonsense because we as humans sometimes reach the absolute limit of our interior resources. He offers an example of a dying person whose burden is so great that there is no hope for survival. Yet, this person is expected to keep hoping and never give up. Lynch refers to the abundance of "eloquent rhetoric" in the literature describing the supposed ability of humans to maintain the spark of indestructibility and to hang on to hope as if they had limitless psychic and physical energy.

On the other hand, Lynch's analysis of hope includes the notion that "above all, there are ways out of illness" (p. 32). Although only implied, the concern here is a relationship between hope and guilt as it might be experienced by the dying person. The individual may be hoping to die as a way (solution) out of illness or because the person *knows* the time to die has come. Hope in this case might be displaced by unnecessary guilt for not hoping to live. Perhaps this is the point Lynch is making when he speaks of the "ways out of illness." That is, death *is* the solution which is acceptable to the person. Lynch maintains that labeling hope as an entirely inward trait could subject it and the hoping person to the scrutiny or quantification of others. He suggests, after all, that we should "relieve hope of its burden of being an absolutely interior thing and recall its context relativity" (p. 32). This opinion is shared by Marcel (as cited in Barnard, 1995) who sees hope more as a *mystery* than a *problem.* In fact, concerted efforts "to pin it

[hope] down with precise, rationalistic categories or empirical descriptions inevitably results in flattening out and distorting our understanding of it" (p. 46).

Snyder's psychology of hope. The mystery of hope has been a challenge for Snyder and his colleagues (Snyder et al., 1991) whose quest for the definition of hope has resulted in an instrument (the Hope Scale) designed to measure hopeful thought. This eminal work has positioned hope within the psychological framework of human development. The focus of their model is on three "mental markers" which are the components of hope: (a) important objects, experiences, or outcomes that we *wish* to obtain (goals); (b) the driving force that propels us toward our goals (willpower); and (c) the capacity for planful thought or mental flexibility which enhances goal attainment (waypower). Together these components produce the definition of hope proposed by Snyder:

> Hope is the sum of the mental willpower and waypower that you have for your goals, or, Hope = Mental Willpower + Waypower for Goals (1994, pp. 5-10).

Although impossible to adequately discuss Snyder's model of hope in a few pages, some significant aspects of his work should be mentioned. First, Snyder (1994) follows hope across a developmental dimension that begins in infancy and continues to old age. This is particularly salient for people with AIDS whose life span development has been drastically fractured. Also the importance of achieving goals throughout the developmental years and beyond is closely tied to Erikson's psychosocial stages which are, of course, supported initially by a foundation of hope (Erikson, 1982, p. 56). According to Erikson, hope is "both the earliest and the most indispensable virtue in the

state of being alive (1964, p. 115). Snyder contends that hope is not innate, but is created over time by way of environmental factors. He believes that one's level of hope as an adult is determined by childhood experiences. Accordingly, to use his words, "Kid hope begets grownup hope" (p. 26). We will return to this *nature* versus *nurture* assumption in subsequent chapters.

In an effort to eliminate the *vagueness* of hope, Snyder's model seeks to provide a new definition of hope for the next century that is, for him, *specific*. Therefore, the Hope Scale index is a "way of thinking about *oneself* (italics added) rather than some nebulous, immeasurable philosophical notion" (p. 25). This comment contrasts sharply with Marcel's view mentioned previously that hope pinned down is hope flattened out, as is our understanding of it.

A sturdy association exists between Snyder's hope model and specific theoretical concepts in psychology. For example, in Lewin's *field theory*, each person is surrounded by a *life space*, or psychological *field*, within which an interaction exists between desired goals and the environment (Lewin, 1951). That there may be conflict in this field is possible and certainly inevitable across time.

Snyder was also influenced by the notion of planful thought proposed by Miller, Galanter, and Pribram (1960), by achievement motivation theory (McClelland, 1958), and by social learning theory (Bandura, 1977). The underlying premise of his book, however, is that careful attention to the mental components of hope over the life span will ultimately yield people who have high hope. High-hope people, according to Snyder, tend to have developed (or learned) adaptive goals during childhood which are facilitated

over time by willpower and waypower. The Hope Scale measures the level of hopeful thoughts expressed in response to statements reflective of the respondent. Examples of the statements are: (a) I energetically pursue my goals, (b) I can think of many ways to get out of a jam, (c) My past experiences have prepared me well for my future, and (d) There are lots of ways around any problem (Snyder, 1994, p. 26). The overall score is obtained from a Likert scale (1-4) based on how true the statement is for the person taking the test. High scores indicate high hope. The implication of this instrument's value is the identification of low, average, or high hope, and by extension, the significance this has for achieving established goals. As an individual differences measure, the Hope Scale has potential for screenings and assessments in clinical settings.

Obayuwana's assessment of hope. In 1978 Alphonsus Obayuwana received an award for the most inspiring paper written by a medical student. His topic was hope, the "unrecognized panacea" (1980, p. 67). Acknowledging the interaction between mind and body, he made clear his view that the inherent function of hope is "simply the promotion of health and happiness" (p. 68). The way hope facilitates well-being, however, depends on the health care practitioners. He recommended a method of anticipatory health care called *hope therapy*. Providers of health care, he argued, should not ignore those aspects of existence that directly affect health (e.g., political, civic, occupational, spiritual).

Hope therapy involves "a collection of positive and health fostering gestures" on the part of the "relaxed" interviewer during a discussion of events perceived by the patient to be stressful (p. 69). Obayuwana's point is that a holistic medical plan includes hope as a vital part of the care. As a means to objectify hope, Obayuwana et al., (1982)

developed the Hope Index Scale (HIS). The HIS consists of 60 yes-no items (no examples are provided in the article), each of which is assigned 10 points for the desired response. Questions assess affective and cognitive aspects of hope in the areas of family support, ego strength, and educational, economic, and religious assets. These five dimensions make up the Hope Pentagram, which is Obayuwana's conceptualization of hope (p. 762). Obayuwana et al. found that suicidal intent among psychiatric patients is more highly correlated with hopelessness than with depression. I think this finding adds credence to his Hope Therapy model which supports paying attention to existential issues before health is jeopardized.

Nowotny's assessment of hope. From a literature review, Mary Nowotny (1986, 1989, 1991) categorized six attributes of hope: (1) meaningful future outcome, (2) related to others or a higher being, (3) what is hoped for is possible, (4) hope comes from within, (5) active involvement is needed, and (6) hope has a future. These served as the framework for her questionnaire. The 29-item Nowotny Hope Scale was used with the Beck Hopelessness Scale (Beck et al., 1974) to establish the statistical reliability and validity of a measure of hope administered to well individuals (N=156) and individuals with cancer (N=150). The final six components varied slightly from the original attributes of hope determined from the literature review. According to Nowotny, this finding supported existing conceptualizations of hope. Interestingly, however, the factor loadings for one of the dimensions (spiritual beliefs) were such that *spiritual beliefs* became a separate category by itself. Nowotny (1989) does not emphasize this separate category, but encourages its recognition in clinical assessments and interventions

(Notowny, 1991). The mean score of hope for healthy adults was 84.4, whereas the mean score for adults with cancer was 82.7. Just *one* person with cancer was listed in the hopeless category. An item from each of the six categories is presented (my selection for these sample items is based on their median position within each category).

1. I am ready to meet each new challenge (confidence in the outcome).
2. Sometimes I feel I am all alone (relates to others).
3. I see a light at the end of the tunnel (possibility of a future).
4. I use prayer to give me strength (spiritual beliefs).
5. I have important goals I want to achieve within the next 10-15 years (active involvement).
6. I want to maintain control over my life and my body (comes from within).

Miller's assessment of hope. Like Nowotny, Miller (Miller & Powers, 1988) extracted the critical elements of hope from an examination of the existing literature. In addition, however, she generated items for her scale from previous qualitative data on hope among survivors of a critical illness (Miller, 1984, as cited in Miller & Powers, 1988). The 40-item Miller Hope Scale (MHS) also used a Likert format to determine scores of hope among healthy students. High hope scores were expected and found. Exemplary items are: (a) I look forward to an enjoyable future, and (b) I feel trapped, pinned down (item is reverse-scored).

Reliability and validity were established by correlating the MHS with other psychometric scales, resulting in the desired research objective of enhancing psychometric precision. My interest in this study stems from Miller's earlier qualitative

work (unpublished) from which the hope dimensions were gleaned. These are important for an understanding of hope, but also because they apparently were identified in some way by people who survived a serious illness. They are:

1. Mutuality-affiliation (interpersonal relationships)
2. Sense of the possible
3. Avoidance of absolutizing (avoid all-or-none conditions)
4. Anticipation (expectation)
5. Achieving goals
6. Psychological well-being and coping
7. Purpose and meaning in life
8. Freedom (not being trapped)
9. Reality-surveillance-optimism
10. Mental and physical activation (energy)

Herth's assessment of hope. The 12-item Herth Hope Index (HHI) is an adaptation of Kaye Herth's earlier 30-item Herth Hope Scale (Herth, 1989, 1991, 1992). The original development of the instrument was based on a model of hope presented by Dufault and Martocchio (1985). This model identified hope as *particularized* and *generalized*. Particularized hope characterized a person's expectation for achieving what is valued and good. Concerned with hope *objects*, particularized hope differs from generalized hope which motivates one "to carry on with life" when particularized hope is threatened (pp. 380-381). Six corresponding dimensions of hope were reported in this model: cognitive, affective, behavioral, affiliative, contextual, and temporal. Herth

utilized this model's multidimensionality in the development of the Hearth Hope Scale and subsequent Herth Hope Index.

The 12-item HHI was administered to 172 adults who were in three designated stages of illness (70 were acutely ill, 71 were chronically ill, and 31 were terminally ill). Ages of the participants ranged from 22 to 94 years. Through factorial analysis, Herth (1992) identified three fractors of hope that corresponded with Dufault and Martocchio's original model and the Herth Hope Scale: (a) temporality and future; (b) positive readiness and expectancy; and (c) interconnectedness. That the multidimensionality of hope was supported by the study was not as figural from my perspective as were the other findings. Herth reported the following results:

1. There were no significant differences in level of hope according to stage of illness.
2. Subjects who reported an illness duration over 12 months had a significantly lower mean hope score than those whose illness was present fewer than 2 months or from 2 to 12 months.
3. Significantly lower mean scores were reported by subjects having inadequate incomes and who were not married.
4. High or overwhelming fatigue levels revealed lower mean hope scores.
5. Subjects diagnosed with AIDS had a significantly lower mean hope score than did the subjects in other diagnostic categories: cardiovascular, gastrointestinal, musculoskeletal, neurological, hematological, and respiratory

(p. 1257). Unfortunately, no other information about patients with *AIDS* was reported (e.g., income, marital status, length of illness or stage, and fatigue).

Summary

These studies show the evolution of hope research over time. It is important to note that each work was designed from earlier theoretical assumptions. For example, Snyder's scale (and others; e.g., Erickson, Post, & Paige, 1975; Gottschalk, 1974; Staats, 1989; Stoner, 1982) had as its foundation the work of Stotland (1969). Stotland conceptualized hope as a "necessary condition for action" (p. 7). If the expectation for achievement of a goal is high, there is more action and more hope. On the other hand, if the expectation of achieving a goal is low, negative affect and low levels of hope will result (McGee, 1984, p. 38). Hope as a unidimensional construct grounded in goal expectation has been revised to encompass additional components, as the previously cited studies indicated. New instruments have been developed for clinical assessment in varied settings. Nurse clinicians, in particular, have advanced the knowledge of hope through their work with children, adolescents, and adults who are chronically or terminally ill (e.g., Dufault, 1981; Fryback, 1993; Hinds, 1984; Raleigh, 1992).

Finally, these studies provide the medical background to which we will return in subsequent discussions of hope. Consistent with the qualitative design, a thorough review of the literature is generally interwoven within the study's findings. While this will be the case here, I believe it has been useful to review the philosophical antecedents of hope which led to its increased interest in psychology and medicine. Since the Hope

Project was designed without prior theoretical assumptions of hope, it may serve a complementary purpose in the overall understanding of hope. What is critical here, then, is that the study started at the beginning--both for the participants and for me, the investigator. And just as the lives of the participants have unfolded over time as revealed in their narratives, so, indeed, has the research. This has become the story of people with HIV-AIDS who are also the original contributors to the evolution of a new study of hope. In the following chapter the story continues with the introduction of phenomenological inquiry. Its application and relevance to the storytellers will be highlighted.

CHAPTER 3

Method of Inquiry

Shirley phoned Saturday evening and whispered, "If you want to see Russell again, you'd better get over to the hospital right away." I said that I understood what she was saying and would leave immediately. It must be time, I thought, as the memories of Russell and his family were playing back like a rewinding video. Entering his hospital room, I struggled with the rush of emotions connecting everyone in the room with each other--silent, stabbing emotions that were felt but not verbalized--just in case a miracle might occur. Russell's face was turned to the right, vacant-looking except for his huge eyes behind the oxygen mask. I recalled a conversation I had with Randy earlier that day. Randy talked about taking care of friends dying of AIDS who clung to life so valiantly and forcefully that in his opinion, they began to act like trapped animals. He said some even fought for each breath until the last was taken. I couldn't help thinking then that the word animal might be hyperbolic. But now, being here with Russell who had experienced 18 hospitalizations in one year, it seemed as if the fight might be like Randy described after all. Even with all his vital organs slowly shutting down, Russell hoped for the eleventh hour reprieve, waiting for the telephone ring to jolt him back to life. Shirley said she hoped this would be the time that her husband would find some peace. It is necessary to put his hands in restraints. The anguish is etched in Shirley's face. But tied to the bed rails, Russell cannot inadvertently harm his caregivers when flailing arms demonstrate his intense agitation. And when he vomits the "brown stuff" there needs to be some control of his aggressiveness so that he can be washed. I sensed the obtrusiveness of the feeding tube dangling from his nose, the IV line, urinary catheter, diaper, monitors for vital signs, and his tied hands. Were the layers of his hope now exhausted? Perhaps not. Astonishingly, Russell's usually reticent demeanor changed with his loud commands, "Please don't wake me when I go to sleep. You hear me? You hear me? Don't wake me, okay? I won't wake you anymore, Shirley." His whole body quivered. "It takes you an hour and a half to wake up!" The strength and sharpness of his requests were uncharacteristic of his normally quiet conversational style. He continued, "Ma'am, please don't wake me. I love you. I bless your hearts. Please don't wake me; going to sleep now. Hear me? Hear me? I'll see you when I wake up again. But please don't wake me!" Russell was lying on his back. The head of the bed was partially raised. He would stretch his legs out then draw his knees up

toward his chest. His left foot was exposed. Several times he slapped at his heart with his restrained hand. The restraint on his right hand had moved up toward his elbow so he had a little more motion. He would stretch out his fingers as if to reach for something or someone, or to point to an object in the corner. Other times he would snap his fingers as if to command attention or to keep rhythm with music. Ironically, a respiratory therapy technologist came in to perform a breathing treatment. He assembled the breathing apparatus and the necessary medications. Shirley asked him to please stop, that the doctor would okay the refusal of the treatment. Then suddenly [in fact, everyone in the room jumped] Russell was able to reach the oxygen mask covering his face and with one quick motion it was flung away from his face. So there! Almost defiantly, and quite powerfully, he repeated his request, "Don't wake me, okay?" We could see that blood was coming up again to the edges of his mouth. His lips and teeth were bloody. Shirley put on gloves and folded a small hand towel in half. She began to wipe the blood away from his mouth. When she put the towel inside his mouth to clean it he unexpectedly bit down on the towel and would not let it go. Shirley kept asking him to "Let go, Russell, let go. Open your mouth, Russell. Turn loose." And with her left hand she reached around his head to the left side of his face to try to open his mouth. Then she realized that he had just stopped breathing. Still holding on to the towel that was still in Russell's mouth, Shirley sat down and kept saying, "He won't let go; he just won't let go." With tears flowing down her face Shirley stood up and looked at her beloved husband's skeletal, motionless body. After four years of living with nearly every infection the AIDS virus can elicit, Shirley hoped her husband was finally at peace.

[Researcher notes]

Introduction to the Phenomenological Perspective

To consider the philosophical question "What is the definition of phenomenology?" seems as absurd as asking *Russell* to explain his perceived level of hope as he lay dying. Sometimes we should quite simply be open to the symbols, metaphors, and meanings that are presented to us in verbal and nonverbal ways. The meanings of hope inherent in Russell's dying and death were exemplified in his request to

be allowed to sleep and not be awakened once he went to sleep. He asked for his family's assistance in allowing him to sleep (die) and hoped to see them again "when I wake up." His physical and emotional connection to Shirley seemed everlastingly poignant as she held on to the towel hoping that he would both let go and yet not let go. He would never again wake her up when he needed care (exhausted herself, she often could not immediately hear his call for help). Shirley is partnerless in her role as mother and grandmother. But there is peace and freedom from pain for Russell.

Phenomenology is a human science research methodology that allows us to *be* and *stay with* our research participants' lived (i.e., human) experiences so as to preserve the bond between meanings and phenomena. Properly defined, phenomenology is the study of the nature of phenomena as meaningfully experienced by human beings (Giorgi, 1967, 1983; van Manen, 1990). Because it is a descriptive methodology, it provides a means to fit descriptive elements into a dynamic whole (Ray, 1985). While methodology implies the qualitative philosophical framework for the pursuit of knowledge, phenomenological *methods* provide the means which shared understanding can be accomplished through descriptive narratives or other techniques. Together, methodology and methods frame phenomenological investigation, analysis, and synthesis. This chapter focuses on the methods used in phenomenological inquiry. First, however, it will be useful to review phenomenology in its historical context and outline the potential benefits of this perspective for medical psychology.

Historical Overview

Hegel's (1770-1831) work on the formal conceptualization of phenomena introduced the term *phenomenology*. Influenced by Hegel, the German philosopher Edmund Husserl (1859-1938) developed phenomenology with the aim of establishing a rigorous science that could focus on the analysis of the conscious person's modes of structuring, feeling, and acting in the world (Kockelmans, 1967b; Lavine, 1984). Husserl's phenomenology is a rejection of the usual scientific method which traditionally focuses on predicting or controlling objects in the world. According to Kwant (1967b), Husserl's focus is on meaning:

> Husserl's philosophy is a philosophy of meaning. However, he is not looking for the meaning which reveals its self as a matter of fact, but for absolute and necessary meaning. Our words always have meaning. When we say *table* or *world*, these words have a meaning. Husserl seeks the conditions which must be fulfilled so that we can speak of *table* and *world*. (p. 397)

That phenomenology is independent of the natural sciences and seeks to describe the structures of daily experience in the lifeworld exemplifies the concept of consciousness. For Husserl, the fundamental component of philosophical phenomenology lies within conscious action. Favoring Hegel's view, Husserl claimed that consciousness is *of* something, not first something in itself which then enters into a relationship with a something else (Kwant, 1976; Lavine, 1984). For Husserl, conscious acts are intentional, that is, directed toward an object. When seeing something or desiring something, there is an object seen or desired (Kolakowski, 1975, p. 61). Thus, intentionality is a critical feature of Husserl's notion of consciousness. As defined by Colaizzi (1978) intentionality

means that "human existence and the world constitute a unity, a unity so vital and basic that either one is absurd and inconceivable without the other" (p. 54).

Husserl's phenomenological inquiry is grounded in "perceptions, judgments, and feelings *as such,* in their a priori nature, in their very *essences* (Kockelmans, 1967b, p. 79). It was a consideration of the essential structure of experience and its objects that prompted Husserl's demand for viewing things without prejudice, to *return to the things themselves* (Husserl, 1962, pp. 91-93; for a review of Husserl's work see Kockelmans, 1994). In doing phenomenology we reflect on essences and their connections.

The profound influence of Husserl's return-to-the-things-themselves phenomenology and its significance for later existential phenomenology became evident in the works of Martin Heidegger, Jean-Paul Sartre, and Albert Camus (for reviews see Lavine, 1984; Natanson, 1973; Spiegelberg, 1967). In contemporary psychology the works of Merleau-Ponty (1962), Giorgi (1975), and others reflect Husserl's influence. Phenomenological psychology has also been useful in psychotherapy (Halling & Nill, 1989; Moustakas, 1988), and in social work (Sherman & Reid, 1994). Accordingly, Hartman (1994) claims that we should not limit our profession by limiting our searches. Each discovery, she says, "contributes to our knowledge and each way of knowing deepens our understanding and adds another dimension to our view of the world" (p. 461). Husserl's goal for phenomenology was an attempt to "correct the fundamental mistakes of traditional empirical psychology by means of a phenomenological psychology which [would] fill the gap between philosophy and empirical psychology"

(Kockelmans, 1987, p. 10). That the gap has been filled is addressed by Giorgi (1983) who specifies three beneficial consequences of phenomenological inquiry:

1. It allows a more adequate approach to the nature of psychological phenomena, the essential nature of which has eluded psychological science thus far.
2. It brings into sharp focus the inevitable presence of the researcher in the process of research.
3. It calls one back to the value of description and qualitative analyses, if not as exclusive methods, at least as valuable steps for scientific psychological analyses. (p. 147)

In my view, there is another aspect of phenomenology that is notably engaging: its language. The language of philosophical and psychological phenomenology facilitates and dignifies questions about quality of life, health and illness, and meanings in lived experience. Since the language is relevant to health-related research it should be included in this discussion, and the work of Raymond McCall (1983) provides the primary framework for this section's translation of terms.

Zeitlichkeit. *Zeitlichkeit* refers to the human quality of being temporal, which is not something *in* which we are but the very *way* we are. Our human presence (Dasein) or Being in the world, is always temporal. We have no existence apart from time. To Heidegger time is "neither an infinite series of instants...nor a kind of spatialized container in which things are, but the horizon or background or setting for all understanding and interpretation of Being" (McCall, 1983, p. 75). Our experience of time

is not remote or dehumanized; it is always lived time, time as already experienced, and anticipated time.

On the other hand, the notion of time in the physical sciences is objective, measured by absolute standards, such as the ticking of a clock. This formal and unalterable time is used by health care professionals who communicate with their patients on an objective dimension of time. It is also incommensurate with lived personal time (Toombs, 1992). Participants' experiences of medical treatment illustrate the meanings of Zeitlichkeit:

> *Sarah was describing her first lumbar puncture, or spinal tap. This is a diagnostic procedure which tests cerebrospinal fluid by drawing a sample of fluid from the lower spine. Sarah explained that she had to lie on her side with her knees drawn up toward her abdomen and her chin pointing toward her chest. She was warned to remain still and not move for any reason. (This reduces the chances for the puncture of a nerve root.) She was warned to expect a "sting" in her back. She held her breath waiting for the pain. The test, she said, felt like it "took forever" to be over with. The pain wasn't too bad, but it was frightening. When she returned to her hospital room, she was exhausted and slept for a "little while" (several hours) before she needed to get up to go to the bathroom. After that, she said her head "exploded" and hurt so horribly that the nurses called the doctor. It "took them forever" to get the medicine and it didn't help much. She thought the pain "would never end." It lasted over a week. She said the doctor had forgotten to tell her not to get up and to stay flat in bed after the test was over.*
>
> [Researcher notes]

Objective time is clearly not identical with the lived time nor is the language used to describe lived time in *Sarah's* experience equal to *objective* time. In terms of clock time, it did not take "forever" to medicate her for pain. Still, if a person is in unbearable pain, time is going to feel quite different than what the observer is experiencing. When

we communicate with patients about pain from stressful diagnostic procedures, we are talking about two separate beings-in-the-world. Time according to my ticking watch is not the same as Sarah's time as she is engulfed in pain. Awareness of personal time can help us understand illness experiences more completely.

Time as defined by Heidegger is time in which human life is lived. It is essentially finite or limited, having, "like human life itself, a necessary beginning and an inevitable ending. Finitude is therefore of the essence of time as we experience it" (McCall, 1983, p. 77). Heidegger (and others) have stressed the point that death cannot be experienced *with* others; it must be experienced alone. Inasmuch as we hope to be understood and respected as we approach our inevitable ending, we may not be able to share our experience of time any more than we can share our dying and death. In the Hope Project, time has been a curiosity, a puzzle without all the pieces with which to make the whole picture. *Randy's* situation provides an example of this.

> *Randy developed septicemia after contracting a bone infection resulting from a fall. He needed a surgical procedure which necessitated hospitalization. Apparently he was unable to breathe independently after the surgery so he was assisted by mechanical ventilation. When he awoke in the intensive care unit he reportedly pulled out the tubes and lines. Since a family member was not present at the time and a Medical Directive or Living Will was not available, he was sedated and placed on mechanical ventilation. Without an authentic record of his wishes, Randy began a slow journey through physical deterioration toward death. He had vehemently expressed his horror of life support measures and dying in a hospital. On numerous occasions he talked about his fear of experiencing the painful struggle of dying. He hoped (he exclaimed many times) that he could have a gentle, peaceful dying and death at home with his cat without "gross machines attached to every part of my body." It was an agonizing five days to observe. The room was noisy and terrifying for his family. Randy's friends brought teddy bears to keep him company. (He confessed that he often slept with his bear especially when he had what he called "night panics".) I spoke to him about photographs and*

clouds, butterflies and birds; about time and space and flying off to take pictures of the universe (he was a photographer). He cannot speak. Each breath collides noisily with his heart-rate monitor marking time. Other machines seem to be swooshing, beeping, or clicking. What is his experience of time? Of pain? Of consciousness? At five o'clock in the evening on the fifth day his family asked me to stay with them because they had made the decision to disconnect all the machines. Randy's physicians explained that his vital organs had been damaged beyond repair and there was no chance of recovery. Was Randy aware that a stop sign had been placed at the end of his life line? Was he angry or relieved? I found his silence suddenly irritating. Randy, the stubborn AIDS activist. Randy, who always had a voice, an opinion, and who forevermore continued his cry to people to "wake up because this plague isn't going to go away on its own." This was Randy, who spent three hours in the graveyard in the middle of the night to "get comfortable" with his eternal resting place. Where was his voice now? The ICU nurse came in to disconnect the machines. I asked her to untie the hand restraints. She did. We were asked to leave the room briefly because some of the procedures were "unpleasant." His mother held tightly Randy's teddy bears. We stood by the door, each with our personal memories and thoughts about what was to happen. When we returned, the machines were turned off and Randy had been suctioned. We waited. I have tried to think of a word that could adequately describe his mother's pain. I cannot find one. And then he inhaled. It was slow, choppy. He exhaled. We waited. He inhaled again, this time more slowly, like a roller coaster creeping up and up toward the highest peak, and then down, the exhale, sure, rapid, and strong. Randy's breaths continued as time crawled; it raced; it stopped; it started. Time seemed to be fractured. It was cruel. Randy was breathing on his own. But he was not supposed to breathe! His family was confused, uncertain. Was this a death or a rebirth? Should they continue to cry or should they rejoice? The nurse said that "it sometimes takes longer than we expect" and left the room. I watched both in horror and amazement. This was a tragedy and a comedy of errors. Silence turned to conversation as his family urged him to get out of bed, to come home because his cat missed him, and also that he needed a haircut. I looked at his grossly bloated abdomen, the black and purple bruises covering his right arm, and I understood. Randy continued to breathe for another five days before he completed his Zeitlichkeit. But his story is not complete--yet.

[Researcher notes]

Verstehen. The meaning of Verstehen is human understanding; to have an appreciation of the possible (McCall, 1983, p. 78). It implies that there can be human interdependence, human togetherness, and reciprocal relationships (Mitsein). To be aware of ourselves, each other, and our communities sometimes means to understand there is hope for transcending the limitation of the present and projecting toward the future and its own not-yet-fulfilled possibilities. Part of what we understand is that there are certain conditions or situations in the world into which we are thrown (Geworfen) without our consent or approval. We understand that this *thrownness* forces us to live confined by social forces (sometimes literally bound or tied, as *Russell* and *Randy* experienced), by rules we have not made. That our fate may be psychological despair and wretchedness (Angst) or dismayed apprehensiveness is something we understand (McCall, 1983, p. 80). When we are thrown into a world not made by us, we are not living (Being) in a world that feels like home to us. Phenomenological inquiry facilitates the quest for knowledge and understanding; for example, during the time of death for both *Russell* and *Randy*. If it is indeed important to human beings that at least one other human being know and *understand* an experience (instead of merely knowing *about* it), then the language of phenomenology should concern Verstehen.

Approaches to Inquiry and Analysis

> Munhall (1994c) had this to say about research techniques and methods:
>
> I have, for years, witnessed students developing method-driven studies rather than phenomenologies. How difficult it is for us in this country to think in ways that are not formula based or theory based. We have been rewarded for assuredness and...for knowing. So I become concerned when students take an interview apart line by line, away from the individual, away from life and the landscape, away from the horizon and the background. To compound this problem students and

> nurse researchers often want to know if computer software programs are available to do this dismantling. I will be candid; here is where I shudder. (p. 95)

The seduction of method-driven studies also has been discussed by Colaizzi (1978) and by van Manen (1990). Van Manen, for example, makes it clear that methods are not meant to be a "mechanistic set of procedures, but [are meant] to animate inventiveness and stimulate insight" (p. 30). Colaizzi (1978) recommends choosing methods that fit what we implicitly view as the value of our research (p. 55). In other words, research methods are tools which should facilitate the ultimate aim of the study. They are not rigid guidelines to be followed blindly. Nor are they, for that matter, signposts to ease the researcher's journey. Instead, research methods should, in my view, (a) evolve from the unique contexts and needs of the study and its participants, (b) advance understanding of the phenomenon being studied, and (c) facilitate the likelihood that research participants will benefit in some way from the study. With these goals in mind, I evaluated the approaches to be utilized in the Hope Project with careful skepticism. As Munhall frequently notes, all guidelines are, after all, lines that serve to block or screen something. Nevertheless, the following overview describes some of the specific characteristics of the methods chosen to be used for this study. The collective methods of van Manen (1984, 1990), Moustakas (1990), and Munhall (1994a, 1994b, 1994c) were integrated with the goals and needs of the Hope Project. There is a distinct overlap in the philosophical and methodological frameworks of the perspectives I have adapted for use in this study. Each has influenced the discovery process and should be rightfully acknowledged.

Van Manen's hermeneutic phenomenology. The hermeneutic phenomenological approach of Max van Manen (1984, 1990) has specifically affected human science

researchers in the fields of education, nursing, anthropology, and psychology. Van Manen grounds hermeneutic phenomenology in both descriptive and interpretative domains which are often used interchangeably (1990, p. 26). As defined by van Manen (1990), hermeneutic phenomenology "is a descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena" (pp. 180-181).

Van Manen has enumerated specific characteristics relevant to hermeneutic phenomenology:

1. It is the study of lived experience.
2. It is the explication of phenomena as they present themselves to consciousness.
3. It is the study of essences (Merleau-Ponty, 1962, p. vii).
4. It is the description of the experiential meanings we live *as* we live them.
5. It is the human scientific study of phenomena.
6. It is the attentive practice of thoughtfulness.
7. It is a search for what it means to be human.
8. It is a poetizing activity; that is, the language used in the results of the study cannot be severed from the means by which it was obtained. (van Manen, 1990, pp. 9-13)

Four research activities developed by van Manen contributed to the "doing" of phenomenology. These activities or procedures did not constitute orderly steps along the

research continuum but are interwoven through the discovery process. Van Manen (1990) proposed that there first should be a "turning" or orienting to the phenomenon of interest. Second, the experience should be investigated as it is lived. Third, there is a reflection on the essential themes which characterize the phenomenon. Last, the phenomenon is described through the "art" of writing and rewriting. Van Manen (1990) suggests that our vantage points in life determine how we orient to the phenomenon. In particular, he reminds us that our own experiences are also the possible experiences of others (p. 54). This has advantages and disadvantages. A good beginning question, then, is to ask, "For what reason is this phenomenon of interest to me?"

Another strategy that highlights the researcher's orientation to the phenomenon is the generation of a personal description of experience. Frequently, this is accomplished by an interview with a phenomenologist (written descriptions are also appropriate). Important insights can evolve from a personal interview. It may bring to the surface attitudes, concerns, feelings, or assumptions about the phenomenon that may be taken for granted or that may have otherwise remained hidden.

The process of *bracketing* facilitates adoption of a clearly neutral position but not uninvolved about what is evident. This concept has been the focus of scientific debate; it remains an enigma. Bracketing has been defined by Munhall as "getting out of your own way," "decentering," and "unknowing as a condition of openness" (1994c, p. 61). Particularly applicable to interviewing, it is a way to be objective, nonbiased, and to be *with* the person who is speaking. In my view, it also may be defined as "I can't hear you when I'm thinking about myself."

Bracketing should not be considered a singular activity. It is a valuable process that should occur throughout the study. During interviews for the Hope Project, my personal experiences about hope were deliberately and consciously *put aside* in order to hear the participants' experiences while being open to them. But, is it possible to put aside or unknow personal experiences? Can I suspend my medical background in oncology and radiology? Can I truly get *away from* my current work in medical psychology? Can there be a fresh view and openness about hope when my son lives with AIDS? Are the research questions objective when they are borne from subjective lived experience? We wonder whether life experiences are removable from any context, regardless of the research approach. Objectivity, therefore, is itself a paradox (Colaizzi, 1978). Merleau-Ponty (1962) argued that the "most important lesson that reduction teaches us is the *impossibility* (italics added) of a complete reduction (p. xiv). If we could set aside our beliefs or experiences, wouldn't that negate the very human experience that we wish to investigate? Would our investigation be honest or biased?

The bracketing interview places these questions in perspective. Its function is not to disengage from the phenomena but to be aware of it; to be focally aware of it. For example, I was fortunate to have an enlightened experienced interviewer who pulled me (albeit gently) through my awareness of hope. Throughout the interview the concept of hope was bashed about--it waxed and waned--its certainty was suspect. But there was a shadow of hope waiting in the wings. After the analysis of the conversation, it emerged. My interview illustrates some critical points that may be helpful exemplars for phenomenological investigators. First, the conversation was valuable to me as a human

being struggling with the many facets of AIDS. Not only did I discover hope where I had thought there was none, I experienced (felt, lived, sensed) a release of some of the pain of isolation and loneliness that comes with being affected by HIV-AIDS. AIDS is seldom a desired topic of conversation over dinner. On the other hand, AIDS *should* be discussed at some point. One benefit of the personal interview, then, was that it was a safe way to *hear* my own experiential messages and meanings. That is in itself a worthy intervention. And in a way, to be able to push open the windows and get some fresh air is to be able, to some degree, to have a fresh outlook. This is particularly relevant to van Manen's procedural activity, *investigating the experience as we live it.* A final benefit of the bracketing interview was that it afforded the opportunity to examine very closely the motives and goals of this research to ensure that I understood *why* I chose to study hope phenomena. Therefore, an important feature of the bracketing interview is *its* analysis and interpretation.

Investigative activities that generate experiential descriptions in van Manen's model are: (a) obtaining narratives from participants through in-depth interviews, (b) close observations, (c) locating experiential descriptions in personal documents, literature, and art, (d) tracing etymological sources of the phenomenon, and (d) consulting the works of other phenomenologists. In phenomenological reflection, the goal of analysis is to disclose the multilayered meanings of the experience. This process involves discovering incidental and essential themes that make a phenomenon what it is and without which the phenomenon could not be what it is (van Manen, 1990, p. 107).

Phenomenological text follows from the repetition of rethinking, reflecting, and recognizing, since depthful writing is not accomplished in one session. Van Manen (1990) stresses the importance of phenomenological writing and rewriting during the construction of a phenomenon. In his view, good descriptive writing is "a creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and sensitive" (p. 39).

Moustakas's heuristic inquiry. Heuristic inquiry comprises "the internal search to discover...an encompassing puzzlement, a passionate desire to know, and a devotion and commitment to pursue a question that is strongly connected to one's own identity and selfhood" (Moustakas, 1990, p. 40). From the Greek (*Heuriskein*) the word heuristic means *to discover*. Like van Manen's hermeneutic phenomenology and Munhall's existential phenomenology, heuristic inquiry has defining characteristics. They are, however, remarkably similar to the other two perspectives in relation to the discovery process. In heuristic inquiry the research question

1. seeks to reveal more fully the essence or meaning of a phenomenon of human experience.
2. seeks to discover the qualitative aspects, rather than the quantitative dimensions, of the phenomenon.
3. engages one's total self and evokes a personal and passionate involvement and active participation in the process.
4. does not seek to predict or to determine causal relationships.

5. is illuminated through careful descriptions, illustrations, metaphors, poetry, dialogue, and other creative renderings rather than by measurements, ratings, or scores. (Moustakas, 1990, p. 42).

Moustakas's early work concerned was the study of loneliness, which, he remarks, became "the center" of his universe. Everything in his existence appeared to be connected with loneliness. He set out to "discover the meaning of loneliness in its simplest terms and in its native state" (1990, p. 94). With an immersion in the topic comes a curiosity; is this phenomenon seemingly everywhere because it *is* everywhere, or because it is everywhere in *my* life? Once you have an awareness of hope (even with this reading), it seems as if the concept emerges in your everyday life. It is this personal engagement with the phenomenon that defines heuristic inquiry.

Having origins in humanistic psychology, heuristic inquiry also emphasizes the relationship between participants and the researcher as they mutually explore the phenomenon. As their stories unfold over time, for example, participants ***remain*** prominent in the study. Essential to the heuristic process is the shared flow of dialogue between participants and the investigator. This dialogical style challenges the traditional scientific notions about objectivity, as explained by Weber (1986):

> We cannot and should not be unaffected by what is said, unless of course we are either not listening or are simply denying what we feel under the false and smug cloak of scientific objectivity....On the contrary it is only in relating to the other as one human being to another that interviewing is really possible...when the interviewer and the participant are both caught up in the phenomenon being discussed. (p. 68)

In heuristic interviewing, the dialogue involves cooperative togetherness. The data generated is dependent upon accurate, empathic listening. The researcher must be flexible and skillful in creating a climate that encourages the co-researcher to respond comfortably and honestly (Moustakas, 1990, p. 48).

Inclusive with engagement and immersion in the topic of study are four additional phases of heuristic research that pertain to data analysis. The following review is adapted from the discussion by Moustakas in his 1990 book, *Heuristic Research.* Although separate phases, the four methods of discovery are part of an ongoing process. They are: incubation, illumination, explication, and creative synthesis. Moustakas uses the metaphor of a seed to describe the *incubation* phase. Once the seed has been planted there is a resting period that allows for "silent nourishment" (p. 29). For the heuristic researcher, this is a time for quiet, nondeliberate cognitive processes. It is a step back from intense preoccupation with the phenomenon. Put another way, incubation occurs when we decide *to sleep on it* and allow the time away to bring new aspects into awareness upon our return to the phenomenon.

Illumination is a naturally occurring consequence of being receptive to tacit knowledge and intuition. Tacit knowledge is defined as our ability to sense the unity or wholeness from an understanding (Verstehen) of the individual qualities or parts. For example, we can understand a person's physical state by noting bodily movements, facial expressions, tone of voice, and other tacit clues (pp. 20-21). Intuition makes possible the perceiving of these parts as wholes. It is our internal capacity to sense, imagine, and make inferences. It facilitates the discovery of patterns and meanings that lead to greater

understanding. Being open to tacit knowledge and intuition illuminates essences, symbols, or thematic moments in the study that may have been misunderstood, overlooked, or fragmented (p. 30). Two examples illustrate how the phases of incubation and illumination intermingle during the analytic process.

> *My first meeting with Hal took place at his apartment. (I should first make it known that visiting strange men at their homes was an uncommon experience for me.) Hal was a gracious host, eagerly showing me his apartment and the crafts he had made. He offered me something to drink which I declined, having just finished lunch before the visit. "Are you sure?" he said, "I've got Coke, coffee, and water--bottled water." Not wanting to impose, I declined again. But later while reviewing my notes I recalled that exact moment and remembered that there was a brief frown on Hal's face when I said no-thanks to his offer. Was it a look of disappointment? And in that frown I saw the meaning which was to be validated again and again over the next two years. For people living with HIV-AIDS, there is a hypervigilance and sensitivity toward issues of isolation and stigmatization. People hope that others will perceive them (and their homes) as being just the same as any other person's home. Hal's hospitality was tied to his need to know that I would feel safe and comfortable visiting him and sharing food or drinks. While my concern was grounded in a different kind of politeness (not being a bother), his frown was a tacit clue that had its own meanings. Since that illuminating experience, I have realized that accepting coffee or other refreshments in this context is more than figural; it is a part of hope. During my second visit with Hal we made coffee in the kitchen and he showed me all his medications while we waited for it to be ready to drink. It was important for him to know for certain that I appreciated his thoughtfulness and enjoyed the visit.*

> *Mark, you may recall, cancelled our interview because of respiratory problems. We met instead at his doctor's office. This was one of those once-in-a-lifetime spontaneous moments that were typical for him, but again, not for me. He decided we should have a leisurely lunch since he'd be hospitalized the next day for treatments. His father suggested that he drive us and pick us up later. Mark selected a restaurant known for its excellent food and its ambience. With his portable oxygen tank on wheels in tow, we settled in for our two-hour lunch. He was able to breathe satisfactorily, although it was sometimes difficult to speak in long sentences. The room was soothing, quiet, and pleasantly furnished. Our server was very competent and thoughtful. Because of severe fluid*

retention, Mark was restricted to a few sips of fluids per day and his food could not be salty or spicy. Since he was a gourmet cook, this was unenjoyable. Nevertheless, he designed a meal for himself. We talked about his former life and his work, his family, his volunteer work, and the pleasures of cooking and having dinner parties. Of course all that had changed with HIV. He knew that his lovely life was nearing its completion. His conversation was poignant, nostalgic, and incredibly funny. It always amazed me that Mark could cry and laugh simultaneously, or so it seemed. There was something not quite right, although, during this luncheon. At one point I nearly felt disconnected from the moment as if I really were not present with Mark. I came away from the visit with the feeling that I didn't do it right; that I had missed the point entirely. After an incubation period it became clear to me. While Mark was talking he would hold his fork just so, sometimes turning it so the food would slowly rotate. He studied the shapes with the eye of a scientist. Once, he held his glass up so the light filtered through the liquid, and then he took a small sip, slowly, holding the glass to his lips as if to imagine the taste of a larger volume. His motions were soft and flowing, precise but not rigid. I, on the other hand, had eaten my taken-for-granted meal and enjoyed my iced-tea without attending to any of this. I had missed the eating ritual on a conscious level but intuitively sensed it on a deeper level. This celebration of eating was illuminated in retrospect. The meal and its symbols, rituals, memories, and conversation all belonged to the quality of Mark's hope at that moment. I know now that he knew I wasn't with him; he understood. Since then, eating has never been the same for me.

[Researcher notes]

Once illumination brings to light the relevant themes or components of a topic, the researcher develops portraits of individual experiences. This explication precedes the final phase of *creative synthesis* in which the researcher completes an integration of the data. This is an intense analytic process that is not separate from the researcher's intuition, imagination, and personal knowledge of meanings and essences of the experience. The final synthesis may take varied forms (i.e., narratives, poems, songs,

drawings), but the goal is to preserve the integrity of the co-researchers. As Moustakas noted, "unlike most research studies, the individual persons remain intact" (p. 51).

In sum, Moustakas claims the validity of the study is contingent upon the judgment of the primary researcher (who has undergone the heuristic inquiry from its beginning to the end) *and* the co-researchers' judgment as well. Verification is achieved by returning to the research participants and seeking their assessment of the study's comprehensiveness and accuracy. Only they have lived the studied phenomenon; only they can claim (or not claim) the findings. Van Manen (1990) would add that this process is contingent upon the researcher's skill in providing an accurate synthesis. He borrows the term *phenomenological nod* from Buytendijk to describe the reader's reaction. The phenomenological nod is "a way of indicating that a good phenomenological description is something that we can *nod to* (italics added), recognizing it as an experience that we have had or could have had" (p. 27).

This final validating step reengages the participant-researcher partnership, although in a different way. It focuses on the study participants as the experts who decide whether or not the creative synthesis captures their experience. There can also be a feeling of closure on the project. Validation by study participants reveals to them the way in which their contribution or part has made up the whole. As *Douglas* recently said, "I'm really interested in hearing what the other people in the Hope Project have said about their lives and hope." The time frame for the study has been frustrating for some of the participants who wanted to know the results earlier and who needed closure. Frank, for

example, asked if anyone else thought that hope was an important aspect of living with the final stages of AIDS.

In my view, the research partnership is an important but neglected dimension in phenomenological research. The participants themselves are a taken-for-granted phenomena. It was *Russell* and Shirley who made this clear to me, not once, but several times during our partnership:

> *During our second conversation Shirley and Russell were sharing their opinions about researchers. It was the pejorative tone of Shirley's voice that I remember still. She said, "researchers have this idea that they can come and pick our brains about something and then it's all over--wham, bam, thank-you ma'am. They really don't care about us. All they want is their information so they can get on with their lives. That's why we waited to call you. We wanted to think it over and decide if we wanted to go through that, or being a guinea pig for someone. We had to find out first if you were really interested in AIDS and us or just yourself. Dr. Rose said this would be a good thing for us to do, so that's why I called you."*
>
> [Researcher notes]

Munhall's existential phenomenology. Nurse researcher Munhall's (1994b) model of existential investigation features the inclusion of diverse experiential data that is especially relevant to participatory research in health-related settings. For example, in addition to descriptive interviews, Munhall suggests that personal experiences, anecdotal descriptions, journal reflections, observations, and experiential descriptions in the Arts all contribute to the holistic portrait of the phenomenon. Like Moustakas, she places emphasis on the role of the researcher's lifeworld during the study. In the Hope Project, it was the unexpected complementary aspect of anecdotal material manifested in storytelling that confirmed Munhall's suggestions. Participants often framed their

experiences in stories that revealed personally sensitive issues. *Raymond's* story is an illustration:

> *An artistic and articulate man, Raymond also had a way with language. It was on Thanksgiving, he mused, that he became more aware of his feelings related to anger and hope. First, I should say that Raymond's struggle with advanced Kaposi's Sarcoma had reached far beyond any human level of tolerance. The widespread malignancy required diligent pain management, not to mention an above-average sense of humor. Combined with inexplicable pain were the quality of life issues that most of us take for granted. But on this day Raymond and a friend decided to have their Thanksgiving meal at a mall restaurant. He explained that he was looking forward to a good meal that was not prepared by him. He had been suffering unrelenting bouts of nausea and vomiting for several weeks but was now ready to get out of the house. After parking the car, they started walking toward the restaurant. Raymond's telling of this occasion was so vivid that you could easily imagine yourself in the parking lot, walking with your friend. And then suddenly, he said, there were about 50 elderly people approaching them. They must have eaten their Thanksgiving meal at the restaurant and were now returning to the waiting bus. As the distance closed between him and the people, Raymond said he could hear their voices and they looked like a jovial crowd, probably very full of turkey and pumpkin pie. So when the nausea attack hit, he debated whether he should vomit right there in front of them (which would "spoil their holiday") or whether he should do something else. He said he pictured the entire scene in a fast-forward mode and barely had time to duck between some parked cars where he "heaved up his guts" unnoticed by the people. Raymond thoroughly enjoyed the possibility of ruining the day for these people (which was part of his anger and pain). But he also enjoyed the fact that his imagination was still working well enough to picture the onlookers' faces if he had not hidden himself between the cars. For him, that was hopeful, since he had always valued his sense of humor. Although it had waned in the past few weeks, this experience brought humor back into focus as a means to make sense of or deal with unpleasant situations. Before he died, Raymond made a point of reminding me to share this story with his physician and others who would understand and appreciate its nuances.*
>
> [Researcher notes]

Summary

The methods of inquiry just described provided the framework for the phenomenological exploration of hope. From the works of van Manen, Moustakas, and Munhall, I utilized those features that best fit the goals of the Hope Project. Since the study participants invited me into the most personal corners of their lives (including their dying and death experiences), this study *necessitated* for me the use of research methods grounded in humanistic, person-centered, and holistic approaches to inquiry and analysis.

When the research topic resides within a health-related context (i.e., living with HIV-AIDS) the benefit of phenomenological inquiry is its openness to discovering the totality of the phenomenon and the lived illness. That is, when less attention is given to diseased parts, there can be a greater awareness of *each* person's wholeness as the phenomenon is experienced by them. There is no right or wrong way to experience hope in the context of HIV-AIDS (or loss, or physical deterioration, or depression, and so forth).

Chapter Four explains the application of the methods chosen for the Hope Project. Interestingly, students of phenomenological science always ask the same question: "How do we learn to *do* phenomenology?" And the answer is always the same: "You will learn by doing it." The next section also discloses the researcher's role when sensitive issues (e.g., AIDS, sexuality, death, homosexuality, drug use, discrimination, confidentiality) are a part of doing phenomenological research.

CHAPTER 4

Application of the Method

My name is [first, middle, last] and I want it used in case I die, so, you know, at least something of me will live on. But I want to be that "out". I want to be that available to people. And I don't have any problem with my full name being used in any context. If something is taken completely out of context, if someone just gets self-serving with it, then I will obviously take them to task on it. But for the purpose of the AIDS crisis and the people that I have been dealing with, I have faith in them and in their conscientious use of such information. Essentially, if it serves the purpose of AIDS education for those people who are at risk or who already have it, for improving quality of life, improving medical or psychiatric treatment plans, I have no problem with lending my name. My name...I mean, I wear a T-shirt that says yes, I have AIDS. Let's talk about it. I'm not afraid. I'm not going to be afraid. I'm not going to live in fear. And so that's a big important deal to me [using my real name].

- Phillip

I really don't want to use that name because it's not my name. My name is [first, middle, last] and that's who I am. You can put my real name down and you can tell your students what happened to me so maybe they'll pay attention to this virus.

- Russell

One of the reasons this epidemic is still going on is because you researchers feel you have to hide behind confidentiality all the time. That makes other people think there's some reason to hide, or something to be ashamed about. There isn't.

- Shirley, Russell's wife

Well, Elliott, when I come back, what shall I bring? What would you like? You can bring me a boyfriend. A boyfriend? Okay, what kind of boyfriend? One that's nice to look at.

- Jeannie & Elliott

I was visiting this guy who didn't have any family, never had visitors in his room. He was in the last stages so I just sat there with him so he could see that someone cared about him. And then, all of a sudden this woman came rushing in his room and started screaming at him that he was a disgrace to her and his father. I guess she was his mother because she said he'd never be a part of the family, she would disown him and God was punishing him. Goodbye. And she left. For once, I was speechless. I wanted to get up and throw her out, but I couldn't move. The poor guy was crying, tears streaming down his face. About 30 minutes later, he died.

- Randy

A friend of mine that died a year ago was one of those people who didn't share much [about his illness] with people. He was very paranoid about people finding out. He had a very long and painful course, finally died. He was Presbyterian. They had a funeral at the funeral home and I swear there was not a tear in that room. And everybody was sitting there in their suits, and even his parents, I mean ***nobody*** *was crying! You wouldn't have known somebody had died. I just thought that was too peculiar...as if, what? Nobody is sorry I'm gone?*

- Peter

What really makes me sick is these people who are so much in denial about HIV that they have sex with anybody without ever telling about their disease or using a condom. It's that don't-ask-don't-tell crap.

- Frank

When I wasn't allowed to donate blood I asked what the problem was, and they said, Well, some of your test results came back abnormal and we need to recheck them before you give blood again. I asked which tests were abnormal, but they wouldn't tell me--said to come back in a week. So in the meantime I asked my doctor to do a hepatitis test, a liver profile, and HIV test, figuring that's what they did to test blood. I called to get the results when they told me to call, but the results were not back. I called the next day and the nurse told me over the phone that I was HIV positive. I was, needless to say, I was really scared, real, real scared. And I was worried about what kind of reaction I would get from other people. And I was so angry, I mean, I called the doctor's office...but how did she know for ***sure*** *that I was who I said I was? Any other time you call to request information they tell you, well, we're sorry, we're not allowed to divulge that information. I changed doctors rather quickly. I got copies of my*

records and told the nurse not to ever give out any information about me. And my doctor never called me about the report, never even came out of his office. He did not care. Maybe he was relieved that I...I don't know what he was thinking.

- Amie

Research as a Process of Discovery

The participants' narratives speak to the diverse social milieu in which I became immersed during this study. As mentioned previously, to discover how hope impacts quality of life issues, relationships, and physiological states among such a nonhomogeneous HIV-affected group, I engaged in participatory research. Grounded in feminist studies, ethnography, and phenomenology, participatory research involves direct, sometimes intimate contact with participants who are viewed as collaborators in an interactive process of exploration. Participatory research has bold aims; each are relevant to the Hope Project:

1. It should promote studies that are nonhierarchical, nonauthoritarian, and nonmanipulative.
2. It should establish a dialogical relationship rather than an impersonal encounter.
3. It should result in knowledge that is mutually useful and empowering to researchers and co-researchers.
4. There should be a safe, empathic climate of reciprocity within the context being studied.

5. Researchers should be mindful of the ethical concerns surrounding the study's sensitive issues (Connors, 1988; Maguire, 1987; Robertson & Boyle, 1984).

Participants in the Hope Project encouraged my firsthand observation of their experiences. Being invited to their worlds provided an authentic, spontaneous view of the complexities of living with hope. Listening, watching, and participating with an active rather than detached awareness contributed more to my understanding of hope than verbal descriptions alone would have contributed. We cannot know what it is like to be on the inside of a lived illness. As outsiders we can, however, try to capture or grasp the others' experiences by *shadowing* them as best we can (Ely, 1991). Participatory observation permitted a different penetration of a world unknown to me. What I saw, what I witnessed and felt during the two-year journey was lived hope. There were moments when each of my senses were awakened or challenged by hope. During a visit with *Lawrence*, for example, Julian said to me, "Come over here and make yourself useful." (Caregivers are wonderfully honest.) We were helping Lawrence eat a few spoonfuls of yogurt. My job was to hold the oxygen mask on his face just so, in order for *Lawrence* to have the benefit of breathing oxygen while Julian put the spoon to his lips. (This was one of those real-life tricks that we didn't learn in nursing school.) Quite suddenly, it occurred to me that what I had been observing all week was hope. I recall saying to myself, "So *this* is hope!" Had I not been invited to *Lawrence's* hospital room I would have missed the essence of this experience.

Ethical Considerations in Sensitive Research

This chapter describes the application of the phenomenological methods already discussed. As mentioned, I attempted to integrate selected features from the works of van Manen, Moustakas, and Munhall that would best accommodate the goals of this study and the needs of its participants. As I describe how these methods were applied in the *doing* of phenomenological research, I will also weave in the ethical considerations that were figural throughout the investigative process. My use of the words *sensitive research* is not intended to mean research that is of a threatening nature. Renzetti and Lee (1993) define a sensitive topic as one that "potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding, and/or dissemination of research data" (p. 5).

Whether or not a topic fits this definition depends on the type of study, the context, and other related factors. The ethical concerns that I address in the Hope Project are related to *being* sensitive about sensitive issues associated with HIV-AIDS. Some of the issues that participants chose to discuss were: same-gender sex, bisexuality, confidentiality, drug use and IV drug use, prostitution, personal secrets, date rape, condom use, safe and safer sexual activities, religious fundamentalism, politics and AIDS, incest, isolation, spousal battering, discrimination, violation of civil rights, reproduction, HIV transmission routes, and medical incompetence. To engage the participants in meaningful, sensitive discussions, it was critical that I explore my personal feelings along the investigative journey so as to avoid researcher bias or personal value judgments about these issues.

All of the original 35 participants were eager to share their stories in honest, uncensored language with the hope that they might contribute to the education and prevention of HIV infections or to help someone yet to come along who will be living with the virus. My partners in this research endeavor were not bashful or intimidated about anything having to do with the physiological manifestations of HIV or its transmission routes. They openly and easily revealed anything that could be perceived as useful information. Our relationship was, however, reciprocal. If a participant asked a question about something that I could responsibly answer, I did so. In fact, I felt a moral obligation to assist however I could. Frequently asked questions were (and still are today), "What do you know about the new protease inhibitors?" "Can anything be done to speed up TennCare approval?" and "How long does it usually take to get on disability?" Sometimes just suggesting that a person's physician be informed about a medical problem served as a helpful response.

On those occasions when my personal and professional boundaries were blurred, I opted for responses that felt ethical, honest, and useful. When *Mark's* sister telephoned to let me know that her brother's death was imminent, the conflict in my roles as a researcher and mother was acute. My son had been vomiting blood and I did not feel comfortable leaving him. At the same time, *Mark* and I had discussed his dying at length. He wanted me to see his experience of a "good" death. He vowed to do it gracefully, with dignity, and without the inexplicable struggle, excruciating pain, or the terror that he had seen others experience. He hoped for a serene death. His parents told me that it was.

There were other ethical issues. For instance, in phenomenological research, the tape recorder is typically turned on throughout the interview. This permission is established in the informed consent process. However, on a few occasions during the Hope Project, the participant would request that the recorder be turned off to allow for statements *off the record*. My immediate sensitivity to the requests was so acute that I later was unable to recall anything that had been said during that time. Similarly, as is common among the terminally ill, there are moments when the dying person will want to share a *secret* about a fear, belief, behavior, or event. Whether the recorder is on or off, secrets are expected to be kept. Honoring the person's privacy about secrets is an issue that should be addressed during the informed consent process. Unfortunately, the researcher cannot decide after the secret is told that it should not have been told. It is helpful to be cognizant of this eventuality, and have a plan in place that is ethical and respectful. In the Hope Project, turning off the recorder when asked to do so was a fitting response. When secrets were revealed during unrecorded conversations, they were not included in the researcher notes. Of utmost importance is the recognition of a person's vulnerability during the dying stages. Telling secrets is only one part of that vulnerability. During this time, the researcher's ethical obligations extend as well to others who are caring for the person who is dying and who may also reveal personally sensitive information.

What might be considered a limitation of qualitative research is the use of language that is not mutually understood. This is especially relevant when terminology applies to unfamiliar cultures or settings related to drug use, sexual activities, prostitution,

and homelessness. In the gay community, for example, terms often have double meanings. I had to learn that *queer* is used affectionately in some instances, but in others, its use can be derisive. I heard the word *flaming* in different contexts before understanding that it sometimes describes people who are flauntingly homosexual. When one of the participants casually remarked that so-and-so was *flaming*, however, I asked for a translation to be certain we were communicating on the same level. Overall, clarification of ambiguous language was an ongoing process.

Similarly, HIV-AIDS medical terminology challenged everyone involved in the study. Some of the participants have made it their life's work (literally) to understand the virus and its treatment protocols. This requires familiarity with virology and both the generic and brand names of pharmaceuticals. Examples are statements like "I took recombinant interferon-gamma for toxoplasmic encephalitis," and "I just began my trimethoprimsulfamethoxazole therapy for *Pneumocystis carinii* pneumonia prophylaxis."

An ethical concern that did not surface was the issue of total anonymity. All participants have requested a copy of their narratives. Some who have died made arrangements for the completed documents to be a part of their estates. Others have given me photographs to keep. *Nathan* even included photographs of his siblings. A dozen or more participants have appeared on television, in the newspaper, on radio talk shows, and in classroom visits. I would be tempted to suggest, that for this study, at least, being "out" about HIV-AIDS as *Phillip* said, was meaningful for these participants.

Without exception, the participants have been openly affectionate no matter the setting. Whether on campus or at the mall, they have always stopped for conversation

and hugs. The point here is that *I* was initially hesitant on these occasions. Should I speak? Should I avoid eye contact? Would they think that I was afraid to talk with them or be with them in public when in reality I was only trying to protect their anonymity? I gathered my courage one day and talked with *Matt* about this issue. My concern was ridiculous, he said. Just because a person has a virus should not mean that he or she must be afraid to greet, hug, or converse with anyone, least of all a friend. Neither should the friend be anxious about this, he said. After all, would a friend with cancer or heart disease be avoided?

Description of Participants

Participants in the study originally included 5 women and 30 men. However, 6 individuals who wished to participate died before successive interviews could be completed within the 6-month period. Their contribution to the study, although brief, has been valuable. One person declined an in-person interview. Of the 28 participants who completed the study, 9 have died, making the total deaths 15 since the onset of the project.

No person asking to participate was excluded on the basis of their illness progression, sex, mental health history, or length of time since diagnosis. I did not want anyone to feel rejected, and I did not want to control factors that might ultimately facilitate understanding and insight. The only criteria required for participation were documentation of having tested positive for HIV antibodies and being 21 years of age or older.

Participants were free to disclose as much or as little information about themselves as they wished. Seven individuals discussed relationships or marriages lasting between 5 and 20 years. Six participants described current relationships with a spouse or partner of 5 years or less, and 6 mentioned the recent loss of a long-term partner to AIDS. All of the participants described their experience of being exposed to the virus, as well as their experiences regarding bisexuality, heterosexuality, and homosexuality.

Diverse religious beliefs and ethnic backgrounds were revealed. Four participants were African Americans. Among the group, 11 were parents, and 2 were grandparents. Ages of participants ranged from 22 to 60, with an average of 29.0 years for women, and 34.7 years overall. Nine individuals relocated to the Southeast from various parts of the country including California, Washington, Georgia, and New York. This is noteworthy because of their experience with AIDS epicenters, medical care and clinical trials, and social support networks. These participants brought valuable experience and information to the study.

All but three of the participants are now disabled from their usual ocupations. They worked (or work) in the areas of business management, education, food preparation and distribution, law, social work, security, health care, photography, physical fitness, landscaping, retail clothing, and computer technology. Fifteen participants have attended college or have college degrees. Nineteen individuals described the importance of their relationships with at least one pet. This is interesting because having pets was often discouraged, particularly if the person's immune system was severely compromised.

None of these participants, however, gave up their pets. In fact, the orphaned pets of the participants who died have been adopted by other participants in the study.

Setting/Access. An information sheet introducing the Hope Project (see Appendix A) was distributed to physicians, hospitals, the Health Department, AIDS resource agencies, and medical specialists, to be shared with patients or clients who might wish to take part in the study. Over 75 percent of the participants were direct referrals from a private infectious disease practice. The remaining referrals came from hospital personnel and other medical specialists. Initial telephone contacts were typically from people who read the introductory letter and either wished to schedule a meeting or wanted to learn more about the study and then decide about participating. I explained that I would be asking them to describe what it has been like to live with HIV, and also to talk about times when they are aware of hope.

Some prospective participants telephoned from the hospital. *Peter*, for example, mentioned straightaway that he had enough experience about hope and AIDS that he could easily write a book. Others were not quite sure their experiences would be helpful but they wanted to try to contribute what they could. It was not unusual for the initial telephone conversations to be lengthy. In some cases, the person said that he or she had little if any opportunity to talk about the experience of HIV-AIDS and was looking forward to taking part in the research. By the time of the face-to-face visit, considerable discussion had already taken place on the telephone. This served as an "ice breaker" for most individuals, except for *Ryan*, who said he was *really nervous*. Over the two-year

study we met at hospitals, in homes, at my office, at their physician's office, at restaurants, and at the park.

Informed consent. The Statement of Informed Consent (see Appendix B) was read, discussed and signed in duplicate, with one copy being retained by the participant. For record identification purposes, a six-digit number was generated by each person. I encouraged creativity for this task after realizing that even *it* could be a chore for some of them. They were reassured that they would not have to recall the number at a later time. The invitation to be creative also distracted those who did not understand the rationale for imposing confidentiality rules against their wishes, or who felt the task was incongruent with the aim of the study.

Pseudonyms were chosen by the participants in compliance with the Institutional Review Board's guidelines for human subject research. There was no requirement to select a gender-specific name, although all the participants did. A new array of names was generated by me for this document as requested by the Review Board. Identifying information about the participants has been altered or deleted to protect privacy.

In addition to the informed consent statement, participants completed a Physical Symptoms Checklist (see Appendix C). This form lists 30 physical conditions generally associated with HIV-AIDS. It also provides a record of drug therapies, T-cell counts, perceived side effects of drugs, and limitations in daily activities. Medical conditions not included in the list were written on the form as they occurred. This information complemented the qualitative data and provided an ongoing record of participants'

HIV-AIDS status. The Physical Symptoms Checklist was self-administered in most cases.

To be sensitive to personal issues, informed consent was recognized as a mutually ongoing process of renegotiation, or to use Munhall's words, *process consenting* (1988, p. 161). Consistent with longitudinal research, unexpected situations occur. My perception of what should take place in the research setting was not always a perfect match with what was perceived by the participants. Each situation had to be reevaluated over time. The ethical obligation to be sensitive to participants' needs was foremost. *Hal*, for example, decided that his companion and caregiver needed to join our follow-up conversation. He said that I should see them together "to really understand how important personal relationships are to people living with HIV" and how these relationships are tied to hope.

Stuart's life partner was present in our first conversation. There was an assumption that this was expected. One's partner should not be separated from any of the experiences of hope. But it was *Russell* who first clarified my awareness that the participant's needs come first and that informed consent is mutually negotiable. *Russell's* situation exemplifies Ely's (1991) statement, "One of the great pleasures in the [qualitative] methodology is that not getting what you expect may be exactly what you need" (p. 52). When I arrived at *Russell's* hospital room for the first visit, his entire immediate family was there, including a grandbaby. His wife Shirley and one of the nurses were standing outside the room waiting for me. Shirley confided later that they were "checking me out" to make sure I didn't have an "attitude problem" about AIDS. If

either of them had sensed a problem, I would have been asked to leave. In retrospect, I now understand how one's intuitive abilities provide this type of information. At the time, of course, I had no idea what was taking place. When the family gathered around *Russell's* bed, I finally grasped that this interview was going to be a family affair. My exact thoughts about this are still vivid today. Since Russell apparently needed his family nearby and assumed that they *should* be there, then perhaps I should take a closer look at the ethical issues involved in this situation. The conflict was not easily resolved. Should his children be in the room? Should I ask if the television could be turned off? Would he be able to talk without bias with his wife present? Would he be able to have a conversation *without* his family present? The words of Elisabeth Kubler-Ross gave me some courage. When you want to find out what something is like for people, you just hang out with them and they'll tell you. That is exactly what I did. And they told me.

> *Russell: My whole family's got AIDS...I mean, they ain't got the virus, I've got the virus, but we've all got AIDS to deal with. I mean, they'll have to suffer after I'm gone. That's my biggest concern, is leaving the family. [This is very difficult for Russell to talk about. He is fighting tears.] My family gives me hope. I couldn't do it without them. She talks to me about the illness [refers to his wife]. [He is coughing now and cannot speak.]*
> *Shirley: AIDS...AIDS is a disease that we can't sit and think about tomorrow. We've got to live one day at a time. It's not just him, it's me, it's my daughter-in-law, sons, granddaughter, son-in-law, daughter, it's one day at a time and we each play a role in helping him. You know, like I said, my granddaughter, she cheers him up. My son and daughter-in-law, they're the ones that fuss at him and brings him out of it. Each one plays a different part. That's what it takes. But it all boils down to one thing: we're all here for him, and he knows it. And sometimes there's nothing we can do but say, I got this shoulder if you want to use it. But, like he said, it's not just him whose got AIDS, it's the family. And the main way we can cope with it is to take one day at a time and not let the anger eat us up.*
> *Jeannie: Can I ask what that means? What do you mean by the anger?*
> *Russell: We got real mad and beat the chicken house down.*

Shirley: We got our anger out. He got out of the hospital and we went outside and beat the chicken house down and that's how we took out our anger.
Jeannie (reacting to the image this created): Were there chickens in it?
Russell & Shirley (laughing): No. No.
Russell: No. Somebody stole all the chickens when I was in the hospital. (laughs)
Jeannie: Somebody stole your chickens?
Russell: Yeah. I guess they figured I'd be too unable to feed them anyway.

[Researcher notes]

Many issues are ingrained within this conversation. What is important, however, is that *Russell* and Shirley were together throughout his illness. She was his advocate, his guard, his nurse, his lover, and the family's liaison. When he was too ill to speak, she spoke for him. She slept in a chair by his bed night after night in case he needed her. It is impossible now to imagine our first interview without his family present. But there is more to this than concerns about privacy or objectivity. *Russell* and Shirley included their children in all aspects of *Russell's* illness, but they had not been able to talk about dying. This meeting with the whole family introduced the subject, and the children observed their father's profound grief at the thought of leaving them. They saw his tears and heard his choked words. They said they hoped their daddy would be one of the first to get a drug that would cure him. They joked with him when their emotions were too unbearable.

Interestingly, during subsequent visits with *Russell*, his family would often leave the room for a cigarette break or to go for a brief walk. During these times *Russell's* conversational style could be described as purposive articulation. When he had nothing

to say, he remained quiet; when he did say something, it was meaningful. Two illustrative examples follow. We were alone together in his hospital room on one occasion when Shirley went outside for a few moments to see what the outdoors was like:

> *Russell: Oh, by the way, you'll have to forgive me if I stop breathing (laughs).*
> *Jeannie: Are you planning on doing that now? Shall I go get the nurse?*
> *Russell (smiling): No, but I did it one day and scared everyone to death. They got the nurses in here and had to work on me. Just so you know it could happen; you never know when.*
> *Jeannie (relieved): Okay. What do you want me to do if you stop breathing?*
> *Russell: Just call the nurses.*

After *Randy* was discharged from the hospital room next to *Russell's*, he stayed all night with *Russell* so Shirley could begin a night job (they had no money and the children needed school clothes). *Russell* remarked that *Randy* was a good old boy for staying all night with him, especially since they barely knew each other.

> *Russell: I've tried to stay away from people with AIDS 'cause I might get an infection or something from their sickness. Don't have nothing against gays, just haven't been around them ever. But we talked a little and then when I looked at him--saw his face--I saw it.*
> *Jeannie: What did you see?*
> *Russell: I saw we're both the same. He knows what this sickness is and what I'm going through.*

Conversational interviews. To explore the nature of hope for *Russell* and other adults living with HIV-AIDS, I audiotaped conversational interviews. By *conversational interview*, I mean an interaction between two people which has a clear focus but also "relies on the spontaneous generation of questions in the natural flow of an interaction" (Patton, 1987, p. 110). That is, neither the questions nor the conversations were

standardized, but the focus of the interviews (hope and HIV-AIDS) facilitated sequential conversations. The strength of an in-depth interviewing approach is the responsiveness to variations among individuals and situations over time (Patton, 1990, p. 282). Since the questions were not predetermined, the conversations were open to the participants' direction and context.

All audiotaped conversations were conducted with the goal of understanding the participants' experience of hope while living with HIV-AIDS. I asked each person the following questions: "Can you tell me about some times when you have been aware of hope?" and "Please tell me what it has been like for you, living with HIV or AIDS." When I asked participants to describe their awareness of hope, they began their narratives with the time of the HIV diagnosis. They seemed to prefer an orderly historical accounting of the experience. Therefore, I changed the ordering of the questions so the conversation could flow in the direction chosen by the participants. An analogous example would be to ask a woman to describe her experience of having surgical breast reconstruction following a mastectomy. She most likely would be unable to extract the reconstructive experience from the initial loss of her breast. Similarly, how could people with HIV-AIDS possibly share their thoughts, feelings, knowledge, and awareness of hope without first describing their experience of being exposed to the virus? None of the participants needed encouragement to talk. The content and depth of their discussions flowed from moment to moment at their discretion. They were eager to make explicit any statements needing to be clarified.

Conversational interviews were not timed to allow adequate time for discussion. They were typically 60 to 90 minutes in length, although some were longer. Subsequent visits varied in length depending on the participants' health. If ill-health caused cancelled interviews, telephone follow-ups were done. Of course, informal telephone visits, spontaneous meetings, or situations in which the participant was verbally unable to give permission to audiotape (e.g., *Randy's* final hospitalization) were not tape-recorded. If audiotaping was inappropriate, field notes were written later to provide a record of observations. An example of this was *Russell's* account of his not breathing and preparing me for *my* role in his care should this happen in my presence. Since I had only just walked in his room when he told me this, the recorder was not turned on yet. Written field notes were meaningful concurrent data that complemented the data collection throughout the study.

What I want to emphasize, however, is that I did not write notes during our conversations. This contrasts with research methods normally advocated in anthropology where the researcher writes notes or summary statements while the participant is speaking (Sanjek, 1990; Wolcott, 1994). Early in the Hope Project, however, I discovered that the participants were observing my every action, facial expression, gesture, or behavior. During one of the first interviews, I attempted to write one-word notes to myself but noticed that each time I looked down to write, the participant stopped talking until I completed my note. This was disturbing because it felt as if the participant might be less focused or spontaneous in deference to what *I* was doing. I worried that any benefits of my taking notes would be at the expense of the participants' empowerment or

naturally-flowing language. It also reminded me of some patient-physician relationships (having asymmetrical power structures) in which the patient waits silently while the physician writes his notes. Or worse, when the patient becomes increasingly mute with each glance by the physician toward the clock on the wall.

My uncomfortableness and self-consciousness prompted a change in my interviewing style: I stopped writing notes while the participants were speaking and learned to trust my intuitive skills. I also avoided all clocks. Recalling the advice of anthropologist Rosalie Wax, I gave myself permission to relax, to become immersed in the conversations, and to be totally absorbed in the fieldwork. Focusing more on flexibility, patience, caring, humility, and humor was pragmatic and congruent with Wax's statement, "The person who cannot abide feeling awkward or out of place, who feels crushed whenever he makes a mistake, embarrassing or otherwise...ought to think twice before he decides to become a participant observer" (1971, p. 370). Study participants consented to at least 2 sequential conversational interviews during a 6-month period. Of the 28 who completed the study, all but 4 continued with the Hope Project for 1 year. Ten individuals remained for 24 months. In all cases, however, participants greatly exceeded my expectations of their willingness to devote time to this study. In addition to the formal interviews, they communicated informally to keep me advised of their experiences, hospitalizations, and health status.

Audiotaped conversational interviews were transcribed verbatim. In some instances this was a labor-intensive task particularly if the participant's voice was indistinct or otherwise affected by medications, illness, or extreme fatigue. An invitation

to review the transcripts was accepted by a small number of participants who opted to edit their own documents. Surprisingly, only superfluous words or utterances (i.e., uh, you know, um) were deleted. The content was unchanged. Words or phrases in italics indicate emphasis by the speaker. Names of the participants are also italicized.

When breathing difficulties or other medical exigencies interfered with taped interviews or when participants desired to communicate about something in writing, they submitted personal documents to supplement the audiotaped narratives. The value of these personal documents is noteworthy because they are, for the most part, written in the lived moment rather than retrospectively. Overall, the combined audiotaped narratives, personal documents, and researcher field notes constituted 800,000 words of experiential text during the 2-year study. All research materials, consent forms, and tapes were stored in a locked cabinet for safekeeping.

The vital importance of a person-centered atmosphere for hospitalized patients facing imminent death should be emphasized. On the other hand, this is not a simplistic goal, and it has an emotional price for both research partners during a longitudinal study. *Mark*, for example, wanted to share an exact accounting of his dying process. He wanted others to know that peace and dignity *can be* a part of death. However, concerned that my working long hours with patients and their families, teaching, and volunteer work would have deleterious health consequences, he decided not to notify me of his hospitalization until he knew he'd be going home. This heartfelt concern was borne from his own work with the AIDS Shanti Foundation. Doing this "work," he explained, requires continuous nurturing and protecting of ourselves and others. The intense

emotional and physical stress must never be ignored. Having an outlet for the pain, and support from peers, helps to soften the sharp edges of the day-to-day work and reduces the likelihood of burn-out. While at first I was deeply disappointed that *Mark* did not notify me of his hospitalization, I had to lay aside *my* feelings and remind myself to attend to *his* experiences and beliefs and listen to the insightful messages he wished to leave with us.

Mark's poignant concern for others was not an isolated case. This behavior was characteristic of most participants. Another example is *Russell*. Two days prior to his death, I visited him at the hospital. He whispered to Shirley that he didn't want me to be there. Shirley asked, "But why, *Russell*? That's Jeannie!" His reply was that he did not "want me to see what my son would look like at the end." His concern for others as he lay dying was profoundly touching. I first thanked him for his concern but asked permission to stay because I could not imagine leaving him or his family. Would he allow me to stay? Smiling, he nodded yes.

Phenomenological Reflection

The Hope Project was an ongoing process of investigating lived situations, collecting experiential descriptions, and obtaining "data" which are, after all, human experiences (van Manen, 1990, p. 63). The investigative process overlapped considerably with the analytic process to the extent that transcribing narratives, journaling, and observing situations allowed. As each person joined the study and described their experiences of hope, the essential questions were brought into focus again and again. Is *this* what it means to hope? How is this representative of hope phenomena? Do

observations and narratives reveal similarities, contradictions, or other distinguishing characteristics of hope? Is this what the experience of hope is like for people living with HIV-AIDS?

This section follows the applied perspectives of Moustakas (1990), Munhall (1994b), and van Manen (1990) through the analytic procedures adapted for the Hope Project. It answers the question, After the phenomenon has been explored and data have been gathered from all sources (e.g., narratives, personal documents, literature, poetry), what happens next?

Analysis of experiential descriptions. One of the challenges of this study was bringing to order the collection of data generated over two years. (Since the purpose of the study evolved from a *lack* of data about hope in HIV-related illness, I use the word *challenge* rather than the word *disadvantage*.) The voluminous data necessitated my utilizing the processes of heuristic inquiry and phenomenological reflection throughout the study.

Overall, four considerations guided the analysis. As each narrative was obtained, transcribed, edited, and retyped, I read the document completely through *without* attending to the realization that the nature of hope would emerge from the data. Instead, my early focus was only to become familiar and comfortable with each person's unique story. This self-imposed requirement served three valuable purposes. First, a careful reading of the text in its totality provided a sense of the whole, or *gestalt*, of the narratives. Even though I was the conversational partner in each interaction, I needed to step out of the narrative, so to speak, to have a view of the participants' lived experience.

Second, by not writing marginal notations or engaging in coding, segmenting, or other categorizing activities during this early stage, I was able to discern similarities and contrasts between men and women in the study. This knowledge, whether gleaned from narratives or field notes, facilitated follow-up conversations.

Third, the readings brought the value of multiple interviews into focus. If, for instance, the study findings were based only on one moment in time, the picture of the participants' experience of hope as it occurred over time would have been distorted. For example, a reading of *Kate's* initial narrative presents a misleading portrait of her lifeworld without benefit of knowing her total contribution to the study.

In the second phase of analysis, I relied on intuitive, indwelling processes that would foster deepened and extended knowledge of hope phenomena (Moustakas, 1990, p. 24). The written texts were combined with the tape recordings for analysis. Listening to the voices took me back across time, into the depth of emotions, memories, and evoked awakenings. While the reading of the narratives served to distance myself from the experiential descriptions, listening to the tapes put me back into the moment. This *indwelling* is defined by Moustakas (1990) as a "turning inward to seek a deeper, more extended comprehension of the nature or meaning of...human experience" (p. 24). He had more to say:

> Indwelling is a painstaking, deliberate process. Patience and incremental understanding are the guidelines. Through indwelling, the heuristic investigator finally turns the corner and moves toward the ultimate creative synthesis that portrays the essential qualities and meanings of an experience. (p. 25)

This procedure intensified emotional and psychological responses. I was immediately aware that hearing the participants' voices during one specific tape elicited memories of other interactions at different times during the study. In other words, a holistic memory that was awakened in me by the sound and quality of a voice.

Being present again in the conversation and the context of the person's life, I realized how much information could be lost in editing or even in the punctuation of dialogue during the typing process. In some instances, I felt that the written word was not sufficient to capture the moment. I found that the speaker's voice would carry me through a maze of emotions, some laser sharp, and the written language would be displaced by the vividly recalled lived experience.

Listening to *Mark's* first tape, for example, I was thrust into a back-and-forth recollection of my memory of him as he walked in the office the day I met him, and the memory of his memorial service. Staying focused on the tape seemed impossible without having explored his entire lifeline during the study. Having already formed a gestalt for Mark, I recalled the way his hope threaded in and out of his experiences, like a basted stitch that is visible only on one side yet is known to exist on the underside of the fabric as well. Hearing his experience of hope triggered my remembering all the feelings--the smells of the hospital and the flowers at the funeral home, the strength of his handshake and always, the laughter. There were memories attached to memories, connected like pearls on a necklace, each one having a distinct character:

Before Mark's memorial service began, I sat in the back of the room and watched the goings on, trying to be objective. If I was very thorough with my observations, I'd be able to describe what happened to Mark, knowing all the while he'd have lots to say about the event. But Mark was dead. "Where's the body?" an older woman asked. "Why isn't there a body?" Bruce Springsteen's song "Philadelphia" was playing in the background,

City of brotherly love,
place I call home,
don't turn your back on me.
I don't want to be alone.

I said something to the woman about Mark's being cremated. She looked disappointed. She said, "Oh," frowned, and walked out of the funeral home. The music calls me back,

Sometimes I think that I know
what love's all about,
and when I see the light
I know I'll be all right.

Willie Nelson was singing about angels. And then Mark's best friend from New York was reading Cavafy's (1975) poem "Ithaka"--

As you set out for Ithaka,
hope your road is a long one...

It doesn't get much better than this. Mark would be pleased. His hope was realized, again.

[Researcher notes]

An outcome of this phase was the realization that as data, tape recordings provided invaluable information that should not be disregarded after transcription is complete. The defining characteristics of language may, after all, contribute to the overall comprehension of dialogue. How participants reveal intonation, pitch, loudness, use of metaphors, or trailing off of speech should be an integral part of the data analysis.

Nonverbal language in the form of body posture, hand gestures, body movements, and eye contact, is equally noteworthy, as is the role of physical pain during conversations. During moments of unrelenting physical stress, participants spoke of "being over it," "being glad when the whole thing is over," or "being sick and tired of being sick and tired." When relief of pain occurred, however, these statements were no longer salient, and the tone of voice reflected a new level of stamina. These subtle nuances were not apparent in the written text alone.

In the third phase I integrated (Moustakas's (1990, p. 25) concept of *focusing* with van Manen's (1984, p. 42) concepts of *uncovering* and *isolating* thematic aspects in lifeworld descriptions. The underlying component of this phase was the utilization of inductive analysis, which means that the patterns, themes, and categories of analysis came out of the data rather than being determined prior to the data collection (Patton, 1987, p. 150). The notion of *essences emerging from the data* and *phenomenology begins in silence* are intriguing phrases in phenomenological terminology that relate to inductive analysis. These seemingly abstract, nonscientific activities bring to mind a stained laboratory specimen which, if placed under the microscope, will automatically reveal significant data. How this happens is not reported. In doing this qualitative research, it was the inductive analytic phase that clarified these two little-understood notions.

Having first formed a gestalt for each participant's experience and then juxtaposing the lived descriptions with auditory data, I began to concentrate or focus on significant perceptions. The focusing process is an "inner attention, a staying with, a sustained process of systematically contacting the more central meanings of an

experience" (Moustakas, 1990, p. 25). To begin identifying essential patterns of hope, I had to focus once again on the participants and set aside my own role and feelings. An outcome of the focusing process was the gradual recognition that every person's experience returned again and again to the same dimensions: relational, corporeal, temporal, and spiritual. That is, experiences seemed to be connected in varying degrees to dimensions involving human relationships, the body, time, and the spirit. (In this case, the spiritual dimension refers to both the quality of an attachment to religious values or supernatural phenomena and the quality of having an outlook, disposition, or attitude about life and living.)

Similarly, specific themes were uncovered repeatedly as the study progressed. The process of isolating thematic statements was accomplished by a selective highlighting of statements or phrases that seemed particularly revealing about hope phenomena. Van Manen describes an alternative detailed or line-by-line approach to this task which involves examining every single sentence or sentence cluster and asking the same question, What does this sentence or sentence cluster reveal about hope? (1990, p. 93). Computerized models are now available for isolating thematic statements from predetermined categories. The concern here is that if predetermined categories of hope were programmed in a computer for confirmation by the data, it seems the purpose for the study in the first place would be invalidated. The intent is not to know the frequency of thematic statements of hope, but instead, *how* participants described it. The potential problem of the line-by-line approach in a longitudinal study is the risk of context stripping, or removing, the human aspect of the lived experience from the gestalt. It

seemed imperative to avoid the seductive trap of frequency summaries for the sake of confirmation, when there was nothing to confirm in this new exploratory study. For these reasons, I elected to highlight statements and include marginal notations throughout the documents. This was a personal decision-making process. Having *lived* with hope phenomena for two years and having already worked through phases one and two in the analytic process, the suitability of this decision was unambiguous.

Another important aspect of the isolating process was the *lack* of data reduction. A frequent recommendation in qualitative research is the gradual elimination of redundant or nonqualifying text. The text is narrowed down incrementally. My concern with this was that some of the subtle descriptors or nonverbal language inherent in the context would be lost during the analysis.

A noteworthy outcome of the isolation process was that the word *hope* appearing in a statement did not carry a definitive weight in the identification of themes or essences. Being naturally hypervigilant in recognizing the word within the text, I ultimately discovered that the nature of hope was not determined simply by using the word. On the contrary, its meaning was typically embedded within the text.

The fourth phase involved phenomenological writing and rewriting (van Manen, 1984, p. 66), and the development of exemplary portraits followed by a creative synthesis (Moustakas, 1990, p. 50). Overall, these procedures are similar to one another, except that Moustakas recommends returning to the participants for a final review of the portraits.

Of the five possible formats suggested by van Manen to organize phenomenological writing (exegetically, existentially, analytically, thematically, or exemplificatively), I chose a combination of two. A *thematic* organization was consistent with the study's objectives. Therefore, my writing is organized around the themes of what it is like to experience hope while living with HIV-AIDS. To illustrate by example how the themes depict the nature of hope, I also chose an *exemplificative* format. This offers a clear contextual understanding of the essences of hope as they are clarified by the participants' own words through anecdotal narratives. Van Manen (1990, p. 121) outlines the value of utilizing narratives (stories) in phenomenological writing:

1. They are compelling; a story recruits our willing attention.
2. They lead us toward a reflective search for significance.
3. They involve us personally in the active search for the story teller's meaning via one's own.
4. They transform us; we may be touched, shaken, or moved; it teaches us.
5. They are a measure of our ability to make interpretive sense.

Exemplary portraits evolved from the marginal notations in the narratives and researcher notes and were explicated in the participants' language. The qualities, essences, and meanings of hope for the participants were depicted with the goal that "both the phenomenon investigated and the individual persons emerge in a vital and unified manner (Moustakas, 1990, p. 52). The tool I developed for achieving this was a color-coded matrix explicating the major dimensions of the lifeworld and their representative themes of hope. The interconnections among these dimensions and the

participants revealed a portrait of hope for the participants. The culmination of this procedure was the writing and rewriting of the creative synthesis. This process is described by Moustakas (1990):

> The researcher taps into imaginative and contemplative sources of knowledge and insight in synthesizing the experience, in presenting the discovery of essences--peaks and valleys, highlights and horizons. In the creative synthesis, there is a free reign of thought and feeling that supports the researcher's knowledge, passion, and presence; this infuses the work with a personal, professional, and literary value that can be expressed through a narrative, story, poem, work of art, metaphor, analogy, or tale. (p. 52)

To summarize, the rigorous, labor-intensive, and disciplined process of data analysis involved five phases:

1. The documents were read from beginning to end without attending to the identification of themes or essences of hope. A familiarization of each participant's gestalt was accomplished by reading all the documents pertaining to an individual, including observational notes, field notes, and personal documents.
2. A careful listening to the audiotapes in combination with the written narratives followed. Intuitive, indwelling processes guided this in-depth immersion into the participants' experiences. Awakened memories generated by the participants' voices carried me along the continuum of lived situations and emotions. Auditory data elicited acute attentiveness to subtle nuances and responsiveness to events not apparent in the written text.

3. Putting aside my role in the study momentarily, I engaged in a sustained focus on significant perceptions. Asking repeatedly, What is the picture like? and, What is going here? I began to identify particular patterns that evolved into four lifeworld dimensions. Isolation of themes was achieved by selective highlighting of statements or phrases as they revealed specific information about hope. Marginal notations captured the overall essence of the statements. The language of the participants was used as thematic exemplars.
4. In the last phase of analysis, portraits of hope were developed with the assistance of an organizing matrix explicating relevant themes in four dimensions of the lifeworld: relationships, body, time, and spirit. Ultimately, a creative synthesis characterized the nature of hope.
5. Finally, findings were presented to participants in order to assess their views on the adequacy of the interpretive accounts.

Evaluation of Methodological Rigor

Qualitative research is based on specific philosophical assumptions and research goals. Munhall (1994c) contends that a goal of qualitative phenomenological research should be that it gives direction to practice or to further research (p. 188). To this end, attention to critical aspects of rigor and merit is required. Rigor and merit refer to the logical value, or usefulness, of a research project (Marshall & Rossman, 1995), and its methodological truth value, applicability, consistency, and neutrality (Guba & Lincoln, 1981). Ultimately, rigor may be defined as *Verstehen*, which is the hallmark of the convergence of phenomenological human science (Ruffing-Rahal, 1986).

For this study, I have adopted Munhall's determinants of methodological rigor. This evaluative criteria consists of ten qualifiers of rigor, which Munhall describes using an alliterative form as a mnemonic device: the letter "R" (1994c). Six criteria were selected for their suitability for the Hope Project. This discussion comes directly from Munhall's perspective.

Representativeness. Does the study adequately represent the various aspects of the lived experience? Was enough material concerning the phenomenon considered? Munhall points out that the serendipitous conversation or the spontaneous reading of an article about the studied phenomena are also material for consideration along with the interviews. In our quest to go to the things themselves, we should be careful not to block our reaching them (p. 190).

Raised consciousness. This is a response to the study that engenders a focus toward and a gaining of understanding of an experience that the reader has not considered. Now brought to consciousness, the experience is seen anew. Munhall's example of raised consciousness is the response of a member of her class to the reading of "The Dwarf's Song" by Rilke (1957). After hearing the poem, the student remarked with surprise, "I never knew dwarfs had feelings." The criterion of raised consciousness is a clear aim of the phenomenological exploration of hope.

Resonancy. This concept or criterion indicates that the written interpretation of the meaning of the experience resonates with the study participants. That is, it sounds correct, fits in with past participation with the experience, explains a puzzle. It prompts familiar feelings and thoughts. It "rings true" (p. 190).

Relevance. Munhall asks, "Why do a study, even if your goal seems primarily to finish a degree, if it does not have relevance?" Our studies should bring us close to our humanness, increase our consciousness, enable understanding, give us possible interpretations, offer us possible meaning, and guide us in our lives, personally and professionally. Our studies should do no less for those we serve. The investigative study should be of genuine interest and it should make a difference in the research experience. Munhall suggests that we consider relevance in a dual way: first, the phenomenon should be relevant to us so that we can become absorbed beyond just our cognitive abilities to do research, and second, it should be relevant to the field of human science and the human beings that such science serves (p. 192).

Responsibility. As researchers, we must always be aware of the ethical consideration of our study. Process consent, sensitivity to issues of conversations, and the reverence for authentic representation are operative areas of our responsibility. Being true and being faithful to our participants and to the other phenomenological material we weave into our study are critical ethical concerns because we are so very close to human beings in the meaning and interpretation of our research (pp. 192-193).

Responsiveness. How individuals, whether study participants or colleagues, respond to the study is important. Closely aligned with resonancy, responsiveness begs the questions, Are individuals moved to something: to think through preconceptions or to follow through on the study? Are their imaginations stirred by different responses based on descriptions and interpretations? Most important, should they act on the research? (p. 193).

In summary, determinants of rigor should ultimately stand as criteria against which the trustworthiness of the project can be evaluated (Marshall & Rossman, 1995, p. 143). The research project should be an authentic encounter in which the integrity of the participants is preserved (Connors, 1988) through a trusting relationship based on mutual rapport (Hall & Stevens, 1991, p. 19).

CHAPTER 5

Findings of the Study

Hope

They wrapped their hope

around them

as if it were a comfortable

swaddling old robe

and it was peeled away,

like an onion,

one layer at a time

until their core was laid bare

and then

to rest.

(Vernon Lee Gillian)

Lydia was sitting in the chair next to the window. Cold air was blowing from the air-conditioning vents. Her hospital room was uncomfortably cold. She was shivering. Her thin pajamas offered little protection from the cold. An oxygen monitor was attached to her right forefinger. When she shivered, the monitor would beep. "That thing's getting on my nerves," she said. Lydia was complaining of pain "all over my body," particularly her feet. Still shaking, she would look down at her feet to make sure they are still there." Her right eye was swollen and painful. She was having a bad day. The monitor persisted--beep, beep, beep--"that's ***really*** *getting on my nerves," she said again. Someone came in the room to check the machine. Evidently, it was working satisfactorily, so the person left. Having lost all hope that a meaningful discussion could occur with such an annoying distraction, I switched focus and sat quietly with Lydia, wondering what her life must be like. Hospitalized with AIDS, away from her family and children, in pain, and lacking a strong support network, she had remarked that "it will all be over soon." The monster machine continued to pester our nervous systems like a fingernail on a blackboard. Who cares anymore about oxygen saturation levels? In desperation I pulled all the blankets off her bed and completely swaddled her tiny body in the welcomed warmth. "Oh, yes, oh, yes, oohhh," she murmured. She stopped shaking. The machine stopped beeping. Wrapped like a mummy, Lydia was asleep almost immediately. I, on the other hand, was exhausted, but grateful for the silence.*

Stuart's mother and I were sitting in the living room waiting for him to join us. I had not seen Stuart for nearly three weeks. His mother was describing her concerns about his health and his inability to eat. As she spoke, I noticed a man in the kitchen purposefully wrapping his bathrobe securely around himself and tying the sash. Then he picked up his cane and approached us very delicately, very slowly. I wondered if an older relative was visiting Stuart, maybe his grandfather? It wasn't until he walked into the living room and I recognized his "twinkling" eyes that I realized this elderly looking gentleman was 33 year-old Stuart. He had aged rapidly, as if he'd been made up to look old for a Hollywood movie.

Les developed a painful opportunistic infection (OI)) that was incapacitating and personally intolerable. He decided to refuse aggressive chemotherapy and opted instead to ask for pain control only. He was worried, however, that his health care providers would think that he had "given up hope" or had chosen to be noncompliant. He deeply appreciated everyone's efforts to save his life and did not want to appear ungrateful. With tears in his eyes, he said, "I'm tired; I hope I can slip out of here gently."

[Researcher Notes]

Overview

An attempt to increase understanding about the long-term experiences of hope for women and men who live with HIV-AIDS was the concern of this qualitative study. The method of study included repeated observations and in-depth conversational interviews with 28 coresearchers who shared their ongoing experiences throughout the 2-year study. As an active participant observer of the natural environment of the participants, my understanding of their lived experience of hope was enhanced by first-hand observations of real-life situations.

Researcher field notes describe these lived observations and the interrelatedness of the participants' hope with their personal lifeworlds. What should be emphasized, however, is that hope cannot be separated from the contexts to which it is bound or the words used to describe it. Consequently, the phenomenological investigation included the collection of data from my field notes, from verbatim experiential descriptions from the participants, and from descriptions of hope found in poetry.

Throughout the collection and analysis of data, the discovery process had the aim of allowing the participants' voices to be heard. To be faithful to *their* voices in the presentation of study findings, this accounting of their lived experience of hope is linguistically mediated. According to Gadamer (as cited in Linge, 1976) to gain insight about the *nature* of things requires that we first pursue the *language* of things. Gadamer argues: "We can still speak of a language of things when we remember what things really are, namely, something that has existence in itself" (p. 71). On the other hand,

Fromm (1968) asks the question: "Can hope be described at all in words or can it only be communicated in a poem, in a song, in a gesture, in a facial expression, or in a deed?" Fromm agrees with Gadamer that other works of art are by far the best-suited media for describing human experience because they are "precise and avoid the abstraction and vagueness of worn-out coins which are taken for adequate representations of human experience" (Fromm, 1968, p. 11). About the specific process of discovering the nature of hope, Fromm's concern is that words are insufficient to describe it because they are obscure, they dissect, and they kill meanings. This relates to Marcel's view that precise definitions, explanations or predictions of hope detract from its mysterious quality. Rather than resolving the ambiguity of hope, Fromm suggests that the possibility for greater understanding arises from dialogue in which people use their *own* words to share their experiences. The outcome of this dialogue is the establishment of "a communication in which the writer and the reader know that they are referring to the same thing" (1968, p. 11).

All this points to the ultimate purpose of this study: to explore what it is that constitutes the nature of hope as described in the words of those who experience it. Although generalizations about hope have been made regarding individuals who live with life-threatening illnesses, this phenomenological study pertains only to those individuals who live with HIV-AIDS: an illness for which a cure is presently unavailable.

Portrait of Hope

Since the AIDS epidemic is an unprecedented event in history, it presents challenges qualitatively different from other known illnesses. For this reason, the best

understanding of hope in the lived context of the epidemic comes directly from those whose stories portray their experiences. The overall nature of hope emerging from the participants' stories is presented in the following portrait of the findings:

> Hope is the lasting belief in possibilities. It is believing in the possibility of living a meaningful, purposeful life, of having physical comfort, and belonging and connecting with others. Hope is the belief in the possibility of managing the illness, holding on to one's independence, living a normal life with humor and love, and doing good deeds. It is the belief in the possibility of acceptance, living *with* HIV-AIDS, dying with some life left, and being at peace.

Themes in the Experience of Hope

From the heuristic inquiry and phenomenological reflection of the experience of hope, shared themes corresponding to the participants' lifeworld dimensions of time, others, the body, and the spirit were discovered. Spatiality, or lived space, is considered one of the four fundamental existentials in phenomenological human science research. Interestingly, this dimension was not as figural for these participants as was the concept of lived spirituality. This may be a consequence of the person's world becoming smaller as the illness progresses. As *Peter* suggested, when people get sick their "horizons come down so far" and they only focus on a few basic aspects of living. The spiritual aspect was significantly important to these participants. Similarly, this finding was reported by

Nowotny (1989) in her analysis of the "dimensions of hope" (described previously in Chapter 2). Phenomenological analyses of the experience of hope described in participants' narratives and researcher notes revealed the overarching essence of hope as being "the belief in possibilities." Emerging from the discovery process, 12 themes characterized the essential nature of hope:

1. Timeless hope/layered hope
2. Purposes/possibilities
3. Being normal/self-esteem
4. Belonging/connecting
5. Humor and love
6. Doing good deeds (mitzvahs)
7. Comfort
8. Managing/planning/controlling
9. Being flexible/practicing hope
10. Being at peace
11. Acceptance/awakening
12. Holding on to independence and determination

Participants (or relatives and partners of participants who have died) were invited to evaluate the findings in order to consider whether what has been uncovered in the study answers the questions that directed the inquiry (Packer & Addison, 1989, p. 289). While reviewing the findings, I asked the participants to also consider these questions: Do the findings correspond with your personal experiences? Is this what your experience of hope is like? The follow-up conversations permitted additional clarifications by the

participants who ultimately determined whether or not the findings resonated with their experiences.

An unexpected response by some participants was their belief that poems characterizing specific themes exemplified feelings and described their experiences better than the "normal" written text. This finding is similar to the study of caring conducted by Watson (1985). Watson's study included a poem about the experience of loss and caring among the Aborigines. The poem was described by Warren (1994) as having "a much greater richness of description" than did Watson's summary paragraph written as part of the phenomenological reflection. Warren contends that a benefit of phenomenological research is the inclusion of both subjective and objective data which can contribute to the richness of the study.

A benefit of conducting longitudinal research is that multiple observations and narratives provide a wide range of thematic exemplars of hope as illustrated in participants' experiences. A thematic exemplar (story; vignette) is an instance of a particularly meaningful transaction, intention, or capacity (Benner, 1985, p. 10). Multiple exemplars enhance the meaning of situations and increase our understanding of the participant's world. They may also add nuances and qualitative distinctions that were unavailable in previous exemplars (Benner, 1994, pp. 107, 117). The next section reveals how the themes in this study give shape to hope experiences.

Participants' Descriptions

Believing in Possibilities

Ryan serendipitously presented a useful symbol for thematic representation of the findings in the study. The youngest of the participants, *Ryan* decided to plant a tree on family-owned property before he becomes critically ill. He hopes to live at least one year after the planting so that "the roots will be settled and it [the tree] will be strong." It took considerable time to decide which type of tree would be better, as he explained: "Part of me wants an oak tree because oak trees are the oldest living trees there are, and then another part of me wants a cherry tree because I love cherries and they're beautiful when they are in bloom." Ultimately, he chose the oak tree "because it is the strongest, and that's more important than beauty." *Ryan* wants his ashes placed around the oak tree after he is cremated. Like his participation in the Hope Project, this plan also relates to his desire to "leave something behind that is helpful." To this end, *Ryan's* symbolic tree epitomizes the stability of human hope for these participants.

Timeless hope/layered hope. Possibilities are grounded in a temporal dimension with hope. Perceived as a lasting though "swaying" aspect of the human condition, hope is like a jet stream; it exits in perpetual motion. Seemingly timeless, it has no specific beginning or end. It is immutable, neither destroyed nor destroyable, at least for these participants. It may touch softly here or forcefully there, depending on each person's situation. In all situations, however, *hope existed within the person.* Their awareness of hope was determined by circumstances making it more or less figural in their lives.

Participants equated their hope with survival as if it were a motion through time, "living from day to day," or "taking one day at a time." Though cliched, these phrases appeared again and again in the narratives. In his review of this theme, Lawrence remarked, "The funny thing about clichés is that they are usually true." Hope lets us "live one day at a time." Surprisingly, hope typically was *not* associated with a cure for AIDS. Instead, hope was associated with "surviving life" as it happens, and "living life according to the way things are."

> *Ben: Hope is just there. It's always been there. It's survival. I mean, that is what has really kept me going. I KEEP hope...but I also realize that what is going to happen is going to happen. I have hope that it don't, but if it happens, I'll just deal with it as it comes...I don't dwell on what ifs.*
>
> *Andy: Yes, it's out there. You have to find it. It could be in a person, or some thing. It's out there. It might take you a little while to find it. I think I've always had it.*
>
> *Ryan: I think hope is life...literally to survive, the willpower to do the things that are important to you.*

The dimension of time was suggested by the research findings reported by Hall (1990) based on data from the study conducted by Allan and Hall (1989). They analyzed data obtained from semistructured interviews with 11 men who had tested positive for HIV antibodies. How these participants coped and maintained hope depended on their ability to establish a connection between the present and the future. Having hope involved: (a) having a future life in spite of the diagnosis; (b) having a renewed zest for life; (c) finding a reason for living, usually one that was not evident before; and (d) finding a treatment in the professional or alternative care system that one believes will

contribute to survival (Hall, 1990, p. 183). Hall, a cancer survivor, wrote, "My experience and those of my informants have brought me to the conclusion that hope is something all people need until they take their last breath. I have seen very little evidence that most people accept death. Rather, they accept life. If they accept life well, then they die well" (p. 178).

Although it may be an effect of the longitudinal design, participants in the Hope Project discussed the topic of hope and death from a different perspective. In their view, to openly accept death is to fully live their lives. As *Erik* concluded, "Once I accepted death and the fact that it *would* come, well, then I could start living again. I think you have to. I mean, some people can never accept it." The significance of *Erik's* statement speaks to the realization that death is a given for each of us, regardless of HIV status. In other words, if death is a certainty and can be completely removed from the equation, how will hope be perceived by those who live with HIV-AIDS? Will hope have different meanings? The participants' emphasis on survival has nothing to do with the goal of living forever; it implies their hope of living each day or year in a meaningful way. *They do not expect to survive life.* I think that the participants' irrefutable acceptance of death contributes to their description of living with hope until they die. How hope is manifested in their lives depends on their individual circumstances:

> *Victor: I just want to survive. I don't care about beating it or finding a cure. I just want to survive because we all are gonna die someday.*
>
> *Peter: No matter what happens, life goes on...you get up every day and it's a new day. Individual lives stop, but the great cascade of replicating DNA that is life goes on forever. But you have to keep your hope in areas where it is realistic to have hope. I suppose you could say you hope you would live forever, but no one would think that was very rational. It's just*

> *that when you are finally confronted with the disease that's going to kill you that it becomes a much more immediate concern of living--perhaps not forever-but for next week would be nice (laughs)...I'm going to live until I die. Being sick is not a failure. Dying is not a failure, everyone does. I have hopes to be able to do the things I want to do, but if I end up not being able to do what I have planned, well then, I'll end up not doing it. I'll probably be pissed off about it, but I'm very realistic at this point as to what to expect. It doesn't bother me too much because there's nothing I can do about it--the horse is out of the barn.*

What is notable about layered hope as contrasted with lasting hope is that it is *not* suggestive of concrete stages or particularized cycles of hope. In fact, it is the antithesis of predictability. This finding was not immediately apparent but emerged after several conversations with each participant over at least 12 months. Not until then was there a realization that hope is layered *because* it is context specific; it is a product of circumstances and lived time. Like a chameleon, hope remained intact, but its layers underwent alterations as each person's situation changed during the course of the illness.

For example, *Kate's* hope was explicit. She did *not* want her parents or family to learn about her illness "because it would kill them." Instead, she'd "rather die in a car wreck, so they'll never have to know." Her next "biggest" hope was that she would *not* have to be on life support which might leave behind a "devastating financial burden." Before *Kate* would allow that, she said, she would rather "go to the top of a roof and jump off." Like many women with AIDS, *Kate* struggled to maintain her health in order to keep her job and medical insurance. She wrapped herself in different layers of hope for protection. Her perceived stressful occupation and the lack of an understanding or empathic husband caused significant distress and isolation. Having only a minimal

support network, *Kate's* hope was mostly based on her private determination. As I mentioned previously, were it not for our lengthy follow-up conversations, my initial impression of *Kate* and her experience of hope would have been inaccurate. Being context driven, there were moments when hope seemed to fade away and then reappear later.

Eventually, *Kate's* lifeworld underwent a metamorphosis. Her physical condition deteriorated visibly with the loss of her long thick hair and marked weight loss. No longer able to engage in the cover-up, she was also concerned that her family might be worried that she had cancer. She made the decision to tell her family that her health problems were due to AIDS. *Kate* also shared her hope so they "wouldn't worry." This was just the beginning of many experiences that affected *Kate's* layers of hope. Like the chameleon, as one layer was removed, another appeared. It is important to emphasize, however, that *Kate's* hope was not disguised denial. She was always exceedingly aware of her life and was in tune with her body, time, her spirituality, and with other people. It was because of her awareness that she has been able to address the other stressful aspects of her life and work toward improving them, which she is doing, "one day at a time." Happily, she is even growing new hair.

That hope is grounded in a temporal dimension is illustrated by phrases like "Time seems to be closing in on me," and "I'll never have time to do what I've always dreamed of doing." The immediacy of time as it comes to the forefront of life is poignantly illustrated in the stories of *Sarah* and *Amie*. For them, to imagine not being able to participate in their daughters' future is heartbreaking. Their hope in relation to

time has more focus and meaning in their daily experiences with their daughters. As the French philosopher Jean-Jacques Rousseau suggested, "Life consists less in length of days than in the keen sense of living."

For others, perceptions of present and future time were permutational, depending on whether their illness states were acute or chronic and whether or not multiple losses had occurred:

> *Douglas: It messes up your whole life--everything--your day-to-day existence. You get up and if you have a sore throat you think, is this going to be the big one? Or, here I'm thinking I've sat on my* ***butt*** *all these years and I could have been doing something more productive. You hear people talking about, oh, it's affected me positively because I got to know myself and got to know my family, and that's all well and good, but the bottom line is really* ***time****. When your physician says, "Well, you've got 10 years at the maximum at 10 percent, 5 years at 50 percent, and each year after that there's a 10 percent increment that you're going to be dead," it's like, you know you're using up your time. It affects whether you're going to buy a house or a car or how much you're going to pay for it, or if you're going to get a dog.*
>
> *Garrett: One interesting side effect is the day I got my diagnosis I lost my ability to even imagine a future. My future just disappeared, poof, gone. I can't see having one. I can't imagine a life without HIV now. When I said that this had changed me, this has scared the hell out of me in a way that, I mean, I don't know what else it would have taken to do this....I hate it. It makes me so mad I could die. That has a new meaning, too, doesn't it? It makes me so mad when I hear people saying, "Breast cancer was the best thing that ever happened to me. It changed my life." That's horse shit. That's pendantic bull shit. There's a meringue pie out there for every person that has the balls to say something like that. That just infuriates me. I would not wish this on my worst enemy. This is terrible. But out of it something has happened. It is value neutral. But I can't see a future anymore. And I'm living my life kind of one day at a time, not because it's a practical strategy for coping with the reality of my condition, but because I can't see any future. I don't have one. It disappeared. The fiction that you create is gone completely. And it's like when I imagine--in everybody's mind they have their ideal life--and I don't have that anymore. I can't imagine, for example, being healthy, having a lover, and a happy life where this isn't there. The best I can imagine is having a lover that*

would be with me to the end and to take care of me if I die, and that's the very best I can imagine. That's hoping, that's hoping.

Purposes/possibilities. As *Garrett* said, "Hope is the belief in possibilities." The findings in this study suggest that *Garrett*'s statement could be the canopy under which all the participants' hope is stored. *Kate*, for example, spoke about hope as the possibility of celebrating the New Year 2000. "When you have hope," she said, "you feel the possibilities. Without hope, you feel depressed."

Victor: Well, sometimes it does seem hopeless, it really does. But there is hope. Like I said, I'm still alive. For some reason God has forgiven me and I have a ***purpose****. I don't know exactly what it is, but I just do the best I can.*

Hal: I decided rather than mope around and give up I was going to live every day to the fullest use. I thought, I can be used...that's my ***purpose*** *in life, I feel, to help people. And I didn't know what it was [before], but I do now.*

Matt: I think that everybody should have some sort of reason to wake up and go every day. I think everybody should have a purpose in life even if it's just to wake up and say, hey, I love myself and let's go make the very best of this day. An example of this is the owner of a bed and breakfast who has AIDS. One of his legs is very swollen and covered in Kaposi's and it's difficult...for him to get around. Yet, he cooks...and does all the shopping. He has a ***purpose****...and I think it keeps him alive. Even in the very thick of AIDS, he's still going full force, he's very active. And that was a very hopeful, a very positive thing for me. If he can be that sick and continue to go and thrive, then I can also do that in my own way, find my own purpose and continue to go even if it's to make other people smile, which makes me smile in the process.*

Having hope for *purpose* and *possibility* was of more concern than having a clear notion of what the purpose or possibility should be. The exception was hope for the possibility of experiencing intimacy.

Julian: I want so much to be a part of someone's life, to be needed, to be loved and wanted, loved and cared for. To be able to give and to get a hug, to talk, to just be with someone to share my love with. I just hope I can do this before I die.

Matt: God only knows I've prayed for it every night, that at least before I die I want to feel that intimacy with somebody. I want to know that. I want to be able to feel and live through that experience.

Phillip: There's a consistency that I miss. There is a physical intimacy that I very much miss. I still miss the sex, pure and simple. I still have a healthy libido, I think. But in a lot of ways I've grieved that loss already.

The loss of one's sexual desire due to illness or to lack of a relationship was a common finding for both women and men. On the other hand, *Ted, Randy, Allyn, Erik,* and *Mark* expressed different perspectives about physical intimacy. For example, *Mark* points out potential possibilities for new life experiences when "sex is out of the way." This excerpt from *Mark's* narrative describes what appeared in the narratives as "stripping away."

I know I have a deep, desire and a deep longing. I've gained so much. I don't look at this--I hate people that say, "Oh, my cancer's such a gift." You know, it's like, take it back! It's not a gift! But yes, indeed it does change everything. It shades everything. I would really like to loose this ascites [abdominal swelling] and have time to experience life unencumbered by these physical restrictions, but with my perceptions the way they are ***now****. Because, whereas before, I was totally--as one of my therapists said--I led with my sexuality, because I was so into working out and all that, I let that be the lead. Whereas now, it's like everything is* ***stripped away****. So it's like* ***your*** *perception and how you are perceived by* ***others*** *is totally different. But you know, people are constant, they respond to you based on their perception of you, and when that changes dramatically--it's like letting my hair go gray and having thick glasses--that you know, I* ***get into it****. So I have a deep desire for that.*

Being normal/self-esteem. This theme concerns the hope for a sense of worthiness, self-value, and self-regard. Issues of anger, guilt and blame are interwoven in this essence of hope. Also included is the hope for "being normal," which pertains to bodily self-image and how one is perceived by others, and to feelings about being a gay person. Underlying this theme is the hope described by all the men and women to feel good about themselves in spite of their physical condition or appearance, and to have "a normal life just like everybody else."

Amie: I was angry with him for a long, long time, but I was angry at myself too, because I kept thinking, how stupid can you be? That kept running through my mind over and over and over, and how much I regretted...I mean, I knew he had not been faithful to me during our relationship. I don't know, it's hard to explain the reasons because they don't make sense. And when I told him [the diagnosis] he promptly left....My mind went around and around in circles just thinking all these morbid thoughts for several months after I found out.

Peter: I think the problem anyone has, man or woman, is that with getting HIV, there is a moral judgment that comes that you did something wrong. Our country is great on deciding when people are bad people. And you have to learn to live with that and you have to fight back. And that's not terribly pleasant. So a lot of men and women just choose not to fight that battle. You know, they just kind of disappear. Well, I wasn't going to disappear. People just want to go on and live their lives as normally as they can--just treat me like I'm normal--but you know, this is always jumping up at them.

Ben: A lot of people still think it's just a gay disease and it bothers me when you're with a group of people and somebody tells AIDS jokes....a lot of gay men-and I'm not an expert--but from observation, they catch it from all angles, society, they catch it from--as far as catching hell--the family that doesn't support them. And a lot of them had already been kicked out and disowned before they even got the disease. I just feel like they have a harder road. They can take me and they can take a gay man, and we could both tell the same person on different days that we're HIV but say

he's gay and I'm heterosexual and they're going to feel more sorry for me than they are for him...that's not right but they will.

Related to self-esteem is the indication by a substantial number of the participants that they feel "like an old person." The youngest participant said, "So this is what it's like to be old."

I had a bad day yesterday. My body just hurt so bad that whenever I'd sit down, I'd have to have people help me to get back up. They'd have to pull me up. I hurt all over. Basically, this affects my joints and muscles. Mainly I hurt in my knees and hips and lower back. And I don't do nothing to make it hurt, it just hurts.

Allyn: I saw him the other day and he looked awful. I mean, he aged real fast, got real skinny, and can hardly walk. He has to use a cane. You can see the age in his face. I hope I never age like that.

Peter: AIDS is such an insidious disease. It eats people. I think what it does genetically is it advances the aging process. Look at people with AIDS, they look old. And the things that happen to them happen to old people. You know, forget the diseases, they look old! They slump over. They get very, very thin and gaunt.

Phillip: One of the things I've been struggling with is the change in my body image, the KS on my face, on my arms, on my chest. It's becoming more and more of a problem...I feel the difference...and so it's a change both in my general physical feeling and in my body image mentally. But it's more mental.

Victor: It really is scary. Here I am, at 25, dealing with things that normal people deal with when they're 70 and 80...but I feel like, borrowing the words of a writer--like my life is going to be finished before it's complete. Do you understand what I'm saying? I just want to be normal. That's the hard thing. You sit and watch yourself deteriorate...I mean, I just hope to look decent enough to where I can go in public without people's children staring at me.

Belonging/connecting. *Lawrence* remarked that hope is the lifeline connecting him to the love and support of his friends and family. "Like an umbilical cord," he said, "hope sustains me and helps me to hang on, to keep going, and to go as far as I can, the

best that I can." Surprisingly, this theme endured over time even in situations when hope seemed to have disappeared.

For example, after *Randy's* girlfriend ended their relationship, he continually was plagued by nausea, vomiting, constipation, pancreatitis, swollen joints, diarrhea, edema, gross abdominal swelling, high fevers, ulcers, skin infections, and stomach pain that he described as "a red-hot poker in my gut." *Randy's* medications filled three shoeboxes, but nothing seemed to ease his pain. Overcome with depression, nightmares, and anxiety, he saw nothing meaningful in his existence. And then a thoughtful friend gave him tickets to a Pink Floyd concert. Before this occurred, he had remarked that "there's no more hope, hope's over." But then he said, "Well, there's always hope. I'll be glad when this is over, but I don't think I'll croak yet. *Randy* talked about his concert adventure in a strong voice, with enthusiasm and laughter. He sounded rejuvenated. His lively description enhanced my understanding of hope as a connection to what is meaningfully experienced in the world.

It is remarkable how deeply hope reaches into the dimension of human relationships. The manner in which hope nourishes life through the behavior of others is illustrated in *Alec's* situation. By his own admission, *Alec* waited too long to get tested. He told a friend, "Don't be like me, don't wait until you have AIDS...it's like, I was in excellent health, doing fine, and then I took a nose dive...and went from feeling fine to having AIDS. If I had known a few years earlier, it could have been treated. I could have taken medications and lived longer."

Alec's hope was the unwavering support of his family and caregiver. Of all the participants, *Alec* suffered the most sensory losses during his illness. Loss of vision resulted from Cytomegalovirus retinitis (CMV). Intravenous drug therapy kept him "hooked up to an IV over three hours each day." Along with the constant ringing in his ears, *Alec* lost his hearing while being treated for *Mycobacterium avium* complex (MAC), a bacterial infection that spread throughout his system. High fevers, profound fatigue, chills, night sweats, chronic malabsorption syndrome, and blood levels that "bottomed out" contributed to his daily challenges. He required frequent blood transfusions for anemia. In addition to his vision and hearing loss, *Alec* lost his appetite and sense of taste, which made the preparation of his meals difficult. Eventually, *Alec* even lost the ability to articulate his thoughts.

In spite of what might appear to be a hopeless and dismal existence, *Alec's* awareness of hope continued until he died. What is remarkable about *Alec's* story is that after his diagnosis of AIDS he did the unimaginable, he fell in love with Stephen, his long-time friend, and caregiver throughout his illness. Their mutual love and synchrony transcended the challenging moments of AIDS.

Secure in Stephen's love and care, *Alec's* world was quite different than some of the other participants' worlds. He said he was "lucky" and "fortunate" and wanted to share his views "in case they might give hope to others." "What's important," he said, "is knowing that you *belong* somewhere and that you can love and be loved. Belonging with and being with Stephen gave *Alec* hope for survival. Although he did not complain to others, *Alec* hoped that some of his days "could be different." Inactivity due to his

illnesses caused him to feel trapped by immobility, particularly after his hearing and vision loss.

> *I almost feel like I'm in prison because I can't go anywhere right now. And it's been like that for the past several months. It's never bothered me to spend time alone, but it's different now because I can't just get in the car and drive somewhere. I can't take a walk and do things like that. I haven't been able to go outside and walk around for the past couple of months...just to enjoy being outside. I used to take Tex [the dog] to the park, but now I don't even feel like playing with him.*

Hope is a connection to others. When the infections affected *Alec's* brain and he could no longer communicate his wishes, Stephen was able to understand him. In spite of major sensory and language deprivation, *Alec* knew that Stephen was capable of seeing things from *Alec's* perspective. This connection existed through touch and nonverbal communication. Stephen's awareness of *Alec's* needs, likes and dislikes, and his sense of humor provided a link between them. For example, although *Alec* could not read, hear, or see very well, and he was not overjoyed at the sight of food, he did have a fondness for Bing cherries--*with* seeds. Eating them slowly, carefully, and relishing each one, he would extract the seeds and hide them under his bed covers. Later, Stephen would hear a "ping!" and then another, and perhaps another. Evidently, *Alec* was target shooting in his bedroom, or maybe he was communicating in some way. We can only imagine his intention and his pleasure as he took aim.

During our first conversation, *Alec* told me that Stephen gave him hope. "Without Stephen," he said, "I probably would not live very long." Laughing, he remarked that

Stephen was such a good caregiver that he was "almost too good!" He watched everything, including all the medications, to be sure they were taken.

> *Taking 20 pills every day is difficult. No one really understands what that's like. I do the best that I can. Stephen comes home...and looks to see how many pills I took. Sometimes I think about flushing them down the toilet. [laughs] That would be cheating.*

The notion that others foster hope was a significant finding of the study. Whether one person or a group, family or friends, or health care providers, all the participants mentioned hope in relation to other people.

> *Stuart: You should have good friends. A good partner. A good family. It helps. Chris is my backbone, he keeps me going. I've been lucky. There's a lot of people out there that aren't.*
>
> *Randy: You need a caring doctor. Most of your hope lies in his hands.*
>
> *Julian: A few months ago I was feeling really desperate to get away. I was in a bad state of mind. I didn't have any money to go anywhere. I don't know if I can describe how I was feeling. I felt trapped. Everything was closing in on me. And then some friends called me up and asked if I wanted to go somewhere with them over the weekend...I still say they saved my life by getting me away for a couple of days. They'll never know how much they helped me.*

The experience of not having hope was also present in the narratives. In the following example, *Walt* describes his awareness of feeling "utterly lonely and hopeless" after his diagnosis of HIV. His past experiences with "mental disorders, drugs, and prostitution" were "not anything" compared to his new lifeworld. He talked about his anger, depression, and intense "fear of dying with AIDS." He felt disconnected and "like

an outcast," since his diagnosis. "I have no friends now, and I don't belong anywhere," he said.

Walt wanted to develop a support network, but he had no hope that he could. He hoped to meet a woman he could "be friends with and date," which might ease his "intolerable, utter loneliness and hopelessness," but who would that be?

> *You don't know how awful it is for a heterosexual male to have HIV. There's no one who'd go out with me, unless I don't tell her the truth about me, but that wouldn't be fair. Who would want to date me? There's nothing in my future but AIDS and death. I tried going to a support group meeting and I was the only person in the group without AIDS...The others looked like they were going to die any minute. It scared me to death. I won't go back. They should have a meeting for straight people only.*

Having been recently diagnosed with HIV, Walt's loneliness and fear was palpable, as well as his anger. His physician made referrals for appropriate care. His story exemplifies the human need for belonging, connecting, and being with others. When the need is fulfilled, however, perceptions of hope can change. For example, after his diagnosis of HIV, *Hal* experienced a divorce and had to "learn to deal with being single again." He described an "overwhelming manic-depressive episode" that culminated in an attempted suicide. He described this experience and how the friend he telephoned "found him just in time to save my life."

> *I was in intensive care for a week...I cut my wrists 14 times and I drunk Liquid Plumber and all that...mixed alcohol and took Prozac. I had that nighttime cold medicine, you know? Mixed it all in my blender and drank it. I used the top of a coke can--the tab--to cut. There's so much depression, mental pain, you just want to give up. You don't care anymore. It's a black cloud. You don't feel nothing...you've been hurt so much all your life...people use and abuse...so you get to where you don't feel it...like there's no hope.*

With medications and rehabilitative therapy, and with help from a support group and friends, *Hal* has regained his awareness of hope:

> *Well, I'm going to admit the truth. I thought it was all over with...the end....When I say that, I was afraid nobody wanted anything to do with me. And I thought, you'll never be able to have sex again. But my doctor is teaching me, you know, dealing with all those issues, safe sex and--it's not the end...I thought it was, but it's not. I thought I'd have to be alone the rest of my life. And the worst thing is I was afraid of dying alone at the end...of course, I don't think that anymore. See, we still need touch, we still need love, we still need intimacy. It ain't the end, it's the opposite and I found that out. There is hope. Yes.*

Gillian's poem "Lifeline" summarizes this theme.

> How can I
> in my so vulnerable youth
> come to terms with my diagnosis of HIV?
>
> I feel I have been caught
> suspended by the magnets of two great forces
> one pulling me toward life
> the other toward the grave.
> How can I have hope
> when so many of my friends have
> succumbed to this devastating
> uncompromising disease?
>
> But if hope
> is all I have left
> how can I not grasp it
> with all my energy
> however real or imagined
> and hang on tightly
> to life and my tomorrows.
>
> Life with HIV
> and without hope
> would be worse than no life at all.

Humor and love. Recently, *Lawrence* had the opportunity to meet Alice Walker, author of The Color Purple. Since *Lawrence*'s recovery from Pneumocystis pneumonia, he has developed Kaposi's sarcoma. This purplish-colored skin cancer is quite evident, and covers a large area of his face, including his nose. Thinking it would help to "break the ice" when they met, *Lawrence* greeted Alice Walker with a smile, pointed to his nose and said, "I just *love* the color purple."

Talking about his grossly swollen abdomen, *Mark* said, "I was as tight as a drum and very uncomfortable. It is extremely painful. I mean, I know what it means to be a pregnant woman. I shocked my mother. I went downstairs and I kind of spread my feet and said, "Ricky, I think it's time!"

Describing his experience of testing HIV positive, *Stuart* explained that "You just go blank. In your mind, you start playing with all *those* thoughts. And your stomach gets a *little* upset. (laughs) And the doctor says, "We'll do whatever we have to." And you go, "Thank you." (chuckles)

Discussing the preparations for his spouse's funeral, *Peter* said, "I told the rabbi when he asked me to do a eulogy, I said, well, all right, rabbi, I'll try it if you can stand all the snot and sniveling you're likely to get....and the Rabbi *said*, *Peter*, we're Jews; we're not Presbyterians; you can show your emotions."

A friend brought homemade rolls to *Lawrence* during his hospitalization. I remarked that they smelled wonderful. He said, "Oh, do have one, they're to die for!"

Mark (and others) emphasize that humor sustains them. In fact, for *Mark*, the best humor was "sick, dark humor." It kept him from seeing how hideous things really were,

he said. *Mark* points out that "people who are into hope" who cannot bear to hear anything unless it is positive should consider the other side of hope.

> *I always try to explain that there are no negative emotions. That the ability to grieve, the ability to express fear, that's the only way that they will ever be transmuted into something useful. You have to walk--and that's walking through the shadows--and then you walk back into the light....And basically, I see the medical community taking hope away because they are so rooted into the numbers and into the empirical. And friends are offering you false hope out of fear, which is..."I know you can beat this. I know you'll be all right." I know blah, blah, blah...and it's like when my mother said something about my stomach and I said, "It's a sign of death," and I realized how blunt that must have seemed to her. But call a spade a spade. Don't be afraid of it.*

Julian remarked that "It seems like when you have hope you can feel the love of others around you; but when you don't, everything feels lonely and depressing." For example, *Elliott* telephoned to talk about the hope and friendship he had experienced recently that "really made me feel good." A friend had brought a complete dinner for two, including the cutlery. Considering that he had been quite ill before, *Elliott's* description was animated.

> *He brought cabbage and potato soup and half a chicken for each of us. It was on a bed of rice with toasted almonds and plum sauce, and there was eggplant with tomato sauce, and I ate almost all of it--what's leftover I'm eating today....That just made my day.*

Finally, hope affords the possibility of love, as *Amie* described, even when it is unexpected. Her emphasis of this point is itself very hopeful, which is why she wanted to share her thoughts.

> *Like I said in the beginning, I thought, it's just over. I'll never get married again. I'll never have another intimate relationship because I thought, well, now, who in their right mind--there's no man or woman in their right*

mind--there's no person in their right mind that would want to get involved, to take that risk, get involved, take that risk physically or emotionally, either one. Why would you want to marry somebody that you knew was HIV positive where you might contract it? And even if you don't contract it, just think of what you might go through watching your partner get sick and die and so on. And I was real depressed and I just thought, that will never be a part of my life again. But that's not necessarily true...just because you're HIV positive, it doesn't necessarily mean that you cannot or will not meet somebody that will love you regardless....I met someone and he knows that I'm HIV positive and he says that he doesn't care, he still loves me.

Doing good deeds (mitzvahs). The theme that hope is the belief in the possibility of doing good deeds was unexpectedly redundant. Also inherent in this theme was the notion of tolerance. I have borrowed from *Peter's* narrative the word mitzvah to show the relationship between hope, tolerance, and good deeds. Many of the participants in the study have described personal experiences concerning stigmatization. Yet, nearly all of the participants have mentioned being consistently engaged in helping behaviors that require endurance, empathy, and patience. *Peter* defines a mitzvah as an opportunity for a good deed.

When a good deed is done, there are two sides of it: the doer and the receiver. And both have to cooperate in it. It is, in Jewish tradition, known that a poor person or somebody who needed help is an opportunity. This is an opportunity for you to be generous or to do something for a mitzvah. This is an opportunity; this is not a burden. And the person receiving it also will look at it that way too. But it's a different way of looking at it. It's a gentle way of looking at it and I really like that.

Nick: This can be sort of life-enriching...I know that I've improved in my respect for other people. I tend to be more tolerant of other people, more tolerant of other people's ideas, and I listen more.

Garrett: It's hard to describe, but I'm not the same person. It's changed me in a way that is impossible to describe. I have a tough time wrapping the words around it. It's made me a lot more tolerant and compassionate

and in ways, a lot more of a compassionate pragmatist....It's made me willing in a real expansive way, to express my emotions a lot more honestly.

Victor: I like to make people happy...what I'm trying to do is just give what I can now. That's one thing that you think about when you're faced with something terminal. You want everybody around you, even people you don't know, you want them to be happy and healthy and you want them to live and appreciate those little things that we just take for granted every day.

Erik: It's frightening for people who don't know what it takes to handle it. But hopefully my contributions might make it easier for one or two people. Everyone's life is different; we have different times and stages. But you can always maybe get something out of the other's life that might give a little strength or a little more understanding. And, knowing that you're not the only one helps.

Andy: I like to help out. I help the neighbors and the owner and just fiddle around. I can't remember when I was happier; it seems real odd, but I can't.

It was *Peter* who emphasized that the "real story of the AIDS epidemic is the response of the gay community to it." One person after another has taken up the challenge in ways that do not exist to help people with other serious illnesses. As *Peter* notes, "It's supremely interesting to me that this community responded in the way that it did with time and money and effort. It's amazing."

You know how things can just perfectly click with somebody when you meet them? That's what it was like with him [a person with AIDS]. People thought we had known each other for years. He wanted somebody to stay with him in the hospital. So, between his mother who is a saint and our friends...by the time he was dying, I had to be traffic cop to arrange who was going to get to stay with him at the hospital. He could never get the meningitis under control, so it was a pretty harrowing experience. Now, he had seven IV pumps going. I mean, you ***can't*** *sleep. One of the damned things is always beeping in the middle of the night. And he couldn't get out of bed, so you were always emptying the urinal. He was vomiting a lot. It was a mess. You had to really* ***work*** *to take care of him.*

And all these people are lined up for the privilege of doing this! That's the kind of human being he was; just extraordinary. But, finally the nurses told me they didn't think he was going to live through the night. He had had some seizures. So I got an aide and we bathed him and changed his bed. He still was out from the seizure. And I picked up the room a little bit and put on his music and I tried to make things presentable before his folks got there, and sat down on the bed and started crying. And he woke up! And he said, "What's the matter?" And I said, "Well the doctors say you're not doing real good." He said, "Get up in bed with me." So I did and he put his arms around me and he said, "Now, there's nothing to be afraid of. Everything is going to be okay."...And about 8:00 in the morning he died.

Comfort. This theme is described in the chapter's opening vignettes about *Lydia* and *Les*. As a thematic representation of hope, comfort emerged from the physical experience of living with HIV-AIDS. Desire for comfort was present in the narratives regardless of the illness duration or severity of symptoms. When I began writing this chapter, my understanding of this theme was unclear, even though it had been given the phenomenological nod by *Peter, Erik, Phillip, Lawrence*, and *Elliott*. Ultimately, the emergency hospitalization of a patient authenticated this theme and resolved my personal uncertainty.

The patient was disoriented, in severe distress, and unable to communicate. Either he did not know or was unable to communicate his knowledge of his whereabouts or his name. "Who are you?" the nurse asked. He could not answer. Had he suffered a stroke? Seizures? He grimaced in pain. His blood pressure was 190/100. The nurse tried several times to start an IV line, but failed with each try. The second and third attempts elicited agonizing cries that sounded like a wounded baby animal. His veins were damaged from previous IV medications. The nurse was turning and twisting the needle. He moaned, holding his breath, teeth bared, his head stiff against the pillow. My fingers blanched in his powerful grasp. The bed was bloody, but the needle was in place. "Don't move a muscle," the nurse warned.

"Can't do it," he whispered. "All over." The nurse left the room to get supplies. Unexpectedly he shouted, "Need box! Box!" Recalling that he'd had projectile vomiting earlier, and knowing that his language skills were impaired, those words suddenly made sense. I dashed to the corner of the emergency room and picked up the trash can. Tossing it up on the bed, I helped him sit up just as a dark, forest green liquid splashed into the can. He vomited again, and then again, each time holding his head in pain. I had no gloves, no wash cloth. Where was the staff? I could not let him lie down for fear that he might aspirate the vomit. "Can't get it over," he cried. He folded up, Bent in two over the trash can, one more time. "Head, all over," he said. I looked outside the room for a nurse or anyone at all. "Can't he have something for pain?" I asked the people at the work station, but I was told that x-rays and a CT scan of his brain had to be done first. Then the doctor needed to see him when he was admitted to the floor. He would just have to wait a while. Hours later he was given morphine. There was a curled body in the bed sleeping comfortably. No visible signs of pain were apparent. His breathing was steady. No frowns, or grimaces of agony were on his face. He looked much younger.

Sitting in the chair by his bed, I watched him sleep, wondering how he and the others with AIDS endure the physical assaults, the inexplicable pain, or, to use their word, the "torture." For that moment in time, however, I saw his comfort as he lay sleeping, wrapped in warm blankets and embraced by morphine. I understood, then, what they meant by the comfort of embodied hope.

[Researcher Notes]

Comfort pertains to the lived body (the body-as-it-is-lived) and to the way it is perceived by those who live with HIV-AIDS. Without hope for comfort, the memories of previous pain and the anticipation of future pain become unbearable and paralyzing. *Phillip's* description captures his awareness of hope as believing in the possibility for comfort during painful chemotherapy treatments:

I was on the drug Neupogen which is designed to increase the blood count by inspiring the bone marrow a little bit. That caused probably the worst pain that I've ever dealt with. Bone pain is typical with Neupogen because it's forcing the bone marrow to produce. It's bone nerve pain. It comes from the nerves surrounding the bone marrow. There is severe pressure

because of trying to force the bone marrow to produce. And at one point I was sitting in bed, not realizing what was going on. It was probably my second Neupogen injection into my catheter. I knew that I was hurting in my lower back, that I had a great deal of tension in my lower back, and the pain just seemed to be sort of spreading out from my spinal column through my chest down into my hips. And I already had neuropathy pain...in my legs and hands. And it got to the point where I was literally sitting up in bed rocking back and forth with pain. I believe my sister came in to visit me that afternoon and I had already asked the nurse for [something]; hey, I'm really in pain. I need something really bad right now! And shortly after my sister arrived they came in with Demerol or morphine. But they gave me a good shot and I settled in and the pain became very manageable after about half an hour.

And so that was about the hardest it got physically. We had to stop doing it intravenously. They had to do it so it would disseminate into my system slower because the pain was the worst I've had....Then they discovered that my pancreas was being damaged by the IV Pentamidine [for Pneumocystis pneumonia] and I started having to do insulin injections and I had to control my diet. And that's the one time that I really just started crying. And I was very angry because I would not be able to eat the way--I mean, I was so debilitated by the Pneumocystis from coughing that I was just miserable. I couldn't get up and walk around and I couldn't sit up for any real lengths of time, and I was determined not to get addicted to television. I really didn't have much that I could do except comfort foods. So I very consciously could tell that I was developing an eating disorder. Well, when the diabetes came to the forefront, I had to be taught to give myself insulin injections and take my blood sugar four times a day. Just ***really pissed me off****. And, it was extremely difficult. And so finally, they had moved me off of the respiratory ward onto the oncology floor, because I have Kaposi's sarcoma and lymphoma, and one of the oncology nurses was helping me get settled in. I was just so angry, and I don't know, part of the change of environment into a new room gave me the ability to sort of release it all. I was having to adapt to new things and also having to release on things...I had a good cry and got it all out so I wasn't suppressing anything. And I was able to confront the thought of dying, the thought of the major change in my life that diabetes meant, the major change in my life that being on chemo and having a catheter in my neck meant. I couldn't take showers--I couldn't get it [points to the catheter] wet--all those things that would comfort me before weren't there, so I had to say, "I want a room where I can have a sit-down bath," because the room that they put me in just had a little stand-up shower thing. And so they moved me to a room where I could have a regular bath and other conveniences. And then, oh yes, I definitely had hope.*

An understanding of hope for comfort comes from experience, as *Phillip* indicated. Although we may read in textbooks how certain illnesses are manifested physiologically, we may be unaware of the personal suffering they cause. As the participants discussed their ordeals with various infections, the element of comfort was salient. Suffering with pneumonia, for example, causes "suffocation," "a sense of smothering," and deep, stabbing chest pains." Pain from shingles is "excruciating" or it "can drive you nuts." Descriptions of neuropathy ranged from stinging and burning to electrical shocks. The focus of these experiences is one of being called back to the body, and for many being reduced to a body (Becker, 1992, p. 241). Underlying the illness is the constant fear of not having any hope for comfort when the "time comes" and "all you can do is hope that your caregiver knows what to do." One of the participants was discussing his interactions with health care professionals who were caring for his lover:

> *It's scary as hell. It really is. You're thinking, what if I were, you know? I remember one time after he'd already had a bout of Pneumocystis. They would have killed him off quickly. And if I had not been there every minute, you know, writing down what he's getting and what was being done for him...and this time he was on the ventilator. Well, the turkey nurse is sitting out there reading her People magazine and watching Mork and Mindy or whatever it was, and he's in here dying. And I went out and got her by the lapels and I said, "You, bitch, are going to get in there and do your fucking job." She was like, well, they hated me. And I walked into the intensive care unit and stayed with him and got him up out of bed. They were giving him morphine. They pounded him with morphine, and the poor guy hadn't had a bowel movement in 10 days. And I said "No wonder he can't breathe. He's so distended he can't use--and this is basic nursing here. This is just basic, basic stuff and you're not doing anything for him because you figure he's going to die, he's got AIDS, he's going to die. Why are you doing this anyway?" And then, of course he recovered with no help from those people and he lived for several more years and worked....They keep you on so many drugs or so much, that you're not*

bugging them about anything. They can go out and do the charting and tidy up and then go home. The only hope that you can really cling to is that your caregivers are educated enough to know what's going on and that they really give a damn. You have to feel comfortable that they are your advocate. But I think that once you initially accept that you're going to die, your only hope is that you don't die a horrible lingering death, and that you have a comfortable death.

As Merleau-Ponty (1962, p. 92) notes, our bodies are not objects of the world, they are the means by which we are in the world. The experience of physical illness changes the way we move about in our lifeworlds. It disrupts, constricts, and makes us vulnerable. For example, when *Stuart's* health declined so rapidly, he used a cane to help connect him with his surroundings. The cane provided a sense of comfort and security. It became an extension of his body. *Erik's* Kaposi's sarcoma (cancer) virtually destroyed his left leg. He described his leg as "it" rather than as "my," saying "it is a useless wooden stick attached to my body." The space around him became a challenge. Getting to the bathroom involved "19 steps." As the pain and disability increased, *Erik* considered his options for remaining ambulatory. He found that crutches provided some comfort while he was inside the house, and a wheelchair worked well outside of the home. Again, this equipment became a part of his physical existence.

Mark's gross abdominal swelling was described as an "alien body part. When speaking about his abdomen, he said "this thing." He experienced enormous comfort from a small pillow placed behind his back. Similarly, *Theo* suffered from recurrent, intensely painful herpes lesions in his entire rectal area. He described the pain and abscess as "terrible, like sitting on a knife you can't get away from." "Nothing stops it,"

he said, "except that IV the nurse brings to the house." I suggested to *Theo* that he might ask about getting a "donut" to sit on. (A donut is a cushion shaped like a donut which allows the rectal area to be free of pressure or contact with a surface.) Just before he died, Theo said he got the donut and it made "sitting more comfortable." Anything that was done to promote comfort and pain relief was considered hopeful, whether it was medication, a wheelchair, potty chair, a pillow, or hugging a teddy bear. *Peter*, a caregiver of nearly 20 friends with AIDS, summed up the importance of comfort:

> *When my friend was talking to his cousin about the realities of his condition, his cousin said, "But you've got to have hope." And he said, "I do have hope. I have hope I will have a dignified death. I have hope I will not have pain." My sense of hope runs along those lines. Now, my lover [of many years] is very sick right now. He would very much like to get better and get back to having a life. That's not going to happen.*
>
> *One of our friends who was visiting Samuel said that he had a lot of life in him. I said, yes, he does, and I think he'd like to die with some of it. One of our friends didn't die with any life left in him. He weighed 80 pounds....When people get really sick their horizons come down so far. It is just a focus on a few very basic things. And one of those things is hoping to die with some life left, with the body intact, like a human being. Samuel wants to be a human being. He wants to sit on a toilet. He doesn't want a diaper on him. And any time he wants to be a human being, I'm going to deliver it if I can. It's been my experience that it's very important--even if it's symbolic--it's very important to keep doing human things like eating, even if you can only eat a bite or two, a grape. Humans eat. Humans get up to go to the bathroom. Humans bathe. It's important to do those things because if you stop doing them you're not human anymore....But you know, I've gone through the whole gamut of emotions with him and I'm trying to, I'm trying to keep him comfortable, is what I'm trying to do.*

Managing/Planning/Controlling. This theme underscores aspects of living with HIV-AIDS that appeared in all the narratives at some point. The discovery of this theme

came from statements such as "The only hope is in managing the illness," "You've got to get everything in order," "Tie up the loose ends," "Put things in their place," "Get things tidied up," and "Take care of business." The antecedent condition for managing was hope, whereas anger and frustration seemed to stifle active behavior.

> *Ryan: It made me really mad because for the past three weeks I've spent three hours every day on the phone with this office or that office and I'm getting tired of it. I'm tired. I'm tired of being tired. I'm tired of being a statistic. Seems like everybody's just trying to make it all that much harder. I mean, you've got enough to deal with without dealing with people that say well, I can't tell you nothing. You need to call such and such. And you call them; well, we can't tell you nothing, you've got to call this other person.*

When an outcome was positive or when there was at least the hope that something would be accomplished, *Ryan* remarked, "It makes me feel more hope. I have hope, now, that somebody is going to actually do something, instead of just sitting and waiting around.

Lawrence, Elliott, Allyn, Erik, and *Frank* commented on the importance of getting things "tidied up," in order to "enjoy the rest of your life." The "loss" of hope appeared in descriptions about experiences related to managing the illness on a daily basis.

> *Ted: I went to pick up my medicine, and I was under the impression that my insurance would pay for it. So I went down there and she said, "That's $175. Your insurance will reimburse you." I said, "No, I can't afford it," you know? So I lost hope then, I really did. You know, here I am, I can't afford to take any precautions to make me feel better this week, or my medicine for pneumonia, so I just felt broke down, because, I want to hold on to every inch of thread I can hold on to. So, I don't want to go any longer and go through living hell with the pain and stuff...when I mentioned pain, I meant mental pain as well as physical pain.*

This theme also concerns the following issues identified by participants as potential problem areas that should be managed early on, before a critical situation occurs:

1. Living Will or Medical Directive
2. Power of Attorney
3. Life Insurance and Viaticals
4. Filing for Disability
5. Nursing Home Placement
6. Health Insurance/Medicaid/TNCare
7. Funeral or Memorial Arrangements and Burial Plans
8. Personal Will/Estate Trusts
9. Protection of Combined Assets for Partner/Spouse
10. Bank Accounts/Real Estate/Taxes
11. Having At Least One Caregiver-Advocate

When these issues are not addressed, or when problems arise, stress takes a toll on the person who is ill, or worse, it seriously affects the person's dying and death. For example, *Randy* claimed to have "tidied up" all the required paperwork outlining his opposition to life support measures and his plans to be cremated. Because the forms were misplaced, lost, or never filed, none of his wishes were honored before or after his death. His peers were greatly sorrowed by this experience, as *Phillip* explained in his narrative.

First of all, it's just the anger, disappointment of having to deal with this, that this was not approached in a way that would have prevented this....

Early this month was the hardest death I've ever encountered, the most pain, the most true suffering I've ever experienced in a person's life in their death process. I was there helping in the hospital room for hours at times and spending time with relatives and trying to evaluate what's going on and what's the next step. What is the next thing that's coming? And it was scary. It was horrifying because it was the most horrible death I've ever encountered firsthand... and that was extremely difficult for me.

As *Douglas* points out, "You have to make sure that you keep strict records and that they are in order." And from *Erik*, "Once I finished getting everything tidied up, I could relax. I didn't have to worry that I'd be in a hopeless situation sometime down the road."

Finally, having hope that one will be cared for by a compassionate advocate who knows how to manage a life-threatening illnesses is an important finding, evident in the following narratives.

Peter: I am wondering if I get really sick, who will look after me?

Julian: I feel myself slipping away as my body gives in to the HIV. I worry how I will take care of myself. I have no one to do for me like others do. My family either cannot or will not do for me. When I am at the point where I can't do for myself, what will I do? How will I take care of myself?

Being flexible/practicing hope. This theme emerged as a strategy used by some of the participants in their managing styles, especially during difficult times. *Lawrence* describes his awareness of what he calls "practiced hope" and "hope in practice."

Hope is difficult to nail down. It doesn't hang on the wall where one can smell it, or admire it. One has to work with it. One has to practice it, both in private and in public. When I have a bout of depression or experience the hole of hell--thank God those days are rare!--I simply stop and take a deep breath and practice hope. To be able to hope is to override fear. Hope is much stronger than fear, you know. And the same applies to being in public. I feel that I have a responsibility to the others, to my peers, to be a role model for hope, to show them that fear can be displaced by hope and that they too can practice it. And, by practicing hope when one approaches the black hole of hell--the depression--one can also feel the hope that's needed to carry on.

Participants described their experiences as being "dark," "dark times," "dark places," and "the darkness." About testing positive for the virus, *Amie* said, "That was a really, really dark time for me mentally and emotionally." For *Garrett*, the diagnosis included making adjustments.

Every morning I wake up with this disease and every night I go to bed with it. And it's hanging over me every single day. And it's right here, and no matter how great things are going, it's always there. It makes every success a little less important. It just darkens everything a shade. And what's happening is--what has wound up happening is--I've gotten used to it. I've adjusted my expectations.

Living with the virus was expressed metaphorically as living on a "roller coaster," a "ferris wheel," in a "battle/war," like a "bouncing ball," and "oscillating in a bipolar hope-despair" lifeworld. In other words, life has a "spin-the-wheel" aspect that requires being flexible.

Victor: Well, sometimes it seems hopeless, but there is hope....It's like a bouncing ball because you have your highs and you have your lows. And I don't think you go through a cycle. It's not like you go through the anger, then the denial, then the resentment, and then the love and the acceptance. You do that all the time. It's like a big ferris wheel that you're on and you go through the whole gamut...over and over. But then, I've gotten to the point where I know I'll get angry about this again. You know, I was angry

this week about it. I wanted those IVs out of there...you just keep going through the circle. But I've learned how to get off the ferris wheel sometimes, and say, look, I'm tired, I need a break...let me take a vacation from me, you know, how we do when we have to have those times? But I used to not be able to do that. I mean, I told you I was a walking basket case. You'd look at me and I'd cry, I'm dying, oh, oh,--I mean, it was horrible. And I mean, my tear ducts would be bigger than Lake Michigan because I would cry all the time...I was a depressing little thing. Looking back, I can almost laugh, it was kind of comical. And now I'm sitting here thinking, it's just real, real weird, so strange.

Underlying these metaphors is the need for flexibility in order to live with whatever might occur. As *Kate* noted, "Every time you sneeze you have to worry." *Douglas* described this as "Russian roulette." The element of uncertainty is part of daily life. In *Allyn's* view, however, "It is better if you just go with the flow and learn how to live with the illness, even if you have to change 90 percent of your life to do it. You shouldn't worry about it."

Amie: Some days you think, oh, God, this is just so awful, my life is the worst...a really big problem. But then, on other days, you think, well, compared to all these other things that could be going on, this is a minor problem.

Finally, that hope facilitates flexibility is described by *Ryan*, who pointed out, "When I don't have hope I wish it was over with. I wish it [death] would hurry up and just happen so I can be free. At other times I keep thinking, well, no, I don't want it to happen. I'm going to...deal with it because tomorrow is a new adventure."

The relation of hope to the contemplation of suicide was a common example of how hope affects one's sense of control, one's choices and plans. The most notable difference among the participants' expression of this theme, however, was their level of

involvement and interest in the management of their illness. The group is evenly divided in this regard: half participated actively and consistently in their care and plans; the other half did not, regardless of illness progression. *Nick* described his experience of hope using the example of a road that winds around a beautiful countryside and connects to a "plan" for his life, or his "journey."

> *Remember, the main thing I'm thinking about is, where is my life going? What's around the corner for me? How do I plan to go down that road? Do I want to make a lot of plans and go quickly to get somewhere? I don't know...there's a lot of uncertainty, but you've got to act like you have some idea of where you are going and make some kind of plans to travel down that road. But try to make it [so you] can look forward to a little excitement. So it's not so dull, you know? And, well, it just occurred to me...always have unfinished business, always have things that you have to achieve, that you want to get done, as though you are not going to die. Even though you know you are going to, you just keep on planning things...you're not ever wrapping things up. I always keep my appointments, always have an appointment, like with you or with the doctor, or therapist, or somebody. Always have an appointment and a plan of things that you like to do.*

Sarah experiences hope in her plan to teach her young daughter how "to do things," and help prepare her for what is to come. She finds hope mostly in her faith and the Bible.

> *I'm really worried about my daughter and how she is dealing with this illness. She sleeps with me now because she is afraid I might die. We talk about it, but I'm not sure how much she really understands. I think the Bible helps her though. She showed me a picture of the Resurrection and said, "See, Mommy, this is you and me when we go to heaven." I'm teaching her all that I know since I won't be there when she grows up.*

For some participants living with the virus, having a sense of control was paramount. As *Nick* pointed out, "It's like an enemy. I think if you understand your

enemy you can defeat it." One person argued that control is only part of the hope; you also "must be vigilant and on your guard."

> *Several years ago, when I was living in [a large metropolitan city], hospital personnel were going around "M&M-ing" AIDS patients. [He] would take an M&M and put it down the endotracheal tubes of the AIDS patients so they would die. M&Ms would melt and there would be no trace...killing off AIDS patients because he hated queers, you know, or giving them a potassium bolus...it's frightening.*

Garrett's hope is grounded in his intellect and his "love for science," making it easier for him to "control" the virus.

> *I think finding out about this is the only way to maintain some kind of control over it. Also, what you don't know in this case really can kill you...you have to become a genius of drug interactions, memorize the PDR....The trick is to track progress by any means necessary. There is no such thing as taking too much time studying the literature. I mean, if you're going to be some passive vessel to be handled by your doctor...what's helped to keep me in control of the situation, or at least feel like I'm in control is the illusion of control. In many respects it is as important as the real thing, I think. I mean, control is an illusion, but I am at least maintaining that illusion. When you find out you have a disease like this, you quickly come face to face with the fact you have no control over your life...but no viral infection in history has ever killed the hope that some people have.*

> *Matt: You know, I think one of the things about this virus is that it does make--you have choices--you can either destroy yourself or you can look inside and see what's good. You can be hopeful about what it is that you have versus being negative about what could happen. And I choose to be hopeful about what I have and what I can do with today.*

How hope affects plans was evident in conversations concerning safe sex, whether or not to take drugs or medications, smoke pot, to eat, or kill oneself. Perceptions of hope also influenced whether or not participants would participate in clinical trials, radiation

therapy, chemotherapy, or hospice care. An excerpt from *Mark's* narrative reveals how curiosity and hope relate to planning and controlling.

> *So I said [to Dr. Rose], "What you're saying is that there is no liver left at all to regenerate, it's totally hopeless." And he said, "Yes, that's what I'm saying." And at the same time, he validated everything. He said, "You're amazing. Your diet is amazing. Your response has been amazing. You have prolonged your life and your quality of life." I was like, "You know, I don't know what quality this is. This is not my idea of quality." Anyway, I went home, and I felt the emotions. I felt the hopelessness. You know, at that point you're faced with, okay, the doctor says it's over, let's go eat a Big Mac and some fries with lots of salt and a chocolate cake for desert. I mean, really, if I was truly hopeless, I suppose that's what I would have done. But it was like, just hang on, and that's when--I don't really have this hope that I'm going to get well--I'm not clinging. And it's not even that I think life is so great. I think life is going to be much better on the other side. But it's like I still have an innate curiosity about things. I still want to experience some things. It's like, okay, it's been a great feast and it's been a fun ride, I want to go one more time around before I have to go home. Sort of like the kid...who says, oh, just one more time on the rides. So maybe...but it motivated me. And I went to the movies. I didn't curl up and die. I saw, strangely enough, Schindler's List. It was very liberating to watch this movie...it allowed me to see how blue the sky was and to appreciate that I still had my appetite and that I'm such a great cook...and that things are not so bad because...before, I always, always was certain that when things got really bad I was going to kill myself, because I'm a control freak. I was going to end it. And now, it's sort of like, let's ride it to the end...things could be a lot worse.*

Being at peace. Hope for being at peace was present in the narratives of those participants whose illness had progressed to the point of profound fatigue with "the battle." *Erik* (and others) spoke about peace within the spiritual dimension:

> *I do pray a lot...not for any miracles, it's just, to be remembered, and to pray for others...I can't change anything now, so the greatest thing I can hope for is just to be at peace. You know, that's the greatest thing anybody can have.*

> *Kate: To me, peace is not the same as comfort. Peace is not being afraid of dying. I know I'm going to a better place and I basically can't wait--not that I'm going to give up living--but I know God's waiting for me and it's going to be wonderful. And there won't be any more illness. That's the best part.*

Hope for peace was particularly significant for gay men who were "hoping to have peace" or "to make peace" with certain aspects of religious doctrine. As *Erik* said, "I don't think I'll go to hell for being gay, although I do think I've sinned in things I've done, but I am at peace with God over it."

> *Nathan: Sometimes I get scared because I wonder if it's going to be the way I was taught--either a heaven or a hell, you know? And then, other times, I think that it doesn't matter. I just don't see God hating no one that way. Because I don't think God wants people to hurt. That is the one I want to believe--that God don't want nobody to hurt--and I just don't see the ultimate end being that we're going to hurt again....The Pentecostals would still tell you that I'm going to hell because I'm gay. I don't believe that. I believe God makes no junk....*

While *Peter* said "my religious life has given me some hope in the midst of all this horror," *Randy* suffered extreme anxiety because of his religious background. During a discussion about religion, he asked, "Can you imagine how horrible my anxiety would be if I *didn't* have any hope? What would my life be like if there was no hope for peace? What would I do?" Without hope for peace, suffering with HIV-AIDS was, for *Randy*, the ultimate despair. In one of his dreams, *Randy* saw an undertaker removing a gurney from the hearse outside his apartment. In another dream, he saw the undertaker putting a body inside the hearse. The body was his. *Randy* described how he had to have hope for future peace in order to ease the present experience of AIDS. He wanted to "feel" peace

at least briefly in the present so that its anticipation would be psychologically comforting. *Randy* asked a friend to take him to the cemetery in the middle of the night. The friend would return in a few hours. *Randy* described sitting at the place where his ashes would be, close to a dogwood tree, and near an angel statue. With the darkness and night sounds around him, he sat on the ground and went inside the deepest places of his heart and soul. He said he was trying to imagine being dead, but the fear of burning in hell "for being who I am, and will always be," was terrifying. He was swallowed at first by anxiety that was "unbearable," but then he felt embraced by hope and peace. He imagined his graveside service, who would be speaking, and what he would have written on his marker. What makes this experience so meaningful for *Randy*, however, is that he said he was "totally horrified by graveyards." Laughing, he concluded that he did not "see anyone else there."

Finally, several of the participants' belief in the possibility of peace was expressed by statements such as "To be honest, I wish it were over," "It seems like it should be over with," "I think I may be going to die soon," and "I hope the end is coming." None of these statements implied hopelessness or giving up. In fact, all these statements were expressed by participants who identified themselves as being very hopeful. A peculiar aspect of this finding was that people with other types of illness, including cancer, who verbalize these feelings, are generally encouraged to keep on going, or, efforts are made to cheer them up. Seldom is this the case for people who have AIDS.

Frank's 10-year illness characterizes the theme of peace. A few months before he died, he said, "I'm getting tired of fighting. I'd like some peace." He talked about having

an unrelenting chemical taste in his mouth that made eating a terrible chore. As his suffering with MAC worsened, he said, "I thought I'd be going on by now." Intolerable pain, "crazy sleep patterns," and constant fatigue were simply wearing him out. *Frank* was "terrified" of getting dementia more than he was afraid of anything else. He thought the "being sick part of dying" was frightening, but dementia would be worse, he said. During his last months, *Frank* was too tired to talk on the telephone, but his caller ID provided a connection with the outside world. He said he appreciated calls "even though I don't feel like talking." Then his worst fear came true. The MAC infection damaged his brain. During our last visit in the hospital, he was cognizant of his lifeworld and what was ahead for him. He was very serene, calm, and pleasant as he waited for a release from the pain. His sister, Constance, explained the irony of *Frank*'s dying: "His biggest fear was of getting dementia. As it turned out, he did, but it was truly a blessing at the end. He wasn't there, so to speak, to know what actually happened. His death couldn't have been better. *Frank* had the morphine pump and the doctor said he wasn't in pain."

Gillian's poem "Peace Through Hope" characterizes this theme:

> Peace has come to me
> in this hour of desperate need,
> delivered to my bedside by a nurse
> and suspended from an IV pole.
> As the honey-colored liquid
> drips into the tube
> and flows into my veins
> I can feel its golden warmth
> penetrating the depth of my ravaged body.
>
> The pain is retreating.
> I can hear the beckoning call
> of much needed slumber,
> of pain-free slumber.
> If I should wake on the morrow,
> or if my sleep is eternal,
> my hope has been granted.
> I hear the pain-free call
> of slumber, of slumber, slumber.

Acceptance/awakening. Acceptance in the context of HIV-AIDS in this study pertains to hope for the possibility of accepting "the end" or other specific situations (e.g., childlessness). *Nathan*, for example, makes the distinction that hope pertains to different circumstances. He had hope that he would live "for a while...how long, it don't matter, as long as I'm comfortable." He had hope that his family would have hope, and that he would not die and "go to hell." In addition, Nathan described that hope--which is a particular kind of hope needed at one's death--"because I've wanted other people behind me to understand what I'm starting to understand." *Nathan's* words capture this theme.

> *I think that when that hope comes, it's going to be time to go. And then that's when you let go, as soon as that...so basically, I hurt a lot because I want that hope, but it's not time to have that hope. And when it's time to have that hope...when that hope hits your heart, you'll know. And it's not hit my heart...when that hope hits my heart, there'll be no more fear*

> *because that hope will be there....When you need that hope the most, and you know there is nothing else left, that hope will come...and I'll be able to just look at Ma and say, my hope is here. Bye, I love you. My angels are here.*

Nathan's hope for "*that* hope" gave him assurance and helped him accept his death. Certain that "God will let you know [when] *that* hope is there," he advises us not to look for the answers in our heads, but rather, in our hearts. His hope for a special kind of hope that would lessen his fears about dying and going to hell facilitated the acceptance of his "fight to keep going until that hope comes." Ultimately, the hope "hit" (came to) *Nathan's* heart, his angels came, and he said goodbye. In a conversation with *Nathan's* mother, she said, "It was all over. Even though I thought it would happen, I still had hope [that] he would live."

What should be emphasized about *Nathan's* hope is that it contributed to his "understanding" and the acceptance of his situation. It was important to him that others "behind me" understand how hope eased his dying process, and how, when the time comes to die, there will be "no more fear."

Kate's acceptance of being childless is eased a little by her hope, as this excerpt from her narrative depicts.

> *I have not had a child yet and I would give* ***anything*** *to have a child but...you might not be around three or four more years and then your child has no mother and that's not fair. And I could say, yes, I'd have one for three or four years--that's what you're fighting against. The infection is not that big a deal. You can deal with that. I would hope the child would not be infected; it would be horrible if it was. But just the separation at an early age would probably be too much. And so that's why I haven't gone through with it. I'm devastated by that more than anything else. If I were to die tomorrow it would be fine, but I have not had a child and that just*

kills me. But in the back of my mind there's still this little itty bitty hope that maybe someday one might fall into my lap.

Matt: Acceptance--this is the thing. At that point [toward the end] I would want to look back and say okay, this is the contribution I've made and this is the hope that I'll leave behind. That is the hope that I would see, I think, at that point, is that other people would see and learn from whatever it is that I've left behind...it's like handing over the rein or passing the torch on to somebody else to hope for you. And yes, at that point, I would have to accept what's inevitable.

Several participants discussed the recognition or awareness of something previously unrecognized. Although these experiences are related to acceptance, the notion of *awakening* seems more appropriate, as shown in the following excerpts:

Victor: When you're faced with this, it's like everything changes. You look at life in a whole entirely different perspective. It's like I'm so happy--you have no idea how happy I am--about going home and being with my plants and my flowers. It's like if I had met someone ten years ago and we were reunited. That's what I feel like. And like I said, it's just those little things that we just take for granted that we really do, and it's kind of ironic. It's ***really*** *kind of ironic. I did stupid things when I was a teenager, you know, like riding on the hoods of cars and just drinking and going out and driving and stuff. I lived such a perilous, reckless life. I didn't even care then. And now I care, but I'm not going to be able to live it out. That's hard, you know what I mean? Now I'm responsible. I can balance my checkbook. Now I pay my bills, now I don't con people. I don't do these things, and it's like, okay, so now you get to die. I mean, you know, that's hard. That's hard.*

Ben, a very private individual, has lived with HIV-AIDS for nearly 14 years. He attributes his enhanced sensitivity toward people to the virus. His awakening occurred when he realized he could speak publicly about having AIDS, which "gives you hope." *Ben*'s experience of having AIDS uncovered something inside him that helped him to feel special and unique.

Having the HIV has made me a better person. I know that it seems crazy for saying that, but I'm more sensitive to children, I'm more sensitive to the elderly, I'm more sensitive to ***everybody****. The fellow down the street--there's a reason for him being a thug....[Speaking to the class], there was a lot of stuff I wanted to say and I just--I couldn't shut up, in fact. I just had to get it out. I can't talk to my wife about certain things, or my dad. I don't want to worry him....[Now] I really feel like since I've been speaking, my calling is to get the message out, to tell people, and I realize that now. I mean, I was just amazed at these big, big old guys and the girls [at school] coming up and really* ***thanking*** *me, and they were appreciative, it wasn't fake, it was genuine. They were really concerned. I don't feel conceited or anything, but I feel special. I'm unique, definitely, because I'm a long-term survivor. They may ask how long, and you know, they just drop their jaw....*

Matt: I think it's taken HIV to really make me dig inside myself and see what it is that I like about ***me****. There's always going to be things about yourself that you don't like. You could beat yourself to death about things you don't like. You can always be your worst critic. But this has made me look inside me and see what I really like about myself. And I* ***do*** *really like myself. I think I am different now.*

Holding on to independence and determination. This theme concerns the descriptions of hope as a belief in the possibility for independence and "doing one's best." In these excerpts, participants describe their fear of not having hope to remain independent:

Frank: I hate having to let someone else take care of me; I'd rather do it myself.

Allyn: You don't want to think that you cannot reach over to pour your own water or to answer the phone. You have to try it at least. But when someone automatically does it for you, it's like taking away your independence. But if you say, ***I*** *can do it, the caregiver feels hurt.*

Ryan: When I was sick she made me feel like I was 7 or 8 years old again. It was very disgruntling and aggravating. She wanted me to stay in bed and not do anything and she wanted to stay home and cook me breakfast, lunch, and dinner and help me to go to the bathroom, and everything else. I told her, I know you're concerned, but I can take care of myself at this

point. I mean, it doesn't bother me if she asks how I feel or if this is a good day or bad, and this, that, and the other, but I told her not to treat me like a child. I can do for myself. There will be a time coming when I can't.

Ben: I'm not afraid of dying--I just don't want to be incapacitated. I don't want to have to rely on somebody. I don't want to linger...I don't want my family to go through it.

Phillip described his hope for independence from a different viewpoint, saying "It is an art learning how to ask for help, when to ask, and in what context. I understand the worry, the personal dignity and embarrassment of having to rely on others, but, it is important if you need it. Don't sit and starve."

Peter: It's always been very hard for me to accept help. My friend is there because he wants to look after me. And he'll say, sit down, I'll do it, or I'll take the dog out, don't lift that, I'll do it. And sometimes I think well, I'm not dead yet. And then other times, I think--let him do what he wants to do. And it's hard to do that. I'm used to doing for myself. And I knew someone who would resent people trying to help him because it was just another sign that he was sick and couldn't do it for himself. But he insisted on doing it.

One of the participants remarked that living with HIV-AIDS and hope is like a coin--it has two sides--and one can be good, but the other side might be bad. For example, *Erik* planned for *every* eventuality with the hope that he would remain independent and be able to take care of himself in his own home. When he became incapacitated, he moved into his parents home. He requires assistance with most everything except eating. His hope changed. Now, he hopes that the orderly won't drop him and that he won't have to wear diapers. But he is doing the best he can.

Most participants have said, "I'm dealing with it," and "I'm doing the best I can." Being independent, productive, and feeling useful was described as an important aspect of living with HIV-AIDS. As *Russell* commented, "I even dream about work--about going back when I get better. When I look around and see how everybody else is doing it [his trade], I wonder if I could do it better!" Many of the participants have maintained a sense of being productive by volunteering their skills (e.g., hair cutting, legal knowledge, planting flowers, babysitting, teaching Sunday school). Others help with transportation to appointments, shopping, and caregiver assistance. Remaining in their usual occupation as long as possible was described as crucial for maintaining independence and quality of life.

> *Phillip: The way I define my quality of life is more in the area of what makes me feel productive and how much I am contributing to the world around me, to my community, specifically to AIDS education and AIDS support, and to my church. I know I have a lot of limitations right now because my finances are shot to hell. I can't do as much as I'd like in driving people around to get things taken care of, like taking friends to their meetings at the Social Security office, and meetings about food stamps, and different agencies they need to go to...it's important for me to be active like that.*

The word "hutzpah" was used often by the participants in this study as they described their hope for remaining stubborn, determined, and strong. An appreciation and understanding of this word's link with hope was not immediately clear to me until *Peter*'s follow-up conversation about the death of his spouse, Samuel. It was his description of Samuel's dog Hutzpah that revealed how this word resonates with holding on to determination and hope.

It was a very strange experience. I think Hutzpah died--started getting sick--the minute Samuel died. I knew exactly what was going on with him. He just had one too many straws on his back and it broke. And I think the same thing happened to Sam, psychologically. He finally suffered so many losses that he just was not going to live anymore. And I don't think that ever rose to consciousness...but that's what happened. That was difficult, and then he got to be bedridden and I had no measure of how long this is going to go on. It went on for more than a year. It was very, very difficult. And every picture that I have of Samuel the last year, every picture Hutzpah is in. He never left Sam's side the entire time, and it just broke his heart and I couldn't fix that for him. I couldn't ever fix that. When I took Hutzpah to the vet, blind, crippled, and epileptic, to have him put to sleep, I said to him, "This is terribly unfair of you. I just want you to know that. I forgive you but it's really unfair of you to put me through this right now...but the poor little guy...I always said that having Hutzpah gave me the slightest inkling of what it was like to have a severely handicapped child, because you can't ever forget. But the grief for the animal...only goes down so far, it's a dog. But I've missed him a lot. And I put his name on the back of our headstone at the cemetery. When I was showing a sketch of it to the rabbi, he said, "What's this Hutzpah?" And I said, "I'm not sure you want to know." I had taken Hutzpah's ashes out and buried them with Samuel. And yesterday for the unveiling I pointed it out to everybody and somebody said, "Together again."

Although the formal definition of hutzpah is "supreme confidence," in the vernacular, it means "guts, or gutsy." Like Hutzpah the dog, people with AIDS become blind, crippled, demented, and so forth. But they and the people who care for them are gutsy, loyal, loving, and courageous. The following excerpts from narratives describe hope in relation to determination and hutzpah.

Kate: You need to have a positive attitude, and hope gives you that. It's the drive to succeed, will to live. It would be so easy to give in--I mean, lock yourself away in a closet and tell someone to check on you in six months. You'd be dead. That's easy, that would be easy. It's ***hard*** *to keep going every day and be thinking, should I be out here, will I get something? Will someone cough on me or sneeze and give me some other lovely bug? I mean, that's* ***hard****. It's living...So you just have to keep the hope at the top so it doesn't slide backwards....*

Julian: I feel myself getting tired of fighting, but something keeps me going, I'm not real sure just what it is that keeps me going...when I think I'm doing good, something almost always knocks me down. But I keep getting back up. Why? Maybe because I'm stubborn or because I see myself as a fighter and not a quitter...and maybe because I know something good could come along.

Ben: You know, I hate to keep saying this, but I really don't worry about this or dwell on it. There's nothing I can do about it...I've accepted that I need to take things as they come, and I'm getting some things under control. But I know there's things I can't do. You've got to know your own limitations. But like I told my wife--I made a decision--from now on if I can roll out of bed and stand up without falling back over, I'm going!

Living many years with the virus has been a constant source of hope for some of the determined participants who consider themselves long-term survivors. As one person remarked: "There are two sides of me; one said *die*, the other said *hell no*!"

Ted: My attitude has really helped me. That's been one of the big keys with this virus. Since I've had HIV I've gained more boldness. Boldness to speak out. Boldness to ask for help, you know? It takes boldness, you have to have it.

Matt: Again, I feel that your attitude is the strongest key to this whole thing. If I sat here and thought day in and day out, I'm going to die, I'm going to die...probably by the end of the month I'd go away or be really sick and I would start the downhill trek. I don't think that way. I think about this virus that I take care of inside my body. But I fight daily, mentally and with medication...and so the virus is an enemy, we're enemies, but it's like, okay, as long as you behave yourself you can stay there, you know? I don't try to get angry about it. Anger doesn't do any good....when I think I'm getting tired or run down and I think it's because of the virus, I fight it. I talk to it. It's like, I'm not going to let you win...and so I meditate from time to time, when I feel like I need some sort of strength.

Amie: I hope that maybe if we get enough folks working on it [the virus] they'll find some kind of therapy to either halt the disease, prevent it, or to somehow repair the damage that it does to the immune system....I mean, I'm determined to to be here as long as--I'm determined to be here until

she's old enough [her daughter] to take care of herself... but I want to be here for the long haul.

Andy: When I found out I was HIV positive, I said well, I'm not going to commit suicide because knowing my luck if I commit suicide today, tomorrow they'd have a cure. And I basically thought that from the day I found out, that I'm not going to do something stupid. But a lot of people give up at the start; they find out and say, hey, that's it, and they wither away. I've never been like that. I've been a fighter.

Summary of Physical Symptoms and Hope

Of particular significance is the overriding finding that hope endured across the illness continuum regardless of self-reported physical symptoms. This finding is applicable to all the participants whether or not they experienced multiple infections or progressed to the late stages of AIDS and death.

The participants' experience of taking one or more antiretroviral drugs such as AZT, ddI, ddC, d4T, or 3TC in combination with other medications, did not affect the lasting quality of hope, even when side effects were a problem. An unexpected finding was the number of medications that participants needed to take each day. Several individuals described having "to learn how to take handfuls of pills without choking." One person described what it was like to be at a dinner party when it was time to take his medications and do the "swish and swallow" for treatment of oral thrush. Nearly all of the participants have taken medication for depression at some time. *Julian* explained why "everyone you see has to run around with a little backpack."

Hope was maintained regardless of known CD4 counts. As *Ben* remarked, "One thing about having only ten T-cells is that it's easier to remember their names."

Unexpectedly, however, those participants whose CD4 counts were highest expressed more concern when there was a downward fluctuation in the lab result. Participants whose T-cell counts were 50 or below were at the highest risk for infections, but seldom commented on their lab results. At the end of the study, all the participants except 9 had T-cell counts below 80. Nearly half of the participants indicated knowing their HIV status for 8 years or longer; the overall average duration was 6 years.

Extreme fatigue and pain were the major sources of the participants' limitations in daily activities. In fact, fatigue and pain were the most frequently reported physical complaints. Of the symptoms on the 30-item Checklist in addition to fatigue and pain, 11 symptoms were described most often by the participants as being "difficult to live with." They were: depression, diarrhea, the opportunistic infections requiring IV chemotherapy, Kaposi's sarcoma, loss of appetite, cognitive dysfunction, shingles, skin disorders, lack of sleep, night sweats, and wasting. Most participants described having between 10 and 20 physical problems.

To summarize, phenomenological narratives portray the fundamental importance of hope for these men and women as they experience the journey of living with HIV-AIDS. There is a noticeable interlacing of the 12 themes that characterize hope. For example, *Ben*'s awakening about his ability to engage in public speaking also strengthened his sense of self-esteem, which he said gave him a feeling of "worth and hope." And there was an overlap in *Garrett*'s example of how tolerating HIV disease is connected with humor and good deeds. Talking about the ways hope affects humor, *Garrett* said:

The playwright Jonathan Miller said that we pity the blind because they make fools of themselves, but we hate the deaf because they make fools of us. And AIDS in a way ends up making fools of everybody. I know a person who was talking about having to take care of a friend and do the death watch, and the guy was really terrible. He was just terribly furious, you know, shrill, uncooperative, and in dying he was unbearable. His friends would try to comfort him and be good to him and cuddle him. Then they'd go down to the lobby and just curse him and laugh because he was so horrible.

Finally, as these participants attempt to balance physical illness, the conspicuousness of time, and their desire for productive activities, love, and play, it is their intrinsic sense of hope that seems to provide fuel for their spirited forging ahead, one day at a time.

CHAPTER 6

Discussion

Erik telephoned to say he thought he was losing his mind. He asked if it would be okay to check in more often. I am unable to imagine what it is like for him to be bedridden, suffering with Kaposi's, watching as it invades his lymph system. Referring to his "wooden stick-leg" he said it's now totally worthless to him. Swelling from the KS has rapidly and cruelly invaded his upper thigh and groin area. He said the pain can be horrible, but worse, the wound drainage is becoming a serious uncontrollable problem. "I never thought I'd be discussing things like this," he said. He was irritated with the aide because he forgets to wash his hands and put on gloves. Erik has to remind him to do it. He is very worried about his parents being exposed to fluids.

Clearly, Erik's pain management is inadequate, which he admitted, but he doesn't want to miss out on any time he may have left. As it is, he said, "I feel like I'm going about two weeks faster than I thought I'd be." The pain and stress of dying while dealing with the basics of survival seems to be causing his agitation, although he sounds quite lucid and articulate. He asked two unanswerable questions: "Is all this normal?" and then, "How much time do you think I'll have?" After asking him to consider how he felt about those questions, he said, "Well, I still feel ornery as hell, so perhaps that's a good sign. But I hope to have some peace at least a week before I go, before I make the journey. I can't tell you for sure, but my gut tells me a month to six weeks, but then it could be sooner. But I really need a week of peace to enjoy my life and enjoy it while I can still eat." In a previous conversation, Erik spoke about this, but at that time he called it quiet rather than peace. He wanted to be quiet, very, very quiet, alone, and he did not want to have the outside world imposed on him. "I want to be able to go inside myself with my own thoughts...recall the good times, and my good life...pretty normal, isn't it?" And he laughed about being a control freak!

I hope Erik will have his peace--pain free--and experience his dying in the way that Levine describes as letting go of ourselves, who we were, and our need to maintain control (1982, p. 99); and to experience death as a

further opening into our true nature--a deeper uncovering of not being the body or the mind (1984, p. 220).

Unlike Erik, Lawrence is ambulatory but living on the tight rope trying to balance pain control and lucidity. He is very active in his photography work and to use his words, "still striving for perfection in my art, and loving my life, working, playing, and eating." Lawrence is taking Megace, an appetite enhancer and says he is eating everything that isn't nailed down. He is not planning to have radiation or chemo for his facial lesions and his purple nose. As he said, there's no point in chasing them all over his body. "Besides," he said, "I've got one shaped like Texas on my leg, here, I'll show you." So far, he thinks that most of his problems are manageable. "Since we can't do anything about them," he said, "we can only hope to keep the good things we have and appreciate those."

Elliott continues to be deeply hurt that his parents "are still in their own little world of denial." He is sad and distressed today, and he said, "This is so scary; I get scared all the time. It's like dying slowly in itsy-bitsy pieces." And then, all of a sudden he was laughing. Concerned, I asked about this. His reply was that tears were running down his face into his beard and they were tickling him. "Oh, you know, you just cry for a while and try to stay upbeat," he said.

[Researcher notes]

Reflections on Meanings and Understandings

Unlike cancer or other serious diseases, AIDS continues to challenge its hosts to survive a viral infection for which there is no known cure. Garrett's remark depicts the battle metaphor characterized in several participants' narratives:.

Don't say, I'm going to beat this. Say, I will not lose. And the joke is, in a big broad philosophical ecological kind of view, I can't lose as long as I don't give it to someone else. The buck stops here. So, from an evolutionary standpoint, all I have to do to win is either not lose or not transmit it to someone else. As a carrier, I'm a dead end. If everybody becomes a dead end, IT'S a dead end. It dies with me. It goes down with the ship. So in a weird way you can't lose in terms of winning the big battle. I may lose the war, but the battle in that case would have been won.

The positive emotional state of the ill person has specific effects on the performance of one's immune system. As Cousins (1989) explained, "It's not unscientific to talk about a biology of hope" (p. 73). This study has explored the positive nature of hope among 28 women and men whose lives and immune systems have been drastically altered by a virus. For the younger participants, HIV infection has been a challenge since they became adults. Older participants who were exposed to HIV infection 8 to 13 years ago traveled through a maze of guesswork as the treatment for HIV was being developed. For both groups, a stressful insecurity tagged along in their lives like a wad of gum stuck to the bottom of their shoes. Uncertainty was a daily companion as they tried to sort out the realities and myths of the epidemic during its infancy. As public opinions moved away from medical issues and toward moral issues, confusion and mistrust piggybacked onto uncertainty. Who and what should they believe? Were the sources of information credible? As *Mark* recalled:

> *It's so vague now, I don't remember [what] it was based on... because it was all just word of mouth. You never read anything. So nobody quite believed it anyway....And everybody said, "See, I told you, it was just a thing like Legionnaires. It's nothing." And so, I think that's when everybody I knew got infected; I mean, it spread like wildfire. So hope didn't get off to a good start.*

Randy confirmed this point, saying "this so-called epidemic became the plague when everyone in the world was having sex as usual--that's what people do--while the debate continued over whether or not God sent the virus to punish queers, and who should get the rightful credit for discovering it [the virus]."

AIDS swiftly restructured social norms, assumptions, attitudes, and behaviors. The customary rules in health care, dying, death, and bereavement were plowed under. What emerged for these participants was an altered life in a climate where some people believed in the just-world phenomenon--that a person with AIDS deserved what he got (Lerner, 1970). This was the antecedent darkness that underscored the questions for this inquiry. Is it possible that hope is experienced by people whose lives are forever changed? Does hope survive over time even with illness progression and death?

This study opened a door to the participants' personal history. Like the exploration of one's own attic, it uncovered bits and pieces of joy here and love there, portraits of human suffering, and layers of hope like old paint peeling off the walls, revealing yet another color. It begged the reexamination of the past, but began with the despair of an HIV diagnosis. As many participants have said, "I cannot recall a life before HIV; I don't remember what that was like."

Embedded in the phenomenological narratives was human hope--sometimes a slight shadow, sometimes a thump on the head--but it was there, existing and functioning within each person. To the finding that hope is lasting, not static like a dial tone, but dynamic, *Lawrence* added a caveat:

> *Hope grows. It's cut from the same cloth as love; it's more intense at the beginning, but it changes. If it stayed the same it would not be truly present. Like caring for a plant, it must be nurtured and fed. Sometimes it's hard work. But, faith and hope are virtues. Together, they sustain life. They help us to survive so that ultimately, we may be face-to-face with God, and, then we'll see love. Look at all the people in the world who endure so much--the Bosnians and others--who are hoping they can go home.*

This final chapter is divided in two sections. In the first section, I will discuss the findings and implications of the Hope Project vis-à-vis existing literature in social, developmental, and health psychology. In the second section, I will suggest a model for creating a context for hope in the care of HIV-affected individuals. It should be noted that it would be premature to broadly ascribe the findings of this study to all people living with HIV-related illnesses. Therefore, this discussion should be viewed from the lens of this research conducted in the specific, naturalistic context of those who have lived with the disease and told their stories.

Implications of the Study

Individual differences. An overarching discovery of this research was the extent of experiential difference among participants who shared similar views of hope. For example, cultural portraits emerged over time, distinguishing married and single gay men, married and single heterosexual men, and parenting or nonparenting men. Portraits of women also revealed differences in marital and parenting status, although issues of reproduction were more salient. How these individual differences affected experiences of hope over time is the focus of this comparison between the existing literature and the current findings.

Social support. One illustration of individual differences among the participants was the decision to disclose their illness to family and friends. In this study, the women and married nongay men initially reported more feelings of isolation and fewer opportunities to discuss their thoughts about the consequences of being HIV infected and having AIDS. As the study progressed, however, these circumstances improved for most

of the participants, particularly *Kate* and *Ben*, whose support networks improved after disclosure.

Regarding social support among gay men, most described meaningful (albeit sometimes small) support networks among friends and family. In fact, families were generally described as helpful and loving sources of support, although there were a few exceptions. This contrasts with reports in the literature in which peer support is preferred over family support, which is perceived as being unhelpful (Hays, Catania, McKusick, & Coates, 1990; Hays, Chauncey, & Tobey, 1990).

In a study of 91 HIV positive males recruited for an investigation of social support in relation to selected variables, Nott, Vedhara, and Power (1995) hypothesized that subjects would report greater levels of support from nonfamily members than from family members. In an effort to control the "social milieu" of the sample studied, they excluded any individuals whose exposure category (e.g., IV drug use), sexual preference (e.g., bisexuality), or gender (reports suggest that women progress at a faster disease rate than men) might influence the social and physical status of subjects. Furthermore, based on Reillo's (1990) report that death within 12 months of an AIDS diagnosis would be more likely to occur among people who have little or no support, only males whose *predicted* survival at the time of recruitment was at least 12 months were selected for the study (p. 973). The men meeting this criteria were gay, nonintravenous drug users whose mean age was 38 years. Results indicated that these men received the "most support from individuals outside of their immediate family" (p. 980). The authors suggest that families may be providing less positive and more negative aspects of support than nonfamily

members. In their study, Nott et al. (1995) identify family members as mother, father, closest sibling, and important relative.

These findings invite further questions about the definition and meaning of *family* for gay men. *Peter's* narrative provides a glimpse of how assumptions of what constitutes a family might affect research findings.

> *It's been very interesting for me because Sam's somewhat better now. It's receded a little, but for weeks I was living on the edge of hysteria all the time. It's a very interesting way to live, not terribly pleasant, but it does focus the mind quite well. And the times when you spill over into hysteria come at totally unpredictable times, like driving down the road, when you aren't even particularly thinking about it. So that's been qualitatively different than any of the other people I've cared for. I loved them, but I've shared a life with Sam.*
>
> *[and after Samuel died] As I said, in every relationship, particularly a long-term relationship, there's a me and there's a you and there's a we, and in this kind of situation both the you and the we dies and me is over here with tatters of memories, and that's all. The we is gone as well...When you compare death and divorce, in a divorce it's just the we that's destroyed, you, sometimes quite unfortunately, are still there (laughs). But the me and the you are still there; but in death both of those die. And I didn't really put that all together...that's why losing Samuel was so much different than anybody else. And the we was SO intimate that there's just a huge hole where most of my life was.*

The findings of this current study suggest that hope is intimately associated with relational belonging and connecting. For example, *Peter* and *Stuart* (among others) were married to their life partners 17 years and 11 years, respectively. They and their spouses perceived each other as family in the same way that a heterosexual couple would perceive each other as family. The exclusion of a life partner as family in a study of human social support negates important relational aspects of the support, since a spouse or life partner is not considered a "peer" by gay men.

The social support environment of the person who is ill has been extensively investigated, delineated, and debated (for a review, see Lynch, 1991). Studies of social support and hope among individuals with HIV-AIDS have included levels of depression using the Beck Hopelessness Scale (described previously in Chapter 1). For example, Zich and Temoshok (1987) found that individuals who perceive social support as being useful and available also reported feeling less hopeless. In a recent study, they compared perceived availability of social support with self-reported physical symptoms and found that patients who reported higher numbers of physical symptoms were less likely to perceive social support as being available to them (Zich & Temoshok, 1990).

Perceived adequacy of social support among people with HIV-related illness has been related to lower levels of depression (Hays, Turner, & Coates, 1992) and to active rather than avoidant coping methods (Namir, Wolcott, Fawzy, & Alumbaugh, 1990). In contrast, inadequate support networks have been significantly related to lower CD4 counts (Persson, Hanson, Ostergren, Moestrup, & Isacsson, 1991; as cited in Nott et al., 1995). Although measures of depression, coping methods, hopelessness, physical symptoms, and CD4 seem to be affected by the perceived adequacy or inadequacy of social support, it would be useful to explore the goodness-of-fit between *what* the person with HIV-AIDS considers adequate and helpful support and *what* he or she *receives*.

The quantitative data collected during the Hope Project was not the focus of this study and it was not subjected to statistical analyses. However, an unexpected finding was the fluctuation reported across time in physical symptoms, CD4 counts, and hope. These data highlighted the presence of individual differences and the "bouncing ball,"

perpetual motion characteristic of hope. In some instances, where patterns of physical symptoms and CD4 counts were established, follow-up reports indicated marked changes. For example, when *Julian* moved to a safer social environment and his nutritional status improved, he reported fewer physical symptoms and a substantial increase in his CD4 count.

During the study, new methods of measuring T-cells appeared in the literature that revealed disease progression better than the standard CD4 absolute count. Study participants who were well read were aware that CD4 *percentages* (representing the proportion of total CD4 and CD8 T lymphocytes) were more reliable than the CD4 counts. They also knew that exercise, stress, infection, loss of sleep, alcohol, and one's circadian rhythm can affect the CD4 count. Furthermore, each lab uses different procedures to conduct the test, which can result in fluctuations of the final count. Finally, variability of CD4 counts can be attributed to antiretroviral drug therapy, or even the lack of it.

The point to be emphasized here is that tracking the CD4 count as a reliable indicator of disease progression can be devastating for the novice patient. As *Garrett* reminded me, "As soon as you're diagnosed, an agency or someone will be sure you get one of those graphs that shows your lifeline dropping off the page." Also important is the recent laboratory test that measures the amount of the viral RNA in the blood. This has been a useful indicator of illness patterns during clinical drug trials. Drops in viral "load" indicate less virus in the blood. Again, however, excessive reliance by patients on this test is not considered prudent because it is, after all, subject to variations in lab

protocols. Its availability is also quite limited. Patients learn quickly that personal survival is not quantifiable. It is instead a matter of one's quality of life, individual differences, and keeping things in perspective.

A promising longitudinal study of psychosocial factors and immunological markers that includes descriptive data is in progress in Australia (Rayner-Brosnan, 1995). The purpose of the research is to investigate wellness and HIV and attempt to understand the development of hope as compared with hopelessness, the reaching for social support versus social isolation, and the relationship between depression and fatigue. By comparing qualitative interviews with standard questionnaires the researchers also hope to determine if low social support and a lack of hope are key risk factors during HIV illness that might influence illness outcomes.

While the relationship between psychosocial factors, immune function and disease progression has been an important focus of research (e.g., Jemmott & Locke, 1984; Kiecolt-Glaser & Glaser, 1987, 1992), there are still individuals whose immunologic and virologic characteristics place them in a "rapid progressors" category (Haynes, Pantaleo, Fauci, 1996). In these instances, the patient's hope, coping styles, and overall life experience should be addressed as well as immunological markers. People with AIDS who read about rapid progression and identify with this "category" should recognize that they have not "failed" to survive because they lacked courage or did not have "enough" hope.

Similarly, there may be occasions when a CD4 count implies an ominous loss of immune function. The person receiving this news may experience immense sadness or

feelings of guilt, as revealed in the statement by a participant, "I guess I had this coming. I should have taken better care of myself." Pennebaker, Kiecolt-Glaser, & Glaser (1988) reported immune function improvements among individuals whose disclosure of traumatic events provided the expression and release of emotions. Generalizing from this finding, patients who are feeling sadness or guilt as a result of a CD4 lab result might benefit from a discussion of the report's meaning for them and how they perceive its overall significance.

In those situations in which the patient has not consciously contemplated mortality, the first receipt of an unsatisfactory lab result may begin a learning process resulting in the tendency to anticipate all future tests with much anxiety, as shown in this excerpt from *Randy's* narrative, which also illustrates the value of social support:

> *Where I used to live on the West Coast, everyone cared. They have the best medical and support network there is anyplace I have ever been. I was very lucky to have one of the best caring doctors in the field and he was not a specialist. I went into a program...where the whole city had pulled together to fight this war against AIDS. I met nurses who knew more than the doctors do in the south now. And so the results were that I had a lot of hope. Everyone kept telling me as long as I had breath I had hope.*
>
> *Then all of a sudden I was called into the doctor's office and was told my T cells had dropped below 200. And that is the point* ***it hit me. I was infected with a deadly disease****. I broke down.*
>
> *When I was told that, my doctor--I will never forget him--he put his arms around me and told me not to give up. They were doing everything they could and they would never give in to this virus. So the support I received helped so much. I was told to hold my head up high because I had nothing to be ashamed of and I would be around for the cure. I felt and still feel that I was in the heaven for HIV and AIDS patients.*

Stigma and stereotypes. This discussion reviews the context in which the study participants began living with HIV-AIDS. The purpose of the review is to enhance our understanding of the social milieu that influenced their lives. During the first decade of AIDS, Kubler-Ross (1987) wrote:

> With such enormous prejudice against AIDS patients, and fear of them, people lose sight of the fact that most--if not almost all--die an early death at a time when their lives have just begun, when they are starting to make their contribution to society....If we are not careful the emergence of the AIDS epidemic will continue to polarize the population, [causing] a split between those who offer to help, and those who judge, label, and denigrate those affected. If we choose not to help persons with AIDS we will find ourselves with no hope for the future and no hope for mankind. (p. 318)

In his role as a self-identified AIDS activist, *Randy* frequently contributed opinions about health care and politics. In his view, historians writing about AIDS will find it peculiar that an illness became a politicized issue rather than a worldwide epidemic, and that "deviant" behavior, rather than a virus, was blamed for the epidemic.

> *Randy: This isn't about millions of sick people in the world. It's about blame and politicians sticking their heads in the sand. No one cares that millions of people are going to die, because this [AIDS] is a good way to get rid of gays, bisexuals, Blacks, prostitutes, drug addicts, and anyone else who doesn't fit the moral majority's ideal.*

An example of the politicization of AIDS appeared in a quote from Buchanan (1987):

> There is one, only one, cause of the AIDS crisis--the willful refusal of homosexuals to cease indulging in the immoral, unnatural, unsanitary, unhealthy, and suicidal practice of anal intercourse, which is the primary means by which the AIDS virus is being spread through the "gay" community, and thence, into the needles of IV drug abusers. (p. 23)

Social psychologists Herek and Glunt (1988) describe AIDS as a social stigma (Goffman, 1963) that leaves its shameful and discrediting mark on those who are affected. Stigmatization and the implication of shame is attributed to being a member of an *out*-group--those people who reside in a *sub*culture. This language alludes to a separate *AIDS culture* defined by high-risk, promiscuous behavior. Therefore, the AIDS-related stigma points directly to people in marginalized groups who live *below* the mainstream culture and engage in other than normal behavior (Herdt, 1992). These metaphors of AIDS (Sontag, 1988) bolster negative public opinion, bias, prejudice, and discrimination against HIV-affected individuals. To this, Herek and Glunt (1988) add that the behavior of those who are HIV infected has been shaped by the intensely negative reactions of a hostile society.

Negative beliefs and overgeneralizations about characteristics of HIV-related illness perpetuated stereotypes about those who were ill. In turn, a "mind set" evolved about how people should be separated into we-them categories. For example, White men diagnosed with AIDS were presumed to be gay. Blacks, Hispanics, and Asians were presumed to be IV drug abusers (Durham, 1987). *Victor* reported that being a Black, gay male was a double stigma, compounded by an assumption of drug abuse that was, of course, inaccurate. This *belief perseverance* phenomenon (Ross & Lepper, 1980) has continued in spite of discrediting evidence that AIDS is a nondiscriminating illness that can affect any human being.

For those who are ill, these stereotypical categories influence their roles in the workplace, at school, and at home. Given the importance of the physical-attractiveness

stereotype (that what is beautiful is good), it is not surprising to discover that hope is believing in the possibility for self-esteem and the desire for being normal. For those whose physical attractiveness has waned, there is still the hope that "people will remember me the way I was."

> *Victor: There's always something to remind me that that I'm not perfect. I'm not saying that I'm perfect, but that there is something* ***wrong****. You know, there was a long time before I could take medicine. I just couldn't because every time I popped a pill in my mouth it was like--there's something wrong with you, you're imperfect, you're going to die.*
>
> *But my biggest fear, seriously, is that...oh, I freak out, you know, when I get in the tub. I'm always looking to see if anything has changed. We're a vain species. Everybody likes to look good...but it really has been depressing because I was usually--or I thought--I was pretty handsome. And people used to come on to me and stuff. They don't do that anymore. In my prime I could turn the heads. You know, when I was 23, 24. But now, well, I don't want to be a runway model or Arnold Schwarzenegger. I just want to be normal.*

Ultimately, the weight of AIDS stigmatization is carried by those who are ill and by their families. As *Douglas* remarked, "What does a woman tell her daughter when the neighborhood children are not allowed to play with her because of the discovery that her mommy has AIDS?" Understanding the stigmatization of AIDS helps us to understand why *Russell* said his "whole family" had the virus and not just him. For families, the stigma is far-reaching; it gathers the entire family in its grasp. *Russell's* youngest son, for example, was suspended from school for fighting "a boy who called my daddy a fag with AIDS." Attributing the illness to his dad's character was more than he could bear. An underlying nagging fear of his mother and all the women in this study was the possibility

of harassment or harm coming to their children or family members as a consequence of the AIDS stigma.

It is ironic that some of the parents have attributed the cause of their children's death to cancer rather than to AIDS. As previously mentioned in Chapter One, cancer was once considered a "stigmatized" illness (Sontag, 1977). Unlike AIDS, cancer is now a socially "acceptable" illness that usually elicits concern, helpful behaviors, and empathy. Family members and friends of a person with cancer eagerly offer support, compassionate listening, and a shoulder to lean on. On the other hand, family and friends of a person with AIDS have described feelings of isolation, loneliness, and the weariness of maintaining secrecy about HIV-AIDS. Several mothers of study participants spoke of being unable to discuss "the illness" with coworkers, friends, or neighbors, due to the fear of rejection. Others' reactions to the participants' AIDS status have been startling and unpredictable. A member of the clergy suggested to one of the participants that he might be happier at another church. This occurred after his diagnosis of HIV-AIDS was revealed. Following the death of her son, one mother sought support from a group for bereaved parents. She expressed her disappointment that the group did not consider her son's death as "the same thing" because he died of AIDS.

In light of the stigma, the lasting quality of hope seems reasonable; for many individuals, hope is all that is left. From a different perspective, however, AIDS has also closed the ranks of those who are stigmatized. For instance, when they learned that *Webb* was alone in the hospital and his mother was caring for him as best she could, some of the men in the gay community inquired about establishing a caregivers schedule to relieve

Webb's mother. She expressed a deep appreciation and surprise at their offer, since her son was not gay and he was, after all, a total stranger to them. *Webb* was also surprised that strangers would offer to care for him, as ill as he was. That, by itself, seemed to offer hope. The point of emphasis is that AIDS is, and has always been, a medical crisis. Persistent stereotypes and stigma often camouflage this fact.

An explanation of this camouflage has been suggested by nurse researchers Meisenhelder and LaCharite (1989) who discuss a specific fear--the fear of contagion--defined as an anxious response to the perceived threat of catching a disease (p. 29). They contend that health care workers, in particular, experience an affective stress response as a result of the perceived threat of AIDS in the workplace. Due to the association of AIDS with death, sexuality, and punishment, health care workers have dealt with the stress by developing coping strategies manifested in avoidant behavior, extreme caution, and fearful verbal behaviors (p. 37). Excerpts of narratives illustrate the fear of contagion theory.

> *Allyn: A few years ago I was in the hospital and this nurse said I had to buy my own stethoscope for blood pressures because I guess they were afraid of getting AIDS through their's. I still have that around somewhere. She was the only who used it, I think. The nurses only came in the room to bring medicine and food. When they weren't in the room they kept the door shut. I would get up and open it, and they would shut it again. So I left it shut. The IV pole was electronic and would beep often. I would ring the nurses station and they would say we'll be in there in a minute. Thirty minutes would go by and no one would come and change the bags around, so I figured it out and changed them myself rather than listening to the beeping all night.*
>
> *One night a doctor came in to check my throat. He had on plastic goggles, plastic hat, plastic pants, shoe covers, top, mask, and latex gloves. He asked three questions and started taking off his protective gear, and said, "That was easy." Seems like a waste of plastic to me. I*

felt dirty and like I belonged in a leper camp. I really learned a lot about the medical profession...and it's really sad that human beings have to be so cold to other human beings.

Garrett: Sometimes I laugh at this; I mean, it's impossible not to. You just have to yield to the absurdity sometimes, just throw in the towel and say, fine, this is great. I've met people, like when I had to go for outpatient blood work. The first time you see them handling that sheet with the order form that says HIV positive in giant letters, and well, there was this girl, she was young, and by her haircut and her demeanor she was a medical technician who apparently had grown up in one of America's many trailer parks. I mean, dumb as a box of rocks. And she comes in to see me, looks at the work order and tries to be very cool about the fact that she steps back out of the room.

When she comes back she emerges in what appeared to be an Apollo space suit. I mean, she had on these booties. She had on double gloves. She had on the paper smock. She had on this full face mask. And I laughed so hard--at her--I didn't try to disguise it. I thought it was the funniest fucking thing I'd ever seen in my entire life....it was just absurd. If this woman could have put on a lead apron or a firefighter's suit, she would have done it. I realize there's a small risk; but, the next time, after the girl came in in the moon suit, this woman comes in and she's about 45 years old and she's wearing this polyester suit, a two-piece polyester kind of suit. And she's just got this long face and she's dour and kind of cranky and she's not very friendly. And she sets the tray down with a kind of a clunk and then she slaps my arm and sort of feels around. She's just, you know, bare arms and all, and she starts tying off my arm. And I said, I'm HIV positive, just so you know. I felt like I had to tell her that. She doesn't even break stride...she jabs the needle in, pulls the blood, does another sample, does another sample, pulls them out, sticks them in. She still hasn't made eye contact. As she's walking out she looks down at the list of stuff and says, Prozac blood level, thanks, and the door slams and that was it. This woman could not care less. I said, I'm HIV POSITIVE. Yeah, I knew it, jab. She didn't care. She knew, she was listening, and that was ***so reassuring****. She trusted her own skill in drawing blood, she was a seasoned pro that had done it before; and you know, a million more like her would be just fine.*

Most of the participants agreed that significant positive changes in attitudes and behaviors have occurred during the past few years. These examples are useful in their

depiction of the cumulative stresses endured by the patients *and* also the health care workers who struggled with their own fears. There are many horror stories to be told, but as one mother pointed out, now, at least, some people are not afraid. She explained that when her son was hospitalized, the nurse brought him a popsicle but she was afraid to go inside the room so she left it attached to the outside of his door, where it melted. These days, she marks signs of progress by the lack of melting popsicles on hospital doors.

On "becoming" old. AIDS has rearranged the customary assumptions about adulthood and aging and death and dying. Events and experiences usually attributed to people who are 60 years of age or older are now being experienced by younger, AIDS-affected individuals. Hope--in the shadows of becoming old--has not been addressed in the psychosocial literature on AIDS. For this reason, it seems appropriate to compare the study participants' "aging" experiences with the existing literature in developmental psychology and specifically with Erikson's psychosocial development. The main point of this discussion is, however, that previous theories or models of aging and dying are not *always* interchangeable with the lifeworlds of people who are living with AIDS and whose average age is 34.7 years.

Older people have identified numerous common fears related to aging and dying experiences. Reported by Rando (1984) and others, they include the fear of:

1. Loneliness (friends move away to nursing homes or die, leaving the older person behind without a support system),
2. Growing dependent on others for daily care (even the oldest person values a sense of independence),

3. Mourning loved ones (the longest survivors have more grieving experiences),
4. Sorrow and sadness (boredom, lack of involvement, and lack of external stimuli may elicit ruminations about past experiences, regrets, guilt, and losses),
5. Disability and immobility (being unable to engage in life or being confined to one space),
6. Pain (uncontrolled pain, relentless, debilitating),
7. Loss of identity (who the person was before is lost),
8. Loss of lucidity and regression (inability to articulate thoughts and feelings, diminished memory, and returning to a childlike state), and,
9. Living longer (having a longer life is not acceptable if the person is unable to participate in it).

By comparison are the experiences of the participants in the current study. Although individual differences shaped their experiences, generally, their awareness of hope corresponded with the following fears of becoming old:

Isolation, loneliness, rejection, abandonment. The person with AIDS may outlive his or her peers, and in some cases (i.e., hemophilia) family members (Goldman, Miller, & Lee, 1993). Friends may move away, move to nursing homes, or family members may be estranged.

> *Nick: The scariest thing is the rejection. I don't want to be abandoned. Another scary thing about this is that--and I think this is like what old people go through too--is that you lose peers. They lose people that they've grown up with and they've known or people they thought would be there. It's like before I left here a few years ago, I was attending a HIV support group. When I came back, they were all dead. None of them had*

> ***made it***. *That's a very sobering and scary thought. And you see, when I found that out and then my family rejected me, well, I don't want to sound like I'm whining, but it really* ***zapped*** *my hope. And when you lose people you know, it's really,* ***really*** *scary to think that life can be just snuffed out like that. And that's why I said I think that's what old people might get depressed about, because people are dying all around you.*

Growing dependent on others for daily care. For many people with AIDS, this fear is a reality rather than a possibility. Several participants have been cared for by their parent or parents whose responsibilities also included other children or an elderly parent. Mothers have provided most bedside care. Fathers have provided other necessary support, such as transportation, shopping, and physical assistance (help to the bathroom, pushing the wheelchair). Financial dependency has been at the heart of many setbacks and hours of frustration, intimidation, and irritation, as elucidated in these excerpts:

> *Ted: I have exhausted all my savings. That hurts more than the virus itself because I have to depend on somebody.*

> *Stuart: He's so willing to do things...and I feel bad sometimes, he's putting up with so much. Sometimes he has to wheel me around, and other times he's constantly asking if I'm all right. You know, I go to the bathroom. "You all right?" (laughs) And my throat goes into spasms constantly, "You're not going to throw up, are you?" And there's just days that things go haywire. And he has to fix my dinner and everything. I can't cook for him after he's been at work all day. He comes home to the caretaker role.*

Mourning loved ones. Kastenbaum (1981) proposed the term "bereavement overload" to describe the cumulative effects of coping with loss of family, friends, and other elderly acquaintances with whom an older person has had a relationship. In the AIDS community, there is evidence of a *traumatic stress response* resulting from the

unrelenting deaths of people who are loved. The degree of stress depends on the meaning of death for the person who is suffering the loss.

> *Peter: What I've seen happen is that you'll have a group of people at about the same stage and they all die at the same time within months of each other. When one goes, the next one goes. It's just like knocking the props out from under people. But as long as they're all together emotionally, they do reasonably well. I am the sole exception. I've survived four or five groups.*

> *Nick: My real family is not very supportive. So I had to find another family, a friend, group of friends, and people in the community that understand the disease. And it's like any other family, you have people that are born into your family--well, the people in the HIV population become positive-so they are sort of born into the family. Then you have people that die in the family...so it's like a life process. Its a family of people like any other family where people are born and they die.*

An aspect of mourning the loss of a loved one that frequently applies to people affected by AIDS is the notion of "disenfranchised grief" (Doka, 1989). Disenfranchised grief can occur when a death is not openly acknowledged, socially sanctioned, or publicly shared. *Peter* summed up the experience.

> *They never even mentioned his name at the funeral. Never said that he had died. He had Generic Funeral 101. The family was isolated from everybody until the service and then they went out a side door and you never got to greet them. The person sitting in front of me stood up when it was over and said, "That's the stupidest memorial service I ever went to!*

Sorrow and sadness. In addition to feeling the sorrow of anticipated separations, people living with AIDS experience intense sadness about their unlived lives. Whereas the elderly may have sorrowful experiences about circumstances in which they participated, people with AIDS can only imagine what it *might* have been like to be a

parent, to have a career, to give birth, to own a home, and so forth. Also important is the sadness surrounding an incomplete life in which the *self* has not been fully developed. Participants in this study expressed deep sorrow about the possibility of dying before their parents die and before their own children had grown. Depending on the communication styles of the family members, there may be sadness about "things left unsaid," that the ill person knows will probably never be said. Finally, participants described a sadness and grief over the loss of their libido, their youth, and their physical appearance.

Whereas a person who is 70 years old has had a gradual experience of physical aging, people with AIDS "watch themselves deteriorate" in a brief period of time. This fear permeated the narratives, as evidenced in statements such as "I hope I don't age like that." Sarah, for example, observed the physical decline of a male patient whose visits to the doctor's office typically coincided with hers. Toward the end of his life, she was so distraught about his appearance that she asked the doctor what *she* could do to help. In tears about his obvious suffering, she confessed to being terrified that she "would end up like that too." Similar to the oldest population, AIDS patients sometimes experience the discoloration of their hair, or they lose it. With the loss of their immune system, they are plagued by constant skin problems, allergies, and infections. Losing weight and muscle tone enhances the perception of their fragility and vulnerability, and indeed, they become so. As Elliott said, "You don't want to be in the wrong part of town."

Disability and immobility. "I hope I never get to the point where I can't get around by myself." This fear, like the fear experienced by older people is grounded in the

possibility of feeling trapped by restrictions, boundaries, and by one's own body. On the other hand, while there is an expectation that this could occur for the very old person, younger people have no experience with this eventuality. A previously healthy, mobile person might have to sell a home and move elsewhere to accommodate physical handicaps, or leave a home to move in with parents or friends. With neurological impairments come further restrictions. *Alec,* for example, was devastated when he could no longer drive a car. The necessity for equipment highlights the reality of AIDS. Wheelchairs, walkers, canes, urinals, potty chairs, hospital beds, diapers, catheters, suction machines, basins, IV materials, gloves, and a plethora of prescription bottles are the "stuff" of AIDS. Underlying all of this, however, is the sense of *embarrassment* described by the participants who have lived these experiences. The comment made by *Lawrence* is an example: "You just never know who might be cleaning your butt." *Stuart* talked about his embarrassment at having to be pushed around a zoo in a wheelchair because he could no longer tolerate walking.

> *What made it really bad was that we had a flat tire out in the middle of gorilla land or something like that, and Chris had to push me and the flat tire all the way back! Oh well, you know what they say about* ***stuff*** *happening.*

Pain. As mentioned previously, pain and fatigue ranked highest in frequency and severity among the participants descriptions. Compounding the physical suffering is the "ferris wheel" of multisystem failures. If one is fortunate to access medical treatment of one problem, another problem will occur on the heels of the first. While the very old person may endure one or more chronic illnesses, the person with AIDS endures both

chronic and acute illness with startling regularity. As one participant said, "You don't want to get *too* excited about anything in the future because you may not get to do it." Pain management is a serious problem. Unlike older patients who may require mild pain medication for long periods of time, younger patients living with AIDS may require very strong medications intermittently over a long period of time. The fears they expressed were that the physician would not medicate their pain when needed, or that the pain medication would not "work" when they needed it the most, and that they would have to sacrifice their consciousness to the pain medicine. As *Allyn* said, "What kind of life can you have if you're zonked out all the time?" *Peter* resents the newest notion that AIDS is "a manageable disease."

> *AIDS is NOT a manageable disease. Everybody who gets sick dies. The people who survive are statistically insignificant, 5 to 8 percent of the total can be classified long-term survivors--more than 6 years after an AIDS diagnosis. I resent those who tell the public that, because people who are not involved with AIDS don't know. Anyway, I don't think it's so grand--the idea of it being as manageable as diabetes. Oh great, we'll go blind, have our legs cut off, and die when we're 50; that sounds like a splendid choice. I would like a little more than that. And kidney failure, let's not forget kidney failure, and all those wonderful things that come with diabetes. That's a grand prospect.*

The fear of pain was always countered by the hope for comfort, like a see-saw always present in their lives, regardless of the status of their illnesses.

Loss of identity. Similar to older people whose identity may be threatened by illness or forced retirement, younger people with AIDS also endure the loss of identity, as *Mark's* narrative reveals:

> *I was getting exhausted, but I worked till the end. And like I said, everything was taken, I was having my health taken, my energy-which I*

> *always define myself by--I had my friends taken from me, my job taken, and my sense of identity. I had my independence taken, and my autonomy taken from me.*

The participants' social identity has also been affected, particularly by the uncommon experience of being on Medicare at a very young age. As someone remarked, "You have not lived until you have the chance to be on welfare and get sucked up in the system. Then you really find out what it feels like to be a second-class citizen. It does wonders for your self-esteem."

Loss of lucidity. During a conversation with *Kate*, she expressed her sense of frustration that her mind "doesn't work like it used to."

> *I have to focus really hard in order to have this conversation with you. I have to pay super close attention to everything, anymore. It's very hard to remember things, especially when I go to the doctor. I need to make lists of everything nowadays.*

Phillip addresses the importance of his intellect:

> *The one eventuality that I just cannot accept, that I have a blatant, uncomfortable fear of, fear that cannot be dissuaded, is dementia, is truly losing my mind. I feel that there's remotely the possibility that the first phases might have begun, and that just scares me horribly, scares the hell out of me sometimes....*
>
> *I just hope that I don't, I just pray, oh God, do I pray that I don't become--because as much of a fear as this is to me, I could just completely go whacko. It's a manifestation of one of your darkest fears and then people that you love telling you you're out of your mind, is one of the most horrific things I could ever conceive of. And I don't purport to be a great intellect, but what I do have, what I've had in my life, I have a great deal of identity based around that.*
>
> *And it just terrifies me, what some people have had to go through because their minds went away before they had come to terms with everything else, before they had been able to develop what they wanted and needed in their*

life, their relationship with their family--to come to terms with all those issues.

Living longer. While we might expect to hear an 80-year-old person say that she is afraid of living longer, it is unusual to hear this from a 26-year-old person. The fear of living longer was never a concern for the participants *unless* there was the threat of HIV-related dementia. This neuropsychological disorder affects a substantial number of patients. HIV-AIDS dementia involves small lesions beneath the cerebral cortex (Buckingham & Van Gorp, 1994). Subcortical dementia involves an inability "to think straight," confusion, psychomotor slowing, and being unable to follow conversations or recall them. Unlike depression, HIV-related dementia is not a response to AIDS and does not yield suicidal thoughts or extreme sadness. The patients still have hope, they simply have no energy to do anything, although language and decision-making skills are present (Stern, 1994, p. 31). Participants (like Phillip) who have witnessed firsthand the apathy and slowing associated with dementia have expressed a fear of living longer if it means they will "lose their minds."

As participants talked about feeling old or becoming old, their stories uncovered the differences between truly old individuals who experience aging and dying, and young individuals who are aging and dying with AIDS. They, like their elder counterparts, endure loneliness, isolation, abandonment, and they become dependent on others for their care. People who survive with AIDS also mourn the loss of those they love. There is a perpetual grieving among long-term survivors of AIDS. And while they have pain and disability and loss of identity, it is the sadness and sorrow that distinguishes them from

the older group. For some, it is manifested in a *quietness* in their demeanor. For others, it is seen in their attempt to, as Nick said, "Take a crash course in life." But underneath it all, there is the realization that these young people are doing at the age of 30 what generally is expected after the age of 65.

> *Erik: I'm sure it must be more difficult for younger people--before they can deal with things, before they have been able to realize anything, any of their dreams and goals in life--and that's probably why they couldn't understand where I was coming from, and you wouldn't expect them to. And I'm not even sure, but maybe you have to be over 50 before you can even begin to understand; because they had their lives ahead of them, they thought. And I think that's much more devastating to get cut down before you can realize--I think it really takes a whole different mind set to come to grips with it at that age, when you've not even had a chance.*

Erik's words point to the human development of hope, its practice, and its lasting innate quality. But they also relate to fear, and to that which is feared. Looking back at the list of common *fears* shared by the older population, we can see that their list relates similar fears experienced by participants living with HIV-AIDS who described their hopes and fears. Ultimately, perhaps *Mark's* view that hope and fear are the same thing strikes an intuitive cord:

> *I believe that hope and fear are two points on the same line. When seen on the same line, hope is just a way of living this moment, just hoping this will be better or that will be better, rather than focusing on one specific thing. A lot of people don't realize it's okay if I live or die. If I have the preference, I would like to stay for the summer, though....but, don't pray for me to be well. It's weird because you feel like you'll know when it's time, because you have let go of all the fear and of all the attachment. The rest is just a reminder of just how beautiful things are here. The sweet lovingness of friends...but then also, you sometimes have to* ***use hope*** *to handle it, to get back in the present...Throughout life you wonder about the true meaning of life. Then, one day, you finally say--****That's*** *what they were talking about.*

Erikson's psychosocial development. Erikson developed a life-span emphasis on the relationship between the developing individual and the social environment. The next discussion is guided by Erikson's (1982) description of the stages (or ages) of human development that unfold throughout the life cycle.

Hope is the fundamental strength of Erikson's "developmental ladder" which corresponds to eight stages of the life span from birth to death. (Wisdom is the final strength.) Erikson reminds us that each stage is grounded in all the previous stages. As each is experienced, the psychosocial crisis and developmental maturation of one strength "gives new connotations to all the lower and already developed stages as well as to the higher and still developing ones" (p. 59).

Continued development leads to links with further strengths (e.g., will, purpose, competence, and love). However, Erikson makes it clear that during illness or stressful times a "semideliberate regression to the earliest developmental stage" may be needed to regain some early hope "from which to leap forward again."

The strength of adulthood is *generativity* which is juxtaposed with the crisis of *stagnation*. While generativity encompasses productivity, creativity, and the origination of new ideas, stagnation depicts inactivity and frustration. The strength emerging from this crisis is "a widening commitment" to take care of everything "one has learned to care for." All the strengths from earlier development now prove to be essential for the generational task of cultivating strength in the next generation (p. 67).

Erikson suggests that human development culminates in old age with the experience of *integrity* versus *despair*. Emerging from this maturational stage is the

specific strength of wisdom. During this stage there is a "sense of coherence and wholeness...an integration and binding together the ways of human life that have come to fruition from earlier stages" (p. 65). The crisis of old age is despair. In Erikson's view, the discontinuity of family life and a lack of vital involvement contribute to the continuation of stagnation from stage seven, which ultimately leads to despair. The hidden theme in this stage is nostalgia, and indeed, Erikson reports that patients seem to be mourning (among other things) "identity potentials bypassed, time forfeited, space depleted, intimacy missed, and generativity neglected" (p. 63).

Finally, when considering Erikson's opinion of the life span, we can see that the developmental ladder bridges the strengths of *hope* at birth with the crisis of *despair* in the final stage of life. There is an implication that to be human means to begin with the *possibility of hope.* Erikson's words capture the essence of this connection: "If, then, at the end, the life cycle turns back on the beginnings, there has remained something in the anatomy even of mature hope" (p. 62).

It should not be overlooked, however, that the entire later adulthood stage of the developmental ladder (generativity versus stagnation) seems to be missing for most of the participants with AIDS; even for those whose lives were changed early in their third decade. For example, Douglas felt that the inability to set life goals, even short-term goals, was distressing.

> *I wish I had never been tested for HIV. No real productiveness has occurred. I changed my entire life focus when I learned I was HIV positive. The focus has been on the dying process ever since.*

It appears that for many individuals with AIDS, two or more decades are excluded from their lives; that is, they spend their lives in the final state of integrity versus despair. For those individuals whose life experiences were few or limited, an integration, understanding, or "binding together" of all that had come before during earlier developmental stages was not a finding of the study. More typical, however, were context-specific descriptions about "awakenings" that occurred during the illness.

Overall, the findings of the Hope Project suggest that Erikson's stage theory of psychosocial development is partially generalizable to people affected by HIV-AIDS. The existence of hope and despair along the same life span continuum is consistent with the course of an HIV-AIDS illness. As patients encounter despair they return again and again to the "earliest developmental stage" for the replenishment and practice of hope. This process suggests a self-sustaining quality of hope that supports patients through times of despair. As *Victor* noted, his life is like a ferris wheel where his hope and AIDS coexist. Although they change with time and circumstances, he knows they are always there. This does not mean that the participants in this study were *always* hopeful; they discussed their moments of despair and used phrases such as "He took my hope away," "I lost all hope," and "It seemed there was no hope left." Remarkably, however, the darkest moments were not everlasting.

Erikson's notion of the psychological development of hope is supported by Snyder (1994) who contends that childhood shapes the level of hope we have as adults. As I mentioned previously, Snyder opposes the view of hope as "some nebulous, immeasurable philosophical notion," and favors instead the use of discernible mental

markers of hope: goals, waypower, and willpower. The value of Snyder's work is that he advocates becoming aware of personal hope, fostering hope in children, and envisioning goals and their pursuit. Based on his Hope Scale, Snyder defines high-hope people as typically (a) setting difficult goals for themselves, (b) using their goals as mental touchstones for success, (c) believing that they will achieve their goals, and (d) viewing goals as welcome challenges that are a normal part of life. He summarizes high-hope people this way: "In short, high-hope people are bullish investors in life goals, and they expect to obtain excellent returns on their mental investments" (p. 53).

Snyder makes the distinction between his Hope Scale and the Hopelessness Scale (Beck et al., 1974): While the Beck scale emphasizes the emotional state of the respondent (e.g., loss of motivation) and psychopathological conditions, the Hope Scale emphasizes positive cognitive constructs derived from health psychology. According to Snyder (1991), these important distinctions have significant implications for how hope is conceptualized (p. 294). In his view, hopefulness should not be conceptualized as the absence of depression or negative affect. Furthermore, scales that measure depression and hopelessness "may have a restricted or different range of measurement because of their emphasis on negative or pathological conditions" (p. 294). Snyder's argument speaks to the importance of how the differences in scale development can ultimately affect the measurement and findings of a study.

This relates to the current study's focus, which was to discover the nature of hope in a unique group of people who have been told they have an incurable illness. The purpose was not to measure depression or hopelessness or to measure goal-directed

behavior. The purpose was to ask the participants to describe their experience of hope. For this reason, questions having a predetermined conceptualization were avoided in order to permit the natural uncovering of personal meanings of hope. In sum, the goal of the Hope Project was not to establish high or low *levels* of hope in people with HIV-AIDS, but to establish what hope *means* to them. It should also be noted that the Hope Scale (and other scales) are linked with the concept of expectancy and expectancy outcomes. Findings from the current study indicate that expectancy is not as important to the participants as is the importance of surviving (living) from one day to the next with hope for meaningful relationships, comfort, and peace. Agich (1995) clarifies this point:

> Hope is a virtue defining one's bearing toward the future. To hope is not to expect, much less demand, a "good" or acceptable outcome, but to experience forthrightly and with fortitude whatever comes one's way. A person without hope is literally a non-person, since hope is required for a person to face autonomously even the most dire future....With hope the individual is attached to and nurtured by others, whereas in despair, one is alone and abandoned. (p. 143)

Summary

Creating a Context for Hope

Caring for HIV-affected individuals. As he struck a match to light a memorial candle at the "Hope for the Holidays" Christmas celebration, a study participant whispered, "I hope somebody remembers me next year." As *Peter* suggested, the *real* story of the AIDS epidemic has been the response of the gay community to it:

> *The parents of the first patient I ever took care of told me they were just overwhelmed by the love and caring shown to their son and that they had never seen such love outside the gay community. And so, to me that's the real unique thing, because a disease is a disease. Any disease is a personal tragedy and AIDS is certainly a personal tragedy. But the gay community perceived it as a corporate tragedy, a holocaust of the*

> *community, for obvious reasons. But you don't have to respond that way. People get sick and die all the time. So many times, we see somebody die and it wasn't of AIDS--well, people do die of other things--we're just not used to it (laughs). But it's that focus that is so fascinating and the political organizing that's gone on. A lot of the things have changed because of AIDS in this country; the way drugs are approved and so forth. So that's the story, how these people who are--this despised minority--how they have responded. I mean, we're saints. You don't see other people out there running around taking care of sick people and providing everything for them. And that, to me, is a wonderful page of history that's been written, and I hope people pay attention.*

As teachers, the participants in the study have offered more than the sharing of their stories and perceptions of hope. They have also been role models. What has ultimately emerged from this current exploration of hope is their gift of *caring* for human beings who are ill. As role models, they are a source of hope.

A hope model. All providers of care can be powerful sources of hope. Both as individuals and as a team, their objective is the promotion of well-being; that is, to help the person be well, healthy, and happy while living with an illness. Although paradoxical, this was an important notion underlying thematic descriptions of hope. When hope strengthened *Ben's* self-esteem, for example, happiness was the result. When hope evoked a good deed, someone was happier. Whether they are family members, friends, or health care professionals, providers of care have a powerful influence on the person who is ill, as these excerpts reveal:

> *He [Dr. Rose] was the first doctor in town to teach people about HIV. The first time I saw him was when I was in the hospital. They called him because they didn't have any idea what was wrong with me. And I remember to this day him coming into the room. It was like he was spreading light all around the room. He had two little interns in tow with him. But I have never been examined so gently or treated so well and, you know, I grew up with a lot of doctors. I know good technique. And I was*

> *so impressed that when I got out of the hospital, his was the first bill I paid. I sent him a little note about how much I appreciated his kindness. He's a healer. He's not just a doctor. He is a physician in the old sense of that term.*

Another participant's experience reiterates the influential nature of health care professionals:

> *They called in a consultant, that horrible doctor, "Dr. No Hope." And he usually had working with him, "Nurse Death." He had nothing good to say, which he should have said to my doctor, instead of making this big announcement--that my doctor eventually said wasn't true to begin with. And so when my doctor came in, I started crying in front of him. I said that I wouldn't go home like that, and that I'd rather die on the operating room table. He held my hand and squeezed it. He listened.*

Participants described the importance of avoiding stressful situations, but in some instances stress was simply part of the lived experience. Providers of care have multiple opportunities to dilute the severity of stressful events by fostering a climate based on optimal physical, mental, and social well-being. As participants have repeatedly noted, we are, after all, more than just our bodies. Obayuwana's (1980) studies of hope make this point clear. He calls for a special method of "anticipatory health care" which attends to the patient's hope, stress, and other existential aspects of living with an illness. Termed "hope therapy," this intervention has the goal of preventing crises before they occur. Providers of care are in the position to acknowledge patients' quality of life issues and the manner in which they influence overall health and well-being.

Findings of the Hope Project indicate that moments of despair are frequently linked with daily stress, frustration, and the inability to obtain the medical care needed to survive. Cousins (1979, 1989) has reported similar findings; that is, it is not a patient's

lack of hope that induces despair but rather a lack of feeling connected, having physical comfort, and psychological peace. These important qualities form the nucleus of the participants' narratives. From their suggestions, specific components of living with HIV-AIDS have been identified as essential issues in a hope model of caring for patients. The next and final section addresses these components.

The notion of a "hopeful death" emerged from this study as an outcome of hope as the belief in possibilities. For example, during his life-threatening illness, *Lawrence* experienced awakenings, enhanced sensitivity, humor and love, good deeds, and the possibility of survival. His determination was strengthened by his hope.

The concept of a hopeful death for people living with AIDS is not a denial of the stark realities of the so-called terminal aspect of the illness. A hopeful death involves possibilities for comfort and peace through caring attention to one's entire being: the body, mind, spirit, and the critical presence of others. Montigny (1993) notes that the role of the psychologist in the palliative care of people living with life-threatening illnesses is to respect their individual beliefs, differences in personalities, and coping styles. In his view, it is not the place of the psychologist to deny a patient's hope but rather to

> recognize the wish of the patient to survive beyond the time of anticipated death and listen to the patient's desire to overcome death through fantasies of biological immortality. The survival instinct demands protection to the end. The wish to survive and the survival of the wish must be recognized and sustained by the psychologist....Hope is still the only shield of protection against the intolerable fear that one will be unable to bear the mounting physical and psychological assaults until the very end. (pp. 6, 8)

In conclusion, the presence of others is vital in a hope model. Even the most hopeful patient needs assistance from other humans to have comfort and peace and to do good deeds. Connecting with others, whether intimately or casually, helps people living with HIV-AIDS to have hope for being normal--in spite of a purple nose. Relationships enhance self-esteem and reduce isolation. As described in the narratives, it may be a simple touch on the arm or the confident presence of a physician that softens stressful moments.

In contrast, however, a significant finding of this study emerged from participants' descriptions of feeling "like a leper," "dirty," and not worthy of care and treatment. Sarah, for example, described a health care worker who told her that her physician probably would not waste a new drug on her, since she was in the late stages of AIDS.

Constance (and others who care for people with AIDS) reported being fearful that any complaint about the ill person's care in the hospital or nursing home would result in *less* care for the patient. Several participants talked about "not getting the reputation of being a troublemaker because then you won't get help when you *really* need it."

Real or imagined, this fear exists and affects one's well-being. *Randy* advised everyone to learn how to "read" other people. He said:

> *No matter how sick you are, you still have to take the responsibility for teaching everyone else about this epidemic. In order to survive a hospitalization, you have to assess the staff and their attitudes about AIDS. You have to find out how smart they are. I had a nurse once who told me she knew nothing about AIDS. I told her what I knew. She wanted to learn. What's scary is those who don't know and don't want to know.*

Finally, how others affect the experiences of people living with HIV-AIDS is poignantly illustrated in the need for empathetic listening: being truly attentive to the patient's experience and needs (and putting aside one's own needs). A definitive outcome of the participants' stories is their concern that other people do not listen or they trivialize the patient's lived experiences.

A participant's question, "Why doesn't anyone listen to what *I* am saying and feeling?" is the theme of Gillian's poem in memory of *Randy*, titled "I know:"

Spare me the cruelty
of having to endure
the "I know's"
for to know
is to bear witness
and to bear witness
is to share
and to understand.
And to share and understand
is to dwell
here
in this house of pain
a house where you will know
your host
well
and be able to stand
toe-to-toe
face-to-face
look him in the eyes
and still stand your ground.
To *know*
is to recognize your host
by sight
and smell
and feel
and to recognize also
his most tender touch,
almost gentle
almost apologetic
and to know
in your heart
what lies beyond.
Please spare me
the "I know's"
and do not deny me
the quiet dignity of my suffering.

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APPENDICES

APPENDIX A

LETTER OF INTRODUCTION AND DESCRIPTION OF STUDY

THE HOPE PROJECT

Dear Friend,

This information sheet is to let you know about a study concerning "Hope" and how it affects women and men who are experiencing HIV or AIDS. Even though the word hope is used frequently to describe many different situations, we actually know very little about what it means for people who have HIV-related illness to speak of hope. We also do not understand how hope may influence the wellness, quality of life, relationships, or long-term survivorship of individuals having AIDS.

This study is an invitation to those directly experiencing HIV or AIDS to describe beliefs, feelings, and perceptions of hope. If you, or perhaps someone you know, would like to take part in this research, I will be pleased to hear from you, and answer any questions as well. Those who decide to participate will be interviewed twice over the next six months, at a time and place of their choosing. Interviews are simple, without a lot of questions, and take about one hour. We will complete a Symptom Checklist as well.

Since this study has been approved by the University of Tennessee's Committee on Research Participation, there are certain guidelines we follow. For example, if you would prefer your identity to remain confidential, you may wish to choose any anonymous name you'd like to have used on the typed transcripts. This name would be used on any future published reports of research findings, or a different name can be chosen. We also keep tape recordings in a locked file cabinet, although they are destroyed after the transcription is completed. Because this study is voluntary, you are free to withdraw at any time if you decide to do so.

Finally, I would like you to know that a very important goal of this study is to offer the opportunity for individuals to discuss, in their own words, in their own voices, the personal accounts of an experience known only to them. Being free to talk about as little or as much as they choose often leads to valuable insights about hope, and some research participants find this to be a worthwhile consequence of the interviews. For more information about this study, please contact me at _____. I hope to be able to meet with you.

Warmest regards,

Jeannie Gillian, Ph.D. (Candidate),
Department of Psychology

A1. Letter of Introduction and Description of Study

APPENDIX B

STATEMENT OF INFORMED CONSENT

HIV AND AIDS: The Hope Project

STATEMENT OF INFORMED CONSENT

This research involves the study of the experience of hope among people with HIV-related illness. Its purpose is to help us understand the meanings of hope and how it impacts lives. Your role in the Hope Project will be to describe your personal awareness of Hope during two interviews conducted over a six-month period. Our conversation will be audiotaped in order to preserve your original remarks, rather than attempting to take notes. Each interview will take approximately one hour and a "Symptom Checklist" will be administered on each occasion. You will select the time and place of the interviews.

In order to minimize any potential risk for you during this study, your identity as a participant will be kept confidential, according to the guidelines required by the American Psychological Association. Therefore, you will be asked to generate a number and fictitious name for the audio recordings and resulting typed transcripts. Any possible identifying items will be disguised or deleted during the transcription of the tapes. All material will be held in the strictest confidence and will remain in a locked file in the office indicated below, where only I (the principal researcher), will have access to your record. The tape recordings will be destroyed after they are transcribed, and any future reports of research findings will only utilize the fictitious names.

Although this study may offer few direct benefits to you, many people find that exploring their experiences with another person can be satisfying and beneficial. If you have questions now, or at any time during this project, please contact me at _____. Of course, your participation in this study is voluntary and you are free to discontinue or withdraw from the study at any time without questions or penalty. You will be given a copy of this form to keep.

Thank you for your interest and participation in this research.

****

I have read and understood the explanation of the study, my role in it, and the risks of participation. I agree to participate with the knowledge that I may withdraw at any time.

_____ _____

Name Telephone

ID# ___ ___ ___ ___ ___ ___

_____ _____

Signature Date

B1. Statement of Informed Consent

APPENDIX C
PHYSICAL SYMPTOMS CHECKLIST

Thanks for your help!

HIV-AIDS: THE HOPE PROJECT

ID_____

DATE_____ **SYMPTOM CHECKLIST** AGE___ SEX___

Please check any of the following symptoms that you have experienced during the past six months:

01 ___ Abdominal pain
02 ___ Anemia
03 ___ Cough (dry or productive)
04 ___ Depression/Anxiety
05 ___ Diarrhea (more than one week)
06 ___ Esophagitis/Problems swallowing
07 ___ Fatigue/extreme tiredness
08 ___ Fever (unexplained or persistent)
09 ___ Functional limitations (in abilities)
10 ___ Headaches (persistent)
11 ___ Hepatitis or liver disease
12 ___ Herpes infection
13 ___ Infections - other:
- a ___ Cytomegalovirus (CMV)
- b ___ *Mycobacterium avium* complex (MAC)
- c ___ Pneumocystis carinii pneumonia (PCP)
- d ___ Toxoplasmosis
- e ___ Histoplasmosis
- f ___ Tuberculosis
- g___ Meningitis/Encephalitis
- h ___ (other)_____

14 ___ Kaposi's Sarcoma (skin lesions)
15 ___ Loss of appetite
16 ___ Loss of concentration, slowness of thought/memory problems
17 ___ Nausea (frequent)
18 ___ Neuropathy (nerve pains, numbness, tingling, burning)
19 ___ Pneumonia (not PCP)
20 ___ Shingles
21 ___ Skin conditions/infections
22 ___ Sleep disturbances/nightmares
23 ___ Sore throat (persistent)
24 ___ Sweats (night/other)
25 ___ Swollen lymph glands
26 ___ Thrush/oral lesions/infections
27 ___ Vision disturbances or loss
28 ___ Vomiting (frequent)
29 ___ Weight Loss ___ weight gain
___ normal weight
___ your weight now
30 ___ Other Symptoms? _____

SYMPTOM CHECKLIST
(continued)

CD 4, T-Helper count, if known:

Length of time since your diagnosis of HIV, if known:

Have you taken any antiretroviral drugs (such as A2T, ddI, ddC, d4T-Zerit, 3TC)? Please list:

What other medications do you take? Please list:

Do you experience any symptoms that you think are related to your medications? Please describe:

Do you have limitations in your daily activities? Please describe:

What type of occupation do you have now, or had previously?

Please list any other medical conditions (diabetes, heart disease, breathing problems, pregnancy, "stomach" problems, kidney disease, cancer, asthma, allergies):

VITA

Jeannie Gillian was born in Los Angeles, California, where she was educated and began a career in nursing. After moving to Georgia, she worked as a Radiology Clinical Coordinator prior to reentering school. She received an Associate of Arts in Psychology in 1987 from Dalton college. In 1987 she continued her educational pursuits at the University of Tennessee, Chattanooga where she received a Bachelor of Science in Applied Experimental Psychology. In 1990, she entered the University of Tennessee, Knoxville where she taught courses in psychology while pursuing the Doctorate of Psychology. The doctoral degree was received in August 1996.

She is presently a medical psychologist working as the Director of the Hope Center affiliated with Fort Sander's Regional Medical Center. The Hope Center provides support and referrals for HIV/AIDS-affected individuals and their families.