To the Graduate Council:

I am submitting herewith a dissertation written by William Chamberlain Hale II entitled A Phenomenological Investigation of Personal Relationships with Persons with 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 Education.

Mark A. Hector
Mark A. Hector, Ph.D., Major Professor

We have read this dissertation
and recommend its acceptance:

Lawrence M. DeRidder

Accepted for the Council:

CW Minkel
Associate Vice Chancellor
and Dean of the Graduate School

A PHENOMENOLOGICAL INVESTIGATION OF PERSONAL RELATIONSHIPS WITH PERSONS WITH AIDS

A Dissertation

Presented for the

Doctor of Philosophy

Degree

The University of Tennessee, Knoxville

William Chamberlain Hale II

August, 1992

DEDICATION

This dissertation is dedicated to
two very special persons who
departed this life far too soon.

Fred Horowitz

and

Denny Johnston

They were deeply loved and are sorely missed.

ACKNOWLEDGEMENTS

I want to express my appreciation to my major professor, Dr. Mark Hector, for his guidance and support throughout this project. I also want to thank the other members of my committee, Dr. Gary Klukken, Dr. Larry DeRidder, Dr. Howard Pollio and Dr. Ron Hopson, for their support over the past three years. I want to thank the members of my data analysis team, Patrice Ryan and Peter Columbus, for their valuable assistance and support in this project. My appreciation is also extended to Charles Avera, Sandy Daigle and Kathy Ehrnschwender for their assistance.

Without the help and support of the staff and volunteers of AIDS Response Knoxville, this study could not have been completed. To them I am deeply indebted. Finally, I want to thank all my family and friends who have supported me throughout this dissertation process, as well as throughout my entire doctoral program.

ABSTRACT

The spread of the AIDS epidemic has brought with it an ever-increasing need for psychological research, addressing not only the issues of persons with AIDS (PWAs), but also the issues of others whose lives are affected by PWAs as well. Through phenomenological interviews, fifteen volunteers from the Buddy program of AIDS Response Knoxville described their experiences of personal relationships with PWAs. Transcribed interview protocols were analyzed by a phenomenological research team. Existential meaning units were extracted from each transcript and divided into clusters representing common points. From these clusters, general themes were derived which depicted the essence of the phenomenon in question.

The three themes which emerged from the transcripts were Impact, characterizing the perceived influence between PWAs and others, Roles, illustrating the perceived identities of PWAs and others in interpersonal relationships with them, and Boundaries, representing the perceived closeness or distance between PWAs and others. These three themes related directly to and comprised the overall experience of relationships with others. The themes emerged against the ground of time in each interview. Each theme was present in every interview.

Results are discussed in terms of current psychosocial issues surrounding the AIDS epidemic, and the relationship of these issues to the lives of those involved with PWAs, and PWAs themselves. The relationships of the findings to psychological and existential theory and another study examining the experience of other people are also examined. Finally, the implications for therapists working with the significant others of PWAs are addressed.

TABLE OF CONTENTS

APPENDICES

CHAPTER 1

INTRODUCTION

During the last decade, the world has witnessed the onslaught of a deadly disease which has recently reached epidemic proportions. Acquired Immunodeficiency Syndrome (AIDS) is a unique disease attributed to the human immunodeficiency virus (HIV) which attacks the immune system, rendering it defenseless against the invasion of a host of infections which would represent no threat to a normal body. The results are lethal and dehumanizing, leading to an individual's loss of mental capacity and control over bodily functions, grotesque transformations in physical appearance and forfeiture of all normal human autonomy.

Literature Review

Sociological Impact of AIDS

The uniqueness of AIDS is manifested not only in the dimensions of the disease itself, but also in the sociological ramifications that accompany it. Sontag (1988) notes that while concepts such as "invasion" and "pollution" have been drawn upon to symbolize this disease, the most poignant metaphor associated with the AIDS epidemic is that of the "plague". Unlike other plagues noted throughout history as collective scourges or catastrophes, AIDS has been associated by some with the 'Wrath of God' rightly visiting certain subgroups of our society, namely homosexual males and intravenous drug users. Appeals to demonstrate more compassion and to ban discrimination against those afflicted with this disease have been met by strong opposition from more conservative fundamentalist factions who suggest that this would lessen our power as a society to segregate and censure by passing judgement on certain behaviors which are linked with 'moral turpitude' (Sontag, 1988).

The attitudes toward AIDS as a 'gay or drug-user's disease' which have been commonly demonstrated among many within the heterosexual population may be waning, as the percentage of new cases rises within the ranks of those who once thought themselves immune. Within the United States, the disease now strikes in every age group, every walk of life, and every subsection of the population (Kubler-Ross, 1987).

Murphy (1989) contends that in the age of the AIDS epidemic, we all fear for our own health, becoming acutely aware of our own mortality. He further notes that this disease is very much a part of our present social experience, as he says:

AIDS has been built into the layers of the lifeworld, altering our

> awareness of the social body from one of health to one of fatal disease. AIDS produces a severe dismemberment of the social body. . . .as AIDS continues to spread throughout the country, we begin to fear the entire social body as being out of control and rampant with disease and death. (p. 52)

Sontag (1988) further maintains the pervasiveness of this epidemic in our social consciousness as she asserts, "AIDS is one of the dysutopian harbingers of the global village, that future which is already here and always before us, which no one knows how to refuse" (p. 93).

Emerging as a primary theme in the examination of the AIDS epidemic is the concept of the "social body". Murphy (1989) notes that the personal body welfare is "cogiven" with the bodily welfare of others:

> The social body gives me my awareness of myself insofar as I am connected with others both in a collective stream of consciousness and as a body among bodies. The social body is the lens through which I can differentiate my private body. (p. 51)

This awareness of self through the social body seems to be acutely manifested within a particular subgroup of society as a result of the encroachment of AIDS upon their numbers. No other sociocultural subgroup has rallied in response to the impact of this disease on their members as the gay and lesbian community has. A marked rise in depression has been seen in the gay male population, as they grieve the loss of an ever escalating number of their friends, and consequently, are left with fewer and fewer sources of comfort and support in their time of sorrow (Kubler-Ross, 1987). As AIDS initially hit gay men the hardest of any "at risk" group, the homosexual community (men and women alike) increased their solidarity to combat the disease and to take care of their own (Katoff & Dunne, 1988; Saynor, 1988). This phenomenon is most readily seen within the "Buddy" programs which have emerged as integral parts of AIDS service organizations located throughout the nation. (These organizations are found in urban areas with substantial gay and lesbian populations. Their purpose is to coordinate various educational and service programs related to combatting the impact and spread of AIDS.) Although the membership in buddy programs includes individuals from several walks of life, the majority of the "buddies" in these programs are gay men (Williams, 1988).

Outside the gay and lesbian community, however, reactions of others to the disease and those afflicted with it have ranged from compassion to irrational fear or hostile condemnation. Friends and acquaintances can withdraw from a person with AIDS (PWA) out of fear, leaving him/her to depend on new, less familiar systems of social support (Donlou, Wolcott, Gottlieb & Landsverk, 1985; Salisbury, 1986). Family members often withdraw from PWAs (Saynor, 1988), which results in a redefinition of the family for the sick person, as a circle of friends become the most significant others in his/her life (Allers & Katrin, 1988).

PWAs have been especially prone to stigmatization from the general public. Specific subgroups, especially gay men, have been blamed for the spread of AIDS as a result of irrational fear of others (Sussman, 1989). Fear of the unknown and deeply rooted prejudices have resulted in a form of internal exile of PWAs by society at large (Triplet & Sugarman, 1987; Lopez & Getzel, 1984; Rounds, 1988). Attacks by society take many forms, from job and housing discrimination (Crystal & Jackson, 1989) to derogatory humor directed at the victims of the disease (Dundes, 1987).

Young children are not immune to the stigma and abandonment which plagues adults with AIDS or HIV. Afflicted children and their families are just as prone to victimization through social ostracism or overt violence as are adults (Belfer, Krener & Miller, 1988). Infants with AIDS are exceptionally vulnerable to the perils of rejection as a result of their disease. While general reactions toward these babies are not based on sexuality or lifestyle issues, the are still most often negative. Abandoned by mothers and relatives, most AIDS babies will live out their truncated existences in special neonatal care units because they are neither accepted by foster homes nor adopted by foster parents. Consequently, any human bonding these children will experience will be with paid caretakers, who are left to deal with the children's emotional as well as physical needs. Such bonding is limited, if present at all (Bennett, 1987; Meintz & Lynch, 1989).

Common reactions of hospital and hospice staff members to a person with AIDS (PWA) include fear of contagion, unresolved feelings surrounding sexual preference and sexual lifestyle, and ironically, embarrassment over irrational responses to AIDS and PWAs (Geis & Fuller, 1985; Pleck, O'Donnell, O'Donnell & Snarey, 1988; Schaffner, 1986). Likewise, medical students have been found to respond to PWAs with discomfort surrounding a patient's homosexuality and presumed sexual promiscuity. These attitudes tended to exacerbate the students' discomfort with the disease in general (Elford, 1987; Royse & Birge, 1987; Wachter, 1986). However, the more contact physicians have with PWAs, the more positive their attitudes are likely to be toward these patients (Linn & Kahn, 1989).

Counseling Issues

Such negative social reactions have prompted many PWAs and their significant others to seek counseling and psychotherapy. Specific issues surrounding the counseling of PWAs have emerged for therapists. Unlike their relationships with most other clients, a loss of hope often pervades the therapeutic atmosphere, due to the extremely high fatality rate with this disease. The counselor must find a way to provide empathic support, while dealing with the stark reality of the client's limited chances for long-term survival (Lomax & Sandler, 1988).

An additional problem seen in group and individual counseling with PWAs is the central nervous system (CNS) deterioration. Therapists must be aware of changes in the quality in the client's communication, which are often manifestations of CNS breakdown (Spector & Conklin, 1987). Not only is this phenomenon a harbinger of further failing health, but another barrier to free-flowing communication between the therapist and client.

Barrett (1989) contends that counselors of PWAs and those otherwise affected by this disease are pioneers in a new area of psychosocial treatment of illnesses. The counselor-client relationship in these situations are in many ways atypical, straying from the paths of traditional psychotherapy. New concerns for the counselor include: 1) fear of contagion, 2) dealing with his/her own sexuality and homophobia issues, 3) the overwhelming needs of the PWA client (especially if he/she has little or no support from other sources), and 4) dealing with and watching the dying process, probably more closely than ever before. Issues of countertransference become figural, especially as they relate to homophobia, overidentification and the need for professional omnipotence (Dunkel & Hatfield, 1986). Categorization and stereotyping of the PWAs by therapists can result in a lack of connection with the client and a therapeutic blindness to his/her existential concerns (Nelson & Jarratt, 1987).

A profound issue that counselors may face in working with PWAs is that of the duty to inform others if they are in danger of being injured by a client. Such a situation is a distinct possibility in counseling a PWA if the client is continuing to have unprotected sex with persons who may not be aware of his/her infection. Such circumstances cannot be ignored, as they create an ethical dilemma for the counselor (Lamb, Clark, Drumheller, Frizzell & Surrey, 1989).

Pastoral Issues

For a number of persons, counseling services are often sought through ministers, priests or rabbis. Clergy are often called upon to pay unsolicited visits to PWAs. Two issues continually arise for clergy as they deal with AIDS. The first of these issues is the conflict they commonly experience between their own religious or moral training and a patient's homosexuality or drug abuse. Their task is to meet patients on their own ground, reserving moral or religious judgement, while displaying compassion for a suffering individual. The second issue is the hostility toward the church often displayed by PWAs, resulting from the condemnation heaped upon them due to their lifestyle, which is in opposition to a number of religious teachings.

(As mentioned earlier, in some religious circles AIDS has even been equated with punishment from God for immoral lifestyles.) These sources of intrapersonal and interpersonal conflict create a special challenge for those dealing with the spiritual needs of PWAs (Bellemare, 1988; Bohne, 1986; Phillips, 1988; Wendler, 1987).

Spiritual concerns of the PWA represent only part of a host of needs which must be met. More often than not, these needs will be met by others within the life space of the PWA. Whether the need to be met by someone else is spiritual, emotional or physical, a relationship must be established with the PWA which can be defined as a 'caring' relationship.

Caring Relationships

Benner and Wrubel (1989) have described caring as "being connected" to things that matter to the individual. Caring incorporates cognitive, affective and behavioral components of the human experience. The authors define caring as ". . . a wide range of involvements, from romantic love to parental love to friendship, from caring for one's garden to caring about one's work to caring for and about one's patients". (p. 1) Caring can be seen as the manifestation of compassion, the sentiment which is the wellspring of individual and collective morality (Prior, 1989).

Gadow (1985) suggests that within the nursing profession, curing takes precedence over caring, although it is the nurse, as opposed to the doctor, who is more often responsible for caring, and partially for curing as an extension of the physician. In this case, caring is defined as ". . . a commitment to protecting the dignity of patients . . . attending to the "objectness" of persons without reducing them to the moral status of objects" (pp. 33-34).

Pellegrino (1985) suggests that the term "care" can be used in four senses: 1) Compassion - being concerned about someone else, sharing a feeling or empathizing with another's plight; 2) Doing for others - helping others with what they cannot do for themselves; 3) Taking care of medical needs; and 4) Taking care - engaging in all care-related tasks in the most conscientious manner possible.

Watson (1989) contends that caring for someone requires knowledge the other person's needs, powers and limitations, with knowledge of how to respond to these within the scope of the caregiver's own powers and limitations. The caregiver must also have the wisdom to learn from another's suffering and the ability to understand the life-world of the sufferer (as opposed to the objective world of medicine).

The definitions of caring seen above were offered by the writers within the context of the medical profession. The AIDS epidemic has brought with it the stark realization that the caring relationship experienced between patient and medical personnel (especially the nurse or hospice volunteer) can quickly overtax the caregiver when the demands are too great. Such a phenomenon is often seen with the PWA, due to his/her many and diverse needs. The result of such a burden is too often burnout on the part of hospital or hospice staff (Andersen & MacElveen-Hoehn, 1988; Masterson-Allen, Mor, Laliberte & Montiero, 1985; McCarthy, 1989; Muldary, 1983).

Kalish (1985) writes that, in relationships with dying persons, we are made more aware of our own mortality. Furthermore, in observing the situation of the dying person, the other person is reminded of his/her powerlessness to control external events - of his/her inability to remove or ameliorate the dying person's physical or mental anguish.

Cohen (1979) addresses the four types of pain that anyone who has a relationship with a terminally ill person must constantly deal with. These are: 1) Social pain - discomfort with the level and intensity of the dying person's interpersonal relationships (Some dying persons need to withdraw from relationships, while others need to intensify those relationships); 2) Psychological pain - fear and anxiety surrounding death; 3) Spiritual pain - endopsychic distress which is very differentiated, yet very real for each individual; and 4) Physical pain - the natural pain that accompanies terminal illness. Both the dying person and significant others will experience all these except for the physical pain.

Weiss (1988) notes the primary relationships which a PWA depends upon for support. These include his/her primary physician, community of friends, family and intimate relationships. Not all these relationships will be experienced as supportive in his/her disease by each PWA; however, some combination of these usually form the foundation for that person's physical and psychological coping.

Martelli, Peltz and Messina (1987) maintain that entering into a caring relationship with a PWA often means accompanying that person on a long journey through many illnesses, emotional upheavals and life-changing traumas. Becoming a caregiver to a PWA (however that role may be defined) can have a parenthetical effect on an individual's own life. The caregiver's needs may be set aside at any moment to offer care to the PWA. The effects of this disease seem to bring with them a profound degree of urgency in the care and treatment of the patient.

Effects of AIDS on Caregivers

The stigma, hostility and isolation experienced by PWAs is also encountered by their significant others. The theme of 'guilt by association' reverberates throughout the often changed lives of lovers, family and friends of PWAs as his/her disease becomes known. Support systems can withdraw at the time they are most needed, leaving a PWA's significant others to suffer compound losses as their loved one declines. Social support systems are often reconfigured in order for these individuals to cope.

The toll taken on caregivers and other support sources of PWAs is noteworthy. As the disease progresses in the PWA, the demands on the primary caregivers seem to increase exponentially. These demands more often than not test the limits of the caregiver's strength and patience, as well as the boundaries of the relationship itself (Pearlin, Semple & Turner, 1988). The problem of role diffusion often arises when too many demands are made on the caregiver in other areas of his/her life.

Fear of contagion often plagues the caregiver, despite the caution observed in dealing with the PWA. For the gay male caregiver, a disconcerting identification with the PWA as someone with the disease is often established, especially since the caregiver in this instance is in a high risk group, and may also be infected (Pearlin, Semple & Turner, 1988).

Tension in family relationships is often observed as it becomes necessary for the PWA to inform his/her relations of sexual preference or drug abuse (Kelly & Sykes, 1989). Whereas this news is most easily shared among siblings, it is often most difficult for a father to accept the information about his son's homosexuality. This is especially true when it is comes on the heels of the tidings concerning his infection with a deadly and stigmatizing disease (Frierson, Lippman & Johnson, 1987).

Severity of emotional stress in regard to relationships with PWAs has been found to be related to the amount of care one provides for the sick person. Mothers of PWAs who are closely involved in the long-term care of their children have been found to suffer a particularly severe amount of stress. Trice (1988) has found that these mothers displayed symptoms of Posttraumatic Stress Disorder after their sons died. Likewise, grief reactions of lovers and close friends of PWAs who had taken care of their significant others prior to death were more intense than reactions of those who had less contact with the PWA during his/her illness (Lennon, Martin & Dean, 1990).

Healthcare workers and families have been referred to as the "hidden victims" of AIDS, in that the disease takes its toll on them in terms of the stress involved in caring for the PWA. In the case of the family, not only must they deal with their loved one's illness and eventual death, but also with possible criticism or ostracism from their own social networks (Rinella & Dubin, 1988). Health care workers who have contracted AIDS in the course of patient care experience the same stigmatization, isolation and loss of status as other PWAs (Clever, 1988).

Unlike other diseases, AIDS creates a unique array of psychosocial stressors that plague the lovers of its victims. Given that many of the homosexual males afflicted with AIDS are engaged in long-term intimate relationships, their lovers are most often involved in their care. This often creates tension and power struggles between the lover and family members who do not accept the relationship (Fuller, Geis & Rush, 1988; Geis, Fuller & Rush, 1986; Greif & Porembski, 1988; Klein & Fletcher, 1986). Furthermore, the lover of the PWA often finds little or no emotional support from others in his life, especially if his homosexuality and his relationship with the PWA had to be concealed from friends, family, employers or co-workers (Murphy & Perry, 1988; Rowe, Plum & Crossman, 1988). Like mothers who were primary caregivers for their sons with AIDS, gay men who had lost their lovers to AIDS also manifested symptoms of Posttraumatic Stress Disorder (Martin, 1988).

Existential/Phenomenological Thought

The philosophical discipline of existential-phenomenology pursues the understanding of elemental human issues (such as joy, fear, freedom, love, etc.) in a manner which sheds presuppositions concerning the human experience, and allows the essence of that experience, its form and structure to emerge through methods of inquiry which are essentially descriptive (Valle, King & Halling, 1989).

Mahoney (1982) asserts that the creation of meaning in one's life is a unique and private phenomenon, which might well lend itself to qualitative as well as quantitative research methods. Likewise, Colaizzi (1978) holds that objectivity in the study of human experience requires faithfulness to the experiential phenomenon being studied. In his essay on existential-phenomenological research in psychology, he states:

> When someone is said to be objective, it means that his statements faithfully express what stands before him, whatever may be the phenomenon that he is present to; objectivity is fidelity to phenomena. It is a refusal to tell the phenomenon what it is, but a respectful listening to what the phenomenon speaks of itself. (p. 52)

Hector, Bradley, Daigle and Klukken (1989) reiterate this position as follows:

> Phenomenologists seek to understand the phenomenon from the first person perspective, rather than from an objective, or third person perspective. The participants in a study are viewed as the "experts", describing their own experiences, unencumbered by the interviewer's presuppositions that in objective studies may bias forthcoming data. (p. 2-3).

A person's experience is in and of the world as he/she moves through and interacts with self and environment (Colaizzi, 1978; Merleau-Ponty, 1962). Perhaps the most significant issue in the conceptual foundation of existential-phenomenology is that of co-constitutionality. Rather than being viewed as merely objects within the world (de-contextualization), individuals are seen as being in unity with their surroundings, in inter-relationship with the world. The individual is seen as being non-existent apart from his/her world, and likewise, the world as being non-existent or meaningless apart from individuals and the meaning they assign to it (Valle & King, 1978). Thus, existence itself is what gives meaning to the world in which one exists (Heidegger, 1962).

This process of being 'at one' in the experiencing of an object, person or event is called 'intentionality'. It implies total interrelatedness of the person with his/her environment, as opposed to one's existing separate from (although within) that environment, the dualistic concept of Cartesian philosophy.

The human experience is 'contextualized', not only within a person's environment, but also within the temporal framework of past, present and future (Heidegger, 1962; Merleau-Ponty, 1962). Husserl (cited in Valle, King & Halling, 1989) refers to this contextualization as the "Lebenswelt" or 'life-world' of an individual. "Lebenswelt", as used by Husserl, actually means "...the world of immediate experience in which everyday life runs its course" (Strasser, 1963, p. 65). Husserl admonishes all who pursue science to make use of the wealth of data available to them through attending to the 'Lebenswelt'. This type of attending is the primary thesis and starting point of existential-phenomenological psychology.

It is from this point we begin to see and understand the experience of a phenomenon through the world of the person who experiences it. A fuller understanding of any experience can be gained through objective observation of the phenomenon as it emerges in the accounts of those who have lived it.

Much attention has been given to the role of language in existential-phenomenology. As Goffman (1986) suggests, it may be that experience takes on meaning for an individual only as he/she is able to cognitively reflect on and express it through language. Strasser (1963) recognizes how one's experience is conveyed in interviews through language as he states, "Name-giving is literally the apex and crown of experience. . . .Speaking about the thing confirms and, as it were, ratifies its reality. In this sense words render secure the minimum order that is required for speaking of a world" (p. 79).

Likewise, Giorgi (personal communication, September 26, 1989) contends that language gives us the <u>structure</u> of experience. Since we cannot relive the experience of another person, it gives us the ability to <u>understand</u> the experience as it is described. Language itself can express the extralinguistic. We <u>do</u> have access to that which is transcendent of language. We use words to begin the process of understanding. However, we cannot get more from language than language can give us. We must accept what we receive as figural, and not demand more than we can understand from the language.

Methodological Issues

Reliability

The issue of reliability in existential-phenomenology concerns precision and accuracy of data. This connotes the presence and persistent threat of error. Reliability is important in qualitative, as well as quantitative research. As Husserl (cited in Wertz, 1986) submits, the very essence of 'seeing' is flawed. Any given experience is capable of invalidating or superseding another. The same could be said for the 'remembering' or reflecting on an experience. Thus, though reflecting on the same experience, a participant may produce very different protocols if interviewed on different occasions. Naturally, the same is true across various participants.

Unlike the quantitative researcher, however, the existential-phenomenologist seeks discrepancies across the span of data in order to displace, and thus modify and amend the meanings which were extracted in the reading of the first of several texts, or the first of several readings of a single text (Wertz, 1986). (Remember, thematic analysis is, in a sense, a 'meta-analysis' of the general structure of the phenomenon as it reveals itself, or 'emerges' through numerous descriptions of that experience.)

Wertz (1986) notes that both quantitative and qualitative knowledge are restricted, relative, and unreliable to some degree or another. Why? Because both find their origins in human subjectivity, suggesting that neither can be free from error. However, the author points out that in the hermeneutic process, this may be more blessing than bane, as he says:

> While on the surface, the quantitative approach seems to favor consistency and the qualitative divergences, we must not be misled by this appearance. Both incorporate "error", each in its own way, into the progress of investigation. This is possible because error and truth, the Many and the One are not strangers to each other, because partial truth is part of truth and subjectivity opens onto objectivity. Just as our truth may be "bad", our error may be "good". (p. 201).

Here the author makes a very valid point . If we were to assume that we 'know' the essence and structure of a phenomenon without allowing it to fluctuate and realign itself during our analysis, or in the second interview with the same participant, what we might call reliability would be a farce. The changes in the way a participant 'sees' his/her own experience and in the way we as researchers interpret those seeings help to create the richness and accuracy in the characterization of the phenomenon.

Validity

Internal Validity (Rigor). The issue of error in our search for knowledge again presents itself as we address the question of internal validity in existential-phenomenological research. In traditional quantitative methodologies, validity connotes a well-founded idea with strong empirical support. Traditional research instruments are considered valid if they are thought to actually measure what they are intended to measure (Polkinghorne, 1989). Such definitions do not hold true in existential-phenomenology. In contrast, one attempting to determine the validity of existential-phenomenological research would be more likely to ask the question, "Does the general structural description provide an accurate portrait of the common features and structural connections that are manifest in the examples collected?" (Polkinghorne, 1989, p. 57).

Wertz (1984) notes several issues that need to be addressed in regard to the validity of a study. The first of these involves the validity of participant selection. By virtue of the research format, in order to be included in the study, a participant must have experienced the phenomenon under investigation. In addition, he/she must be articulate enough to reflect on the experience and describe it to the investigator. (Wertz notes, however, that even the less articulate, with little command of their language may be accurately expressing <u>their</u> experience of the phenomenon. Thus, as Goffman (1986) has suggested, limited language capacity may result in a different or limited way of being in the world.)

Next is the issue of validity in the data collection situation. What is the best way to allow a particular phenomenon to manifest itself? Various studies require various procedures, such as one-on-one interviews, writing out descriptions of experience, or perhaps reconstructing physical situations in order to facilitate recall. Careful consideration must be given to the mode of data collection in order for the phenomenon to best be described.

A third issue the author notes is that of the validity of the actual data. Arising here are the questions of deletions, omissions, deceptions and concealments on the part of the participant as he/she reports his/her experience of the phenomenon. Likewise, the effect that the researcher might have on the participant (intimidation, leading or confusing questions, etc.) must be considered. Whether the influences are internal or external, participants may sometimes not be aware of just what is influencing their responses, or how (Nisbett & Wilson, 1977).

Finally, the issue of the 'handling' of the data must be addressed. Returning to Polkinghorne's (1989) question, the critical reader will want to know to what extent the thematic structure effectively and reliably reflects the phenomenon under investigation. Two questions could arise here: Does the final characterization of the phenomenon make sense? If so, is this characterization an accurate reflection of the phenomenon as it was revealed?

External Validity (Relevance/Generalizability). The issue of generalizability in existential-phenomenology is related to the specificity of the description of experience, as opposed to parameters of a population (Polkinghorne, 1989). For instance, findings from the examinations of the experiences of reparation of relationships (Hawthorne, 1988), death and dying (Ross, 1987), time (Dapkus, 1985) or significant life changes (Hale, 1989) may be quite generalizable to the population at large, given the fact that these phenomena seem to manifest themselves throughout the human experience. On the other hand, studies focusing on experiences such as being an athlete (Alpack, 1972) would only be generalizable to athletes, as opposed to the larger population. Needless to say, as in any form of research, the argument created for generalizability of findings should reflect the degree to which such findings relate to the experience of others not involved in the research.

Statement of the Problem

In recent years, the psychological community has witnessed an upsurge in AIDS-related research. New psychosocial issues are constantly emerging as the epidemic continues to spread (Backer, Batchelor, Jones & Mays, 1988). Given the magnitude of the health crisis AIDS has sparked, the psychosocial issues accompanying the epidemic are often given second hand consideration in terms of research and policy development (Morin, 1988).

Despite this fact, numerous studies and position papers have emerged which address the issues of the PWA's caregivers and significant others (Frierson, Lippman & Johnson, 1987; Geis, Fuller & Rush, 1986; Kelly & Sykes, 1989; Klein & Fletcher, 1986; Murphy & Perry, 1988; Pearlin, Semple & Turner, 1988; Rinella & Dubin, 1988; Rowe, Plum & Crossman, 1988; Trice, 1988).

As the AIDS epidemic spreads, the number of caregivers (friends, family, professionals and volunteers) involved with PWAs will also increase. Education and training requirements (related to AIDS support) for mental health professionals will also be increasing as the disease spreads (Morin, 1988). These professionals will be serving not only PWAs, but others who, though not infected with the disease, have had their lives touched by it in some way. As these training needs increase, the need for related research increases as well.

To date, no phenomenological studies have been produced which illuminate the experience of having a personal relationship with a PWA as portrayed by the individual through his/her lived world. This experience certainly lends itself to investigation through phenomenological methods.

The purpose of this study was to explore the phenomenon of having a personal relationship with a PWA as it is experienced by the individual. Through the analysis of phenomenological interviews, concerning the experience of personal relationships with PWAs, it was hoped that a better understanding of this experience may be gained.

CHAPTER 2

METHOD

Data Collection

Participant Selection

In his characterization of participants in phenomenological research, Polkinghorne (1989) distinguishes them as 'informants' who are able to offer in-depth descriptions of the phenomenon under scrutiny. He delineates two criteria for their selection. The first is that the individual has had experience with the research topic (such as feeling lost, or being satisfied). The second is that he/she is able and willing to offer an honest, articulate and insightful description of that experience. The participants for this research were selected based upon these criteria.

Rather than attempting to satisfy any statistical requirements in the search for participants, the existential-phenomenological researcher seeks to obtain a wide range of descriptions of the phenomenon in question. As the total of dimensions of the experience and relationships described by the participants expands, so does the richness of the characterization of the phenomenon (Polkinghorne, 1989). Given this correlation, it behooves the existential-phenomenological researcher to seek out a wide variety of participants who can share their experiences of a given phenomenon.

Participants were solicited from the AIDS Response Knoxville Buddy Program. Following a procedure employed by Hawthorne (1989), the participants were mailed a description of the study and solicitation to participate (see Appendix A). No controls for demographic variables within the chosen population were established. Furthermore, no incentive of any sort was offered for participation. The reasons for following this procedure were twofold: First, it offered the researcher assurance that those volunteering to participate understand and have experienced the phenomenon in question, and second, it guaranteed that the participants were truly motivated to participate in the research out of their own interest. Participants were chosen from the population described above, not only because of their accessibility to the researcher, but also because individuals within this group were very likely to be quite reflective and articulate. The likelihood of participants possessing these qualities, coupled with their motivation to participate, offered the researcher reasonable confidence that rich, in-depth interview protocols would be produced.

Fifteen participants responded to the solicitation and were chosen to be interviewed for this study. (Demographic data of the participants can be found in Appendix B). The decision to interview this number of participants was based on a survey of similar phenomenological studies, in which the number of participants ranged from twelve to twenty (Dapkus, 1985; Hawthorne, 1988; Parks, 1987; Seidner, 1987; Young, 1986). In phenomenological investigations of this type, the number of interviews to be used is most often determined by noting the point at which the emergence of new themes has ceased, and then adding a few more interviews. Due to the narrow definition of the experience under investigation in this study, the researcher was confident that fifteen interviews were more than adequate to obtain the data necessary for thematic analysis.

The Interview

Data were collected via face-to-face interviews. Each participant participated in an interview lasting approximately sixty to ninety minutes. All interviews were held in a private setting to insure confidentiality. During the interview, each participant was asked to talk about his/her experiences with PWAs. Interviews were audiotaped for verbatim transcription.

At the beginning of the interview, each participant was given two copies of an informed consent form (see Appendix C), one of which was signed and returned to the researcher, and one of which the participant took home and peruse at his/her leisure.

Each participant was asked to describe an experience he/she has had with a person with AIDS (PWA) (see Appendix D). The experiences solicited for description were not necessarily be limited to those the participants have had within the context of a "Buddy" relationship. However, due to the participant pool from which participants were drawn, it was anticipated that descriptions of "Buddy" relationship experiences would comprise the majority of the data collected in the interviews. (A sample interview can be seen in Appendix E).

As suggested by Kvale (1983), the focus of the interviews was maintained on the participants' actual descriptions of their experiences with the topic, avoiding theoretical or conjectural discussions. Thus, participants were asked to describe specific situations in their lives, rather than to give personal opinions about the topic. If any part of the descriptions seemed ambiguous, the researcher immediately asked for clarification. Although the interview is an interpersonal exchange, the focus is not on the participant (participant), but on the experience which the participant has been asked to reflect on and describe.

Interviews were unstructured, with open-ended questions used to prompt free association by the participants. The amount or depth of reflection engaged in by a given participant determined the length of the interview. As opposed to surveys or other question-answer formats, existential-phenomenological interviews are more dialogical, requiring interpersonal engagement from both parties involved (Polkinghorne, 1989). For this reason, those being interviewed are referred to throughout this study as 'participants', as opposed to 'subjects'.

The content of interviews varied, not only across participants, but also within each interview. Different participants share different types of experiences related to the phenomenon in question, while one participant may also share a variety of different experiences within his/her interview.

A 'rich' interview is one in which the interviewer has garnered as many in-depth descriptions of experiences as a participant is able to reflect on and share with the interviewer. In this study, the majority of the interviews were, extremely rich and descriptive of the experience under investigation.

Protection of the Participants

Due to the confidential and potentially sensitive nature of the material revealed in the interviews, prudent steps were taken to protect the identity of the participants in this study. The audiotape of each interview was coded with a number prior to it's release to the transcribing typist. No one except the primary researcher had knowledge of who was being interviewed. In addition to this precaution, the transcribing typist signed a written pledge of confidentiality, stating that he/she would in no way reveal any information from the interviews which he/she may become privy to as a result of the transcription process (see Appendix F). Each participant was also be asked to sign a release form, giving the researcher permission to reprint appropriate segments of the protocols to exemplify the structural elements of the phenomenon as they emerged (see Appendix G).

Data Analysis

In order to determine how each participant experienced the phenomena in question, a variation on the phenomenological analysis procedure outlined by Hycner (1985) was followed.

Bracketing

In order to further promote rigor within the research, the phenomenological analysis process first involved the bracketing of assumptions of the researcher in regard to the research topic (Hycner, 1985). Bracketing is done in order to identify any presuppositions the researcher might have with regard to the research topic, and to make him/her aware of those presuppositions throughout the course of the research. The task of the researcher is then to 'set aside' these presuppositions as much as possible, in order to limit their influence on the analysis of protocols. A bracketing interview was conducted in which the primary researcher described his experiences with PWAs. His protocol was analyzed by the analysis team in order for him to become aware of his own biases in regard to the research topic.

Analysis Team

Phenomenological research can produce results that are predisposed to subjective bias and the restricted hermeneutic knowledge and skills of the investigator (Hawthorne, 1989). Authors of recent studies have proposed the use of research analysis teams as another method of controlling for such bias in the evaluation of data (Hill, 1981; Thompson, Locander & Pollio, 1988).

In an attempt to further limit the effects of interpretive bias, a team composed of the primary researcher and two other doctoral students from The University of Tennessee, Knoxville (one in counseling psychology and one in experimental psychology) was established to analyze the interview transcripts. The function of the analysis team was to discuss, confirm and validate the findings of the primary researcher. In addition, selected transcripts were analyzed in the Phenomenology Research Group at The University of Tennessee for further validation of thematic structure. Members of the research analysis team also signed pledges of confidentiality (see Appendix H).

Reading Protocols for a Sense of the Whole

After the researcher addressed his/her experiences with and interpretations of the topic, making every possible effort to suspend them, the team read each transcript in order to get a sense of the 'whole' of each interview. This was done in order to establish familiarity with the protocol, and to provide a contextual base from which themes could begin to emerge.

Delineation of Meaning Units

This process was followed by the delineation of units of general meaning (identifying words or phrases which express a singular, understandable intention). Following this, units of meaning relevant to the research question were outlined. Repetitions were then eliminated. However, the number of times a meaning unit appears was recorded, given that this in itself indicated its significance to the participant. (A sample of the delineation of meaning units can be seen in Appendix I).

Clustering

The units of meaning were then grouped into clusters representing a common point, for which specific themes were determined. General and unique themes were then identified for each interview. The themes were then considered in terms of the general context of each interview in order to achieve a clearer understanding of each theme. (A sample of the clustering of meaning units into themes can be seen in Appendix J). Finally, a composite summary of all interviews was created to characterize the essence of the phenomenon in question, and to describe relevant individual differences which appeared within each participant's description of his/her experience.

Summarizing and Confirming Findings

After all transcripts are analyzed, a summary of each protocol was prepared. A follow-up letter was mailed to each participant (see Appendix K), along with copies of each interview and a protocol summary of each interview, composed of the meaning units extracted from the text. A follow-up interview was subsequently scheduled. During this interview, participants were asked to respond to the protocol summary. They were encouraged to critique the summary for its accuracy of reflection of his/her experience. Any additions, deletions and corrections the participant deemed appropriate were made at this time. Each participant was also given an explanation of the thematic structures derived from the protocols.

CHAPTER 3

RESULTS

The purpose of this study was to explore and describe the experience of having had a personal relationship with a person with AIDS (PWA). Analysis of the interviews revealed three major themes which emerged as figural throughout the protocols: Impact, Roles and Boundaries. These three themes related directly to and comprised the overall experience of relationships with others. The themes can be considered components, or elements of the overall theme of relationships, and are dealt with as distinct structures comprising the experience of relationships with PWAs.

In the participants' descriptions of their experiences, these themes emerged against the distinct ground of time. (A visual representation of this thematic structure can be seen in Appendix K.) This chapter will begin with a description of the existential ground upon which the themes emerged. This will be followed by a description of the three experiential themes as they emerged in the texts.

The Ground for the Experience

In all of the protocols, the experience of having a personal relationship with a PWA was cast against the existential ground of time. This ground was present in all of the transcripts.

The essential context within which participants' experiences were set was that of time. The ground of time was manifested in three ways:

1) Time is <u>limited</u> in these relationships.

2) Limited time changes the relationship norms.

3) Time passes, marking changes in the PWA's health and changes in the relationship.

Participants described their experiences in terms of the limited amount of time they expected to have with PWAs, due to the fatality of the disease. Consider, for example, the following statement made by a participant as she punctuates the limits that time has imposed on the young life of her PWA:

> The first thing she said to me. . .was "Do you have to die?". . . .I thought, of course, everybody has to die. But that wasn't the question she was asking. She was twenty-one years old. She was really asking 'do I have to die soon?' She really wanted to see her child grow up.

The limited amount of time one has for a relationship with a PWA was directly related to the intensity of the relationships described. The <u>brevity</u> of the time span of a relationship often resulted in dramatic alterations in the norms of that relationship. Examples of how time changes relationship norms are seen in the following statements:

> You don't have time to put up with a lot of bullshit when you have AIDS, so people tend to get rid of the unnecessary clutter in their lives. . . .The nurse introduced us and we just hit it off. We've already become pretty close, I think. That was another example that you can really cut through the bullshit of the social back and forth of getting a relationship going. You very quickly come down to very important things in your conversation. . .

> Rather than the usual spending months of feeling somebody out and deciding if you want to begin a relationship with somebody, you can get very intense very quickly, cause you never know how much time you've got. . .within two days we were talking death and dying. . . about his religious feelings, and most people don't talk about those things freely with someone they have known for 48 or 72 hours.

> I know that she's sick and I won't always get to have her around. Knowing that I'm going to lose her, I think that sort of intensifies the feelings that you have.

Descriptions of relationships were also set in the context of the passing of time. As relationships to PWAs were described, the changes occurring in these relationships often became figural for the participants. The following passage exemplifies how time marked these changes for participants:

> When I started with people - depending on what stage they were in--if they were not critically ill then I wasn't very much aware of dealing with someone with Aids and my relationship was very much social. . . . Then the next stage was what I would say would be chronic illness. A series of pestering problems that would interfere with their ability to get out. I remember [he] went from wanting to do something all the time to wanting to do something quite rarely. Staying home a lot and wanting me to visit him at home. And this stage lasted from a period of weeks to

> in the case of [another PWA] to more like a year and a half. You go from basically a normal social relationship punctuated by the knowledge that one has HIV to physical situation where one is having good days and bad days. . . .Then the third stage is what I'd say would be terminal illness. I have seen and experienced that again with people being terminally ill or in a stage of terminal illness. When people I have been involved with have entered that stage of terminal illness, my attitude completely changed. Whereas, I was interested in carrying on the social relationship when they reach that stage, the terminal stage, my attitude became more to just doing something to make someone comfortable. Caregiving. I protected myself emotionally by becoming very practical. I dealt with most problems in terminal illness on a very practical level. Whether or not there were clean sheets or whether or not there was somebody there to take care of a person. Whether or not there was food, that type of thing.

The Experiential Themes

Emerging against the ground of time was the thematic structure of the experience of relationships with PWAs. This structure is comprised of three experiential themes or "existential meaning structures" (Ross, 1987, p. 216). The themes are: 1) Impact, 2) Roles and 3) Boundaries. They reflect participants' ways of being in the world in regard to their relationships with PWAs. The themes comprise the basic structure of the experience in question because they are implicit in all protocols. The themes can also be considered existential, since they illuminate the meaning that participants gave to their lived experiences (Ross, 1987).

Theme 1: Impact

Participants described their relationships with PWAs in terms of the impact, or influence that they had on each other. The interpersonal impact was a phenomenon which unfolded as reciprocal between two persons. Not only was the participant aware of the ways in which the PWA influenced him/her, but also of how he/she had influenced the PWA.

PWAs' Impact on Participants

As significant others in their lives, PWAs effected significant changes in the experiences of participants. The following statements reflect participants' awareness of the impact PWAs had on them:

> Obviously this has been a major impact on my life, dealing with all this. I am forever changed.
>
> . . .I believe that AIDS brings out the best and the worst in people. . . .It has been an extraordinary experience. And as hard as it's been, I'm a much better person for it, I think. A completely different person than I was three years ago.

More specifically, participants described how their relationships with PWAs impacted on them through learning experiences and being made more aware of life and death issues, especially regarding their own mortality. Consider the following statements concerning existential issues which are stirred up in participants through their contact with PWAs:

> I think talking to folks who have this virus that seems to lead inevitably to death raises all kinds of metaphysical questions. The existence of a soul. The human spirit. The ways that people deal with something - such a foe. Something that's so overwhelming.

> . . .my gratitude is that they are willing to share so much of their life, so much of their stories with me, because there is no way you can work on such a raw edge of life and death without coming to terms once more with your own mortality and recognizing that love is what life is all about. . . .This has happened to me and I'm grateful to every one of those guys.

Issues of loss were brought to the awareness of participants by the impending mortality of the PWAs as feelings of grief, helplessness and survivor guilt emerged. Anticipated or experienced death of PWAs resulted in a barrage of feelings for participants, reflected in these statements:

> It's hard to sort through the degree of loss, the impact that each different individual had. They're more like a sea of faces now, rather than distinct individuals.

> You know the effects that it had on my lover - they were very, very close friends - were devastating. It had a strong impact, negative impact on our relationship. It was like a part of us was now missing.

> I know part of it is just the real pain that finding out you're negative doesn't change the fact that this virus is wiping out your life. That didn't make everything okay. [My test result] was one of the best pieces of news that anybody could give me in this epidemic short of a cure and it didn't make anything okay. I didn't bring any of those people who died back to life. It didn't mean that any of the people I knew were sick weren't going to die. It didn't mean any of those things, so it was painful and there's a lot of guilt. There's a lot of "why me?" As much as I did why is it that I'm negative and these other people are dying?

> I think people who spent a lot of time with HIV positive folks and PWAs end up in some way feeling guilty because they're not sick. And it may dictate some of our behavior... .Survivor guilt is there for sure. Not that I'd volunteer to get it. I don't want it. But it causes you to wonder all those 'why' questions. Why am I spared? Why is it okay for me and not for them?
>
> . . .you think "Damn it, AIDS is a horrible thing and I'm going to do something about it! And, you know, on one hand you can't do a damn thing about it. They are still going to get sick, they are still going to get crazy, and they are still going to die.

Perceived Impact of Participant on PWAs

Impact was experienced as a reciprocal phenomenon. In addition to the influence a PWA had on a participant, impact was also experienced in terms of the participants' awareness of their influence on PWAs. Participants described this influence in terms of the teaching and prodding they engaged in to effect positive change in PWAs' lifestyles and to help them to take responsibility for themselves. These statements characterize participants' awareness of their impact on PWAs in these ways:

> I used everything I could think of to get her more healthy. I encouraged her, I yelled at her, I shamed her and there was a really close bond there. I think she needed me. In the last six months she's cleaned up her act a great deal...
>
> I have seen [her] approach go from denial and running away and running into drugs to acceptance. She's facing more readily the possibility that she may get sicker and die, but it's in a very positive sort of way instead of running away and dying... .I think my influence helped her to have a more wellness-oriented lifestyle...

> I realized that I was a part of that emotional healing for him.
>
> I told him, "Well, you don't have to sit in a dark room with the shades drawn and wait for the angel of death - you can take control of this." And within two days he had the minister and his mother in there and talked about his funeral and where he wanted to be buried and the clothes he wanted to be buried in and all this.
>
> I think I try to maintain [the support group] in a way that they learn some skills.
>
> So this is what I consider an important part of my contribution as far as being a buddy - pushing these people to see a physician.

Another way in which participants experienced themselves as impacting on PWAs was through support, friendship and advocacy. PWAs were often described as being without friends and family who understood their experience or supported them in their suffering. It frequently fell the lot of participants to be the only friend of a PWA upon whom others had turned their backs. The following statements exemplify participants' awareness of this phenomenon:

> . . .she was my buddy and I probably went overboard like the amount of time I spent with her was probably more than I should have. It was just hard sometimes when I didn't necessarily want to be with her but would be. Like I said, she was pretty dependent on me.
>
> I walked the extra mile with her. She was here by herself for the most part.
>
> Being a friend and a witness and a support person for those folks. . .a witness to suffering and struggle. . . .They still don't get the support they need. . . .One thing that really does help a lot of folks, especially in a

> heroic struggle, is that they have a witness. . .someone who understands what they're going through and sees it. That makes it real. I think very often there's a lot of time when they feel they're not in this world - that things are not real. Having buddies who have a knowledge of this disease and a knowledge of the struggle that the people who have it have to go through just trying to get their basic needs met. It's real valuable. I think that's why they share so much stuff with us.

Theme 2: Roles

Participants experienced PWAs as playing certain roles in their relationships. PWAs were described as having certain identities, performing certain functions and holding certain positions in the relationships. Likewise, participants saw themselves as playing certain roles in these relationships. The roles of PWAs were also described in terms of how participants saw them interacting with others.

Roles of PWAs in the Lives of Participants

The roles that the participants saw the PWAs playing in their lives were all characterized by the fact that they went well above and beyond their identity as a 'person with AIDS'. Consider the following passages as participants describe the roles of PWAs in their lives:

> . . .it wouldn't matter what he died with, I would have been devastated, because he was such an important part of my life. From the time I can remember, he was like a father to me. . .he really played so many roles

> in my life. I'm just so sad he's gone. And still miss him so much that the fact that he had AIDS, I know it sounds odd, but it's almost secondary.
>
> He also taught me that people with AIDS are much more than just people with AIDS. In [his] case, he was a brother, he was a lover, he was a friend. He was a person. He had wants and needs and desires and dreams, just like anyone else does. And he had them all the way to the end.

Roles of PWAs in Relationship to Others

Participants were also aware of how PWAs were viewed by others in their world. As close interpersonal relationships were developed, participants became increasingly aware of how unfairly PWAs were labeled by others in terms of their disease, being cast in the role of a 'sick person', while the gestalt, or 'wholeness' of their personhood was disregarded. The following excerpt is a poignant representation of this phenomenon:

> I think that is the reason I am so adamant about expressing it in that manner because people get 'tagged' PWAs and that's all they are. . .and that pisses me off. That makes me mad. They are everything that every other human being is. They are people and they have lots of needs and desires just like everybody else. That having AIDS is only one aspect of their life. And that just doesn't seem fair to me. I think that it should be at least acknowledged that they are many more things.

Perceived Roles of Participants in Relationship to PWAs

Again, reciprocity existed in this theme, as participants also described their perceptions of the roles that they played in the lives of the PWAs. The perceived importance of the participant in the life of a PWA was clearly evident in the descriptions of the relationships. The following passages characterize participants' perceptions of their own identities and the positions they held in their relationships with PWAs:

> So if all you can do when you go out there to be a buddy to a person with AIDS, if you can only be an accessory to the fact that they are a music lover, then that's good enough. You don't have to address this health problem, then you don't have to be their counselor. You don't have to be their lover. You can be their friend and talk to them about music, and I think that's real important to know that.

> . . .it's probably not unlike working in an ER, or someplace where acute situations occur all the time with very little notice. Except that you're not doing it as a professional. As a buddy, you're doing it in this sort of pseudo - this kind of gray area between friendship and family and some kind of professional helper, so the boundaries aren't as clear. In spite of our training and what they tell us about what buddies are and what buddies are not, when you are out there, there's also this feeling of you and your buddy against the world.

> We got to be real friends. I never could consider myself an official "buddy" of [his] even though I did a lot of buddy like things with him, especially when he got sick. You just couldn't presume to be [his] buddy. It was a friendship.

Similarities and Differences in Perceived Life Roles

In addition to their roles, or identities, and those of the PWAs within the relationships described, participants also described an acute awareness of the degree to which they were similar to or different from the PWAs. Their similarities served to enhance their relationships, while their differences often hampered them. Roles in the relationships seemed to become more circumscribed as differences between two persons grew. Depicted in the following excerpts are participants' awareness of similarities and differences between themselves and their PWAs:

> The first people that we served, for the most part were well educated, upper class, or upper middle class gay men. And they were articulate and even though they might be real frightened or in denial, they were pretty much able to tell us what they wanted or expected of "buddies". The people who I've worked with over the last three or four years for the most part haven't been that kind of folk. They've been hookers or junkies, people already so damaged by life that they don't ask for much unless they're hustling for survival issues.
>
> I guess another challenge for me was not only the social-economic conflict and the cultural conflict, like middle class v. lower class but that he grew up lower class and I grew up middle class and we had that conflict of values systems.
>
> The things that have gone on in that family, I've just never known a family like that. Those people using intravenous drugs, all the hatred and betrayal and inconsistency and abuses. . .it's a different world.
>
> That rudeness grated against my nerves. But that was his culture. That was the way he was raised. That was not the way I was raised. And I didn't like their homes. These other people, they weren't intelligent.

> They just weren't. Maybe that was why they got AIDS, but hey, AIDS knows no educational background. AIDS is an equal opportunity disease and I do know that.

The profound differences described in the preceding passages suggest a sociocultural gap that would normally never be bridged. However, as noted in the last passage, AIDS is no respecter of persons; and, in service organizations such as the one to which all the participants in this study belonged, strange and unlikely relationships are often formed:

> This situation we find ourselves in, I've been put in contact with these people. I would never know these people if it were not for AIDS and their condition. So to that extent it put us together and gave me the opportunity to meet these people.
>
> So you could end up having someone and being in this kind of intimate relationship for maybe four or five or six years, when under normal circumstances - had that person never been sick - you'd have never met them. It might just be an acquaintance. Certainly they wouldn't have been somebody you'd become best friends with. So all of a sudden you're in this.

Differences between the participants and PWAs were also described in terms of physical abilities and health status. As PWAs lost strength, the gaps in shared activities widened, making sick/well or weak/strong identities more pronounced:

> He was having to rest a lot and this was the thing. . . .I had kind of high energy a good bit of the time and I had to make myself slow down and realize that he could not go as much and that he would have to rest a lot more.

> He'd get real angry about me going faster but he'd always been an athlete so I guess it really hurt him to face slowing down like that.

In the same sense, participants were also aware of similarities between themselves and PWAs in terms of their humanity and ultimate mortality, despite the fact that they were still alive at the time. While this aspect has been treated as part of the theme of Impact, it can also be considered as an awareness of the similarity between PWAs and participants.

Theme 3: Boundaries

Participants described their relationships with PWAs in terms of the boundaries they experienced within these relationships. Not only were these boundaries figural in terms of the participant-PWA relationship, but also in terms of relationships between participants and significant others in their lives, and in terms of participants' awareness of PWAs' relationships with significant others in their lives.

Boundaries Between Participants and PWAs

The transcripts yielded powerful descriptions of the contraction, or diminution of boundaries between participants and PWAs, as two virtual strangers became very close within the context of a PWA-Buddy relationship.

Consider the following excerpts in which participants describe the closeness they experienced with their PWAs:

> I guess in a sense I had almost seen her as my child, because some of my feelings for her are certainly kind of motherly. . . .She and I have developed a closer bond probably than she and her mother had.

> I've also had the experience of loving people very, very deeply. . . .I was very much in love with him. When he finally died, it was like losing a lover, I guess. I felt like with [him] I had lived a lifetime with him when he died. . . .We lived very intensely for those nine months.

> There's one thing that somebody at one of the buddy meetings said - that there's sort of an "in love with" feeling. I think that's true and I've had that happen with one of the other PWAs.

> I think it's important that we really be friends and not just her caretaker. You don't get the same kind of intimacy that way. She wouldn't feel like she really knew me if she didn't know what was going on in my life.

Reduction of boundaries between participants and PWAs was also evidenced in descriptions of the absence of fear of infection so often prevalent in PWAs' interactions with others:

> I've always been concerned about catching the virus. . .but I came to the conclusion that I can't be afraid of it. If I was afraid of anything, then I couldn't live my life fully. If I can't live my life fully, then why should I do it at all?

> . . .I just took my fork and stole olives off his plate - started taking food out of his plate, and he started crying. I said "What the hell's the matter with you?" He said "You're eating food from my plate." It was a big deal for him because apparently even with the support and help he did have, that was an area of his life where he noticed people's behavior changing. I understood that I wasn't going to get AIDS from his goddamn olive.

In contrast to this phenomenon, participants also experienced the boundaries of their relationships with PWAs becoming more extensive, as PWAs chose to become more distant through social withdrawal. The following passages characterize the creation of social and emotional distance by the PWAs as they voluntarily withdrew from the participants:

> After he really got sick he became very withdrawn. He didn't want to talk about it anymore, because all the talking was done. He was just very impatient for it to all be over with.
>
> He was being such a whiner. It really just pushed me right back. I just felt like "God, I don't want to deal with this." I almost felt like he intended to push me away.
>
> I think that I'm going to visit him for half an hour and I end up staying for two hours and just talk about all kinds of stuff. But that can be a problem. I guess it's boundaries or something. . .if he doesn't feel like he can carry on a conversation, then he may not be able to be coherent enough so he just won't answer his phone. And that's been good for him to set up that. I guess that's a type of boundary - whether he wants to be sociable or not.

Another way in which participants experienced withdrawal of the PWA from their relationship was through dementia. With the onset of brain deterioration, a PWA's thought processes disintegrated, making it virtually impossible to communicate with him/her in a meaningful way. The following passages exemplify this phenomenon as boundaries became more pronounced as a result of the ravages of AIDS complications:

> The dementia began to set in. The last time I saw him before he went into a coma, dementia was pretty complete. He was disoriented. He recognized me but quickly lost my identity and didn't know what to call me because at one point he looked at me and said "I don't know who you are and I don't know why you're here, but I thank you."
>
> He was so articulate. I was just impressed by the words that rolled off his tongue. Yet, he didn't know where he was. He didn't have the slightest idea. In a way I was happy for him. I mean he was in a much happier place.
>
> It would be one thing if your mind just went one time and it would be gone but with these folks they come in and out of it. So you never know from one day to the next where they're gonna be or if you can contact them.

Boundaries Between Participants and Others

Participants were also aware of boundaries between themselves and others in their world. They described their relationships with significant others in their lives as becoming more intimate and intense, bonding more closely for support and comfort as their loved one came closer to death. Participants' experience of their boundaries among family and friends diminishing are portrayed in the following passages:

> Since then, my big concern in [my mother] not knowing was feeling like I was going to have to sort of take care of mom as well as be strong emotional support for my brother. And in fact, it's turned out that we're all just sort of there for emotional support for each other. . . .That has felt wonderful to see that we can pull together and be there for each other.

> Overall, it's been a close family. But this crisis has definitely brought us closer. I'm not even sure if it's closer or if it's brought more of an openness. By being able to really share what's going on with us. We've never shared what's happening in our lives. . . .Sure we all get information as far as lifestyle. But a certain vulnerability has opened up. And I guess a crisis often does bring families together. I guess it's something that I've always desired in my family. We also have created certain barriers around us. We share but only up to a certain point. And in this situation, it seems to have just melted away some of those experiences we need to talk about, or feelings on a deeper level than what we have before.

> As he got sicker, the family just really became very close. Then I really got pulled into the family - became part of the family. . . his parents and I became very close, and particularly his mother and I had become very close since [he] died.

Participants also experienced others in their world moving away from them as their relationships with PWAs became known. Boundaries were extended and distance was created by others - sometimes abruptly and sometimes gradually - as others became aware of participants' relationships with PWAs. Consider the following excerpts as participants portray the withdrawal of others from their lives as a result of their associations with PWAs:

> One day in the spring. . .one of the women at the school (we had become good friends) said "You are so sad. What's wrong?" So I told her that my brother was dying of AIDS. Never carpooled again. That was it. Over and done. Total cutoff. Didn't want her kid playing with my kid. Didn't you know that I just thought it was stupid. I mean that's all you can think.

> I think part of the reason that I ended up dating a lot of guys who are positive as opposed to a lot of guys who are negative has to do with the fact that when I tell them what I did - when I'm meeting a guy who finds out what I do - there are guys that have been scared away by that. And you deal with AIDS so they move away from that like anybody who has contact with AIDS they automatically assume I have AIDS just by association. They are afraid to go to bed with me.

> I think one thing that I didn't expect to happen that did was I knew that PWAs were isolated from society and felt cut off by people. . . .even though I'm not going to catch AIDS from anybody, I sure as hell caught the isolation. It's a real infectious thing. . . .You can't even talk in general terms about what you do to friends and family because you get one of two reactions. They either make you start eating off paper plates when you come to family gatherings, or they say really helpful stuff, like, "Well, why do you want to do that?" . . .you can't go home and say, "Geez, I'm tired, this is a rough day." 'Cause what you'll get in response is, "Well, I told you not to do this" or "What's wrong with you that you want to do this?" or "Why in the world do you want to be around people who are dying?" Or "You don't have any junkies in your social circle normally, so why do you want to hang around with junkies and hookers now?" So, you get isolated.

Boundaries between PWAs and Others

Finally, participants were aware of changes in boundaries between PWAs and others in their world. Again, such boundary changes were precipitated by the PWA moving toward others, the PWA moving away from others, and others moving away from the PWA.

Participants were aware of the ways in which PWAs bonded to others for support and comfort. This was done as a result of the progression of their disease, or in attempts to better themselves in some way. The following passages denote the ways in which participants saw PWAs drawing closer to others:

> About the last five or six months or so she has gotten really involved in the church. Now everything we talk about, everything she talks about centers around the people in her church. . . .She's cleaned up her act a great deal and has developed some very close ties in her church. . .there is a support mechanism there for her. There are some people she can trust to do things for her and her daughter.

> An extraordinary thing happened to [him] over the nine months that I knew him. He came from a family that did not touch. At all. Ever. And over the course of that nine months, I got him to be a "touchy, feely" person and he really liked being touched. And he told me that on Thanksgiving, which was three days before he went into the hospital for the last time, at their Thanksgiving dinner, the whole family was there. He went up and gave his Dad and his brothers a big hug and they were completely startled by that, and did not know how to react to it at all. It just startled them because they don't do this. And he just wanted to touch them just once in his life and he did. And I thought that was a pretty extraordinary change for a person to make at his stage in life.

> I called him at home just to check on him and make sure that he really wanted to spend his energy in that kind of way coming to group. Each time he gave me the same answer. "Yeah." He said, "It's my major social outlet and I know that everyone in that room loves me and there's no place else in the world that I'm sure that everybody loves me."

Just as PWAs moved toward others, they were also seen as moving away from others in their lives. Recalling participants' experience of PWAs' withdrawal from them, it is apparent how distance was also created between PWAs and others in their world also. Consider again how a PWA's withdrawal through illness or by choice affected not only the boundaries between themselves and the participants, but between themselves and others, as well:

> After he really got sick he became very withdrawn. He didn't want to talk about it anymore, because all the talking was done. He was just very impatient for it to all be over with.
>
> . . .there are some of the [PWAs] , some of the people they are trying to work with who are distant, very resentful, or just not very receptive to being helped.
>
> He alienated himself from people. He had plenty of people around him if he treated them with respect. They would probably have helped him and done anything they could for him, but he abused them. He ran a lot of people off. He was just a real piss ant sometimes. He'd just be meaner than hell.

Rejection of the PWA by others was common when his/her disease became known. As others turned away from the PWA, his/her social realm and support system rapidly collapsed. Not only did this rejection come from society at large, but also from significant others in the life of the PWA, including friends, family and lovers. Participants delineated their awareness of such rejection in descriptions exemplified by the following passages:

> I always try to hug on everybody and flirt with everybody. I just think that matters, because there so much of a tendency for people to be like "Oooh, you've got AIDS, I'm scared of getting it from you, or I don't want to touch you or be close to you." I just think that matters a lot.
>
> . . .as far as colleagues or neighbors or people like that, she doesn't want to get into [her illness] with them and risk word getting out that would

> come back to her child - that her child might be mistreated, or that her house might be broken into or just having to deal with the rejection.
>
> You get those things from PWAs all the time when you hug them or do things. They're starved - starved for the most part for physical attention. Even people who weren't real "huggy, kissie" before they got sick, did get some kind of physical contact. And a lot of them don't get it after their diagnosis is well known.
>
> His mother was a trip - didn't want to touch him. Spoke to him in a third person. Talked to me, right in front of him in the third person. Just made me mad. And she said, "Look, do you think he's ready to go?" And I said, "I don't know, are you ready to go?" I had to communicate to him which made me angry at her. This is still your son. This is not a sack of potatoes over here.
>
> Her mother told her if it did come back positive she didn't ever want to see her again.
>
> We have distorted the picture of families, lovers, whatever. . .supporting the person that's ill. And in my experience that's not terribly accurate, or terribly likely to happen. . . .Only one instance did the lover put in what I would call the "ideal" helpmate of the person who was sick.

On occasions, a PWA's significant others would not directly reject him/her, but would create another form of distance through their denial of the issues going on in terms of the disease. Consider this participant's description of his experience with the family of a PWA when they refused to accept the reality of AIDS in their midst:

> His family would not deal with any of these issues. The doctor described it perfectly. . . . .The family situation [was] like being at a formal dinner, and everybody noticing that a cockroach was crawling up the center of the table and no one would say anything about it because it would be

> rude, but everyone was aware of the cockroach. I thought that was a perfect description of the dynamics going on in that family.

A final way in which participants experienced PWAs as being rejected by others was through society's ignoring the problem of AIDS. Participants often proffered descriptions of negative, rejecting public attitudes toward the AIDS epidemic, as well as government policies which reflect these viewpoints. The general public was also described as being ignorant of the scope and threat of AIDS, epitomizing disconnection from it, as well as those who are afflicted with it. The following excerpts depict the ways in which public rejection of PWAs, as well as the AIDS problem as a whole, were experienced:

> I was and I still am disappointed with the boundaries that are made on these [people], and I don't think it will ever change until the boundaries - the initial boundaries of family and friends - are eliminated. There's never going to be a point where the heterosexual community is going to totally envelope the disease as a cause until fifty percent of the people getting AIDS are the heterosexual people, which won't be long, you know. . . .I find most of my friends are sympathetic to me, but certainly no one would believe that their children going to college could possible have a chance of getting AIDS. I think that is pretty darn scary. [It is] something I am well aware of, but I can guarantee that ninety percent of my friends won't be. I just think there is too much boundary. I found that through the disease all along and I still find it.

> As I recall, we've cried on each other's shoulders more than once. . .and probably will again before this terrible thing comes to an end. We're spending millions of dollars a day in the Middle East and people are dying right here in town in front of us - alone when they've been abandoned by families. One could get on a soapbox about governmental priorities, but I choose not to.

Summary

As seen in this chapter, the three themes emerging against the background of time (Impact, Roles and Boundaries) presented themselves in several ways. Each theme had various elements, or forms, in which it revealed itself. Impact was perceived as reciprocal between participants and PWAs, as each exerted influence on the other at various times. Roles were described in terms of the perceived identities of PWAs and of participants, as well as the perceived similarities and differences between participants and PWAs. Boundaries were described as they were perceived to exist between participants and PWAs, between participants and others, and between PWAs and others. These three themes comprised the overall experience of relationships with others.

The themes were not mutually exclusive as they emerged within the protocols. As can be seen in various passages, more than one theme may emerge within any description of experience, adding depth and richness to the accounts of relationships with PWAs depicted in this study.

CHAPTER 4

DISCUSSION

The three themes emerging from the descriptions of personal relationships with persons with AIDS (PWAs) were Impact, Roles, and Boundaries. These three themes comprised the overall experience of relationships with others. These themes emerged against the ground of Time. In this chapter, each theme will be discussed in terms of the psychosocial issues that surround that theme, and the relationships of these issues to the lives of those involved with PWAs, as well as the PWAs themselves. The relationships of the findings to psychological and existential theory and another study examining the experience of others will also be discussed. Finally, the implications for therapists working with significant others of PWAs will be addressed.

Impact: Interpersonal Influence and Reciprocity

The social phenomenon of altruism seems to proliferate within the helping professions and in volunteer organizations. This phenomenon has most recently been manifested in the onslaught of AIDS volunteers (Omoto

& Snyder, 1990). Those who become helpers, either by profession or through volunteer activities, most often do so in hopes of learning about themselves or having an impact on others to whom they offer their time and efforts. Although these motives may often be unavowed, they are still thought to be present as driving forces of all forms of altruistic activity (Edelwich & Brodsky, 1980).

These needs seemed to be met repeatedly in participants' experiences with PWAs. Accounts of the positive influence exerted over PWAs ranged from being one person's only friend and support to prompting another to take charge of preparations for his own death and burial. More often, however, participants perceived themselves as motivators for PWAs, encouraging them to take charge of their lives and maintain the fight for survival in the face of death. It has been suggested that a PWA's survival can often be dependent on or enhanced by the empowerment others give to him/her (Haney, 1988; Jimenez & Jimenez, 1990). Thus, the impact participants had on PWAs is not only a crucial factor in bonding, but also in survival.

Interpersonal influence assumes the dimension of reciprocality in human relationships. Just as participants were aware of their impact on PWAs, they were also keenly aware of PWAs' impact on them. A significant way in which PWA relationships impacted on participants was in their being made aware of their own mortality as they witnessed the decline and deaths of PWAs. Cohen (1979) notes that one person's experience of the death of another makes him/her more mindful of his/her own life, suggesting that we cannot be closely involved with death or the prospect of death without being aware of its inevitability for us, as well.

Thus, as one person enters into a relationship with another, the naked humanity of one inevitably bears witness to the humanity of the other. As Kalish (1985) notes, the experience of another's decline and death makes us aware not only of our own mortality, but also of our powerlessness to prevent suffering and death. As participants' accounts have shown, this sense of powerlessness may also be felt in our inability to circumvent the inevitability of our own deaths.

Suffering is inevitable for those close to PWAs due to the fatality of the disease. The impact of loss is certain for significant others who care for their loved ones (Fortunato, 1987). Frierson, Lippman and Johnson (1987) note that the sickness and decline of a PWA often render family members feeling helpless to change their loved one's situation. This most often leads to survivor guilt, especially surrounding their perceived responsibility for their son's homosexuality. Such negative feelings have sometimes been exacerbated to the point of suicide (Frierson & Lippman, 1988). Similar negative feelings were experienced by participants in this study, and were by no means confined to biological family members. As participants experienced the decline and death of PWAs, they often felt the same pangs of guilt and helplessness over their inability to change the PWAs' conditions. This experience was described by gay men in this study, however with an added dimension. _Their_ guilt was often further aggravated by the realization that they had been spared from the ravages of AIDS, despite the fact that they had led lifestyles similar to those who were afflicted with and had succumbed to the disease. Thus, survivor guilt took on another dimension for an already frightened and grief-stricken group of people touched by AIDS.

Buber (1947) contends that interpersonal impact is inevitable in an _I-Thou_ relationship. No two individuals can truly meet each other without the occurrence of mutual influence:

> My _Thou_ affects me as I affect it. We are moulded by our pupils and built up by our works. . . .How we are educated by children and animals! We live our lives inscrutable included within the streaming mutual life of the universe. (pp. 15-16)

The relationships described in the present study are indicative of _any_ interpersonal relationships. The theme of impact delineates the quintessential element of instrumentality, which prevails in all human interaction.

Roles: Understanding the Human Identity

Des Pres (1976) speaks of a concentration camp survivor as one who "...must preserve an identity apart from the one imposed by his environment ..." (p. 100). Society has been quick to label PWAs in derogatory or limiting ways, categorizing them either as pariahs or as simply 'sick with AIDS', in which case this disease becomes their sole identity. However, participants experienced PWAs in a radically different way. They were able to enter the life world of PWAs in order to understand them in the fullness of their humanity. Thus, through the participants' understanding of the PWAs, the true life roles of the PWAs were maintained.

As Watson (1989) contends, in order to truly engage in caring, we must be able to understand the life world of an individual. Likewise, Flaskerud (1987) contends that the entire life experience of a PWA must be recognized and respected before we can truly 'de-objectify' that person, and allow him/her to maintain the status of a human being in our eyes. Participants were able to truly accomplish this task in their relationships with PWAs. They did not assign labels, or look upon PWAs as having a disease. Rather, their recognition of the personhood of PWAs emerged in spite of their having AIDS. In this way, PWAs were 'rehumanized' against the dehumanization imparted to them by the rest of the world.

The practice of labeling others runs rampant, even pervading the major religions of our society. Taylor (1989) argues that the religious response to suffering is to adhere to the dogmatic structure and meaning the religion assigns to the world and its events, and then to eliminate others' suffering, regardless of the meaning assigned to it. While the Judeo-Christian world may take up the fight against human suffering and indignity, 'tagging' of certain groups of PWAs as homosexuals or drug-abusers could be considered 'religious demoralization' and objectifying of suffering persons. Ironically, the assistance religious organizations offer can be nullified by the rift created through religious condemnation of the very ones they attempt to help.

Similarities and differences in life roles of PWAs and participants arose as a significant issue in this study. PWAs from lower socioeconomic status (SES) brackets have been found to put more stress on those trying to help them cope (Tiblier, Walker & Rolland, 1989). This premise rang true throughout participants' descriptions of their relationships with PWAs of lower SES brackets. Given the fact that participants were all from middle to upper class SES brackets, relationships of this type were described as unusual, with AIDS being the one and only reason for a social bond to exist. This made interactions difficult and strained, taking an unusually hard toll on helpers. As one participant noted, however, AIDS knows no social or economic boundaries. As the epidemic begins to spread to new populations in this decade, more cultural differences between PWAs and their helpers are likely to emerge (Day, 1990). Helpers are well advised to remain aware of possible differences in the life roles between PWAs and themselves. In order to avoid objectifying a person whose life experiences are radically different from those of the helper, the differences will need to be addressed and reconciled (as far as possible) by remaining attuned to the reasons the relationship exists.

Boundaries: Bonding and Disengagement

Kubler-Ross (1987) contends that while the gay/lesbian community has rallied forces to take care of their own in the face of the AIDS epidemic, society at large continues to reject PWAs, as well as their families and friends. Despite the efforts exerted in the past decade to dispel the myths and fears surrounding AIDS, stigma and discrimination toward those with the disease still runs rampant in the 1990s (Walkey, Taylor & Green, 1990). Surprisingly enough, this stigma is still present even among medical professionals (Norton, Schwartzbaum & Wheat, 1990).

Weiss (1988) notes that as others withdraw from PWAs, social circles become tighter and take on new meaning for PWAs as well as those associated with them. This phenomenon is readily apparent in participants' descriptions of their awareness of PWAs' interactions and bonding with them, as well as with others. Participants understood that PWAs were losing their external supports on many different levels, which necessitated their seeking support from new, less familiar sources or from each other. Such bonding was described as reciprocal, as participants felt a special intensity in the relationships. This was true even for participants who had known PWAs only in their official 'buddy' capacity. The meanings that participants assigned to their relationships with PWAs are indicative of a social phenomenon in Nazi concentration camps described in <u>The Survivor</u> (Des Pres, 1976). Oppression was resisted and morality and dignity were kept alive through collective social bonding. New relationships were formed while old ones were strengthened in a united struggle to survive in the face of persecution. Likewise, in this study, participants experienced their relationships with PWAs as mutual struggles against suffering and social isolation. As we recall one participant's portrayal of her alliance with PWAs, these relationships are clearly described as follows:

> . . .being a friend and a witness and a support person for those folks. . . .a witness to suffering and struggle. . . .One thing that really does

> help a lot of folks, especially in a heroic struggle, is that they have a witness. . .someone who understands what they're going through and sees it. That makes it real.

Benner and Wrubel (1989) suggest that "caring" implies a cognitive, affective and behavioral connection to someone who matters to a person. This requires "presencing", which involves being able to make meaningful contact with that person. This definition of caring may be called into question as we examine participants' descriptions of their boundaries widening and intimacy decreasing as dementia thwarted the cognitive and emotional exchange between PWAs and participants. Although the level and quality of contact diminished, it would be difficult to assume that participants' caring for the PWA diminished as well. At this point, perhaps caring takes on a different meaning. It is doubtful that participants cared any less for PWAs as their health declined. However, changes in relationship norms necessitated modifications in boundaries. Caring, at this point, could be seen as becoming more practical than emotional.

Interpersonal Movement and the Reduction of Anxiety

Horney (1945) contends that individuals' interactional styles are the products of inner conflicts, which provoke them to act in a particular way in relation to others. These conflicts may result from internal struggles over problems such as religious/spiritual issues or moral/social values. Horney suggests three interpersonal strategies individuals adopt to cope with their conflicts: a) moving toward others (protecting oneself by attachment, dependency and bonding); b) moving away from others (protecting oneself through withdrawal and isolation); and c) moving against others (protecting oneself through aggression and hostility).

These three coping strategies are seen clearly in participants' relationships with PWAs and others in their lives, as well as in their awareness of PWAs' relationships with others. In terms of moving toward others, PWAs and participants were able to bond and form intimate personal attachments very quickly due to the prospect of impending death of the PWA and the anxiety this would naturally produce. Ironically, as PWAs prepared for death, participants were often aware of their moving away from others, as they withdrew from those to whom they had previously been close. Participants also described their awareness of PWAs being abandoned by others when their disease became known. Likewise, they recounted their experiences of others in their lives moving away from them, as their association with PWAs became known. One participant offered a powerful description of the experience of others' withdrawal as she remarked:

> ...I knew that PWAs were isolated from society and felt cut off by people. . . .even though I'm not going to catch AIDS from anybody, I sure as hell caught the isolation. It's a real infectious thing.

As we consider the social body's rejection of PWAs and their companions, we are compelled to consider how much more insidious and pernicious the fear of AIDS is than the disease itself.

Finally, this fear manifests itself in terms of others moving <u>against</u> PWAs and participants. This is exemplified in one participant's awareness of a PWAs fear of violence being done to her or her family if her disease was revealed. Such malevolent reactions of others to PWAs and their companions are common occurrences within a society in which attitudes and actions are so often the manifestations of fear and prejudice.

The Social Body, Plague and Moral Revolt

Murphy (1989) has stated, ". . .AIDS produces a severe dismemberment of the social body. . ." (p. 52). As AIDS continues to spread, little relief from fear and prejudice has been witnessed. AIDS has been identified with plagues of past centuries, as plague becomes the central metaphor for the epidemic (Sontag, 1988). In the last decade, AIDS was primarily associated with risk groups which were already held in contempt by society at large. The attachment of this deadly disease to already tarnished identities rendered such groups a "community of pariahs" (Sontag, 1988, p. 25) in the public eye.

The general tendency to blame the victims and pass judgment is a social phenomenon depicted by participants in this study. This phenomenon bears alarming resemblance to the public reaction portrayed in The Plague (Camus, 1948), an allegory depicting the psychosocial ramifications of an outbreak of bubonic plague in one city. In his comments on Camus, Murphy (1989) notes that the existential revolt in the face of the plague was not only a revolt against death, but also against intolerance and irrational fear brought on by the mass hysteria of the citizenry frightened for their lives. This produced a splitting of society into factions of those whose actions were driven by fear and those whose actions were based on compassion and prudent judgment. The latter become the models for a modern day world faced with a similar sociological crisis. The compassionate can become healers for a social body torn apart by fear of a disease, but more so, by fear of its victims.

The revolt against social intolerance toward AIDS and its victims is clearly seen in participants' experience of PWAs as whole persons and their adamancy in expressing this to others. In the face of being stigmatized by society and significant others for their association with PWAs, participants remained faithful to their convictions. They were steadfast advocates for their PWAs, helping them to maintain dignity and individuality against a barrage of prejudicial labeling and aberrant reactions precipitated by fear and the collapse of reason. These modern day good Samaritans were fearless in their support of others in the absurd struggle against disease and malignity.

Existential Issues

Everyday Experience and the Context of Time

Heidegger (1962) contends that everyday being (Dasein) is grounded in temporality. An individual is aware of his/her present being in the light of his/her own past and future. As participants described their relationships and the ever-changing roles they adopted with PWAs across time, they were always aware of themselves within the context of that relationship at any given time. This awareness was cast against the background of time. As participants witnessed the decline and approaching death of a PWA, they were aware of their own mortality and ultimate demise - an anticipated event to be realized at some future point, but yet very much a part of their present awareness. In their descriptions of the roles they played in the lives of PWAs, participants were also aware of the potential for their roles to change with the passing of time, effectively transforming who they were in that relationship. Here again, their present awareness incorporated potentiality, as well as the immediate experience.

The Meanings of Death

In a study by Ross (1987), death was often perceived as meaningless, creating a barrier which thwarts the maintenance of relationships with others. This barrier to life's meaning was experienced by participants as the physical and mental decline of PWAs redefined their relationships, creating obstacles to communication and shared activity.

In the same study, death was also perceived as meaningful, as it appealed to the meanings of life. As the inevitability of death loomed closely over the relationships between participants and PWAs, they created meaning in these relationships by developing intense, intimate bonds in relatively brief periods of time. This brought new significance to these relationships, which might otherwise have had little or no meaning.

Time, Limits and Choices

In a study by Dapkus (1985) time was experienced as limited, thus creating limitations of existential choices. The result of limited time is a restriction of alternatives. This affects not only what individuals do, but also how they choose to be with others. Again, this phenomenon is manifested in relationships between participants and PWAs, as they chose to become very close to each other very quickly, circumventing the usual social dance performed in the early development of friendships (due to the limited time in which they could accomplish this). AIDS brings death and loss. Therefore, those who establish new relationships with persons already afflicted with the disease are keenly aware of the time limits on such relationships, and the resulting need to cut away from less essential aspects of human bonding.

In the same study, time was also experienced as a marker of change. In the present study, as the health of PWAs declined, boundaries became wider, as participants perceived their roles with PWAs as becoming more practical. Thus, participants experienced their relationships with PWAs as changing, as cognitive and emotional contact diminished and interpersonal roles were modified, contingent upon the passing of time.

The I-Thou Relationship: Reflections on Buber

Buber (1947) contends that we are capable of two basic relationships with others. The I-Thou relationship between two persons involves one person experiencing another in the other's wholeness, rather than in part, or a sum of those parts. In order for an I-Thou relationship to exist, the 'other' cannot be objectified. This intersubjectivity is the fundamental rudiment of one-on-one relationships. Objectifying the other in any way transforms the relationship into an I-It connection.

Poignant comparisons of these two relationships are seen in participants' descriptions of lost communication and intimacy with PWAs across time. Participants' awareness of and interaction with PWAs in his/her 'fullness' diminished as dementia set in, and emotional and intellectual contact decreased. Another contrast between I-Thou and I-It relationships is seen in participants' acknowledgements of and interactions with PWAs as whole persons, while the social body categorized PWAs as 'sick', 'unclean' or unacceptable in some other manner, thereby objectifying those individuals.

Regardless of how intimate one's relationship with another has been, no I-Thou relationship can be maintained forever. As the Buber notes:

> . . .every Thou in our world must become an It. It does not matter how exclusively present the Thou was in direct relation. As soon as the relationship has been worked out or has been permeated with a

> means, the Thou becomes an object among objects - perhaps the chief, but still one of them, fixed in its size and limits. (pp. 16-17)

One participant aptly characterized Buber's premise in a description of her present experience of past relationships with PWAs:

> It's hard to sort through the degree of loss, the impact that each different individual had. They're more like a sea of faces now, rather than distinct individuals.

Despite the amount or quality of direct experience with the other, recalling a relationship objectifies the other, as well as the relationship itself.

Normalizing the Experience of Relationships with PWAs

In a study by Carper (1991), the experience of other people was examined to find three themes similar to those emerging in the present study: a) Benefit (suggesting utility or hinderance of the other through interpersonal relationships); b) Comparison (suggesting perceived similarities and differences between individuals; and c) Connection (suggesting relatedness or alienation between individuals). In comparison with the present study, the benefit one experiences from others correlates with impact in terms of the interpersonal effect one person has on another. Likewise, the comparisons one makes between him/herself and others correlates with the roles one is aware of in relationships with PWAs, particularly in terms of perceived similarities and differences between two individuals. Finally, the connection one feels with others correlates with boundaries as an awareness of the closeness or distance one experiences with others.

The significance of these similarities lies in the portrayal of the normality of relationships with PWAs. Homophobia and lack of knowledge of the disease itself have created a wide chasm between the social body and those afflicted with AIDS. Views of PWAs and others associated with them have historically been negative, fear-ridden and contemptuous. Comparisons of the experiences of relationships with PWAs and with others in general suggest that the existential experience of others does not change based upon a given characteristic of the other person.

As we are reminded by participants that a PWA is a human being first, the normality of the relationship one has with a PWA becomes even more evident. The lack of acceptance of PWAs witnessed in the past decade thus shows itself to be clearly a phenomenon born out of fear and prejudice, rather than out of reason.

It is interesting to note that in the questions asked of the participants in the interviews, it was not suggested that they talk about their relationships with others, but about their experiences with PWAs in general. However, in every interview the focus was always on their interpersonal relationships with others, including not only PWAs, but other persons in the participants' lives, as well.

Pre-existing Relationships: A Comparison of Experiences

It is important to note the contrasts observed between participants' relationships with PWAs as buddies and their relationships with PWAs in other capacities. In examining the interview protocols, several differences emerged between the relationships participants had with PWAs to whom they had been assigned as buddies and relationships they had with friends and family members who developed AIDS after the relationship had been established.

In 'buddy' relationships, participants described the boundaries between them and their PWAs as diminishing at a rate of speed incongruous with that expected in the development of other social relationships. The intensity of such relationships seemed to be closely related to the amount of time available for both parties to develop them. Buddy relationships were always punctuated by the reality and closeness of impending death.

Furthermore, in regard to 'buddy' relationships, participants related accounts of having experienced the true humanity of PWAs after they had developed friendships with them. In buddy role, participants sometimes objectified PWAs whom they had just met, relating to them as clients or sick persons. Only after developing relationships with the PWAs did the participants gain insight into their lives, understanding that they were whole persons rather than objects of a single-faceted perception.

In contrast, participants who described relationships with friends and family members who later developed AIDS were not necessarily aware of a new intensity or urgency in the relationship when the disease became an issue. The norms of such relationships were already established and stable, the intensity already being present. Ways of being with friends and family were predicated by fear of losing loved ones to the disease, rather than fear of losing the chance to develop the relationship.

Furthermore, participants who had already established significant relationships with PWAs in ways other than through 'buddy' contacts were already fully aware of the personhood of the PWA. Their perceptions of PWAs were contingent of their relationships with friends and family members, rather than upon meeting a stranger within the context of a deadly disease. In these cases, AIDS became simply an additional facet of, rather than the sole descriptor of the PWA.

Therapeutic Issues

The accounts of relationships with PWAs portrayed in this study have made it clear that the needs of the significant others of PWAs often go far beyond those of caregivers for others. As Morin and Batchelor (1984) have noted, the stigma surrounding AIDS precipitates a host of new psychological issues, not only for the PWA, but for significant others, as well. In order to be effective with persons facing these challenges, therapists must be aware of and sensitive to these issues.

The stigma of AIDS often prompts secrecy within families or other social units. Significant others of PWAs often feel the need to hide the reality of their relationships from others who may be unsympathetic, fearful or hostile. This lack of social support can result in additional hardships for caregivers in the face of increasing chronic care needs or significant losses. The roles of significant others can become increasingly demanding and interpersonal relationships less fulfilling as a PWA's health deteriorates and/or dementia sets in. Thus, the loss a caregiver experiences can be further compounded by losing an intimate, gratifying relationship even before death. These compound hardships become additional psychosocial stressors for those who are already faced with the difficult task of caring for a sick or dying loved one.

Individuals engaged in relationships with PWAs are faced not only with the untimely death of a significant other, but also with the realization of their own mortality as they deal with a fatal disease. Not only do they feel helpless to save the other, but also feel helpless to save themselves from ultimate death. As in the case of anyone dealing with issues surrounding disease and death, existential concerns are very likely to arise in the context of therapy.

Grief and loss issues can be especially intense for significant others of PWAs. Given the age range of those afflicted with the disease, the illness and death of a PWA is most often untimely. Furthermore, multiple AIDS deaths may have to be dealt with by one individual, especially if that person is a member of or deeply involved in the social community of a high risk group. (Although this is especially true of the gay community at the present time, the face of such groups is beginning to change, as AIDS spreads further into the heterosexual population.) Worden (1982) stresses the importance of accepting the reality of one's loss as one of the tasks of healthy grieving. This can be difficult for someone who must hide his/her loss from others who are unsympathetic. Such situations can often result in complicated grief reactions for those who have experienced losses.

Therapists can help significant others of PWAs become aware of and make use of available support systems for those dealing with AIDS-related issues. For those acting in volunteer capacities (such as the participants in this study), 'buddy' or other volunteer support groups are most often organized and promoted within the AIDS support organizations. Community agencies and other networks provide support groups for significant others of PWAs. It is important for therapists to be aware of these groups and/or other organized support systems available for their clients. Also, the therapist can help the client explore and identify individuals within his/her family and circle of friends who would be understanding and supportive. It would be prudent to identify these support systems as early as possible in order for the client to take the best advantage of them.

Therapists also need to be pay attention to the coping strategies of clients. In the face of stress in the relationship with a PWA, the significant other may elicit some maladaptive coping mechanisms which could be harmful to the individual. These may include smoking, over/undereating and abuse of alcohol or other drugs. Therapist can help clients become aware of changes in living patterns, while advocating and reinforcing positive, more adaptive coping strategies, such as exercise, meditation, and use of support groups.

Finally, therapists are responsible for being aware of their own issues surrounding AIDS and at-risk populations. Even though the face of endangered/infected populations is shifting, currently the disease is still largely associated with gay males, intravenous drug users and other minority groups. Even though the significant others may be once removed from the actual PWA, prejudicial biases can arise for therapists and countertransference issues can impede the therapeutic relationship. This can be especially true for therapists working with clients from a population with which they are unfamiliar and have little or no experience, including gay lovers of PWAs or minority clients. Therapists need to address their issues surrounding prejudice or bias, and deal with them through professional consultation and/or therapy. Otherwise, referral of clients with AIDS/minority-related issues would be necessary.

Limitations of the Study

The limitations of this study can be discussed in terms of methodological considerations surrounding qualitative research, particularly existential-phenomenology. The issues of reliability and validity relating to the precision and accuracy of data must be addressed in order to discern the restrictions of this study and the possibilities for variations.

Reliability

Wertz (1986) states that in existential-phenomenology, the researcher seeks discrepancies across the span of data in order to modify and amend the meanings initially derived from the first few texts, or several readings of one text. Since both quantitative and qualitative research find their origins in human subjectivity, the information gathered from them can be considered restricted, relative (and therefore unreliable) to a certain degree. The number of interviews collected for this study (fifteen) was chosen based upon the methodological considerations of similar studies. After the analysis of several interviews, no new themes emerged from the data. This indicated that the structure had presented itself as it existed, thus suggesting reliability of the data.

It is important to note, however, that participant selection was somewhat restricted. Although all volunteers were members of the AIDS Response Knoxville Buddy Program, three family members and two personal friends of PWAs described their relationships with PWAs in capacities other than 'buddies'. The remainder had been assigned to PWAs as official buddies. No one described experiences with lovers or spouses. If the purpose of existential-phenomenological research is to seek discrepancies across the data span, perhaps inclusion of participants displaying a wider range of relationships with PWAs could have provided a broader array of descriptions of the experience from which to obtain the structure of the phenomenon. Although the basic thematic structure would probably have not changed, descriptions of the experiences may have offered more comprehensive insight into the phenomenon under investigation.

Validity

Addressing internal validity, Wertz (1984) notes three issues which need to be addressed in order to maintain rigor in existential-phenomenological research: a) participant selection, b)data collection, and c)actual data validity. Participant selection in this study was valid, since all participants had experienced the phenomenon in question, and were willing and able to talk about it intelligibly and articulately. Likewise, data collection seemed to be valid, since interviews produced rich, in-depth protocols from which a clear thematic structure emerged. However, the validity of the actual data can be called into question, as is true of any study of this nature. The possibility of deletions, omissions, deceptions and concealments on the part of the participants must not be overlooked. The issues of AIDS and relationships with PWAs are sensitive and affect-laden. Thus, participants may have consciously or unconsciously chosen to delete or modify certain material from their reports. Also, the interviewer may have unintentionally had an effect on participants' responses as a result of leading or confusing questions, or other interpersonal dynamics. Although participants may not have been aware of them, such internal or external influences could have affected their full and accurate portrayal of their experiences (Nisbett & Wilson, 1977).

Regarding external validity, this study could be considered limited in its relevance, or generalizability to the population at large. Although the thematic structure which emerged is quite similar to that of experiences with other people in general (Carper, 1991), the restricted focus of this study might suggest that inferences from it could be made only to those who have had relationships with PWAs. Furthermore, it may elicit interest from a smaller group of readers than a study of a more general nature.

Suggestions for Further Research

In the last decade, AIDS has been relatively confined to a limited number of sociocultural subgroups, especially gay men and intravenous drug users. However, the current decade is signaling a change in the face of the epidemic. Outbreaks of the disease are becoming increasingly prevalent in the heterosexual population. As this happens, the sociological ramifications of having AIDS are likely to be recast in light of the fact that it will no longer be exclusively a 'gay' or 'junkie' disease. As the stigma, prejudice and fear associated with AIDS and its victims (hopefully) diminish, society will be faced with decisions regarding how to feel about and respond to the victims of this epidemic.

The results of this study have shown how fear and stigma have affected interpersonal relationships and perceptions of PWAs and their significant others. As PWAs take on different demographic characteristics and society becomes more aware of the reality of the disease and the extent to which it touches people from all realms of life, the experience of relationships with PWAs may take on a different thematic structure. Therefore, it is suggested that future studies be conducted to determine how the sociological phenomena surrounding AIDS has changed, and to examine the possibly different ways in which this disease affects the lives of its victims and their significant others.

REFERENCES

REFERENCES

Allers, C. T., & Katrin, S. E. (1988). AIDS counseling: A psychosocial model. Journal of Mental Health Counseling, 10, 235-244.

Alpack, R. (1972). The phenomenology of the natural athlete. (Doctoral dissertation, Duquesne University, 1972). Dissertation Abstracts International, 33, 6098B.

Andersen, H., & MacElveen-Hoehn, P. (1988). Gay clients with AIDS: New challenges for hospice programs. The Hospice Journal, 4(2), 37-54.

Backer, T. E., Batchelor, W. F., Jones, J. M., & Mays, V. M. (1988). Introduction to the special issue: Psychology and AIDS. American Psychologist, 43, 835-836.

Barrett, R. L. (1989). Counseling gay men with AIDS: Human dimensions. Journal of Counseling and Development, 67, 573-575.

Belfer, M. L., Krener, P. K., & Miller, F. B. (1988). AIDS in children and adolescents. Journal of the American Academy of Child and Adolescent Psychiatry, 27, 147-151.

Bellemare, D. (1988). AIDS: The challenge to pastoral care. Journal of Palliative Care, 4(4), 58-60.

Benner, P., & Wrubel, J. (1989). The primacy of caring. Menlo Park, CA: Addison-Wesley.

Bennett, K. (1987). A generation of children at risk. Journal of Psychosocial Nursing, 25(12), 32-34.

Bohne, J. (1986). AIDS: Ministry issues for chaplains. Pastoral Psychology, 34, 173-192.

Buber. M. (1947). I and thou (R. G. Smith, Trans.). Edinburg, G.B.: Clark.

Camus, A. (1948). The plague (S. Gilbert, Trans.). New York: Knopf.

Carper, B. (1991, March). The experience of other people. Paper presented at the conference of the Southeastern Psychological Association, New Orleans, LA.

Clever, L. H. (1988). AIDS: A special challenge for health care workers. Death Studies, 12, 519-529.

Cohen, K. P. (1979). Hospice: Prescription for terminal care. Germantown, MD: Aspen Systems.

Colaizzi, P. F. (1978). Psychological research as the phenomenologist views it. In R. F. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 48-71). New York: Oxford University Press.

Crystal, S., & Jackson, M. M. (1989). Psychosocial adaptation and economic circumstances of persons with AIDS and ARC. Family and Community Health, 12(2), 77-88.

Dapkus, M. A. (1985). A thematic analysis of the experience of time. Journal of Personality and Social Psychology, 49, 408-419.

Day, N. A. (1990). Training providers to serve culturally different AIDS patients. Family and Community Health, 13(2), 46-53.

Des Pres, T. (1976). The survivor. New York: Oxford University Press.

Donlou, J. N., Wolcott, D. L., Gottlieb, M. S., & Landsverk, J. (1985). Psychosocial aspects of AIDS and AIDS-related complex: A pilot study. Journal of Psychosocial Oncology, 3(2), 39-55.

Dundes, A. (1987). At ease, disease: AIDS jokes as sick humor. American Behavioral Scientist, 30, 72-81.

Dunkel, J., & Hatfield, S. (1986). Countertransference issues in working with persons with AIDS. Social Work, 31, 114-117.

Edelwich, J., & Brodsky, A. (1980). Burnout: Stages of disillusionment in the helping professions. New York: Human Sciences Press.

Elford, J. (1987). Moral and social aspects of AIDS: A medical student's project. Social Science Medicine, 24, 543-549.

Flaskerud, J. H. (1987). AIDS: Psychosocial aspects. Journal of Psychosocial Nursing, 25(12), 9-16.

Fortunato, J. E. (1987). AIDS: The spiritual dilemma. San Francisco: Harper & Row.

Frierson, R. L., & Lippman, S. B. (1988). Suicide and AIDS. Psychosomatics, 29, 226-231.

Frierson, R. L., Lippman, S. B., & Johnson, J. (1987). AIDS: Psychological stresses on the family. Psychosomatics, 28(2), 65-68.

Fuller, R. L., Geis, S. B., Rush, J. (1988). Lovers of AIDS victims: A minority group experience. Death Studies, 12, 1-7.

Gadow, S. A. (1985). Nurse and patient: The caring relationship. In A. H. Bishop & J. P. Scudder (Eds.), Caring, curing, coping (pp. 31-43). Tuscaloosa, AL: University of Alabama Press.

Geis, S., & Fuller, R. L. (1985). The impact of the first gay AIDS patient on hospice staff. The Hospice Journal, 1(3), 17-36.

Geis, S. B., Fuller, R. L., & Rush, J. (1986). Lovers of AIDS victims: Psychosocial stress and counseling needs. Death Studies, 10, 43-53.

Goffman, E. (1986). Frame Analysis. Boston: Northeastern University Press.

Greif, G. L., & Porembski, E. (1988). AIDS and significant others: Findings from a preliminary exploration of needs. Health and Social Work, 13, 259-265.

Hale, W. C. (1990). The experience of life change: A phenomenological investigation. Unpublished manuscript.

Haney, P. (1988). Providing empowerment to the person with AIDS. Social Work, 33, 251-253.

Hawthorne, M. C. (1988). The human experience of reparation: A phenomenological investigation. Unpublished doctoral dissertation, The University of Tennessee, Knoxville.

Hector, M. A., Bradley, K., Daigle, S., & Klukken, P. G. (1989). A phenomenological study of counseling process using videotape assisted recall. Paper presented at the annual meeting of the American Educational Research Association, San Francisco, CA.

Heidegger, M. (1962). Being and time (J. Macquarrie & E. Robinson, Trans.). New York: Harper & Row.

Hill, C. E. (1981). Counseling process research: Philosophical and methodological dilemmas. The Counseling Psychologist, 10(4), 7-19.

Horney, K. (1945). Our inner conflicts. New York: Norton.

Hycner, R. H. (1985). Some guidelines for the phenomenological analysis of interview data. Human Studies, 8, 279-303.

Jimenez, M. A. & Jimenez, D. R. (1990). Training volunteer caregivers of persons with AIDS. Social Work in Health Care, 14(3), 73-85.

Kalish, R. A. (1985). Death, grief and caring relationships (2nd ed.). Monterey, CA: Brooks/Cole.

Katoff, L., & Dunne, R. (1988). Supporting people with AIDS: The gay men's health crisis model. Journal of Palliative Care, 4(4), 88-95.

Kelly, J., & Sykes, P. (1989). Helping the helpers: a support group for family members of persons with AIDS. Social Work, 34, 239-242.

Klein, S. J., & Fletcher, W. (1986). Gay grief: An examination of its uniqueness brought to light by the AIDS crisis. Journal of Psychosocial Oncology, 4(3), 15-25.

Kubler-Ross, E. (1987). AIDS: The ultimate challenge. New York: Macmillan.

Kvale, S. (1983). The qualitative research interview. Journal of Phenomenological Psychology, 14, 171-196.

Lamb, D. H., Clark, C., Drumheller, P., Frizzell, K, & Surrey, L. (1989). Applying Tarasoff to AIDS-related psychotherapy issues. Professional Psychology, 20, 37-43.

Lennon, M. C., Martin, J. L., & Dean, L. (1990). The influence of social support on AIDS-related grief reactions among gay men. Social Science and Medicine, 31, 477-484.

Linn, L. S., & Kahn, K. L. (1989). Physician attitudes toward the "laying on of hands" during the AIDS epidemic. Academic Medicine, 64, 408-409.

Lomax, G. L., & Sandler, J. (1988). Psychotherapy and consultation with persons with AIDS. Psychiatric Annals, 18, 253-259.

Lopez, D. S., & Getzel, G. S. (1984). Helping gay AIDS patients in crisis. Social Casework, 65, 387-394.

Mahoney, M. J. (1982). Psychotherapy and human change processes. In J. H. Harvey & M. M. Parks (Eds.), The master lecture series, vol. 1: Psychotherapy research and behavior change (pp. 77-122). Washington, DC: American Psychological Association.

Martelli, L. J., Peltz, F. D., & Messina, W. (1987). When someone you know has AIDS. New York: Crown.

Martin, J. L. (1988). Psychological consequences of AIDS-related bereavement among gay men. Journal of Consulting and Clinical Psychology, 56, 856-862.

Masterson-Allen, S., Mor, V., Laliberte, L., & Montiero, L. (1985). Staff burnout in a hospice setting. The Hospice Journal, 1(3), 1-15.

McCarthy, M. (1989). Burnout: What price caregiving? Loss, grief and care, 3, 67-71.

Meintz, S. L., & Lynch, R. D. (1989). The human right of bonding for warehoused AIDS babies. Family and Community Health, 12(2), 60-64.

Merleau-Ponty, M. (1962). Phenomenology of perception (C. Smith, Trans.). London: Routledge & Kegan Paul.

Morin, S. F. (1988). AIDS: The challenge to psychology. American Psychologist, 43, 838-842.

Morin, S. F., & Batchelor, W. F. (1984). Responding to the psychological crisis of AIDS. Public Health Reports, 99, 4-9.

Muldary, T. W. (1983). Burnout and health professionals: Manifestations and management. Norwalk, CT: Appleton-Century-Crofts.

Murphy, J. S. (1989). The AIDS epidemic: A phenomenological analysis of the infectious body. In E. T. Juengst & B. A. Koenig (Eds.), The meaning of AIDS (pp. 50-60). New York: Praeger.

Murphy, S. P., & Perry, K. (1988). Hidden grievers. Death Studies, 12, 451-462.

Nelson, M. O., & Jarratt, K. (1987). Spiritual and mental health care of persons with AIDS. Individual Psychology, 43, 479-489.

Nisbett, R. E., & Wilson, T. D. (1977). Telling more than we can know: verbal reports on mental processes. Psychological Review, 84, 231-259.

Norton, R., Schwartzbaum, J., & Wheat, J. (1990). Language discrimination of general physicians: AIDS metaphors used in the AIDS crisis. Communication Research, 17, 809-826.

Omoto, A. M., & Snyder, M. (1990). Basic research in action: Volunteerism and society's response to AIDS. Personality and Social Psychology Bulletin, 16, 152-165.

Parks, L. K. (1987). A phenomenological investigation of the experience of emotional pain. Unpublished doctoral dissertation, The University if Tennessee, Knoxville.

Pearlin, L. I., Semple, S., & Turner, H. (1988). Stress of AIDS caregiving: A preliminary overview of the issues. Death Studies, 12, 501-517.

Pellegrino, E. D. (1985). The caring ethic: The relation of physician to patient. In A. H. Bishop & J. R. Scudder (Eds.), Caring, curing, coping (pp. 8-30). Tuscaloosa, AL: University of Alabama Press.

Phillips, J. M. (1988). AIDS and ARC: Pastoral issues in the hospital setting. Journal of Religion and Health, 27, 119-128.

Pleck, J. H., O'Donnell, L., O'Donnell, C., & Snarey, J. (1988). AIDS phobia, contact with AIDS, and AIDS-related job stress in hospital workers. Journal of Homosexuality, 15(3-4), 41-54.

Polkinghorne, D. E. (1989). Phenomenological research methods. In R. S. Valle and S. Halling (Eds.), Existential-phenomenological perspectives in psychology (pp. 41-60). New York: Plenum.

Prior, W. J. (1989). Compassion: A critique of moral rationalism. In R. L. Taylor & J. Watson (Eds.), They shall not hurt: Human suffering and human caring (pp. 33-51). Boulder, CO: Colorado Associated University Press.

Rinella, V. J., & Dubin, W. R. (1988). The hidden victims of AIDS: Healthcare workers and families. The Psychiatric Hospital, 19(3), 115-120.

Ross, L. M. (1987). The experience of death and dying: A phenomenological study. Unpublished doctoral dissertation, The University of Tennessee, Knoxville.

Rounds, K. A. (1988). AIDS in rural areas. Social Work, 33, 257-261.

Rowe, W., Plum, G., & Crossman, C. (1988). Issues and problems confronting the lovers, families and communities associated with persons with AIDS. Journal of Social Work and Human Sexuality, 2, 71-88.

Royse, D., & Birge, B. (1987). Homophobia and attitudes toward AIDS patients among medical, nursing and paramedical students. Psychological Reports, 67, 876-870.

Salisbury, D. M. (1986). AIDS: Psychosocial implications. Journal of Psychosocial Nursing, 24(12), 13-16.

Saynor, J. K. (1988). Existential and spiritual concerns of people with AIDS. Journal of Palliative Care, 4(4), 61-65.

Schaffner, B. (1986). Reactions of medical personnel and intimates to persons with AIDS. The Psychotherapy Patient, 2(4), 67-80.

Seidner, B. G. (1987). A phenomenological analysis of the experience of "falling apart". Unpublished doctoral dissertation, The University of Tennessee, Knoxville.

Sontag, S. (1989). AIDS and its metaphors. New York: Farrar, Straus & Giroux.

Spector, I. C., & Conklin, R. (1987). AIDS group psychotherapy. International Journal of Group Psychotherapy, 37, 433-439.

Strasser, S. (1963). Phenomenology and the human sciences. Pittsburgh: Duquesne University Press.

Sussman, M. B. (1989). AIDS: Opportunity for humanity. Marriage and Family Review, 13, 229-239.

Taylor, R. L. (1989). Compassion, caring and the religious response to suffering. In R. L. Taylor & J. Watson (Eds.), They shall not hurt: Human suffering and human caring (pp. 11-32). Boulder, CO: Colorado Associated University Press.

Thompson, C., Locander, W., & Pollio, H. (in press). Putting the consumer back in consumer research: The philosophy and method of existential-phenomenology. Journal of Consumer Research.

Tiblier, K. B., Walker, G., & Rolland, J. S. (1989). Therapeutic issues when working with families of persons with AIDS. Marriage and Family Review, 13, 81-128.

Trice, A. D. (1988). Posttraumatic stress syndrome-like symptoms among AIDS caregivers. Psychological Reports, 63, 656-658.

Triplet, R. G., & Sugarman, D. B. (1987). Reactions to AIDS victims: Ambiguity breeds contempt. Personality and Social Psychology Bulletin, 13, 265-274.

Valle, R. S., & King, M. (1978). An introduction to existential-phenomenological thought in psychology. In R. S. Valle and M. King (Eds.), Existential-phenomenological alternatives for psychology (pp. 3-17). New York: Oxford University Press.

Valle, R. S., King, M., & Halling, S. (1989). An introduction to existential-phenomenological thought in psychology. In R. S. Valle and S. Halling (Eds.), Existential-phenomenological perspectives in psychology (pp. 3-16). New York: Plenum.

Wachter, R. M. (1986). The impact of acquired immunodeficiency syndrome on medical residency training. New England Journal of Medicine, 314, 177-180.

Wakely, F. H., Taylor, A. J., & Green, D. E. (1990). Attitudes to AIDS: A comparative analysis of a new and negative stereotype. Social Science and Medicine, 30, 549-552.

Watson, J. (1989). Human caring and suffering: A subjective model for health sciences. In R. L. Taylor & J. Watson (Eds.), They shall not hurt: Human suffering and human caring (pp. 125-135). Boulder, CO: Colorado Associated University Press.

Weiss, R. S. (1988). The experience of AIDS: Hypotheses based on pilot study interviews. Journal of Palliative Care, 4(4), 15-25.

Wendler, K. (1987). Ministry to patients with acquired immunodeficiency syndrome: a spiritual challenge. Journal of Palliative Care, 41, 4-16.

Wertz, F. J. (1984). Procedures in phenomenological research and the question of validity. In C. M. Aanstoos (Ed.). Exploring the lived world: Readings in phenomenological psychology (pp. 29-48). Carrollton, GA: West Georgia College.

Wertz, F. J. (1986). The question of the reliability of psychological research. Journal of Phenomenological Psychology, 17, 181-205.

Williams, M. J. (1988). Gay men as "buddies" to persons living with AIDS or ARC. Smith College Studies in Social Work, 59, 38-52.

Worden, J. W. (1982). Grief counseling and grief therapy. New York: Springer.

Young, J. G. (1986). A phenomenological study of the earliest memory. Unpublished doctoral dissertation, The University of Tennessee, Knoxville.

APPENDIX A

Study Description and Solicitation to Participate

My name is Bill Hale. I am a fourth year doctoral student in Counseling Psychology at The University of Tennessee, and am currently preparing to collect data for my dissertation.

The research I am doing is a study of the experience of personal relationships people have had with persons with AIDS. In order to study this phenomenon, I need the help of people who are willing to share information concerning their personal experience with one or more PWA.

I asking for volunteers who would be willing to participate in this research. Your part in this research would involve participating in a confidential question-and-answer interview which would last approximately one to one and a half hours. You will be asked to share only those experiences related to the research topic that you feel comfortable talking about. The interview will be audiotaped, and later transcribed for study of thematic content. However, at no time will your identity, or that of anyone you might mention in the interview be revealed to anyone except me. Your name and any identifying information you might give during the interview will be removed at the time the tape is transcribed. Your tape will be erased at the completion of the study. At a later date, I will schedule another short interview to give you a summary of your interview and to share the results of the study with you.

Your participation in this study will be greatly appreciated. It is also completely voluntary. You may withdraw from the study at any time you wish.

If you are interested in participating in this study, please call me at one of the numbers below. If I am not available, please leave your name and number on my answering machine (home), or with the secretary (work).

Home: 983-3746 Work: 974-0858

Thank you for considering participating in this research. I will be looking forward to speaking with you further about it.

Sincerely,

Bill Hale

APPENDIX B

Demographic Data of the Participants

	Number of Participants
Gender	
Male	9
Female	6
Race	
Caucasian	14
Asian	1
Age	
26-35	4
36-45	4
46-55	5
56-65	2
Length of Time as an ARK Buddy	
0-2 years	3
2-4 years	8
4-6 years	1
6 + years	3
Occupation	
Medical	3
Social	4
Academic	4
Legal	2
Journalism	1
Housewife	1
Religious Affiliation	
Catholic	1
Protestant	5
Jewish	2
Non-Denominational	3
None	4

APPENDIX C

Informed Consent Form

You have been invited to participate in a study of the experience of relationships with persons with AIDS. Your part in this research will consist of participating in a private question-and-answer interview in which you will describe your experiences with a person with AIDS. This interview will be audiotaped. The entire process will last approximately one to one-and-a-half hours.

Since your participation in this research involves only a confidential question and answer session between you and the researcher, there should be no risk or discomfort on your part. In the event that you should experience any distress as a result of recalling an experience, appropriate referral to a qualified counselor will be made. Your participation is completely voluntary, and you may withdraw from the study at any time without penalty or prejudice.

Your sharing of information about your experience of your relationship with a person with AIDS can aid the psychological community in gaining a better understanding of what such relationships mean for individuals, and may offer you an opportunity to clarify and understand the experience for yourself. Please understand that your identity will in no way be revealed to anyone except the researcher at any time. The researcher will conduct all interviews and numerically code all audiotapes before they are transcribed in order to maintain your anonymity. Any identifying information given in the interview will be removed or disguised in the transcript. Your tape will be erased by the researcher upon completion of the study.

This consent form will remain in a locked filing cabinet in the Department of Educational and Counseling Psychology, Room 113, Claxton Education Building. Upon completion of this study, the researcher will provide you with an explanation of the findings. Any further questions you might have concerning this study or your participation it may be answered by contacting Bill Hale or Dr. Mark Hector at 974-5131, 108 Claxton Education Building, Main Campus.

****

I have read and understood this explanation of the research project and have had my questions regarding the study and/or my participation in it answered to my satisfaction. I voluntarily agree to participate.

______________________________ ____________

Name Date

APPENDIX D

Sample Interview Questions

1. Please tell me about some of your experiences you have had with a person with AIDS. You may talk about whatever you wish.

2. Can you tell me about some other experiences you have had with that person, or another person with AIDS?

APPENDIX E

Sample Interview Protocol

I: I'd like for you to tell me about some of your experiences with persons with AIDS, that you have known. You can talk about anything you want.

S: Okay. It's kind of, this is harder than I thought it was going to be. Uh, right now I'm kind of bouncing back and forth between thinking about the early days when we first started and then thinking about the present right now.

I: We being?

S: Uh, ARK. I always thought it was '85 but I finally realized that it was '86. It just seems like it's been an extra year. It's, I started in February of 1986, so that's what? Five or six years? Doing this work. Now I'm tired.

I: When you say tired, do you mean at this moment? Or, you're tired of this work?

S: I'm tired of AIDS. I'm tired of people being sick and dying. Uh, P1 was the first person I met who I knew was HIV positive. And my experiences with him were real positive ones all along. We fought sometimes but he taught me a whole lot and he, his openness enabled me to see a lot of things that I probably wouldn't have otherwise seen. We got to be real friends. I never could consider myself an official "buddy" of P1's even though I did a lot of buddy like things with him, especially when he got sick. You just couldn't presume to be P1's buddy. It was a friendship. He was the one who started me on the path of really being able to talk about death with people and not feel quite so uncomfortable. I'd talk to, I mean, professionally, I do some work with death and dying but that's usually because of my line of work. That's usually with parents who've lost a kid or something. You know, it's not with a contemporary, a peer, who's facing their own death. Uh, mostly death stuff. You know, I would love to be able to say that my experiences with people with AIDS has taught me how to enjoy life. They have in some way, but now, probably because I'm tired, most of what comes to mind right off is gloomy stuff. Sad things, you know, things about death and dying and losing chances.

I: Can you tell me about some of this?

S: Well, it's just that because of the age group, you know, so far and in our country the people here in [this city]. The people that I've met, who are HIV positive, or have AIDS, or died have all been young. They have not been people whose lives normally are supposed to stop at this point. So there's a tremendous amount of lost opportunity and uh, that feeling of no future. It's one of the most, you know, the first people that we served, for the most part were well educated, upper class, or upper middle class gay men. And they were articulate and even though they might be real frightened or in denial, they were pretty much able to tell us what they wanted or expected of "buddies". The people who I've worked with over the last three or four years for the most part haven't been that kind of folk. They've been, uh, hookers or junkies, people already so damaged by life that they, you know, they weren't, they don't ask for much unless they're hustling for survival issues.

I: Right.

S: But they don't they don't bring to a relationship insight and uh, much joy. With P1 and P2 and P3, some of them, they could, there were other positive things going on in their lives for the most part, in spite of the fact that they had AIDS. But with the drug users and long time abused prostitutes, their lives were already pretty shitty to begin with and then AIDS on top of it...just like the final blow. So they tend to not have a whole lot to give back. Mostly they have just this tremendous list of needs that you can't fill.

I: I understand.

S: It's a trap that you get into as a "buddy" trying to fill those needs. So you don't get a whole lot back in the way of positive stuff. From them.

I: Do you experience being in that trap?

S: Huh? Oh, the trap of feeling like I need to fill all the needs? Oh yeah! You know, and even as a mental health professional, I know where those traps are and I can recognize them but knowing it doesn't always prevent me from doing it. And I think AIDS is very seductive in that way. I think it's real easy to get caught up in and so you always either feel like you're not doing enough or you feel guilty because you didn't do enough or you feel overwhelmed because there are so many needs that can't be met. Very hard for some reason. I suppose part of it is the, uh, what's the word? Uh, not chronic but the acute nature of the illness and the crisis that makes everyone feel like you've gotta move quickly and the PWA's do too. You know, if they, for the most part, if they discover a symptom, if they wake up with the sniffles or wake up with a new pimple or a bruise, it's a crisis because we've got to make sure it's not Pneumocystis or it's not Kaposis. We've gotta get to the doctor, gotta get the medication, we gotta do....There's always this gotta, gotta, gotta.

I: A sense of urgency there?

S: Yeah, yeah, pretty much all the time. And I think, uh, it's probably not unlike working in an ER, or someplace where acute situations occur all the time with very little notice. Except that, you're not doing it as a professional. As a "buddy" you're doing it in this sort of pseudo, this kind of gray area between friendship and family and some kind of professional helper and so the boundaries aren't as clear. In spite of our training and what they tell us about what buddies are and what buddies are not, when you are out there, there's also this feeling of you and your buddy against the world. You know, that there will be other family members, see, I said the word "other" family members. There will be family members. There will be friends or ex-friends or work people who don't respond appropriately to a PWA's needs. So, there are things that they will talk to you about that they won't talk to anyone else about. And that strengthens that perception of "it's us against the world." Even though that's not real.

I: There are things that the PWA will talk with you about?

S: Yeah, and so even though that's not real, you, I think, even subconsciously, you start feeling that way. You know, like, if somebody gives you the gift of intimacy, then you, it's real hard not to respond the same way.

I: Sure.

S: So, there you're stuck with some stuff to deal with. It's just the constant knowledge that death's going be just around the corner. Early on it was more acute, you know, people with exception of P1, in the early days, we didn't find out about them until they were in deep trouble. And so several of the early ones, they weren't around very long. Maybe six months, maybe even less than that and they died. Nowadays, with earlier identification of the syndrome and better treatment, people are living a lot longer. So you could end up having someone and being in that kind of intimate relationship for maybe four or five or six years. When under normal circumstance had that person never been sick, you'd have never met them. It might of just been an acquaintance, certainly they wouldn't have been necessarily somebody you'd become best friends with. So all of a sudden, you're in this. I mean, you start out to provide X number of things to somebody for what you believe to be a certain time period and then the needs, the things you're supposed to provide, that list gets longer and the time period gets longer. And sometimes you'll find yourself just wishing it was all over. I have wished that certain of my PWA's would just go ahead and give up and die.

I: Can you tell me about some of those times?

S: Yeah, let's see, there was old (P9) in the hospital and he, I don't even think he even knew me. I knew him, but he sure as hell didn't know who I was. And he was already in severe dementia when we got the call about him. And he was from a, a small town outside of Knoxville and nobody in the family was dealing with it. He had one sister who would visit him, maybe twice a month. The hospital desperately wanted him out of there, cause they wanted money.

I: Uh, huh.

S: And all I could do for him, was, I'd go in and sit, and rub his feet and talk to him, I didn't know if he could understand me. And I wasn't his only buddy. He had a couple of others and we'd talk on the phone. You know, "Well, do you think he hears when you talk to him?" "Do you think?", or "what do you do?" Cause he would just lie there and shake. His arms would shake and his head would shake and he was blind, we believe. We don't think he was deaf because sometimes he would calm down or get less agitated when you read to him.

I: Uh, huh.

S: And I really wished that he would go ahead and die. I didn't really see any point in him suffering. My assumption was that he was suffering because he sure looked like hell. And he'd moan.

I: Uh,huh.

S: You know, and he'd make noise. And then I told you the story about P2, I think.

I: No, I don't think you have.

S: He was one...that's something that I haven't done since P2. When we did our training early on and when you read the stuff from other AIDS organizations, there's a lot of talk about. Not just AIDS organizations, but any hospice people. Uh, there's a belief that sometimes folks are ready to die but they just hang on because they feel like they have responsibilities here.

I: Uh, huh.

S: You know, there will be family at the bed side saying, "Oh, please get well", "Don't leave me", "I can't live without you", "We need you". And that they're somehow, some people, even in a coma, will struggle against death, just because they feel that they are needed. There's a body of belief that one of the things you can do for the dying is that you can go ahead and give them permission to go. And P2 was this guy from another state whose family visited occasionally. I think they were probably supportive, as best they could be. And I was one of his buddies and the doctors called me and said, "He's in a coma and he's on his way out. And he's dying. You better go ahead and call the family and come on over to the hospital." So we called the family, and we went to the hospital and sure enough, he looked awful, he'd slipped off into a coma. He was nonresponsive and he looked like he was going to die. The docs and nurses all said, "Anytime. There's nothing to be done. This is it." His sister was on her way in from Kentucky and so I'm sitting there on the bed with P2. Notice that I'm yawning..I told you that I'm tired of this shit. Uh, and I've got him in my arms and I'm saying things like, you know, like, "We love you and people are going to miss you but that's Okay", "P4's going to be Okay", "Your folks are going to be Okay", "If you need to, you just go on". "You don't need to wait for anything". "There's nothing else anyone here needs." You know, stuff like that. And I've done that before with people and I, his sister came in and I went home. And when I came to the hospital the next morning, he was sitting at the bed eating. And the first thing I said to him was, "P2, do you remember yesterday?" Because I had this God awful fear that he would remember what I'd said to him. Uh, and it would sound like I was trying to talk him into dying, and that was not what I was trying to do. And, as luck would have it, he didn't. But, I feel real uncomfortable about that experience. And what had happened about that was some new medication had just shown up and they tried it. And it bought him a little more time. He died in a month or two. And he probably had a few good days between then and then. But most of it was being sick and being in pain. He was, looked like an Auschwitz survivor. And, uh, a lot of them do. They get do damn thin. I think it's easier to meet somebody in the beginning of their dementia and deal with that than to, like P1, uh, or, that was the hardest one of, knowing him so well, he was so healthy and in control and then watching that deterioration. And having the belief that he really didn't want to do that.

I: Right.

S: But then realizing that his religion forbade suicide, and I know that he made a new peace with his faith and returned to it after many years. My assumption was that in spite of what he said, he always wanted to do, this new resurgence of faith changed those plans. And that he was just going to let things take their course.

I: You're saying there, that he might have been willing to commit suicide?

S: Yeah, I believe there was a time when P1 did not want to go through that long debilitating process. That he'd watched so many other people do. I'm saying that because he told me it was not his intention to do that. And yet, when the time came, that's exactly what he did. And he did it as well as anybody. You know, but it was very difficult to see him demented.

I: After seeing him very lucid?

S: Yeah, and the other part that's hard is, you know, it'd be one thing of your mind just went one time and it would be gone but with these folks they come in and out of it so you never know, from one day to the next if they're gonna be, where they're gonna be or if you can contact them. And I think living at home like P1 did for so long, that his caretakers, you know, they didn't get any sleep for a long time. Because they never knew from one night to the next, was he going to get up and toast the same piece of bread six times at 3:00 AM and set fire to the joint or not? And those are really real. It may be a lot like dealing with Alzheimer's patients. You know, I just don't know. Except with Alzheimer's, those people while not ancient, have at least lived a good portion of their lives. And watching somebody, you know, in their 20's or their mid 30's lose their shit and die is real hard to deal with. Just real hard. I've had kids die, infants.

I: What was that like for you?

S: Well, I'm used to, "used to"... well, at the time I was working in and intensive care nursery, so I was used to, infant death, in the intensive care nursery, and most of the babies who die there are either born so early that they're barely viable. You know, they're just little one pounders. And so, you can kind of rationalize and say, well, they're not really real yet. Mother nature didn't mean for them to survive. And it was only by a bad accident that they ended up here. Or they are born with real serious anomalies and then again you can say that Mother Nature didn't, she screwed this one up and this kid just isn't to be. And that's different somehow from someone who has already been here and made a mark and is part of the world. Yet finished, I guess. Yeah, it is. Cause the little guys haven't gotten started yet, and the old guys are done and us middle guys ain't finished yet. And there seems to me to be, I still have a hard time accepting that I guess. It's a real infantile belief that your life starts and you live it and then you die. And AIDS has just chopped that process just right in half. In a very brutal way. So, that's a stress all the time. That pisses me off. That makes me angry. And it may be part of what gives me energy. To do it. But back to the kids.

I: Can you tell me how that gives you energy?

S: Well, cause when I get pissed off about something, I feel like I have to do something about it. Which is another double edged sword. You know, or the trap that's hiding for you on the path. Cause you think, "Damn it, AIDS is a horrible thing and I'm going to do something about it." And on a very practical - you know, on one hand - you can't do a damn thing about it. They are still going to get sick. They are still going to get crazy and they are still going to die. What's hard to remember, especially as the numbers mount, is that in fact, you did make a difference. Being a friend and a witness and a support person for those folks. Even today, when we like to think that things are somewhat better as far as the way people are treated, it's still hard. They still don't get the support they need.

I: A witness?

S: Yeah, a witness to suffering and struggle. I think one of the best things, well, I think this about psychologists and clinical therapists too, that, you know, if you leave most people alone that they'll get better eventually anyway. But one thing that really does help a lot of folks especially in heroic struggle is that they have a witness. Who, that, the belief that they have someone who understands what they're going through and sees it. That makes it real. And I think AIDS is a real, in the minds of PWA's, I think, very often there's a lot of time when they feel that they're not in this world. That things are not real. Having buddies, who have a knowledge of the disease and a knowledge of the struggle that the people who have it have to go through just trying to get their basic needs met. It's real valuable. I think that's why they share so much stuff with us. I mean, there's not much point in a total stranger telling you all kinds of stuff about themselves and their fears and their feelings if they don't have a belief that you understand, and that it's important to them that somebody else understand. And they can do that with us without putting the burden on lovers, or family, or friends, that they would put if they were that brutally honest about how they feel. And you can say, "You can tell me anything and I can take it" but you are thinking "I don't want to hear this", "I don't want to hear this."

I: That's happened to you?

S: Humm? Sure!

I: Can you share some...

S: Some I can't share with you without violating confidentiality of other areas. This study aside, the fact is you were involved in ARK and PWA's too. Okay, let me think, what was her name? The baby's mom, the hooker. Ummm...just her life, you know. How a kid born with a very little chance of getting anywhere. You know, just a long history of abuse and neglect led to her becoming a prostitute and getting hooked on drugs. And her dedication to self destructive behavior that she really believed she deserved. And it's the same with P5, and P6. These women, had it not, I mean, if AIDS had not come along, something else had already destroyed their lives.

I: Sure...

S: AIDS just made it that much more painful and that much more worse. And much worse on their children. Had they not had AIDS, at least their kids might have survived. But now that baby didn't and it looks like P6 isn't going to.

S: P6' is P5's child. And she's on a, she has a broviac catheter going into an aorta right above her heart. She carries a little backpack and she's only two and a half. She has a backpack and a 24 hour drug infusion. All the time, so. And she's also delayed developmentally, she doesn't have much intelligible speech yet. I don't think it's because of the AIDS, I think it's environmental deprivation. Her mom is a real quiet, passive kind of woman who doesn't talk much. And P6, without the stimulation she needs, isn't learning to talk. I want her to talk because I want to know where she hurts and what she wants. That's become this big thing for me that P6 has to learn to talk. And we're working on it.

I: You were going to tell me about something, you were going to tell me about a time when you said "You can tell us anything" but you might not want to hear what they had to tell you.

S: Oh yeah, I was just saying that people will tell you things that you don't want to hear. Uh, they're hard to hear because they're painful. They're frightening or they make you angry. And it's real hard when somebody's doing that to not try to make others feel better. You know, you want, it's just normal to want to deny ("Oh, not it wasn't that bad", "they didn't do that to you", "that couldn't have happened") Well, you can't do that to them for Christ sakes. They're telling you really tough stuff, but it's a struggle to not want to either deny that it's real or to not try to make it better. And you can't. The minute you do that, you've lost them. You know, what you've done in effect is tell them, "Well, she lied. You really can't tell her anything." "There's a lot of stuff she really doesn't want to hear." And then, so, it's like somebody opens up a closet door and you end up with a lap full of snakes. When you looking. You can help them sort through the snakes and say, "Well, those are non-venomous, and Ooops! These two you gotta watch out for!" Uh, but it's not always easy to do that. And then at the end, they're feeling better, somedays I'm feeling better, but more and more lately, it's less able to shed that. The layers of painful experiences. And you know, as a professional, I mean, most of the time, the people I counsel with, are gonna get better. You know, they're working toward some goals. And even though we've got to wade through some pretty scary swamp, we know that there's some higher and drier ground on the other side. And that's where we've headed. With AIDS, it's just this endless, somedays it looks like this endless swamp and it's not high and dry on the other side. It's quicksand. And they're just going to disappear. And so that's very hard.

I: Like the struggle's for nothing?

S: Sometimes, and it's why I'm having a really hard time with some of our drug abusing PWA's. There's a bunch of moral stuff that, I mean, the moral swamp is just - YUK! Why in the world would you expect somebody whose had a diagnosis of AIDS to stop abusing drugs? I mean, drugs make them feel better. I mean, logically number 1, it's against the law, and number 2, it's not good for their health, they'll probably get sicker faster. But realistically, if they weren't able to stop doing drugs when they were well, and now, they've just gotten a death sentence, how do we expect them to stop doing drugs?

I: You said the moral swamp... your moral swamp?

S: Oh yeah. That particular issue - oh yeah. Yeah, it is. Of course, it is. Well no, that's not true, it's one for them too because they feel guilty. Society puts all this pressure on them to clean up. You know, "You've got to do into a program, you've got to get straight." So, uh, and they know, that they're hurting themselves. And they know they're not supposed to, but the fact is, a greater truth is, that doing drugs for them eases some pain. They're dying, so who's going to expect them to stop?

I: I know.

S: Yeah, it's the same thing with hooking. You got the extra problem of the fact that a hooker may not hook safely and they may in fact be spreading the disease. Right now, we don't have a law that says you have to turn in somebody if you know they're screwing around and you know they're HIV positive. I mean, if we did have a law, I don't know what I'd do. What I believe, deep down inside is, is that if anybody screws anybody else in an unsafe manner, they deserve what they get. Be it herpes, or syphilis, or gonorrhea, or AIDS. I mean, it's not like we all don't know what we have to do to stay safe. But when you're working with a PWA and you develop a close relationship and you know or you suspect that they are putting someone else in danger, that colors, that makes it harder for you to have that unconditional positive regard that we're supposed to have. You know, you get real mad at them. Then you have PWA's that you are reasonably sure that are selling their drugs for money. And they may very well be doing it to buy groceries, or pay rent. Or they may be doing it to buy a different kind of drugs to get higher.

I: Uh huh. Are these issues that you confront them on?

S: Uh - huh. It depends. If they have made it so obvious that I can't pretend I don't know what's going on anymore, then yes, I have to. Then we have to confront it, we have to talk about it. If it's just some thing I suspect is going on and I have no ability to improve the quality of life. Like, if I don't have the food, I'm not going to call them on it. Because if I admit that then I've got to do something about it. And I don't know what to do. So, I just, we agree to disagree and we agree that's something we're not going to discuss but I know it happens and I think, uh, part of me feels like we've got to get it out in the open and deal with it but since there is no solution, then I don't know what good it would do. It may just be part of life.

I: Like your hands are tied?

S: Yeah, not just mine but theirs. You know, I don't think most people would sell their antidepressants if they didn't need to. For one reason or another.

I: Yeah.

S: If I needed them and had them, I wouldn't. Now if I had them and I didn't need them, which is a whole other problem, I think physicians probably over prescribe for some of these folks either out of guilt, or overwork, or just not wanting to get into it that deeply. I mean, you give somebody a prescription for 90 pills and then they come back in two weeks and they've lost it. Huh, I mean, I'm not stupid and I assume that most physicians aren't but they'll rewrite the prescription. I think one thing that I didn't expect to happen that did, was, you know, I knew that PWA's were isolated from society and felt cut off by people. But, I didn't realize that even the AIDS, I'm not going to catch AIDS from anybody, but I sure as hell caught the isolation. It's a real infectious thing. Uh, for the most part, you know, you've got a couple of problems, one is confidentiality because we have to protect the confidentiality of our PWA's, we can't talk to other people about them.

I: That's right.

S: And two, you can't even talk in general terms about what you do to friends and family because you get one of two reactions. They either make you start eating off paper plates when you come to family gatherings, or they say really helpful stuff, like, "Well, why do you want to do that?"

I: Oh yeah.

S: You know, you can't go home and say, "Geez, I'm tired, this is a rough day." Cause what you'll get in response is, "Well, I told you not to do this" or "What's wrong with you that you want to do this?" or "Why in the world do you want to be around people who are dying?" Or "You don't have any junkies in your social circle normally, so why do you want to hang around with junkies and hookers now?" So, you get isolated. And I think all the buddies, if they haven't told you that on these tapes, they're feeling it. They just haven't recognized it or identified it. Because there's not a one of them who ever comes to a buddy meeting and says, "You know, my family's just really helped out with this". Or "My friends can't wait for me to get home and tell them what's happened today". So you "catch" that isolation.

I: Like a tainting or something?

S: Uh huh. Exactly. And it's not a good feeling. It's something I think people can deal with over a certain period of time but as the years drag on, you know, I have intimate friends, who I have known for 15 or 20 years and for the last 5, they don't even want to talk to me about this, there's a big chunk of my life I'm not allowed to bring up. So, that has taken a toll. It really has.

I: When you say, that you're not allowed to bring up - does that mean - within the norms of your friendships or within the confidentiality norms?

S: That's within the society's refusing to deal with this problem. That's within the "afraids" epidemic and with the denial that most people are in about AIDS.

I: So, the norms of your friendship.

S: Oh, and acquaintances. I mean, it's not just mine. I think that if you check with every other buddy, they for the most part, would say the same thing. Unless they have friends who are Buddies.

I: Uh huh.

S: There for me personally - another problem has been that - as "buddy" supervisor. At the "buddy" support meetings, which is supposed to be a place where we can get rid of this stuff, or deal with it, or share it. There too, I have a responsibility that takes precedence over my own needs, and that is for the other "buddies". Which is why I am drafting a letter of resignation. From several areas. But that's a problem. You know, and it wasn't like somebody held a gun to my head and said, "You have to do this". It was, it was just the way, either I volunteered or I got stuck and didn't get out of it.

I: And now you're seeing the toll that it's taking?

S: Yeah, I think this kind of stuff is hard to do even under the best of circumstances. And we appear to be doing it under close to the worst circumstances. You know, let's give people a really, really, hard job and not only are we not going to reward them for it, but we're going to punish them every time they try to do it. And some days that's the way it feels.

I: So, you've been one to take action over the years. And now you're taking action for yourself? By resigning from some things?

S: I think so, yeah. I've about made that decision. I hate to do it, but, uh, I think it's another problem too in that we've gotten real incestuous as a small group. And there are a few of us who are, just by virtue of longevity and big mouths tend to guide or steer what happens. And I think, that we've been dong it for way too long. I can't see the forest for the trees anymore. I think we need new blood and new ideas and different ways of doing things and the only way that's gonna happen is if I jump ship. That's why P7 jumped ship. He didn't have any choice. He kept asking, you know, for people to take more responsibility, or do things and we all just leaned back and let, you know, daddy P7 do it.

I: Uh huh.

S: And I think I've gotten caught in that same trap. So, I'm gonna get off the board, I'm gonna get off the support and services committee. I'm going to stop being a buddy supervisor and I would like to continue "buddying" P5 and P6 if the organization will let me. But if they don't want me to, well, then, that's a decision they're going to make.

I: I understand.

S: I'm not going to, uh, I can't continue to work out of town and as many hours as I work at my regular job and do all of this shit and be any good to anybody. And there are, there are some buddies that we have that can probably do a lot better job.

I: In taking over your responsibilities?

S: Yeah, and hopefully at a lot less cost to themselves. But, maybe that'll have to be a battle they'll have to fight out and discover. You know, on their own. It's been too long, way too long. (Long pause)

I: Can you tell me about other experiences with a person with AIDS?

S: Oh, lots, are you looking for anecdotal stuff like, "Can you believe this happened?" kinds of things. Or, I mean we do stuff like, Oh, P3 was in the hospital at H1, he didn't wanna, that, that hospital, I mean, I don't know how they are now, but, back then, they didn't treat their PWA's very well. They took no notice of his nutritional status, I mean, his food came in disposable cartons and paper and plastic and if he didn't eat, it just went into the trash can. I mean, no one was keeping track of his caloric intake or what he wanted or anything. And he said he was having a "grease withdrawal". He wanted fried fish and hushpuppies from Long John Silvers and strawberry pie from Shoney's. And so, I went and got him all this food and he couldn't sit up because he was so weak. So we propped him up in bed and I sat on the other side of the bed with him leaning against me. He porked out on all that stuff and the next day he died. I still swear that I killed him with all that fried fish. I don't think I did but it's that thing of never knowing like, people can be like chronically sick and it goes on forever and you keep thinking, "Oh, God, I wish they would get it over with." Cause nobody can stand it anymore watching all that suffering. Or they'll check out on you before you're ready. I mean, you're never ready, but those unexpected deaths are real hard too..I mean geez, I just saw him yesterday, he seemed Okay and I think there's probably some guilt that goes along with that. That, you know, if you'd been paying attention you'd know how sick they were.

I: So with P3, you weren't expecting it?

S: No, I didn't figure he was going to die the next day. If I'd known he was going to die, I wouldn't have bought him fried fish, I'd have said, "You can't eat fish, you're going to die tomorrow". "Fish isn't good for you". But I've had a lot of...I mean, I used to, when I teach the buddy classes and stuff, I mean, I'm always making these noises about how wonderful it is to have a PWA as a buddy and how many wonderful things they can teach you and they do. Maybe one of the things they've taught me is that I ought to stop doing this for a while. I mean, you do learn to look at life differently and appreciate the things, friendships, and family, and the positive things in your life. But for the most part, right now, in my sort of debilitated and bummed out state that being a buddy is not all that great.

I: It's hard.

S: And I've had buddies that I was intimately involved with and saw on a weekly basis and has some phone contact with all the time and I've had buddies who didn't need a whole lot and I had very little contact with. And I'm not so sure if the impact, well obviously the impact of the loss should be different. But now it's just all, it's this big pile. So it's hard to sort through. Maybe in six months or a year.

I: You said, it's hard to sort through...Can you tell me about that?

S: It's hard to sort through the degree of loss, the impact that each different individual had. They're more like a sea of faces now. You know, rather than, uh, distinct individuals.

I: Where none stick out?

S: Oh yeah, a few. I mean, it's a sea of faces. I mean it's like looking through a telescopic lens, you know, some are closer than others.

I: Yeah.

S: But, uh, it's definitely more of a mass tragedy than an individual struggle. I think, and I'm not sure how healthy that is for people to deal with on a daily basis. Plus, you know, the change in the client's population. And that has changed. And the next batch scares the pee out of me because that's going to be the teenagers.

I: I know.

S: You know, it's been difficult to make the transition from the nice, well educated, upper middle class, gay men to junkies and hookers. And it's going to be even more difficult to make the transition from junkies to teenagers. But that's what we're looking at next. I think. My belief is that the next major population is going to be kids and teenagers. Kids from being born with it and teenagers from sexual activity. Cause we deny them the information they need. Which is another whole set of frustration cause I think all the buddies feel like educators. You know, you feel so helpless about the ones that are sick, who you are buddying, you have this drive to make people understand where the dangers are and make changes in their life - so they don't have to go through it. So, we're all frustrated educators. And frustrated mostly because people are not able to hear us or because of organized religious groups or politicians we're not allowed to give out information we think is necessary for people to stay safe.

I: And you as an individual are feeling these frustrations?

S: Uh huh. Now if I wasn't on the board of directors and didn't know what restrictions are on the organization, then maybe I wouldn't have that frustration. But I think I would. Cause I'm not stupid. I'm smart enough to know that prevention is the best way to go.

I: That's right. Uh, you asked about what kinds of things I wanted in terms of talking about experiences. Just whatever personal experiences come to mind for you.

S: Oh, uh, I'll think of a thousand nifty things after you're gone. Geez, I wish I had told Bill that. Uh, I remember one time, I took somebody, who was a PWA, we went out to dinner. And this was a very well educated person, who you know was dealing pretty well with his disease and education and doing real well. We were, we ordered a pizza but he ordered an antipasto plate before the pizza came and I was hungry so while he was eating that, I just took my fork and stole olives off his fork and started taking food out of his plate.

I: Uh huh.

S: And he started crying and I said, "What the hell's the matter with you?" and he said "You're eating food from my plate". And it was a big deal for him because apparently even with the support and help he did have that was an area of his life where he noticed people's behavior changing. They weren't sharing his food.

I: So his crying was out of being touched that you were eating after him.

S: Well, that I was smart enough or that I understood that I wasn't going to get AIDS from his goddamn olive.

I: That you understood the situation.

S: Uh huh and I hadn't expected that. You know, you get those things from PWA's all the time when you hug them or you do things, they're starved, starved for the most part for physical attention. Even people who weren't real "huggy, kissie" before they got sick, did get some kind of physical contact. And a lot of them don't get it after their diagnosis is well known.

I: I'm sure.

S: You know, I don't know D1, he's not a "huggy" doctor, but I would imagine, he pats people, if anything. Uh, family members, you know, they'll withdraw, physically so hugging and when people are in the hospital and they are really debilitated, I really love to do things like, you know, give foot rubs and back rubs and stuff cause it gives you a chance to get some tactile love to them.

I: Right.

S: Some comfort. A whole other area that's real hard that I haven't talked about at all is in this particular, with this disease, the people who started the support group ARK, and the people who still work in it are, many of them are HIV positive.

I: Uh huh.

S: And even though they are not sick yet, it is my belief over the years of learning, that they're gonna get sick, and they're gonna die. And I know that we're not supposed to say that, and I don't say it to the people who are sick but my experience has been that anyone who is HIV positive gets sick and dies. Well, with planning to do things, I have a hard time fighting with these folks. Uh, in some way, I've handicapped myself or tied at least one of my hands because, I'm disinclined to argue and to fight with someone who I know is going to die over something that's very important to them and is academic to me.

I: So, uh, you're treating these people...

S: Differently!

I: As though you were a buddy?

S: In some ways. I don't want to, I don't like it when I recognize that I'm doing it. I'm afraid I do it even more than I'm able to recognize and see but the fact that I mentioned it means that I figured out, so you know, that's a problem. I think, most of us tend to do that, I don't think I'm extraordinary in that area. And it's an area where I think buddies can get into trouble. That you feel, you know, I think, what middle class America kids in the 60's felt racial guilt because they weren't native American and they weren't black. Well, I think people who spend a lot of time with HIV positive folks and PWA's end up in some way feeling guilty because they're not sick. And it may dictate some of our behavior.

I: Like a survivor guilt?

S: Oh yeah, Survivor guilt is there for sure. Not that I'd volunteer to get it. I don't want it. But uh, you, it causes you to wonder all those why questions. "Why them? Why am I spared? Why is it OK for me and not for them?" You know, and it's not as if my behavior throughout my life has been pristine. I'm a child of the 60's and behaved whole heartedly as one. For many, many, many years, and if this epidemic had hit the shores of the United States a few years earlier, I very well might have been one of my first clients. Instead of one of the first volunteers. So survival guilt is there. It's a phenomenon I know exists and I recognize it in myself and I see it in other buddies when they're, you know, when they're talking about how they made decisions to do or not do certain things. And sometimes you can suggest to them that maybe that's what's going on and sometimes you can't.

I: What other experiences with a PWA would you like to share?

S: Oh, like stuff that we do. You know, we go to the movies, if they, we read books, we watch television and we go out to dinner. Uh, uh, that's another thing that's changed. When I had buddies, the good PWA's rather than the "poopie heads", you know, they came to my house, you know, P1 came to my house a lot. Uh, P5 doesn't know where I live and never will. Cause I'm likely to get ripped off if she does.

I: So you don't trust her?

S: No, I don't think you can trust junkies. Uh, people who are involved in stealing stuff, and selling it for drugs, or hooking and have a pimp, uh, you can't afford to let them. She has my phone number and I suppose if she wanted to find me she could, but I have not invited her here, nor will I.

I: I understand.

S: And that's very different from P1 and even P3. Hell, I came home from work one day and found P3's doberman chained to my front door. I'd never even met the dog before but I recognized her from things he's said about her and he'd gone to Atlanta for the weekend and just felt free to chain her to my door. He knew I'd take care of her and I did. But, uh, that kind of free, open, easiness and friendship is different from what you have with some PWA's. And I'm not the only buddy whose PWA doesn't know where they live. You know, and I'm not the only one who, uh, those folks who have to learn good manipulative skills in order to survive, as drug abusers often do, uh, are very good at wheeling and dealing. I don't give P5 money. I'd have given P1 every cent I had if he'd needed it, and would have had no fear or doubt about it. I give P5 money and I know exactly where it goes. And it ain't for food for the kid. So, I don't know. You end up feeling a little bit like a policeman or chaplain or something. I don't want to make those decisions. I don't want to say, "No, you can't have $5.00" or "No, I'm not gonna loan you $30.00. Number 1, I can't afford to loan her $30.00 and if I do, I'll never see it again. P8, we all took all kinds of things to P8. She showed up and had an empty apartment. And we completely furnished it. We did all kinds of stuff for her and she disappeared on us and took it all with her. So, those kinds of things happen. And on the one hand, you realize that here's somebody dealing with a life threatening crisis and they're going to cope the best way they can. And it's not a real personal attack.

I: Right.

S: And, you do after a while, you know, end up feeling, uh, not really used and abused but it's harder for me to go back to the same resources I've been going to for years and ask for yet another set of something when the last four sets I've been given have been sold for drugs or thrown away or stolen. So that's harder.

I: So your relationships with these people are different?

S: Very different. Very different across the board. Depending on who they are and I suppose who I am at the time.

I: Who you are at the time?

S: Yeah, you know, I'm certainly not the wide eyed, I'm not as nonjudgemental in 1991 as I was in 1986. Like it or not it's true.

I: It's been an education for you?

S: Uh huh. You know, I have the professional education. It's just different when it comes on a personal level. You know, I get ripped off by clients all the time. That feels very different than when you get ripped off by a buddy. Very different indeed.

I: You mean, ripped off financially, or???

S: Yeah, you know some, I'll have a client who will uh, sell her food stamps in order to pay the rent or pay the electricity bill and then I take food to the kids, and then she sells some of the food for something else. She's doing that because that is her belief that is how she is going to survive. And as a professional, and her professional helper, I understand and I can look at that as, well, she's got some survival skills. I should be able to do that, same thing with a buddy, because that's a personal relationship. It feels more personal when the same thing happens.

I: So, it's a different reaction to the same violation? Of trust?

S: It's a different reaction to the same behavior from a person in need. Cause, I don't even want to call it a violation of trust, I don't consider it a violation of trust when it happens with a client. Because for the most part those people don't trust me and I know that. And that's part of our job is to develop a trusting relationship with these people who've never had one in their lives.

I: Right.

S: Wouldn't know one if it was shoved up their butt sideways with a sign on it. It's uh, very difficult for people who have to survive on a daily basis and don't have, you know, and a lot of folks say, well a lot of my clients, if you were going to use a DSM-III - they'd have an attachment disorder. Most of our PWA's don't have attachment disorders unless it's something that comes up because of the way society treats them once they get the diagnosis. I suppose it could be something called acquired attachment disorder. You know, I never even thought of that. Yet it may be some syndrome that you could identify where people who used to be able to become capable of intense intimate relationships are no longer, based on some traumatic incident that happens in their adulthood. Something for the psychologists to think about.

I: Is there anything else that you'd like to talk about?

S: Uh, I don't think so. Unless you want specific questions, I'll answer those all day, but just this stuff that comes rolling up.

I: No.

S: No. Mostly right now, it's a belief that I've let AIDS dictate my behavior for the last five or six years and I'm going to have to take the reins of power back and steer in a different direction, at least for a while. I'm not honestly sure I can do it. I am not sure, I just get so shaky when I think, "Well, how can you walk by these people, you know, how can you face not helping when you know it, it's needed?" I think what I'm doing is doing some refining and you know, in the state I'm in right now, I'm not all that much help, in fact, I might even be a hinderance. And that belief just may be what helps me say, "Okay, I gotta stop for a while." I can't stop with P5 and P6 cause they're still alive and I owe them that as well as I owe myself that. But I can stop the other stuff, the other stuff, and I guess that's what I'll do.

I: Stop taking on more?

S: Uh huh.

I: That's it?

S: I guess. Bye now.

APPENDIX F

Transcriber's Pledge of Confidentiality

As the transcribing typist of this research project, I understand that I will be hearing tapes of confidential interviews. The information on these tapes has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information on these tapes with anyone except the primary researcher of this project (William C. Hale) or his doctoral committee chair (Mark Hector, Ph.D.). Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

Transcribing Typist

Date

APPENDIX G

Reprinting Release Form

As a participant in this study, I understand that some of my statements may be used to clarify the researcher's explanation of the phenomenon under examination. I am aware that total confidentiality will be maintained in doing so. I also understand that if any statement I made in the interview is reprinted, it will be done in such a manner as to maintain my total anonymity and that of any person I might have mentioned in the interview, with any identifying information removed prior to its release.

I hereby consent to portions of my protocol being reprinted, as the researcher deems appropriate.

______________________________	__________
Name	Date

APPENDIX H

Research Team Member's Pledge of Confidentiality

As a member of this project's research team, I understand that I will be reading transcriptions of confidential interviews. The information in these transcriptions has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these transcriptions with anyone except the primary researcher of this project (William C. Hale), his doctoral committee chair (Mark Hector, Ph.D.), or other members of this research team. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

____________________________	__________________
Research Team Member	Date

APPENDIX I

Sample Delineation of Meaning Units

1. This is harder than I thought it would be.
2. I'm thinking about the past and present.
3. I've been a buddy for five or six years now.
4. I'm tired of AIDS.
5. One PWA and I got to be real friends.
6. I wasn't his buddy. I was his friend.
7. I can talk about death and dying professionally, but it is hard when it relates to a contemporary or peer.
8. One PWA taught me how to talk about death and dying without being uncomfortable.
9. My experiences with PWAs have taught me about death, dying and losing chances.
10. The PWAs I have known have all died young.
11. Their lives are not supposed to stop at this point.
12. The first people (the organization) served were upper middle class, well educated and articulate.
13. They could tell us what they wanted.
14. Now we serve more junkies and hookers who are hustling for survival issues.
15. They don't bring much insight or joy into a relationship.
16. They mostly have needs, and take without giving.
17. I get into the trap of trying to fulfill all those needs.
18. I recognize the traps, but get into them anyway.
19. AIDS is seductive. It's easy to get caught up in it.
20. I can feel like I'm not doing enough, or be overwhelmed with too many needs.
21. There is a sense of urgency in working with AIDS.
22. As a buddy, the boundaries between professionalism and friendship are not as clear.
23. I feel like it is me and my PWA against the world.
24. When someone gives me the gift of intimacy it is hard not to respond in the same way.
25. The inevitability of death for PWAs is always present.
26. Nowadays, PWAs are living longer.
27. So an intimate relationship with a PWA can last five or six years.

28. Under normal circumstances, I probably would never have met them, or at least not be best friends with them.
29. They need more and more from me as time goes on.
30. I have wished that some would give up and die.
31. One PWA that I knew was already in severe dementia when I met him.
32. His family was ignoring him. Only his sister would visit, and then only rarely.
33. I would rub his feet and read to him, but there was minimal communication.
34. I wished he would go ahead and die.
35. I assumed he was really suffering.
36. There is a belief that even though some people are ready to die, they hang on because the feel they have responsibilities here.
37. Family members may not want them to die and beg them to stay alive.
38. I can give them permission to die.
39. I gave a PWA permission to die (when he was in a coma), but he got better the next day.
40. I was afraid he had heard me say it when he was in the coma.
41. PWAs are sick and in pain.
42. They are too thin.
43. It was hard watching a PWA deteriorate, believing he did not want to.
44. One PWA returned to his faith after many years, knowing his religion forbade suicide.
45. He decided to let things take their course.
46. He did not want to go through the debilitating process, but that is what he did, anyway.
47. It was very difficult to see him demented.
48. Their minds come and go, so you never know if you are going to be able to communicate with them.
49. His caretakers did not get any sleep for a long time.
50. He was incompetent and had to be looked after.
51. It is much like Alzheimer's disease.
52. It is hard to watch young people lose their shit and die.
53. Infants can die and it can be considered an accident of nature - Old people have finished their lives - but young people are dying during viable periods in their lives.
54. AIDS cuts life short.
55. That is stressful for me.
56. That makes me angry.

57. That may be part of what gives me energy (to work with PWAs).
58. When I am angry about something, I must do something about it.
59. But I really cannot do anything about this. With AIDS, people will get sick and die.
60. I must be a friend, witness and support person for PWAs.
61. I must validate their struggle - make it real by being a witness.
62. It is important that they have someone to help them and to understand.
63. I need to let them be totally honest and tell me how they feel, even though I do not want to hear it.
64. Some PWAs' lives were bad, with little chance of getting better, even before AIDS.
65. AIDS makes it that much worse.
66. It is much worse for children.
67. One little child I work with cannot communicate her needs to me.
68. I want to know where she hurts and what she wants.
69. It is hard to hear about other people's pain when I cannot make it better.
70. It is very difficult to hear their troubles.
71. AIDS is like an endless swamp.
72. It is like a moral swamp, too.
73. They do drugs because it makes them feel better.
74. They are going to die, so why should they stop doing drugs?
75. Doing drugs eases the pain, so why should they stop?
76. The same moral swamp is in hooking. Hookers may be having unsafe sex.
77. I think everyone who has unsafe sex now deserves what they get.
78. But if I know someone is HIV+ and is having unsafe sex, it makes it harder to keep quiet.
79. They may be selling their prescription drugs to get money for groceries or rent.
80. We agree to disagree on these differences.
81. I feel isolated through my work with PWAs.
82. I did not catch the disease, but I caught the isolation.
83. Isolation is a real infectious thing.
84. Because of confidentiality, I must not talk to others bout my problems with PWAs.
85. Family members do not understand and do not support me in my work with PWAs.
86. None of the other buddies say they are supported be family and friends.

87. So we catch the isolation.
88. Even my close intimate friends do not want to talk to me about this.
89. It is a large part of my life I cannot share.
90. Society refuses to deal with AIDS.
91. All buddies experience the same isolation.
92. Being a buddy supervisor, it is even hard for me to share what is going on with me at the buddy support meetings - I have to maintain my responsibility to the group.
93. I am drafting a letter of resignation. I need out.
94. This kind of thing (buddying) is hard to do, even under the best of circumstances.
95. We do it under close to the worse circumstances.
96. I feel punished for doing this work.
97. We have a very small group. A few of them run things.
98. This has gone on too long.
99. Only if I get out can changes (in management) take place.
100. The former leader of the organization left. He got caught in the trap.
101. I feel caught in the same trap.
102. I want to stop being a buddy supervisor, but continue being a buddy.
103. I cannot work as I do and do a good job at this, too. Others can do it better.
104. Others will have to experience it for themselves.
105. It has been too long for me.
106. I brought one PWA the food that he wanted from Long John Silvers and Shoneys. He ate and enjoyed it.
107. He died the next day.
108. It is hard to see PWAs suffer.
109. I want them to go ahead and die.
110. Sometimes they die too soon, and I am not prepared.
111. I feel guilty when someone dies suddenly, as if I should have known.
112. PWAs can teach us many things, and they do.
113. One thing they taught me is that I need to stop doing this for a while.
114. I have learned to look at life differently and appreciate friends, family and the positive things in life.
115. Right now I am burned out.
116. My level of involvement with buddies ranges from very little contact to being intimately involved.
117. So, the level of impact of loss should be different.
118. But right now, it is all the same.

119. Rather than individuals, they are more like a sea of faces.
120. Some are closer than others.
121. It is more of a mass tragedy than an individual struggle.
122. The population infected with HIV is changing.
123. The next batch is going to be teenagers and that scares me.
124. It is difficult to make the transition from nice upper middle class educated men to junkies and hookers.
125. It will be more difficult to go from junkies and hookers to teenagers.
126. I think the next population will be kids and teenagers.
127. I feel helpless about the ones who are sick.
128. I feel frustrated that we cannot properly educate people.
129. People do not want to hear us.
130. Religious groups and politicians thwart education efforts.
131. I am aware of these restrictions from my involvement with the organization.
132. One PWA was touched deeply when I shared his food with him, eating off his plate.
133. He had noticed people's behavior toward him changing.
134. Others would not share his food.
135. I was smart enough to know that I was not going to get AIDS that way.
136. PWAs are starved for physical attention.
137. They do not get much after their diagnosis is well known.
138. I enjoy touching PWAs.
139. It gives them some tactile love.
140. Many people who work with the organization are HIV+.
141. At some point they will get sick and die.
142. I have trouble fighting with these people for that reason.
143. So I treat them differently (in terms of administration issues).
144. People who spend a lot of time with PWAs feel guilty because <u>they</u> are not sick.
145. Survivor guilt is present.
146. Why am I spared and not them?
147. My behavior was such that I would have been a prime candidate for AIDS.
148. I see survivor guilt in other buddies.
149. My activities with PWAs depend on how much I trust them.
150. I trusted my earlier clients, but I cannot trust the junkies and hookers.
151. Some of these PWAs can manipulate me. I have to watch out for that.
152. It is not personal, just self-protection.

153. Some have abused the trust I had for them.
154. I am getting wiser.
155. Relationships with PWAs are all different.
156. I have learned a lot in the past five years.
157. Clients rip me off all the time.
158. It feels different to be ripped off by a PWA.
159. This is more on a personal level.
160. It is a violation of trust.
161. Part of our job (as buddies) is to develop trusting relationships with PWAs.
162. Some PWAs have never had a trusting relationship and could not recognize one.
163. I have let AIDS dictate my behavior for the last five or six years.
164. I need to take power back and redirect my life.
165. I am not sure I can do that.
166. It is hard to ignore others' needs.
167. I will continue with my current PWAs.
168. But I will stop the other activities.

APPENDIX J

Sample Clustering of Meaning Units

The following clusters of statements are created by grouping the meaning units in Appendix I. The statements are grouped according to the general themes they represent.

Impact

Reciprocal Teaching & Learning:

8. One PWA taught me how to talk about death and dying without being uncomfortable.
9. My experiences with PWAs have taught me about death, dying and losing chances.
112. PWAs can teach us many things, and they do.
113. One thing they taught me is that I need to stop doing this for a while.
114. I have learned to look at life differently and appreciate friends, family and the positive things in life.
156. I have learned a lot in the past five years.

Loss & Grief:

7. I can talk about death and dying professionally, but it is hard when it relates to a contemporary or peer.
25. The inevitability of death for PWAs is always present.
110. Sometimes they die too soon, and I am not prepared.
117. So, the level of impact of loss should be different.
118. But right now, it is all the same.
119. Rather than individuals, they are more like a sea of faces.
120. Some are closer than others.
121. It is more of a mass tragedy than an individual struggle.

Survivor Guilt:

54. AIDS cuts life short.
55. That is stressful for me.
56. That makes me angry.

57. That may be part of what gives me energy (to work with PWAs).
58. When I am angry about something, I must do something about it.
111. I feel guilty when someone dies suddenly, as if I should have known.
144. People who spend a lot of time with PWAs feel guilty because they are not sick.
145. Survivor guilt is present.
146. Why am I spared and not them?
147. My behavior was such that I would have been a prime candidate for AIDS.
148. I see survivor guilt in other buddies.

Feelings of Helplessness:

20. I can feel like I'm not doing enough, or be overwhelmed with too many needs.
35. I assumed he was really suffering.
36. There is a belief that even though some people are ready to die, they hang on because the feel they have responsibilities here.
37. Family members may not want them to die and beg them to stay alive.
43. It was hard watching a PWA deteriorate, believing he did not want to.
54. AIDS cuts life short.
55. That is stressful for me.
56. That makes me angry.
59. But I really cannot do anything about this - with AIDS, people will get sick and die.
69. It is hard to hear about other people's pain when I cannot make it better.
70. It is very difficult to hear their troubles.
108. It is hard to see PWAs suffer.
109. I want them to go ahead and die.
127. I feel helpless about the ones who are sick.
128. I feel frustrated that we cannot properly educate people.
129. People do not want to hear us.
130. Religious groups and politicians thwart education efforts.
131. I am aware of these restrictions from my involvement with the organization.

Friendship & Support:

23. I feel like it is me and my PWA against the world.
61. I must validate their struggle - make it real by being a witness.
62. It is important that they have someone to help them and to understand.
63. I need to let them be totally honest and tell me how they feel, even though I do not want to hear it.
106. I brought one PWA the food that he wanted from Long John Silvers and Shoneys. He ate and enjoyed it.

Roles

PWA's Role:

12. The first people (the organization) served were upper middle class, well educated and articulate.
13. They could tell us what they wanted.
14. Now we serve more junkies and hookers who are hustling for survival issues.
15. They don't bring much insight or joy into a relationship.
16. They mostly have needs, and take without giving.

Participant's Role:

5. One PWA and I got to be real friends.
6. I wasn't his buddy. I was his friend.
22. As a buddy, the boundaries between professionalism and friendship are not as clear.
29. They need more and more from me as time goes on.
60. I must be a friend, witness and support person for PWAs.
61. I must validate their struggle - make it real by being a witness.

Similarities & Differences:

28. Under normal circumstances, I probably would never have met them, or at least not be best friends with them.

64. Some PWAs' lives were bad, with little chance of getting better, even before AIDS.
65. AIDS makes it that much worse.
66. It is much worse for children.
67. One little child I work with cannot communicate her needs to me.
72. It is like a moral swamp, too.
73. They do drugs because it makes them feel better.
74. They are going to die, so why should they stop doing drugs?
75. Doing drugs eases the pain, so why should they stop?
76. The same moral swamp is in hooking. Hookers may be having unsafe sex.
77. I think everyone who has unsafe sex now deserves what they get.
78. But if I know someone is HIV+ and is having unsafe sex, it makes it harder to keep quiet.
79. They may be selling their prescription drugs to get money for groceries or rent.
80. We agree to disagree on these differences.
122. The population infected with HIV is changing.
123. The next batch is going to be teenagers and that scares me.
124. It is difficult to make the transition from nice upper middle class educated men to junkies and hookers.
125. It will be more difficult to go from junkies and hookers to teenagers.
126. I think the next population will be kids and teenagers.
150. I trusted my earlier clients, but I cannot trust the junkies and hookers.

Boundaries

Between Participant & PWA:

5. One PWA and I got to be real friends.
22. As a buddy, the boundaries between professionalism and friendship are not as clear.
30. I have wished that some would give up and die.
31. One PWA that I knew was already in severe dementia when I met him.
33. I would rub his feet and read to him, but there was minimal communication.
38. I can give them permission to die.

39. I gave a PWA permission to die (when he was in a coma), but he got better the next day.
40. I was afraid he had heard me say it when he was in the coma.
47. It was very difficult to see him demented.
48. Their minds come and go, so you never know if you are going to be able to communicate with them.
116. My level of involvement with buddies ranges from very little contact to being intimately involved.
132. One PWA was touched deeply when I shared his food with him, eating off his plate.
133. He had noticed people's behavior toward him changing.
134. Others would not share his food.
135. I was smart enough to know that I was not going to get AIDS that way.
140. Many people who work with the organization are HIV+.
141. At some point they will get sick and die.
142. I have trouble fighting with these people for that reason.
149. My activities with PWAs depend on how much I trust them.
150. I trusted my earlier clients, but I cannot trust the junkies and hookers.
151. Some of these PWAs can manipulate me. I have to watch out for that.
152. It is not personal, just self-protection.
153. Some have abused the trust I had for them.
154. I am getting wiser.
155. Relationships with PWAs are all different.
157. Clients rip me off all the time.
158. It feels different to be ripped off by a PWA.
159. This is more on a personal level.
160. It is a violation of trust.
161. Part of our job (as buddies) is to develop trusting relationships with PWAs.
162. Some PWAs have never had a trusting relationship and could not recognize one.

<u>Between PWA & Others</u>:

32. His family was ignoring him. Only his sister would visit, and then only rarely.

44. One PWA returned to his faith after many years, knowing his religion forbade suicide.
45. He decided to let things take their course.
46. He did not want to go through the debilitating process, but that is what he did, anyway.
133. He had noticed people's behavior toward him changing.
134. Others would not share his food.

Between Participant & Others:

81. I feel isolated through my work with PWAs.
82. I did not catch the disease, but I caught the isolation.
83. Isolation is a real infectious thing.
84. Because of confidentiality, I must not talk to others about my problems with PWAs.
85. Family members do not understand and do not support me in my work with PWAs.
86. None of the other buddies say they are supported be family and friends.
87. So we catch the isolation.
88. Even my close intimate friends do not want to talk to me about this.
89. It is a large part of my life I cannot share.
90. Society refuses to deal with AIDS.
91. All buddies experience the same isolation.

Unique Themes Specific to This Interview

(Discussed with Participant in Follow-up Interview)

Lost Opportunity:

10. The PWAs I have known have all died young.
11. Their lives are not supposed to stop at this point.
53. Infants can die and it can be considered an accident of nature - Old people have finished their lives - but young people are dying during viable periods in their lives.

54. AIDS cuts life short.

<u>AIDS Burnout</u>:

3. I've been a buddy for five or six years now.
4. I'm tired of AIDS.
92. Being a buddy supervisor, it is even hard for me to share what is going on with me at the buddy support meetings - I have to maintain my responsibility to the group.
93. I am drafting a letter of resignation. I need out.
94. This kind of thing (buddying) is hard to do, even under the best of circumstances.
95. We do it under close to the worse circumstances.
96. I feel punished for doing this work.
97. We have a very small group. A few of them run things.
98. This has gone on too long.
99. Only if I get out can changes (in management) take place.
100. The former leader of the organization left. He got caught in the trap.
101. I feel caught in the same trap.
102. I want to stop being a buddy supervisor, but continue being a buddy.
103. I cannot work as I do and do a good job at this, too. Others can do it better.
104. Others will have to experience it for themselves.
105. It has been too long for me.

APPENDIX K

Follow-up Letter to Participants

Dear__________ :

After several months of working with your interview, I am ready to discuss the results of the study with you. As you remember, the purpose of this study was to take a close look at the experience of having had a close relationship with a person with AIDS.

The nature of phenomenological studies such as this one is to examine in-depth descriptions of an experience (through interviews, in this case) and to determine the themes that emerge across all the descriptions. Your interview was very helpful in the study.

You are receiving a transcript of your interview as well as a brief summary of it for you to review. Please look over these and decide if there is anything you would like to add or change. You are also receiving a description of the themes that emerged from the interviews, and examples of how those themes were manifested in the experiences you described. At the end of that summary is a list of code translations for your particular interview. As you remember, the names of persons and places you mentioned in the interview were assigned codes in order to protect your anonymity and that of anyone you talked about with me. Finally, you are receiving a list of quotes from your interview which might be used in the final dissertation text. Please look over your quotes to determine if there are any you would prefer not to have printed.

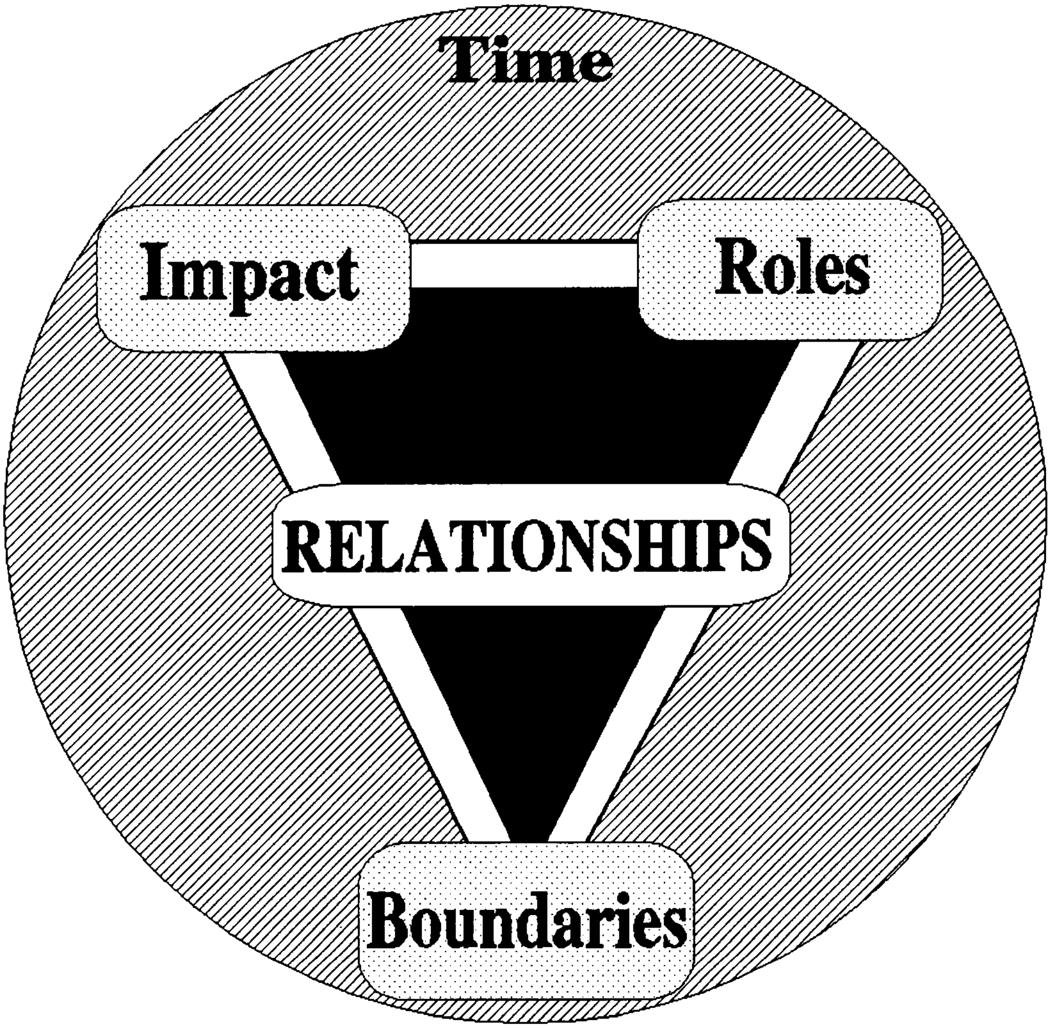
I will be contacting you beginning next week in order to schedule a follow-up interview. At this time, you may add, change or clarify anything you like in your description of your experience. We can do the interview in person or by phone, depending upon which is more convenient for you. If you have any questions in the meantime, please feel free to call me at 983-8746. I will out of town during the week, but will be back on Saturday, June 8.

Thank you again for your participation in this study. Your input was extremely helpful. I am looking forward to talking with you in the next few weeks.

Sincerely,

Bill Hale

APPENDIX L



Thematic Structure of the Experience
of Personal Relationships with PWAs

VITA

William Chamberlain Hale II was born in Johnson City, Tennessee on November 22, 1954. He attended public schools in the Johnson City School System, graduating from Science Hill High School in June, 1972. The following August, he entered Milligan College and graduated with a Bachelor of Science degree in Business Administration in May, 1976. After working in the banking industry for nine years, he entered East Tennessee State University in August, 1985, and graduated with a Master of Arts degree in Community Agency Counseling in May, 1987. In September, 1987, he entered The University of Tennessee, Knoxville, and graduated with a Doctor of Philosophy degree in Education in August, 1992.