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Caregiving behaviors and coping skills of caregivers to people with Acquired Immune Deficiency Syndrome

Gabbay, Sarah G., Ph.D.

The University of North Carolina at Greensboro, 1991

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CAREGIVING BEHAVIORS AND COPING SKILLS OF CAREGIVERS TO PEOPLE WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME

by

Sarah G. Gabbay

A Dissertation Submitted to
the Faculty of the Graduate School at
The University of North Carolina at Greensboro
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Approved by

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The purpose of the study was to describe the behaviors, attitudes, and coping skills of caregivers to people with Acquired Immune Deficiency Syndrome (AIDS) in the population of a moderate size metropolitan area in central North Carolina. Utilizing an ethnographic design based in Symbolic Interaction theory, 31 caregivers to people with AIDS (PWAs) were interviewed using an open-ended questionnaire. The Culture Free Self Esteem and Coping Inventories were used to measure aspects of the caregivers' personality and coping, and the Katz ADL was administered to estimate the degree of dependency of the PWA on the caregiver.

Findings generally support those of national studies on caregivers to individuals with diseases or handicaps other than AIDS. Participants were found to have high degrees of filial responsibility, volunteerism, compassion, intelligence, resourcefulness in coping skills, and self esteem. Many primary caregivers find themselves overwhelmed with the requirements of the role. Secondary and attenuated caregivers are often recruited to assist in care, especially in the later stages of the disease. It is in this way that the disease drives the caregiving. The stigma associated with the disease often isolates the person with AIDS and the caregivers. Many caregivers reported negative reactions from others when their caregiving role was revealed, although a positive reaction was often received from well chosen individuals.

Issues with regard to research in a stigmatized culture, effect of research on participants, and future needs of the AIDS caregiving

population are discussed. Researchers involved with a stigmatized population must take extra care to preserve confidentiality and safety of subjects. Caregivers to PWAs were found to need support from a network of public and private assistance programs to increase future coping and insure successful caregiving.

The effect of the changing face of AIDS on the AIDS service community is reviewed. Almost half of the AIDS population is now from the drug abuse subculture. These individuals were found to be especially difficult to care for due to their lack of resources and support network, and poor mental health. Recruitment of caregivers for former drug addicts may be very difficult.

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CHAPTER I

INTRODUCTION

Purpose of the Study

The primary purpose of this research was to study caregiving attitudes, behaviors, and coping skills of persons providing care to individuals with Acquired Immune Deficiency Syndrome (AIDS). A secondary purpose was to address alternatives for private and public programs to fill the unmet needs of caregivers to persons with AIDS (PWAs). The goals of the study were to identify: 1) successful and unsuccessful caregiver attitudes, behaviors and coping skills of caregivers to PWAs; and 2) areas of unmet needs in caregiving to PWAs for private and public programs to address. Thus, this study was designed to provide basic information on caregiving to PWAs that would lead to addressing interventions to facilitate caregiving to PWAs.

The focus of this study addressed the psychosocial aspects of providing care to PWAs in order to facilitate families, friends, and the professional community in their ability to effectively respond to the needs of PWAs and their caregivers. It is necessary that we know more about the attitudes, values, decision making, behaviors, and coping skills of caregivers. Both stressful and nonstressful day-to-day responsibilities and experiences of caregivers need to be understood. Other factors, both internal and external to the caregiving arrangement, such as societal values, as well as those among or within the immediate family, also need to be identified (Macklin, 1988, 1989; Morin, 1988; Pelosi, 1988; Watkins, 1988a, 1988b).

Studying caregivers to PWAs is an important area of research in a new field (Backer, Batchelor, Jones & Mays, 1988; Macklin, 1988). However, it is related in many ways to caregiving in general, and specifically to the psychosocial aspects of caring for a terminally ill loved one (Brody, 1985; Cantor, 1983; Kubler-Ross, 1987; Macklin, 1988; Mailick, 1979; Montgomery, Gonyea & Hooyman, 1985; Northouse, 1984; Sheehan & Nuttall, 1988). Unlike other terminally ill individuals, PWAs carry the stigma associated with the disease which is problematic for them and their caregivers (Gabay & Morrison, 1985; Herek & Glunt, 1988; King, 1986; Macklin, 1988; Morin, 1988). This study, therefore, addressed gaps in the literature regarding social stigma and chronic illness, specifically research that focuses on caregiving to PWAs.

AIDS Epidemiology

While the AIDS virus, Human T-Cell Lymphotropic Virus III (HTLV-III), was first isolated in 1984, doctors speculated that it had been introduced into the U. S. population some time in the 1970s. The first known case of AIDS was of a 15 year old male prostitute in St. Louis, Missouri, in 1968. This adolescent presented with deteriorating health in serious condition from a myriad of systemic and rare infections. After his death, doctors took serum and tissue samples for freezing to be studied later. When, in 1984, AIDS was classified as a viral disease, some of the symptoms described reminded these doctors of their young patient 16 years prior. After retrieving and studying tissue and serum samples from the young man, it was discovered that he had AIDS (Mental Health Aspect of HIV Disease, Washington D. C., December 9-10, 1988, Dr. Janice Hutchinson, AIDS and Youth).

How was this child exposed to AIDS? Where had the disease come from? Where was it for 16 years? It is hypothesized that the boy had been living on the streets of St. Louis for several years. He was black and had been brought to the hospital by a male friend who said the boy was a runaway and that he was afraid the boy was dying. He may have been exposed through unsafe sexual practices. If he was an IV drug user, he also could have been exposed through the sharing of needles.

Gonda (1986) provides a plausible scenario for the worldwide origin of the disease and why it was dormant in the U. S. for such a long period of time.

> Although no one knows whether the HTLV-III-induced syndrome is a new disease or where it came from, serologic data are now accumulating to suggest that the virus was in Africa at least a decade before it came to the United States, probably via Haiti. What we don't know is whether the virus was present in humans before the first documented evidence or whether it came from an animal reservoir. We can only speculate on these possibilities. If the virus was widely present in humans before that time, it must have gone through a genetic change that made it more pathogenic. But there are not data at present to substantiate the coexistence of pathogenic and nonpathogenic forms of the virus. It is hard to believe that the nonpathogenic version could have died out in the few years since giving rise to a pathogenic form. (pp. 80-81)

Gonda (1986) speculated that the AIDS virus was initially spread from an isolated, semi-immune, infected population through migration as the African continent became more open due to immigration from rural populations to large cities. This is not unlike the spread of small pox and the measles from European explorers to Native American and Pacific Islander populations centuries ago. In European populations these diseases had been relatively mild infections due to built-up immunities, but they were quite deadly to the non-immune natives of other continents.

History of AIDS in the United States. In 1981 the first medical classification of the AIDS Human Immunodeficiency Virus (HIV) in the United States was made. In 1984 HTLV-III was isolated from human blood as the causative agent of AIDS (Gallo, 1987; Gonda, 1986). Since 1981 over 164,000 cases of AIDS have been reported (U. S. Department of Health and Human Services (USDHHS), 1991). AIDS is generally recognized as a serious public health problem of epidemic proportions (Batchelor, 1984a, 1984b; Faulstich, 1987; Urwin, 1988). Almost 99% of those testing positive (HIV+) to the virus develop AIDS (Lui, Darrow & Rutherford, 1988). As of the winter of 1991 at least 1.6 million Americans were HIV+. There have been no substantiated cases in the United States of an HIV+ person subsequently testing negative for the disease, although recent news reports indicate there may be some medically unsubstantiated cases of seropositive individuals subsequently testing seronegative (Phillips, 1991). AIDS is eventually terminal in everyone who contracts it, though it may take upwards of a decade for half of the HIV+ population to progress to full blown AIDS.

Pathology. There are four phases of the disease. The time interval varies by individual between exposure--Phase I; testing serum positive for HIV and symptoms of AIDS Related Complex (ARC) (or pre-opportunistic infection symptoms such as weight loss, swollen glands, and night sweats)--Phase II; onset of initial opportunistic infection (OI)--Phase III; and length of time from first OI to death--Phase IV. There is no clear-cut pattern to describe the action and direction of HTLV-III in the body after exposure. However, by attacking white blood cells and the central nervous system, over time the virus reduces the body's immunity to dangerously low levels. Once natural immunity is reduced to a certain level, the body is at risk for OIs that so weaken the patient that death is inevitable. This process takes a varying amount of time in each person (DeVita, 1985).

There is some growing evidence that AIDS and ARC take on different patterns in men and women (Halpern, 1989). In many cases women do not experience the AIDS-associated OIs such as Kaposi's Sarcoma, but often have long term genital infections that are unresponsive to medical treatment. There is some evidence that women remain healthier during the ARC period, unless they become pregnant. In some cases the process of gestation exhausts the body's resources and can hasten the experience of OIs, eventually bringing about death. On the other hand, Kaposi's Sarcoma seems to be primarily a male OI.

It is believed that the exposure source also affects the rate of development of ARC and AIDS. While it is not clear how many exposures and to what extent a single exposure can lead to infection, it is argued that direct blood-to-blood exposure, such as through a transfusion or IV drug use sharing of needles, could be a more at-risk exposure than sexual contact. Oral sexual contact seems to be less risky than vaginal or anal contact for the previously unexposed. This could be due to the fragile nature of the virus. If it is exposed to digestive juices, it may not survive. This is supported to some extent in the lack of infection of PWA household members, even if mouth to mouth kissing occurs (Koop, 1986).

Unlike the rest of the world, where AIDS has been a disease of heterosexual transmission (Piot, et al., 1988), the history of the introduction and spread of AIDS in the United States has been associated with several stigmatized minority groups: gay men, intravenous drug users, prostitutes, and Haitians (who are stigmatized because they are black, from the Third World, poor, and from a culture alien to mainstream U. S.). Thus "the AIDS epidemic has been accompanied by intensely negative public reactions to persons presumed to be infected by the . . . virus" (Herek & Glunt, 1988, p. 886). In many areas, the testing for HIV antibodies appears to be an attempt to quarantine or persecute those testing positive (Coates, et al., 1988; Morin, 1988; Shilts, 1987).

In the absence of a clear national plan of public education in AIDS prevention there has been a dramatic shift in the at-risk populations. While gay male communities in many of the major cities have undertaken extensive prevention education programs with their own members, little prevention education has been done in non-gay populations. This lack of prevention activity may be the reason that there has been a demographic shift in rates of new exposures. Currently the IV drug abuse and minority heterosexual populations show increasing rates of reporting of HIV+ and AIDS, while the gay male population is experiencing a decreasing rate of HIV+ and AIDS reporting (Urwin, 1988). Therefore, the epidemic now threatens the white and black heterosexual middle class (USDHHS, 1991).

CHAPTER TWO

LITERATURE REVIEW

Definition of Caregiving

Barer and Johnson (1990) described the problematic status of the multiple definitions of caregiver in the research literature. Methodological problems arise in defining the caregiver. Barer and Johnson expressed a preference for the definition of caregiver used by Stone, Cafferata, and Sangl (1987),

> who restrict the term primary caregiver to those having total responsibility for the provision of care. Their three other categories include 1) primary caregivers who have informal help (having the main responsibility but assisted by other unpaid caregivers); 2) primary caregivers with both informal and formal help; and 3) secondary caregivers who do not have the main responsibility. (p. 27)

This researcher would like to define caregivers by type, inclusive of the four above mentioned categories and a fifth category of support team member. Many PWAs have a group of family and friends or assigned buddies to render care. It is these people who give the majority of care to PWAs in the U. S. It is projected that this private sector, volunteer care reduces the cost of treatment of the disease (Anderson, 1989). In some cases each individual is assigned specific tasks--medication, physical hygiene and comfort, food preparation, house maintenance, transportation, or medical and social service agency liaison. It is believed that restricting the sampling definition to the above primary caregiver designation would reduce the wealth of the descriptive data.

Caregiving duties vary with the course of the disease. Due to the wasting nature of the disease and the serial infections that generally weaken the patient to the point where employment and normal daily activities are decreased, many PWAs need assistance in daily living in addition to caregiving during acute medical crises. This situation may be like caregiving to a progressively weakened elderly individual or any other person who is losing the ability for self care. However, between bouts with OIs there may be long periods of independence from physical care needs. During these times emotional support may be the primary type of care received. On the other hand, the use of a group of caregivers at the most advanced stages of the disease could document the need for extensive caregiving that might exceed the role of a single caregiver in the chronically ill or non-hospitalized terminally ill person.

Psychosocial Aspects of Caregiving

There are no empirical data available on the experiences of persons who provide care to PWAs. However, Macklin (1988) gives an outline of some of the problems associated with caregiving experiences to PWAs. She lists eight areas of concern: social stigma and isolation, fear of contagion, fear of infection, fear of abandonment, guilt, anger, grief, and economic hardship. These issues are discussed as they apply to the PWA and those persons who know, live with, or work with a PWA. Her listing of these eight areas of concern was gleaned from personal accounts of lovers, family, and professional health care providers to PWAs. Each of these eight areas of concern deals with the perceived relationship of the caregiver to the societal reaction of family, employer, and community at large. For example, with regard to social stigma and isolation of PWAs and their associates, Macklin notes that out of fear of prejudice and reprisal, many PWAs and their families are loathe to acknowledge the illness to their friends, neighbors, coworkers, and even to other family members.

The remainder of this literature review provides a detailed discussion of the type of information Macklin (1988) provided. This is designed to shed light on understanding the possible behaviors and coping skills of caregivers to PWAs.

Some of the personal account information on caregiving to PWAs takes the point of view of an individual family member giving care to a PWA (Peabody, 1986). Other works describe the care given to a spouse or lover, sometimes when the caregiver is HIV+ (Monette, 1988). Still other works relate the experience of a medical or mental health professional caring for PWAs (Bradley, 1988; Dilley, Ochitill, Perl & Volberding, 1985; Mohr, 1988; Volberding, 1985; Walker, 1988).

Personal Accounts. Personal and historical accounts of caregiving to a PWA include the following examples. In *And the band played on*, Shilts (1987) described several cases where tragic circumstances sadden, anger, or otherwise appeal to an emotional response in the reader with regard to AIDS response history, treatment, public policy, PWAs, and caregiving to PWAs. Peabody (1986) gave a heartrending account of her experiences as the mother of a PWA early in the epidemic. In *Borrowed time*, Monette (1988) described his lover's AIDS experience and then his own.

Effects on Relationships. Carl (1986, 1988) gave a brief description of the effects that AIDS had on gay couple relationships and dating. This description was taken from case study accounts of clinical populations. These reports dealt with prevention behaviors, fear of contraction, and some decisions with regard to continuing relationships in response to HIV serum-positive diagnoses. Faulstich (1987), Frierson and Lippman (1987), and Harowski (1987) also reported on some of the psychological distress in the worried well--currently asymptomatic persons who realize their past lifestyles have put them at risk for AIDS. Some of this distress includes fear of contraction, disrupted social relationships, and the surfacing of internalized homophobia. While these studies focused on gay relationships, many of the same issues arise in heterosexual liaisons.

Filial Responsibility. Cleveland, Walters, Skeen, and Robinson (1988) described the results of a poll of 763 subjects who were parents of gay children. When asked how they would feel about discovering their child had AIDS, most responded that they would try to be supportive. This demonstrates that filial or parental responsibility strength can survive the disclosure of alternative (stigmatized) sexual orientation. This could be an important consideration in recruiting family members for caregiving.

Reducing Stigma and Prejudice. Gabay and Morrison (1985) reported that people who were uninformed about gay people and expressed prejudice against them were more likely to be uninformed about AIDS and express prejudice against PWAs. Prejudice against PWAs and antigay sentiments in the medical and professional health sectors have also taken their toll in under-reporting of AIDS and inferior medical and social services care (Heagarty, 1987).

Recruitment to Give Care. To date there is no information on recruitment of PWA caregivers. Do PWAs ask informed individuals to help them with care? Do PWAs ask prejudiced individuals to help them? Do people who know little about homosexuality, drug abuse, or AIDS at the time of recruitment become successful caregivers? Is knowledge of these issues useful in caregiving? Is the choice made more difficult when a gay or IV drug user has to come out to family and friends to request care? In a review of case study work with gay men, Gilbert (1988) discussed the impact that these kinds of issues may have on family relations. These are some issues in which future research is needed to expand our understanding not only of caregiving to PWAs, but also of the behaviors of coming out, and requesting care.

Related Issues in Caregiving

Caregiving to demented elderly. In light of the fact that no empirical data exist on caregiving to PWAs, a discussion is provided here on caregiving experiences with other types of diseases and situations in order to shed light on understanding caregiving to PWAs. As with senile dementia, much of the disability experienced with AIDS is in the area of mental health. Many PWAs experience the loss of clear thinking skills such as how to organize daily activities, and decreased ability for categorization and classification of information. Because of this effect of AIDS dementia on PWAs who may otherwise be relatively physically healthy, there has been a suggestion in the literature that caregivers to PWAs may bear similar burdens to those of caregivers to people with mental illness or Alzheimer's Disease (AD) (Macklin, 1989). As with AD and senile dementia, the stigma of AIDS also provides possible complications to care.

Stigmatized illness--leprosy. Leprosy, or Hansen's Disease, is a worldwide, chronic disease that infects the skin, eyes, mucous membranes, nerves of the body extremities, and the testes. It is caused by a bacteria that is similar to that of tuberculosis. The disease is rarely fatal. Leprosy has long been a stigmatized disease, and many of the infected individuals have been social outcasts. At the height of outbreaks there were often hundreds of quarantine areas or leper colonies established to hold lepers. These were often very isolated geographically. It was not uncommon for there to be no communication or transportation out of the colony. However, leper colonies might be considered a more humane treatment of the population than stoning, burning at the stake, or live burial--the alternatives previous to colonization. There is still a mistaken widespread belief that segregation from the general population helps prevent the spread of the disease. However, leper colonies or treatment facilities today are primarily meant to congregate the infected for more effective and economical treatment.

The fear and loathing associated with leprosy is similar to that associated with AIDS. While the quarantining is more severe with leprosy, the social stigma that isolates PWAs itself serves as a quarantine. Caregiving to PWAs carries stigma, much like the stigma associated with leprosy caregivers. Leprosy caregivers, sometimes including the entire family of the patient, were often forced to accompany the patient to leper colonies. Usually the caregivers were not allowed to leave the colony, even though they showed no signs of the disease, and even when the infected individual for whom they cared had died. There are numerous examples in leprosy and AIDS case histories of individuals going "underground" to avoid detection and stigma. The labeling of leprosy patients as unclean or cursed is similar to that of

AIDS patients as being deviant, or not like the general population. The blame of the leper for his condition parallels that of the blame of the PWA.

What we can learn from the treatment of lepers with regard to AIDS is that until the disease became widespread there was no humane or medical treatment of the leper. Mostly these people were social outcasts. When the disease began to threaten whole populations, then isolation of the infected was instituted. Once isolated, the leper population was virtually forgotten. Leaders of social conscience would occasionally decry the horrible conditions of leper colonies and lack of medical cure. However, it was not until the 1950s that it was discovered that the use of sulfa drugs could decrease the effects of the disease (Encyclopaedia Britannica, 1969).

Caregiving to terminally ill children. In literature describing caregiving to terminally ill children there is also frequent personal experience or case study description similar to that about PWAs. However, there is some empirical information on the larger population of caregivers, the effects of caregiving on the family, and caregiving burden. (Binger, Ablin, Feuerstein, Kushner, Zager & Mikkelsen, 1969; Soricelli & Utech, 1988; Tull & Goldberg, 1984). Koch (1985) studied a small group (n = 32) of families of children with recently diagnosed cancer for the effect it had on family relations. She found five patterns of reaction to the diagnosis: "experience of increased negative affect, rules prohibiting emotional expression, health and behavior problems following the diagnosis, role changes, and increased closeness" (p. 65). Findings similar to Koch were reported by Velasco de Parra, Davila de Cortazar, and Covarrubias-Espinoza (1983) in a study of the reaction of 10 families of leukemic children.

Kupst, et al. (1984) described work with 64 children with leukemia and their families in a psychosocial model. They found that certain adaptive dilemmas for the families of terminally ill children include anticipatory mourning, maintenance of confidence, and mastery in the face of the illness. Caregiving to a terminally ill loved one, especially offspring, may be one of the most stressful life events one can experience. It may be that caring for an adult child has a similar impact on parents of PWAs (Margolies, et al., 1988).

Many of these same issues are present in families with children who have sickle cell anemia (Dilworth-Anderson & Slaughter, 1986). Sickle cell anemia is a chronic, eventually fatal disease of the blood, characterized by episodes of pain, decreased blood circulation, and life threatening blood clots. For the most part, the patient's family attempts to organize around a normal or non-medical model of family life. The sickle cell trait and the actual disease are considered "bad blood" in the black community and carriers are stigmatized. Thus, disclosure of the trait is considered risky, causing the family social stigma.

Similarly to people with leukemia or sickle cell disease, the PWA may receive care from a parent. What is the experience of the parent of a PWA of giving care? Is this relationship clouded by the anticipatory grief reported in literature on leukemic families (Kupst & Schulman, 1980; Kupst et al., 1984; Kupst et al., 1982)? What types of stresses are evident in parent caregivers to PWAs? What can be done to help these families cope?

Stress and caregiving. Cobb (1976) discussed the importance of support in helping patients under stress cope better with their illness. Indeed, stress and bereavement have been shown to decrease immune function (Irwin, Daniels, Smith, Bloom & Weiner, 1987; Kiecolt-Glaser & Glaser, 1987, 1988; Pennebaker, Kiecolt-Glaser & Glaser, 1988; Schleifer, Keller, Camerino, Thornton & Stein, 1983; Solomon & Temoshok, 1987). This concept is also applicable to caregivers (Kiecolt-Glaser et al., 1987). Friedman (1967) discussed how physicians and other medical personnel should try to help families of the terminally ill cope with the diagnosis and treatment of cancer in their child. It is generally suggested that attention should be paid to reducing the stresses and emotional shock of the initial diagnosis and treatment in illness.

Nichols (1985) and Macklin (1988) suggested that an ecological approach be applied when treating the newly diagnosed PWA and family or support group of friends. Nichols cautioned not to rush ahead with abolishing resistance and denial in the PWA, but rather help the PWA and caregiver to elicit improved health behaviors. Care should be taken to help the PWA adjust to the new realities of a terminal illness, one of the most important of which may initially be the disruptive complications to relationships. Siegel and Krauss (1991) report three adaptive challenges of newly diagnosed AIDS patients: "dealing with the possibility of a curtailed life span..., dealing with reactions to a stigmatizing illness..., and developing strategies for maintaining physical and emotional health" (p. 21) Some of the behaviors related to adapting to the illness that a caregiver or professional helps the PWA with may include finishing projects, establishing improved health behaviors, asking for or giving forgiveness to important people in their lives, and making plans for dying and burial. Many of these tasks directly involve the caregiver, and may be psychologically difficult for that individual if there is a strong emotional attachment present.

Cantor's (1983) work on caregiver stress gave support to these findings in that degree of closeness of relationship was found to be positively correlated with level of stress and burden in the caregiver. We may find that difficult as caregiving may be, it may be even more so when: 1) a parent is giving care to an adult child, 2) the care recipient's (child's) lifestyle is significantly different from the parent's, and 3) there are a series of medical traumas that heighten anxiety.

Little is known of the emotional effects on the PWA caregiver. Caregivers to the elderly have long been seen as overburdened (Brody, 1985; Cantor, 1983), but what burdens or issues do caregivers to PWAs face? Macklin (1988) discussed some of the long term and common effects of the caregiving process on families of PWAs. While she found that the family should be included in care, she also stated that the impact on the family continues long past the PWA's suffering and death.

AIDS is not usually a one-crisis disease, but may include a long series of OIs that serve to weaken the PWA and threaten life. These medical crises may be overcome to some degree with proper medical intervention. However, this series of crises has a prolonged emotional effect on the PWA and caregiver that may produce adjustment disorders or depression in either person (Nichols, 1985; Salisbury, 1986). One alarming statistic associated with the diagnosis of AIDS is the increased suicide rate and depression among PWAs (Dilley et al., 1988; Glass, 1988; Marzuk et al., 1988; Nichols, 1985; Shipp, 1986; _Sixty_

Minutes, 1989; Tross & Hirsch, 1988). This may be due to fear of the stigma of having the disease, a depression reaction to the sequential crises creating increased dependency on others, financial strain, lack of desire to continue living with the pain of the OIs, or a combination of these and other factors.

Conflicted relationships. Halpern (1988) discussed the issues of caregiving to an elderly parent with whom there has been a long term conflict. Are these circumstances similar when the caregiving role is reversed--when a parent takes care of an adult child? In many families the conflict may have been over the child's lifestyle choices, the very choices that might have put him or her at risk for AIDS: IV drug use or unsafe sex within the context of socially ostracized forms. What types of reconciliation are needed in a family to encourage caregiving? Does the presence of a gay lover or drug addicted spouse weaken the family response? How can the professional human studies community help families come to more congenial decisions and reduce the stress of the terminal diagnosis and subsequent caregiving?

According to the current literature, fear and prejudice can be reduced through public education and private discussion with relatives of the AIDS patient (Christ & Weiner, 1985; Cleveland, et al., 1988; Coates, Temoshok & Mandel, 1984; Herek & Glunt, 1988; Macklin, 1988). This type of education of potential caregivers to PWAs may be useful in increasing the numbers of friends and relatives who might be willing to become caregivers. This homecare will in turn help alleviate strains on the social and medical service agencies and perhaps raise the quality of care to the PWA.

Clearly, caregiving to a PWA has similarities to giving care to the terminally ill, demented, serially ill, or elderly person as stated above. There are many treatment and emotional issues associated with these care situations that may extend to AIDS caregiving. Unlike other caregiving experiences, providing care to PWAs carries many social stigmas and related psychosocial implications. This study attempts to address these stigmas and provide additional information on how a socially non-acceptable disease influences caregiving behaviors and coping skills.

CHAPTER THREE

THEORETICAL FRAMEWORK

There are a variety of theoretical sources for caregiving role behaviors; among them are role, symbolic interaction, social exchange, and social learning theories (Doherty & McCubbin, 1985). While this research will utilize a variety of concepts from different theories in design and discussion, symbolic interaction theory will be the primary theoretical focus.

The use of a theoretical framework in developing and analyzing research is helpful because it allows the researcher a basis of organization of thought. This has a twofold benefit. First, in caregiving research there is a plethora of theoretical resources, some well developed and others less developed. Choosing a specific theoretical framework within which to work gives focus to the work, and eliminates much peripheral and sometimes underdeveloped theorizing and conceptualization. Second, by choosing a specific theoretical framework, the researcher has the opportunity to add to the body of research in caregiving within the specific chosen theory. This benefits the caregiving research by strengthening it in specific theoretical terms, aiding in replication of research by simplifying concepts into one specific framework, and providing a theoretical grounding for interventions and policies.

Symbolic Interaction Theory--Concepts

George Herbert Mead, a major developer of symbolic interaction theory, broke from both behaviorist and Freudian systems with the belief that behavior is subjectively determined within a specifically social context (Schellenberg, 1978). Behavior carries with it implicit understanding between doer and observer, speaker and listener. This understanding is symbolic in nature. Behaviors represent significant symbols in many contexts, and have specific meanings within the social process in which they arise. Social process "is primarily a matter of human groups . . . which carry on action together and have come to share common significant symbols for carrying out this action" (p. 49). These symbols may have group or individual meaning. In part this is a developmental issue in that the individual is socialized to think and feel according to societal values or norms. The individual either accepts and adopts these norms or rejects them during development to selfhood. "A self is any individual who is a social object to himself. To be a social object to himself means that the individual acquires meanings for his gestures similar to the meanings held by those around him." (p. 49) The generalized other emerges from this capacity to take the role of the other and adopt or at least understand "the organized set of attitudes that are common to a group, and that are taken on by the individual as a context for his own behavior." (p. 49) There are two types of self that emerge with this development: the "me" self that reflects the societal attitudes in behavior, and the "I" self that is the "active and impulsive aspects of the self. . . allowing for new forms of behavior to emerge in action." (p. 51)

In developing the concepts of caregiving and coping skills utilized in this study, attention was paid to discerning the social meaning of actions and roles in light of the concepts found in symbolic interaction theory. Much of the decision to become a caregiver to a PWA may hinge on the anticipation or assumption of what behaviors would be required of a caregiver, and on assessing the social costs of associating with an individual with a stigmatized illness. The first activity of assuming or ascertaining the caregiver behaviors deals with the individual's (social) self. Was the caregiver socialized to believe that the altruistic act of giving care would have value? Does the caregiver believe he or she has the necessary skills to give competent care, or at least can learn these skills? After the caregiver decided to give care, what coping skills were needed? Was there a real or a perceived social cost of associating with a PWA?

The concept of role-taking in symbolic interaction theory addresses this situation in part. "Role-taking is a central concept in the social psychology of Mead" (Lauer & Handel, 1977, p. 60). It is "the process whereby an individual imaginatively constructs the attitudes of the other, and thus anticipates the behaviors of the other" (Lauer & Boardman, 1971, p. 137). This may apply in two ways. First, what does the caregiver anticipate as the response of society at large to caregiving to a PWA? Second, what does the caregiver anticipate as the response of the PWA to caregiving?

There are four subcategories of role-taking: 1) basic, 2) reflexive, 3) appropriative, and 4) synesic. The first three have some application to the process the caregiver undergoes in deciding to provide care. Basic role-taking is primarily concerned with the anticipatory process described above. It is defined as "imaginatively constructing the attitudes of [society] so as to anticipate the behavior" that is expected from those with whom we interact (Lauer & Handel, 1977, p. 62).

Second, reflexive role-taking is where the role of the other is used to reflect "the expectations or evaluations of the self as seen" by others with whom we interact (p. 62). Reflexive role taking allows for determining positive or negative reactions to the self-in-the-role of caregiver to PWAs.

The third type of role-taking, appropriative, is the "process of imaginatively constructing the attitudes of the other and internalizing them into the self" (Lauer & Handel, 1977, p. 63). This pertains to the caregiver seeing the role as positive, negative, altruistic, guilt-induced, humanitarian, or necessary. It also involves assessing cultural norms that govern behaviors regarding caregiving. Preconceptions the caregiver brings to the decision to provide care can affect how the caregiver feels about giving such assistance. This reflects the caregiver's view of their behaviors as being a part of providing care to a terminally ill person.

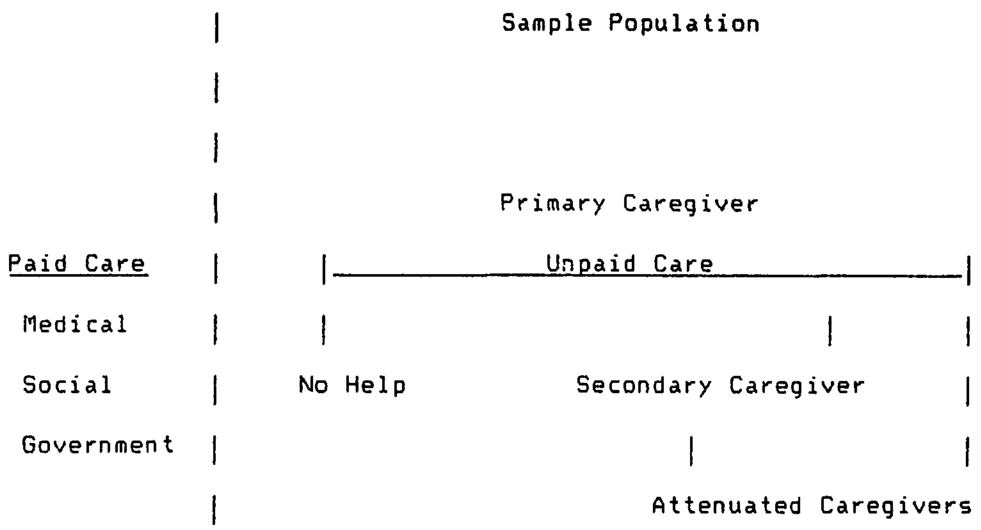
CHAPTER FOUR

METHOD

Sample

A convenience sample of 31 current and former unpaid volunteer caregivers to PWAs in the Piedmont area of central North Carolina was obtained. The sample was drawn from a population known to the researcher through her association with the Triad Health Project (THP), the grassroots AIDS service organization in central North Carolina. Figure 1 describes the sampling frame of caregivers to PWAs. A sampling frame is "the list, or reasonable facsimile, of elements from which a . . . sample is selected" (Babbie, 1973, p. 89). This frame is representative of the disease and the course of the disease. The variant chronicity of AIDS dictates that in Phases I and II there is little need for the PWA to have a primary or secondary caregiver. However, with the progression of the disease there is increased need for more attenuated care. In Phases III and IV there is a tendency for the PWA to have a primary and secondary caregiver. As the disease is prolonged or more intense care is needed, additional support for primary and secondary caregivers is often necessary. This extra care can be in the form of attenuated care which can support both primary and secondary caregivers. Nonetheless, only caregivers to PWAs in Phases III or IV of the disease were interviewed.

Figure 1. Sampling frame model.



Other Environmental Care (May be part of sample if unpaid)

Family

Charity/Religious Organization

Employment

Caregiver identification and contact. Caregivers were identified through the list of PWAs associated with THP volunteers and the list of THP attenuated buddies to PWAs. Caregivers were contacted in the following manner. After receiving permission from the Executive Director(s) of THP, 1) The researcher spoke to all buddy team leaders at THP and described the project and recruitment of volunteers. 2) Buddy team leaders contacted the buddies assigned to their teams regarding the study. An explanation of the research was given. Buddies were then asked if they would ask their PWA if he or she wanted to participate. 3) The researcher was given the names and telephone numbers of volunteer buddies. She contacted them and requested that they contact their PWA for permission for the researcher to contact the PWA and explain the project. A brief written explanation of the research and the researcher's qualifications was given to the PWA. 4) When the PWA agreed to participate, a list of all caregivers to each PWA was constructed and permission to contact them by telephone obtained in writing from the PWA. 5) Caregivers were contacted by telephone and recruitment was finalized.

Non-THP caregivers (family and friends) were contacted in the following manner. 1) PWAs known to THP were contacted by THP and Moses Cone Hospital during treatment visits, or by telephone. 2) The project was explained, and permission for the researcher to contact caregivers was obtained from the PWA. 3) The researcher contacted the caregivers by telephone or in writing to finalize the recruitment process.

After recruitment was finalized appointments were set up to conduct the interview. Caregivers were given a choice as to the site for the interview. Sites for the interview chosen included the caregiver's home, the researcher's business office, and the business office of the interviewee. All interviews were conducted within a six week interval in the summer of 1990.

Confidentiality. Due to the sensitive nature of this disease, special care was taken to insure strictest confidentiality of participants. Coded case numbers were used to provide privacy, and audio tapes were erased as soon as the transcription was completed. No real names were used to describe case studies, and all data were kept under lock and key. Other generally accepted confidentiality standards were met.

Procedures

<u>Interview format.</u> The format for the interview was first, a general demographic questionnaire, followed by the audio-taped, open-ended questionnaire on caregiving developed by the researcher (see Appendix A), the Katz Index of Independence in Activities of Daily Living (Katz ADL) (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963) (see Appendix B), the Culture Free Self Esteem Inventory (Battle, 1981) (see Appendix C), and the Coping Inventory (Horowitz & Wilner, 1980) (see Appendix D). The final phase of the interview consisted of a brief discussion of any information the subject felt might be interesting to the study, introduced with the question: "Is there anything else you would like to tell me about your caregiver experience that we have not covered today?" The participants were interviewed in-depth to document why they became caregivers, the emotional impact of caring for a terminally ill person, successful and unsuccessful caregiving behaviors, and the unmet needs of caregivers and PWAs. All interviews were conducted in one session, and lasted from thirty to ninety minutes.

Measures

The open-ended questionnaire (see Appendix A) was designed by the researcher to ascertain information on caregiving behaviors, attitudes, and coping skills. The areas of interest included a brief history of the subject's involvement with PWAs.

<u>The Culture Free Self Esteem Inventory-Adults.</u> The CFSEI-A (Battle, 1981) is a 40-item self-report scale measuring an individual's perception of self. There are four categories or subscales in the inventory: 1) general self esteem, 2) social self esteem, 3) personal self esteem, and 4) lie items (which indicate defensiveness). The items

are divided into two groups, low self esteem indicators and high self esteem indicators. Answers are dichotomous, "yes" or "no". The CFSEI-A is hand-scored. Intercorrelations of the subscales of the scores on the standardized group reported by the developer indicate the test-retest correlations for all subjects to be .81, for males .79, and for females .82. This instrument was administered because it was felt that self esteem is a component of coping with the stress of caregiving.

The Coping Inventory. The Coping Inventory (Horowitz & Wilner, 1980) measures the usefulness of different strategies for adapting to stressful life events. It is a 33-item self-report instrument allowing for reference to specific life events in the subject's history or current experience. The Coping Inventory has three areas of types of coping behaviors: changing attitudes and activities, working through the event, and socialization. There are no nationally normed reliability figures for this instrument. Therefore, Cronbach's alpha was used to measure reliability within the inventory as a whole. Cronbach's alpha was .86 for overall reliability. There are three levels of response to each item: 1) does not apply, 2) does apply, and 3) does apply and was very helpful, thus allowing for a simple rating of the helpfulness of certain strategies. Measuring coping to the role of caregiver to a PWA was an essential goal of this study, requiring the use of this type of instrument.

Katz ADL. The Katz ADL (Katz, et al., 1963) (Appendix B), a well-known and studied ADL test, is designed to rate overall dependency in health care subjects. Six hierarchical areas of daily living are rated dichotomously, providing a Guttman scale. The Katz ADL is hand scored. Nationally reported reliability figures are as follows: coefficients of reproducibility of .976 and .948 were reported in clinical populations (Kane & Kane, 1984). This instrument was administered to determine the relative state of dependency of the PWA. It was hoped that this information would identify levels of care in different stages of the disease and the subsequent caregiver adjustment or coping skills required.

Data Analysis

In this study, using an ethnographic design, both quantitative and qualitative data were collected (Fetterman, 1989). The demographic and psychological inventories were hand-scored. Each taped interview was transcribed verbatim. Answers to open-ended questions were studied (as described below) to determine if there were general categories of responses. These responses were analyzed for an assessment of the overall adjustment of the caregivers to the medical and emotional crises in the lives of their care recipients.

Appropriate frequency and bivariate statistical analyses, primarily Chi-square, were used to describe the sample and analyze the data. Data was analyzed to determine what attitudes and behaviors were evidenced by caregivers to PWAs. A coding scheme was developed to assist in the analysis of the open-ended, qualitative sections of the interview (Olson, 1976) with the assistance of an English language professional.

Interrater reliability, to enhance the reliability of the coding scheme and subsequent axial coding of the data, was established through the assistance of three professionals in the fields of caregiving and psychology. A 75% agreement rate was set as the standard of reliability for the analysis of the data (Strauss, 1987). Interrater reliability was established in the following manner. The transcripts, or major parts of transcripts, of two to five interviews were submitted to three professionals in the fields of psychology and caregiving along with a preliminary coding scheme developed by the researcher. Definitions of the coding categories were provided. The raters were asked to code the interviews using the coding scheme. Reliability was established when three of the four raters (researcher included) agreed on classifications of the interview codings in 90% of the cases. There were no discrepancies or disagreements in the coding scheme that had to be worked out to make it more reliable. The final codebook is reproduced in Appendix E.

Classification of Caregivers and PWAs for Data Analysis

The following classifications of caregivers and PWAs served as the initial data analysis categories. Caregivers were defined as those volunteers who gave care to PWAs on at least a part-time basis. Primary caregivers were those individuals who were, at the time of the interview or had been, the main source of care to one or more PWAs. Secondary caregivers were defined as those individuals who lent assistance to a specific primary caregiver. Attenuated caregivers were defined as those individuals who gave occasional care to assist a primary or secondary caregiver in specific, limited tasks. Questions regarding the type of caregiver and caregiver's experience, behaviors, and coping skills were used to identify caregiver situations and characteristics that may contribute to successful or unsuccessful experiences.

Theory grounded analysis. The use of a primarily qualitative approach to generate a description of the caregiver function required a massive data analysis of subjective case study material (Lofland &

Lofland, 1984; Strauss, 1987). Theory grounded analysis (in this instance, symbolic interaction), as outlined in Strauss, was utilized to give the most complete report of the experiential data. Theory grounded analysis requires a series of codings of data into micro- and macro-categories, through the use of the coding scheme described below.

Transcript analysis. Initially, transcripts of the first five interviews were analyzed by the researcher to gain insight into any areas of inquiry that might be missing and would require subsequent interviews or a change in interview substance or style. With questions of content answered, the second analysis of the first five to ten interviews consisted of minute line-by-line open coding into categories of experience or observations such as conditions, interactions, strategies or tactics, and consequences (Strauss, 1987, pp. 27-28). The use of the interrater reliability format helped assure a more complete and accurate coding of these categories.

The codebook was expanded as the transcripts were analyzed resulting in over 560 separate variables (responses) to the 20 questions, demographic data sheet, Katz ADL, Culture Free Self Esteem Inventory, and Coping Inventory. Variables were then entered by question groups or instruments utilizing the SPSS-X Data Entry package to create the data files. A command file was then created to analyze the data. Frequency data were generated on all 560 plus variables utilizing the Multiple Response command in SPSS-X. The Multiple Response and Crosstab commands were utilized to group data and investigate any significant statistical relationships that demographic data and open-ended questionnaire answers revealed.

Axial coding was conducted to further delineate and define salient themes. Axial coding allows the grouping of related answers in like categories. This reduces the numbers of categories of answers (micro-categories) to meaningful groups of manageable size (core categories or macro-categories) and allows for critical examination of trends in the data. Thus, examination of the categories of experiences in caregiving as revealed in the interviews made the choice of the core categories logical. This intensive micro-and macro-analysis was designed to yield the most thorough analysis of a small set of cases.

Caregiver variables. Cantor (1983) developed a list of 14 variables associated with strain from giving care to the elderly. This list served as a useful starting point in the research development and data analysis. Six demographic variables were included in the list: age, sex, race, SES, marital status, and relationship to caregiver; and five situational variables were identified: health status of care recipient, geographic proximity of caregiver to care recipient, work status of caregiver, caregiver's ability to manage financially, and the amount of assistance provided by the caregiver. Three attitudinal variables conclude the list: degree of worry, compatibility of relationship between caregiver and care recipient, and attitude of caregiver towards the importance and value of family. It was thought that the micro- and macro-analysis of data might yield similar categories of situational and attitudinal variables.

Question 1, example of axial coding. The following example of Question 1 illustrates the method used in coding and analysis of all questions in the open-ended questionnaire. The first question in the open-ended questionnaire was: How did you come to decide that you would help the PWA? Nine responses were identified from the transcripts, they were: 1. The caregiver's close relative with AIDS is the care recipient. There was no question but that they would give care to the family member. 2. The caregiver's close friend or lover is HIV+ or has AIDS and is the care recipient. There was no question but that the caregiver would give care. 3. The caregiver needed to deal with his or her emotions regarding AIDS, wanted to work through grief, feelings of powerlessness, etc. 4. The caregiver needed to deal with his or her anger regarding AIDS and wanted to combat prejudice or government and establishment negligence. 5. The caregiver wanted to do some sort of important volunteer work. 6. This decision took a long time. Many factors contributed to it. 7. The caregiver was assigned a buddy through Triad Health Project. There was no previous relationship to the PWA. 8. The caregiver wanted to do volunteer work with PWAs specifically out of compassion and a sense of community. 9. The caregiver was asked by another person to help this specific PWA, who may have been a friend or acquaintance prior to caregiving.

These nine micro-categories of responses were condensed into four macro-categories representing major themes regarding why the respondents were providing care to PWAs. Here, as well as for the remaining questions, axial coding techniques were used to identify salient themes under each question. In the conclusion section further macro-categorization will be utilized to better describe overarching themes or symbols of interaction relative to the caregiver experience. The four macro-categories of answers to Question 1 were as follows: 1. (1, 2, 9) The caregiver is giving care to someone with whom they have a close relationship (friend, lover, relative, or acquaintance) who is HIV+ or has AIDS. For purposes of discussion these relationships will be referred to as "filial". 2. (3, 4) The caregiver needed to deal with his or her emotions with regard to AIDS. He or she wanted to work through anger, grief, powerlessness, or feelings or frustration with establishment negligence or community hysteria. 3. (5, 7, 8) The caregiver wanted to do volunteer work that made a difference, AIDS seemed like a worthy cause. This reflects compassion and caring on the part of the caregiver. 4. (6) There were numerous unnamed contributing factors accounting for the caregiver's decision to give assistance.

After the macro-categories for each question were established data analysis began. Demographic and descriptive variables were assessed against frequencies of responses in each macro-category utilizing the Crosstabulation format in SPSS-X. Chi-square values were computed to determine statistically significant associations ($p \leq .05$). The findings for this process are reported in Chapter Five.

CHAPTER FIVE

FINDINGS

Demographics

Care recipients. Due to the nature of the interview process and needs to protect PWA confidentiality, only anecdotal information on the 18 care recipients was collected at the time of the interview. No attempt was made to verify the data with those care recipients still living. Six of the 14 male PWAs were still alive as of this writing. Two of the four female PWAs were still alive as of this writing. A description of the care recipients represented in this sample population is as follows. The youngest care recipient was two years of age, the oldest was in his mid-forties. Caregivers represented 9 (50%) white and 9 (50%) black PWAs. There was no attempt to sample PWAs by race. Of the care recipients, four individuals were female (22.2%), as represented by five caregivers; 14 were male PWAs (77.8%) and were represented by 26 individual caregivers.

All of the four female care recipients were black and heterosexual, and all were at risk for AIDS through a drug-using male sexual partner. Two of the four PWA females were also at risk for AIDS through a drug use history of their own. All of the HIV+/PWA male sexual partners of the female PWAs represented in this sample had died prior to this study due to complications from AIDS.

Of the 14 male care recipients, eight were gay and six were heterosexual, five were black and nine were white. A further breakdown of this classification is as follows. There were four black heterosexual males, and one black gay male PWAs. There were seven white gay males and two white heterosexual males. All of the black heterosexual males contracted AIDS through illegal intravenous drug use. One of the white heterosexual males was a hemophiliac and contracted AIDS through contaminated blood product early in the epidemic. It is believed the remaining heterosexual male, a preschooler, contracted the disease perinatally (he has since been adopted into another family). All of the gay males (one black, seven white) are believed to have contracted AIDS through a sexual partner. Only the black gay male was known to be a drug user, and thus could have been at risk from multiple sources of infection.

All of the female care recipients had at least one child. No children of these women had tested positive for HIV or AIDS. Only one of the males (black, heterosexual) had children, and none of them had tested positive for HIV or AIDS. This male was also the only currently married care recipient in the study. His wife had repeatedly tested HIV-. It is believed that they practiced protected or safer sex methods (condoms and spermicides).

Caregivers. A description of the participant sample follows. There was no attempt to sample the caregivers by race, gender, or sexual preference. The 31 caregiver participants ranged in age from 24 to 68, with an average age of 39. Thirty (96.8%) were white, and one (3.2%) was black. Nineteen (61.3%) of the caregivers were female, and 12 (38.7%) were male. The caregivers were related to the care recipients as follows: seven were family members or lovers/spouses; ten were friends of the PWA; and 14 were total strangers to the PWA at the beginning of care. Of the relatives and lover/spouse category, five of the caregivers were parents of the PWA (two married couples, and one mother to three care recipient-sons); one was a sister, and the remaining one a gay lover.

Per annum income for caregivers ranged from $4,000 to $68,000, with a mean of $25,000. Caregiver education was relatively high, with all participants having at least a high school education. The mean and the mode for education was nine college graduates. Twelve of the participants had a master's degree or better, with five holding a Ph.D. Eleven of the male participants were employed full time, and one was retired. One female caregiver was retired, and one was a full time homemaker. The remaining females were employed full time (15) or were full time students (2).

Nine (29%) of the caregivers were married (two couples accounting for four of the total were married to each other). Eight (25.8%) caregivers were single, and seven (22.6%) were divorced. A fourth category "cohabiting in a long term relationship" was utilized to account for variety of lifestyles and homosexual marriage. Seven (22.6%) individuals were counted as cohabiting, with a lesbian couple accounting for two of the seven. Of the 12 male and 19 female caregivers, 10 of the men were gay, and two were heterosexual. Four of the women were lesbians, and 15 were heterosexual. The one black female was heterosexual.

The respondents were asked to rate their own health on a scale from one (low) to ten (excellent). The responses ranged from three to ten, with the mean being nine and the mode being ten.

Chi-square tests were performed on all descriptive or demographic variables. Recent findings in statistical theory have indicated that

Chi-square is robust "even when the average expected frequency is as low as 2" (Glass & Hopkins, 1984, p. 288). Therefore, Chi-square tests were performed on all matrices fulfilling this requirement. For purposes of reporting of data analysis, unless otherwise stated, only those Chi-square tests whose p-values compute to $p \leq .05$ will be reported as statistically significant. Statistical trends will be defined as having a Chi-square p-value of $.10 \geq p > .05$. The following summarizes statistical relationships found in these demographic data.

Statistical relations in demographic data. Of these 31 caregivers, men were more likely to cohabit, and women were more likely to be divorced ($X^2=10.52$, df=3, n=31, p=.01). Divorced and cohabiting caregivers were more likely to have been giving care for over a year ($X^2=11.00$, df=3, n=31, p=.01). Notably, higher numbers of caregivers were associated with a more dependent Katz ADL score ($X^2=7.74$, df=3, n=31, p=.05). No other statistically significant relations were found in the demographic data on caregivers.

Culture Free Self Esteem Inventory

Participants' scores for the Culture Free Self Esteem Inventory (Battle, 1981) (see Appendix C) were slightly higher than national norms. For the men, the range of scores was 20 to 31, where 32 would have been the highest possible score. The national median for men is reported as 23.7, the median for this sample was 26.01. Women's scores ranged from 21 to 32, with 32 being the highest possible score. The national median for women is reported as 23.43, the median for this sample was 25.75.

The results of a Chi-square test comparing actual scores and the sample medians for males and females showed no statistically significant relationship at the p=.10 level (X^2=.02, df=1, n=31, p=.85). The 2x2 matrix comparing actual scores and the national median for males and females computed to X^2(df=1, n=31) = .79, p=.40, which was also not statistically significant at the p=.05 level. The within sample median test also revealed that while there was a slight tendency for women to score below sample median (25.85), this was not significant (X^2=.02, df=1, n=31, p=.85). Thus, while the sample scores appeared somewhat higher than those reported nationally, they were not statistically different from the norms. This may be a surprising finding if one believes that self esteem suffers when individuals face what may be a powerless situation. The sense of powerlessness that accompanies AIDS caregiving may not affect caregiver self esteem. However, a larger sample may reveal a significant relationship here.

This finding may also be surprising if one believes that caregivers may be predisposed to higher self esteem. They may have volunteered to give care because they felt good enough about themselves to enter a difficult situation. While self esteem scores from the sample group may not be significantly different from those reported nationally, they are elevated. It may be that a larger sample may produce significant results here.

Coping Inventory

Coping with caregiving to an individual with AIDS was thought to be an important aspect of the experience. The Coping Inventory described by Horowitz and Wilner (1980), Appendix D, was chosen as one sensitive to specific life events, such as caregiving. It has three areas or types of behaviors--changing attitudes and activities, working through the event, and socialization. The table in Appendix F lists the

33 items on the Coping Inventory in order of their effectiveness as reported by the respondents and measured in the "does apply and helpful" response category. In the first six categories responses were equal to or greater than 50% of cases.

It was found that behaviors pertaining to working through the event and socialization were the most helpful. Changing attitudes and activities was not found to be helpful.

Because the Coping Inventory is arranged to allow for a comparison of choices from among the categories (those chosen, those chosen and helpful, and those not chosen), it was possible to compare categories appearing to be a solution but found to be of little help. The table in Appendix G lists the 33 items on the Coping Inventory in order of their responses in the category "does apply", or this category was <u>tried</u> in attempting to cope with caregiving. By implication, the higher the response rate in this table, the more disappointing the use of the category was in the population. The first four categories of the table in Appendix G appeared in the "does apply" category and were listed by 50% or more of the respondents.

The least reported helpful categories in coping behaviors were those with <u>low</u> scores in Appendix F. For purposes of description, those categories equal to or less than 25% of cases in Appendix F (nine categories) were considered to be least helpful. When the three areas of types of coping behaviors in the Coping Inventory were utilized in analyzing the nine least reported helpful categories (25% of fewer cases), it appeared that changing attitudes and activities was less likely to be chosen as a helpful coping behavior than what was randomly expected. Working through the event was a little more likely to be chosen than what was expected. Socialization was chosen generally as expected.

Overall, respondents seemed to be a resourceful group in that all of the 33 coping behaviors were tried by at least one respondent. Those coping behaviors utilized the least (15 or fewer responses in both Appendix F and Appendix G) were as follows: 1. 7 responses--I tried to put the event out of my mind. 2. 12 responses--I tried doing things impulsively, that I might have thought about before, if they made me feel better and didn't bother anyone else. 3. 14 responses--I looked for a person who could provide direction for me. 4. 14 responses--I tried to find new interests. 5. 15 responses--I tried to remind myself that what has happened could have been worse. The category of changing attitudes and activities was also overrepresented in the five least chosen coping behaviors. Working through the event and socialization were underrepresented in the least helpful categories. The results of the comparisons show that caregivers to PWAs find coping behaviors classified as "working through the event" and "socialization" as most helpful in coping with the role of caregiver to a PWA.

Putting the event out of mind was not listed by a single individual as helpful in coping. Evidently, this behavior was not seen as an alternative in coping with AIDS. Perhaps this reflects the conscious choice of many individuals to work with AIDS and thus would seem counter-productive to them as a coping mechanism.

Age and coping. The results of a Chi-square comparison of age and Coping Inventory (Table 1) did not reveal any significant relationships. The values in the Coping Inventory were very close to those expected from age distribution.

Table 1

Age Distribution of Coping Inventory Categories

Age categories			Coping Inventory categories	
Age	n	%	Applies %	Helpful %
20-29	5	16.1	14.3	16.9
30-39	10	32.3	28.1	36.6
40-49	9	29.0	31.6	25.1
50+	7	22.6	26.0	21.4
Totals	31	100.0%	100.0%	100.0%

Gender and coping. The Chi-square test for gender and Coping Inventory responses revealed no significant relationships (Table 2). However, women seemed to find more successful coping behaviors than men, though not so many as to be statistically significant. This was indicated in that women reported an increase in helpful over applied behaviors and men reported fewer helpful than applied behaviors.

Table 2

Gender and Coping Inventory Response

Gender		Coping Inventory categories	
M/F	%	Applied %	Helpful %
Female	61.3	53.3	63.7
Male	38.7	46.7	36.3
Total	100.0	100.0	100.0

Education level and coping. The results of a Chi-square comparison of education level and Coping Inventory skills did not reveal any significant relationships, as shown in Table 3. Only one variation from expected frequencies was found in this comparison. The one high school graduate did not find any of the 33 listed coping skills to be helpful, although 19 of the 33 were utilized. It is not known if the participant did not truly understand the instructions to the inventory or the definitions of the categories. Her situation was particularly painful as her son was seriously ill in the next room during the interviews and she was very worried about his imminent death. This situation may have distracted her from reading the instructions more carefully.

Table 3

Coping Inventory Demographic Data Summary

Demographic categories (%)	Coping Inventory categories (%)	
	Applied	Applied & helpful
Respondent education level		
High school grad & + (29.0)	29.9	32.3
College grad & + (32.2)	33.7	28.0
Post graduate degree (38.8)	36.3	39.7
Respondent income level		
$0-10K (12.9)	15.4	9.4
$10,001-20K (25.8)	18.3	32.9
$20,001-30K (25.5)	37.9	38.3
$30,001 to 40K (9.7)	14.1	6.6
$40,001+ (16.1)	14.3	12.9
Respondent marital status		
Single (25.8)	32.4	21.4
Married (29.0)	24.1	31.4
Divorced (22.6)	23.1	20.6
Cohabiting (22.6)	20.4	26.6

Table 3, continued.

Respondent health level		
Poor (3.2)	3.2	2.0
Moderate (6.5)	9.5	3.1
Good (29.0)	30.5	32.9
Excellent (61.3)	56.8	62.0
PWA's Katz ADL rating		
Independent (38.7)	34.2	43.7
Independent xcpt 1-2 (12.9)	17.5	7.4
Dependent in 3-4 (16.1)	16.7	15.0
Dependent in 6 (32.3)	31.6	33.7
Number of caregivers for PWA		
1-2 (32.3)	31.6	29.1
3-4 (22.6)	22.5	21.4
5-6 (6.5)	7.7	5.1
12+ (16.1)	17.8	19.4
20+ (22.6)	20.4	24.9

Table 3, continued.

Respondent's hours of care/week		
1-3 (12.9)	14.3	16.9
4-6 (35.5)	35.5	30.0
7-10 (16.1)	15.9	17.4
11-24 (16.1)	15.6	18.3
15+/day (19.4)	18.6	17.4

Income and coping. When income levels and coping were compared, utilizing the Chi-square test, Table 3, the $20,001 to $30,000 per annum middle income group was found to have a slightly higher attempt and success rate in utilizing coping behaviors than would be randomly expected (but not statistically significant). They comprised 25.5% of the sample, but accounted for 37.9% of the attempted and 38.3% of the helpful behavior categories. The $40,001 and over group showed a slight trend towards utilizing fewer coping behaviors and a trend towards finding helpful coping behaviors, meaning that they utilized fewer but more successful coping behaviors. The remaining groups showed mixed results between attempted and helpful coping behaviors.

Marital status and coping. As shown in Table 3, when marital status and coping behaviors were compared there were no tendencies based on marital status found to be statistically significant utilizing the Chi-square test. Single individuals were slightly more likely to try unsuccessful coping behaviors. This was true in two ways. The comparison of expected vs. reported values for attempted vs. helpful behaviors showed an increase in attempted and a decrease in helpful behaviors, besides being different from the randomly expected values.

Married individuals were less likely to attempt unsuccessful coping behaviors, both in the differences between expected values in attempted vs. helpful behaviors, and in the increase found between attempted vs. helpful behaviors. A larger sample size may reveal a significant relationship in these categories.

Health status and coping. The relationship between health status of the caregiver and coping behaviors was investigated, as depicted in Table 3. The Chi-square revealed no significant relationships between these variables. Only one category showed any difference between expected and reported behaviors. Caregivers in excellent health showed a trend towards attempting fewer unsatisfactory coping behaviors than would have been expected. However, this finding is not statistically significant.

Katz ADL and coping. Table 3 also summarizes the relative dependency of the care recipient as reported by the caregiver in the Katz ADL and compares this with coping behaviors. Two categories of the Katz ADL findings showed (nonsignificant) tendencies in coping behaviors, as measured by the Chi-square test. The independent category showed a tendency toward the choice of helpful coping behaviors. This was reflected in the choice of fewer than randomly expected unsuccessful coping behaviors and greater than expected helpful coping behaviors. In the case of slightly dependent care recipients, the opposite tendency was found. Caregivers to people who were only marginally dependent in one or two areas showed a tendency to choose unsuccessful coping behaviors over helpful ones.

Numbers of caregivers and coping. The relationship between coping behaviors versus the actual number of caregivers present for the care recipient (as reported by the participant) was investigated. The actual number of helpers did not influence the success or use of coping behaviors, as there were no deviations in the cell distribution from what would have been randomly expected given the caregiver numbers' distribution, as revealed in Table 3.

Hours of care and coping. The relationship between relative hours of caregiving versus coping behaviors was investigated. As can be seen in Table 3, only one cell revealed a slight trend. Respondents giving care four to six hours per week showed fewer helpful coping behaviors than would be randomly expected. However, this difference was not found to be statistically significant.

Length of time as caregiver and coping. Table 4 illustrates the findings of coping behaviors compared with length of time having been a caregiver to the specific PWA reported in the interviews. While this relationship was not found to be statistically significant using the Chi-square test, caregivers with less than a half year of experience with the care recipient showed increased activity in seeking and finding coping behaviors beyond that randomly predicted by their numbers.

Table 4

Coping Behaviors and Length of Time as Caregiver

Time as caregiver		Coping behavior categories	
Category	% of N	Applied %	Helpful %
1/2 Year	41.9	40.6	46.9
1 Year	22.6	26.8	22.0
1 1/2 Yrs.	12.9	10.3	12.0
2+ Yrs.	22.6	22.3	19.1

This tendency of increased activity in seeking coping behaviors seems to level off at about one year's time of caregiving. At about one and one-half years, fewer coping behaviors seem to be attempted or helpful. After two years or more this downward tendency levels off and we see no appreciable differences between coping behaviors attempted or found helpful and those percentages expected from the distribution of N.

These tendencies may indicate a certain active period in coping skills attempted overall at the beginning of the caregiver relationship. This does not explain why respondents who had been giving care for a longer period of time did not seek a larger number of coping behaviors. The actual amount of time in caregiving was measured by weeks of care, so individuals who gave care two years ago for six months would be included in the same group as those who started giving care six months ago. This would eliminate a cohort or historical effect. What may be reflected here is that longtime caregivers do not report their initial coping behaviors but only current ones, or only those associated with the PWA's death. Further investigation of these variables is needed to determine if there are significant relationships between aspects of coping and length of time giving care. A larger sample size may reveal these relationships.

Caregiver Attitudes

Participants were asked a series of seven open-ended questions with regard to their attitudes about beginning caregiving, worries regarding caregiving, the relationship with the PWA, and revelation of caregiving to others. The responses were classified into related categories. After the initial frequencies of responses to each question were catalogued utilizing the Multiple Response formula in SPSS-X, categories were condensed to more general and similar responses in the manner described by Strauss (1987) as axial coding and discussed above.

Question 1. The following complete summaries of Question 1 data are an illustration of the variable matrices constructed and analyzed for descriptive trends. All other questions (two through twenty) were analyzed in a similar manner. Where appropriate, Chi-square tests of association were administered. All Chi-square information is reported in the Question 1 data summaries, but only statistically significant relationships or trends are reported in the remaining data. Summaries of the analyses of the remaining questions will follow Question 1.

Table 5 depicts the frequencies of responses of the resulting four categories. From these responses we can see that the main reason given for people giving care to PWAs is that they wanted to volunteer (43.1% of responses, 61.4% of cases). The second most frequent reason given for becoming a caregiver can be attributed to feelings of filial or friendship responsibility. Finally, some individuals have used their caregiving experience to process emotional issues around AIDS or combat the general hysteria and perceived government and medical establishment inaction.

Table 5

Reasons for Becoming a Caregiver

Category	Frequency	% Responses	% Cases
1. Volunteerism	19	43.1	61.4
2. Filial responsibility	18	41.0	58.0
3. Emotional processing	5	11.4	16.2
4. Other factors	2	4.5	6.5
Totals	44	100.0	142.1*

* % of Cases totals to more than 100% because respondents were allowed to give more than one category of answer.

Question 1, Chi-square results. Chi-square tests were performed for these responses to see if any of the demographic variables were related to response categories. When age of participant was further reduced to two categories ("under 40" and "40 and over"), and reasons for giving care were reduced to two categories ("filial" and "volunteer and other"), X^2(df=1, n=44) = 3.01, p=.09. This weak association indicates a trend. With regard to age of respondent, younger respondents were less likely to have a close relative with HIV or AIDS, and older respondents were more likely to have a close relative with AIDS. This may be explained in this sample in that 50% of the 50+ age group had a child with AIDS, and one in twelve of the 40-49 age group had a child with AIDS, accounting for all five of the responses in that initial micro-category. Responses in the friend with AIDS subcategory showed the greatest percentage of caregiving to friends in the youngest caregiver group (20-29), with fully half of that group stating that it was the primary reason for deciding to give care. Otherwise, about one-third to one-fifth of the responses in each of the remaining three age groups depicted care to a friend. Clearly filial and friend responsibility rated very high in reasons for caregiving among all age groups. Table 6 depicts the frequency and percentage of findings for all final macro-categories.

The younger respondents seemed to need to deal with their emotions of anger and grief with regard to AIDS as a reason to give care. Older respondents showed a tendency toward filial responsibility and volunteerism as reasons to become caregivers.

Table 6

Age of Respondents and Reasons for Giving Care

Participant age	Categories of responses for reasons to give care				
	Filial	Emotions	Volunteerism	Other	N
20-29	3 (50%)	1 (16.7%)	2 (33.3%)	0 (0%)	6
30-39	4 (22.2%)	4 (22.2%)	8 (44.4%)	2 (11.2%)	18
40-49	5 (41.6%)	0 (0%)	7 (58.4%)	0 (0%)	12
50+	6 (75%)	0 (0%)	2 (25%)	0 (0%)	8
Total numbers	18	5	19	2	44

With regard to gender and reasons to give care, Table 7 illustrates the responses. With reasons for giving care reduced to "familial" and "volunteer and other", a Chi-square test was performed. The Chi-square test found no significant relationship ($X^2<.01$, df=1, n=36, p=.95). In this caregiver population that is disproportionately gay male, there seems to be no emotional processing response to AIDS through caregiving. This may be a surprising finding or it may illustrate the overwhelming cultural proscriptions against American males acting on emotions (or reporting that they do). The researcher did note that emotional responses to several questions were evident in male and female participants during the interviews. However emotionally charged this topic may be for caregivers, it may not explain male participation. Women, on the other hand, responded 18.5% of the time with emotional processing reasons for giving care.

Table 7

Gender of Respondents and Reasons for Giving Care

Respondent	Categories of responses for reasons to give care				
gender	Filial	Emotional	Volunteerism	Other	N
Female	11 (40.8%)	5 (18.5%)	10 (37%)	1 (3.7%)	27
Male	7 (41.2%)	0 (0%)	9 (52.9%)	1 (5.9%)	17
Total numbers	18	5	19	2	44

Another difference between male and female caregivers' reasons for giving care can be seen in the volunteerism category. While both men and women list volunteerism as a reason for giving care, men seem to do so more often than women. It is also the most frequent response for men (52.9%), whereas filial responsibility is the most frequent response for women (40.8%).

Next, education and reasons for giving care came under scrutiny. Table 8 depicts the matrix of education level versus reasons for giving care. Of these findings there seemed to be more variety in reasons for care as education level increases. However, in each reason for care category, overall trends were followed in that the two primary reasons for care--filial responsibility and volunteerism--remain so in each education level. The variables were reduced to dichotomous categories ("less than a college degree" and "college degree or better"; "filial" and "volunteer or other"), and the Chi-square test performed. The Chi-square test showed no significant associations (X^2=.04, df=1, n=36, p=.85).

Table 8

Education Level and Reasons for Caregiving

Respondent	Categories of responses for reasons to give care				
education	Filial	Emotional	Volunteerism	Other	N
High school+	4 (44.4%)	0 (0%)	5 (55.6%)	0 (0%)	9
College+	6 (50%)	1 (8.3%)	5 (41.7%)	0 (0%)	12
Postgrad	8 (34.8%)	4 (17.4%)	9 (39.1%)	2 (8.7%)	23
Total numbers	18	5	19	2	44

Table 9 demonstrates the results of the matrix of reasons for deciding to give care and income level. Caregivers in the lower middle income bracket of $10,001 to $20,000 showed a greater variety of reasons for giving care than any other income group. The remaining income levels showed a remarkably similar proportion in reasons for giving care. When reasons for giving care are dichotomized as in previous analyses, and respondent income is reduced to two categories "$20,000 and below" and "$20,001 and above", the Chi-square test revealed no significant relationships (X^2=.17, df=1, n=36, p=.40).

Table 9

Income and Reasons for Caregiving

Respondent	Categories of responses for reasons to give care				
income	Filial	Emotional	Volunteerism	Other	N
$0-10,000	2 (50%)	0 (0%)	2 (50%)	0 (0%)	4
$10,001-20K	4 (23.5%)	5 (29.4%)	7 (41.2%)	1 (5.9%)	17
$20,001-30K	7-53.8%	0 (0%)	6 (46.2%)	0 (0%)	13
$30,001-40K	2 (50%)	0 (0%)	2 (50%)	0 (0%)	4
$40K+	3 (50%)	0 (0%)	2 (33.3%)	1 (16.7%)	6
Total numbers	18	5	19	2	44

Reasons for giving care were next classified according to marital status. Table 10 illustrates the findings. The divorced caregivers exhibited more variety in reasons for caregiving while married individuals exhibited the least variability. Married individuals gave filial responsibility as the primary reason for giving care 77.8% of the time, which may reflect the sampling of two married couples (four individuals) giving care to sons with AIDS. In cohabiting individuals, the overwhelming reason for giving care was volunteerism, although several gay men were giving care to their friends or lovers. Single respondents listed volunteerism (54.4%) as the most common reason for giving care.

The variables were placed into dichotomous groups ("married or cohabiting" and "single or divorced"; and "filial" and "volunteer or other") and the Chi-square test performed to determine if there were any statistically significant associations. The Chi-square test revealed no significant relationships between marital status and reasons for giving care (X^2=.63, df=1, n=36, p=.40).

Table 10

Marital Status and Reasons for Giving Care

Respondent marital status	Filial	Emotional	Volunteerism	Other	N
Single	4 (36.4%)	1 (9.1%)	6 (54.5%)	0 (0%)	11
Married	7 (77.8%)	0 (0%)	2 (22.2%)	0 (0%)	9
Divorced	3 (30%)	2 (20%)	4 (40%)	1 (10%)	10
Cohabiting	4 (28.6%)	2 (14.3%)	7 (50%)	1 (7.1%)	14
Total numbers	18	5	19	2	44

Note: the spanning header "Categories of responses for reasons to give care" stands above Filial, Emotional, Volunteerism and Other.

Findings with regard to caregiver health and decision to give care are shown in Table 11. Chi-square could not be performed on this matrix due to low cell size. There seemed to be no apparent relationships in health category and reasons for becoming a caregiver. People with good to excellent health, however, seemed to be more likely to give care as an outlet to work through emotions about AIDS. With such a small distribution of poor and moderate health caregivers though, there is little opportunity for variability until larger numbers of participants are interviewed.

Table 11

Caregiver Health Status and Reasons for Giving Care

Respondent health status	Categories of responses for reasons to give care				
	Filial	Emotional	Volunteerism	Other	N
Poor	0 (0%)	0 (0%)	1 (100%)	0 (0%)	1
Moderate	1 (50%)	0 (0%)	1 (50%)	0 (0%)	2
Good	6 (40%)	3 (20%)	5 (33.3%)	1 (6.7%)	15
Excellent	11 (42.3%)	2 (7.7%)	12 (46.2%)	1 (3.8%)	26
Total numbers	18	5	19	2	44

Table 12 shows the distribution of variables between relative dependency of the care recipient as measured by the Katz ADL versus decision to give care. While the Chi-square test could not be administered here due to small cell size, some figures are worth noting. Giving care was split between relatively independent and very dependent care recipients. In the moderately dependent categories (some care recipient dependency in one to four areas), filial responsibility seemed to be a strong motivator to give care. As the care recipient grew more dependent, volunteer caregivers were increasingly utilized. Half of the caregivers to dependent care recipients decided to give care for reasons of volunteerism. Volunteerism may also be associated with relatively independent care recipients. Many PWAs seek some emotional support and help with the medical community or federal red tape when they are first diagnosed and still relatively well. Usually volunteers are assigned to the PWAs then, or family members receive training through Triad Health Project at this time. Those caregivers listing filial responsibility as a factor in giving care were generally evenly distributed across care recipients' independence in activities of daily living. Caregivers who listed emotional or volunteerism reasons in the decision to give care seemed more likely to have an independent (40% and 42.1%, respectively) or very dependent (40% and 42.1%, respectively) care recipient.

The next most frequent assignment or training time is when the PWA truly starts to lose independence. This would probably correspond to the third category of the Katz ADL depicted in Table 12. Fully one-third of the caregivers describing their care recipients as somewhat dependent were volunteers, and 50% of the filial decision caregivers also described their care recipients as somewhat dependent.

Table 12

Care Recipient's Relative Independence in Activities of Daily Living and Caregiver's Reasons for Giving Care

PWA's	Categories of responses for reasons to give care				
Katz ADL	Filial	Emotional	Volunteerism	Other	N
Independent	6 (35.3%)	2 (11.8%)	8 (47%)	1 (5.9%)	17
Ind xcpt 1-2	3 (60%)	1 (20%)	1 (20%)	0 (0%)	5
Depnd. in 3-4	3 (50%)	0 (0%)	2 (33.3%)	1 (16.7%)	6
Depnd. in 6	6 (37.5%)	2 (12.5%)	8 (50%)	0 (0%)	16
Total numbers	18	5	19	2	44

Next a comparison was made between numbers of caregivers and decision to give care. Table 13 illustrates the matrix for this comparison. If there is some relationship or trend between family cohesiveness and recruitment of caregivers it should show up in this chart. Also, if volunteers are recruited to assist family caregivers there should be some indication of this in growing numbers of caregivers in the volunteerism category. On the other hand, if AIDS is an isolating disease, there may be a tendency for fewer caregivers overall, and a lack of family or volunteer support. In this case numbers of caregivers will be clustered in the first and second categories.

What might have been expected with regard to volunteerism caregivers is confirmed here. Almost half (47.3%) of the caregivers doing so to volunteer were giving care in situations where there were 12 or more volunteers for the care recipient. Almost half (45%) of the caregivers in situations of 12 or more were volunteers. Caregivers doing so out of filial responsibility were split almost evenly between smaller groups (44.4%) and the larger network (38.9%) of caregivers. Filial responsibility caregivers accounted for three quarters of the smaller group (one to two) of caregivers, with volunteerism caregivers accounting for the remaining 50% of small group caregivers.

Table 13

Size of Care Network for PWA and Respondent's Reasons for Giving Care

PWA's	Categories of responses for reasons to give care				
care network	Filial	Emotional	Volunteerism	Other	N
1-2	8-75%	0-0%	4-25%	0-0%	12
3-4	3-30%	2-20%	4-40%	1-10%	10
5-6	0-0%	0-0%	2-100%	0-0%	2
12+	7-35%	3-15%	9-45%	1-5%	20
Total numbers	18	5	19	2	44

Another possible consideration in caregiver behaviors is the number of hours they perform caregiving duties per week. Does the nature of the decision to give care affect the amount of time spent per week in caregiving? A comparison between number of hours of caregiving per week and decision to give care is shown in Table 14.

The categories of decision to give care and numbers of hours involved in care per week were logically reduced to investigate a possible relationship between family and nonfamily reasons for caregiving and low and high amounts of time in caregiving. When the matrix is reduced to a four cell grid it appears that volunteers and other nonfamily caregivers perform fewer hours of caregiving. The Chi-square test for this matrix reveals X^2(df=1, n=36) = 6.73, p=.01. Thus we find that there is a statistically significant relationship between decision for giving care (volunteer and other nonfamily) and lower hours per week of caregiving. Caregivers providing a lower number of hours per week were volunteers. Therefore, it may be possible that nonfamily reasons are a stronger factor in devoting fewer hours to care than familial responsibility reasons.

Table 14

Hours of Caregiving and Reasons for Giving Care

Hours per week	Categories of responses for reasons to give care		
	Filial responsibility	Nonfamily	N
Low (1-10)	8 (36.4%)	14 (63.6%)*	22
High (11+)	9 (64.3%)	5 (35.7%)	14
Total numbers	17	19	36

*X^2(df=1, n=36) 6.73, p=.01

Table 15 describes the relationship between length of caregiving and reasons for giving care. When this information is reduced to a four cell grid of dichotomous categories ("filial responsibility" and "volunteer and other nonfamily", versus "one year or less" and "over one year") the Chi-square value is 1.74 (df=1, n=36, p=.19). While the level of significance (p=.19) is above the p=.10 chosen to delineate trends, there may be a slight trend toward family members and friends giving care to PWAs for longer periods of time than do persons who are giving care for emotional, volunteer or other reasons. A future study with a larger sample may reveal a significant relationship.

Table 15

Time in Caregiving and Reasons for Giving Care

Respondent care length	Categories of responses for reasons to give care: Filial	Emotional	Volunteerism	Other	N
1/2 year	5 (16.7%)	2 (11.1%)	10 (55.6%)	1 (5.6%)	18
1 year	5 (41.6%)	3 (25%)	4 (33.3%)	0 (0%)	12
1 1/2 years	3 (75%)	0 (0%)	1 (25%)	0 (0%)	5
2+ years	5 (50%)	0 (0%)	4 (40%)	1 (10%)	10
Total numbers	18	5	19	2	44

Questions 2 Through 20

The following findings are on Questions 2 through 20 of the open ended questionnaire. The statistically significant relationships will be highlighted ($p \leq .05$). Trends will be reported at the $.10 \geq p > .05$ level. Otherwise, all questions were analyzed utilizing the Multiple Response category of the SPSS-X program. Caregiver variables used in analyzing data were: age, gender, education level, income level, health, PWA's Katz ADL score, number of caregivers, hours per week of care given, and length of time giving care.

Question 2. The answers to Question 2--what worries if any do you have about the PWA's health--yielded 17 categories of responses. They were reduced to the following five categories. 1. Worried about the mental or physical decline of the PWA (29 responses, 80.6% of responses, 93.5% of cases). 2. PWA has many needs--financial, medical, social, etc. (3 response, 8.3% of responses, 9.7% of cases). 3. Worried about how AIDS phobia might affect the PWA (1 response, 2.8% of responses, 3.2% of cases). 4. Worried the caregiver will contract AIDS (1 response, 2.8% of responses, 3.2% of cases). 5. Not really worried (2 responses, 5.6% of responses, 6.5% of cases).

Of the 36 total responses from 31 participants, 29 responses indicated concern for the declining physical or mental health of the PWA. Three responses showed concern for the overall neediness of the PWA, indicating that sometimes health needs were overshadowed by other fundamental needs of shelter, food, clothing, and financial concerns. Only one individual was worried about how AIDS phobia would affect the PWA. Only one caregiver was worried about contracting AIDS. This is surprising in that there is public concern that AIDS is quite contagious. However, this is a very well educated group and it is possible that this high level of schooling has provided the participants with the tools to determine their own health risk from medical information available to the public and in buddy training with THP. Two individuals indicated that they were not worried about the PWA's health. As has been noted previously, many of the PWAs were in relatively good health thus providing the caregiver an opportunity to be worry free with regard to this aspect of the relationship. Denial of poor health in PWAs is usually high prior to the first OI, so it may also be high in caregivers.

There were no statistically significant relationships found between the types of worries about PWA health expressed and the following caregiver variables: age, gender, education, income, health, PWA's Katz ADL, number of caregivers, hours per week of care given, and length of time giving care. A larger sample size might reveal more variation in some of these categories and thus deduce some statistically significant relationships.

Question 3. The third question in the caregiver attitude section was: How well do you and the PWA get along? The responses were scaled from very well to poorly, as shown in Table 16 below.

Table 16

PWA/Caregiver Relationship

Category	Frequency	% of Cases
Very well	22	71.0
Well	6	19.3
Okay	3	9.7
Not well	0	0
Poorly	0	0
Total numbers	31	100.0

In Table 16 we find that caregivers in this survey overwhelmingly felt that they had a very good relationship with the PWA. Over two thirds (71%) reported that they got along very well with the PWA. An additional 19.3% reported getting along well with the PWA, with 9.7% reporting an okay relationship. No caregivers surveyed reported a less than satisfying relationship with the PWA. In future studies of the caregiver population, a larger sample may reveal more variability to this question, thus allowing for factor analysis of dimensions of a good relationship between caregiver and care recipient.

When the relationship between caregiver and PWA (as reported by the caregiver) was compared with caregiver income level, the following results were found. The five caregiving income categories were reduced to two--"$0 to $20,000" and "$20,001 and above" annual income. How well the dyad got along was reduced to "very well" and "okay to pretty well". This 2x2 matrix yielded X^2(df=1, n=31) = 4.18, p=.04. Here we see a statistically significant relationship between caregiver income and relations in the care dyad. Caregivers with higher incomes are significantly more likely to report better relations with their PWAs.

When the quality of relationship between caregiver and PWA was compared with marital status of the caregiver the following results were found. The four levels of marital status were reduced to two--"married or cohabiting" and "single or divorced" Quality of relationship between caregiver and PWA was dichotomized as above. The 2x2 matrix produced X^2(df=1, n=31) = 4.39, p=.04. Apparently, married and cohabiting caregivers are more likely to report a better quality of relationship in the care dyad.

A trend was noted between quality of relationship among caregiver and PWA and the Katz ADL score for the PWA. Here when the dichotomous level of quality of relationship was compared to Katz ADL categories of "relatively independent" and "relatively dependent" the following trend was noted. Chi-square computes to X^2(df=1, n=31) = 3.48, p=.07. As the PWA's level of dependence increases, the quality of the relationship decreases.

Finally, when hours per week of care and quality of relationship were compared a trend was noted; $X^2(df=1, n=31) = 3.45, p=.07$. Here we see that as hours of care per week increased there was a tendency for quality of relationship to decrease. No other descriptive caregiver variables were found to have a significant impact on the quality of the relationship between the caregiver and the PWA.

Question 4. The answers to Question 4, how do you feel about being a caregiver to someone with AIDS, yielded 10 categories of responses. These categories were further reduced to the following four. 1. Want to do it for a variety of reasons (26 responses, 70.3% of responses, 83.9% of cases). 2. It is hard to do, but rewarding (9 responses, 24.3% of responses, 29% of cases). 3. Afraid if others find out, there may be problems for the PWA and caregiver (1 response, 2.3% of responses, 3.2% of cases). 4. Disappointing experience due to the PWA's substance abuse making it difficult to maintain contact, not very rewarding (1 response, 2.3% of responses, 3.2% of cases).

Twenty-six responses from the 31 caregivers indicated a general positive feeling of wanting to do the caregiving. Nine responses indicated that this was a hard thing to do but rewarding. One response each expressed fear of others finding out about AIDS, causing problems for the PWA or that the caregiving experience had been generally disappointing due to drug abuse by the PWA. The overwhelming positive response to feelings about caregiving is particularly interesting in that it is tempered by the response that there was some fear to be overcome about the disease (20.8% of responses) or that the caregiver's fear of AIDS phobia, or a disappointing relationship with the PWA, had produced a negative response to being a caregiver (3.8% of responses).

Of the demographic factors analyzed, level of income seemed to be associated with certain feelings about giving care. In Table 17 the 2x2 matrix comparing high and low income versus positive or negative feelings about giving care is shown. Those individuals with an annual income of over $20,000 were more likely to have a positive experience of feelings related to giving care to someone with AIDS (X^2=5.09, df=1, n=37, p=.03).

Table 17

Caregiver Feelings About Giving Care to a PWA Versus Caregiver Income Level

	Feelings about giving care		
Income level	Positive	Worried or negative	N
$0-$20,000	8	7	15
$20,001+	18*	4	22
Total numbers	26	11	37

*X^2(df=1, n=37) = 5.09, p=.03

The remaining variables had no statistically significant relationship to the caregivers' feelings about giving care to someone with AIDS. These included participant age, gender, education, marital status, caregiver's health, PWA's Katz ADL score, numbers of caregivers, hours of care given per week, and length of time giving care.

<u>Question 5.</u> Continuing on with the investigation of caregiver attitudes, Question 5--what do you think others might say to your being

a caregiver to a PWA--brought ten different micro categories of responses. These were collapsed into the following three macro categories. 1. Positive or neutral responses, may be curious about caregiving or AIDS in general (26 responses, 55.3% of responses, 83.9% of cases). 2. Generally negative or disapproving response (18 responses, 38.1% of responses, 58.1% of cases). 3. Fearful of too much time away from family, friends, or work (3 responses, 6.4% of responses, 9.7% of cases).

From the response rates noted above it is clear that the caregivers are split between fearing negative and hoping for positive or neutral responses when they reveal their caregiver to a PWA status to others. Over half of the caregivers feared negative responses prior to revealing their caregiver status, yet 83.9% hoped for a positive or neutral response. This reflects the way caregivers may see how others view their acts of care. While they may be able to overcome a fear of the disease or of giving care in general, they are aware that there is a stigma attached to the disease or to caregiving in general (that it will take time away from family, friends, or work).

Demographic and other participant variables were investigated in relation to reasons for giving care. All of the following variables seemed to have no impact on what the caregiver thought others might say to giving care to a PWA: age of caregiver, gender, education, income, marital status, health of caregiver, Katz ADL score of PWA, number of caregivers, hours per week of care, and length of time giving care.

Question 6. Nine categories of responses were recorded to Question 6--what brought you to become a caregiver. They were reduced to two macro-categories of responses as follows. 1. I wanted to do something for and with other people--volunteer, meet people, etc. (21 responses, 58.3% of responses, 67.7% of cases). 2. I knew someone, a friend or relative, with AIDS and am giving care to that person or in honor of him or her (15 responses, 41.7% of responses, 48.4% of cases).

As indicated by the above responses, many caregivers reported that wanting to volunteer to help others was an important reason for becoming a caregiver (67.7% or cases). Almost half also reported that they knew someone with AIDS and this spurred them to give care (48.4% of cases).

Demographic and other participant variables were investigated in relation to reasons for giving care. Participant age, gender, education level, marital status, health status, and length of time giving care, in addition to the PWA's Katz ADL score, and number of caregivers did not appear to be associated with what brought the caregiver to give care. However, when hours per week of care and reasons for giving care were compared, as shown in Table 18, there seemed to be a statistically significant association (X^2=3.31, df=1, n=36, p=.07). Here the caregiver variable of hours of care per week is reduced to two categories: "10 or fewer hours" and "11 or more hours". It would seem that those caregivers giving care for 10 or fewer hours per week did so as a way to do something for others and not because they knew someone with AIDS.

Table 18

Reasons for Giving Care Versus Hours per Week of Care

Hours per week of care	Reasons for giving care: Wanted to do for others	Reasons for giving care: Knew a PWA	N
10 or Fewer	16*	7	23
11 or More	5	8	13
Total numbers	21	15	36

*X^2(df=1, n=36) = 3.31, p=.07

Question 7. Question 7--have you told anyone you are giving care to a PWA, if so who--produced nine distinct micro-categories of answers. They were reduced to the following three. 1. Told specific people in the caregiver's life already known to the caregiver (24 responses, 51.1% of responses, 82.8% of cases). 2. Caregiver has told many people in general--either through lecturing or personal contact (21 responses, 44.7% of responses, 72.4% of cases). 3. PWA refused to allow caregiver to tell anyone else (2 responses, 4.3% of responses, 6.9% of cases).

The most frequent category of people told about the caregiving experience was "friends" (72.4% of cases). Only two individuals reported that the care recipient refused them permission to tell anyone (6.9% of cases). Co-workers and relatives were told 11 times each, or 37.9% of cases each. Only two people told their clergy (6.9% of cases) and only three told their neighbors (10.3% of cases). Personal medical personnel were told once (3.4% of cases), but six individuals (20.7% of cases) had gone public by lecturing on the situation, and 20 cases (69%) had told the general public.

These figures may help us understand the degree of closeness or vulnerability people feel with certain levels of kin, friends, and acquaintances. Friends are chosen as the most trusted individuals to reveal potential stigmatizing information to, and complete strangers are also seen as not as potentially harmful. This might seem puzzling at first glance, but upon examination it may be explained. Evidently informing a complete stranger is less threatening than telling a neighbor as there is little risk of having to deal with a stranger's reaction in the future. Neighbors who react in a negative manner may have to be dealt with on a daily basis for some time, and thus pose a threat of actualized stigma.

Demographic and other participant variables were investigated in relation to telling someone about giving care to a PWA. The following caregiver variables were not statistically significant in association with telling anyone about giving care to a PWA: age, gender, education, income, marital status, health, PWA's Katz ADL score, numbers of caregivers, number of hours per week of care given, and how long the participant had been giving care to the PWA.

Subcategories of Question 7 included an attempt to investigate the degree of anticipated responses to revelations of caregiving to a PWA. Respondents were asked what they thought people might say prior to telling others about giving care to a PWA. Seven separate responses were recorded and reduced to the following three macro-categories. 1. Anticipated a generally negative or fearful response (8 responses, 22.9% of responses, 40% of caregivers). 2. Anticipated a generally positive or neutral response (6 responses, 17.1% of responses, 30% of cases). 3. Not sure or didn't really care what others might say (5 responses, 14.3% of responses, 25% of cases). In the face of revealing their caregiver status, these individuals were split between anticipating a negative or neutral-positive response. Thinking about the possibly destructive aspects of a negative response, those individuals anticipating negativity showed a certain level of bravery or disregard for public opinion in revealing their caregiver status. This may reveal a certain level of pride in conviction about what they were doing as volunteers or filial caregivers.

To investigate the relation between caregiver variables and anticipated response, the anticipated responses were further condensed into two categories--"anticipated a negative response" and "did not care or anticipated a positive or neutral response". The following caregiver variables did not seem to be associated with the type of anticipated response: age, gender, education level, annual income level, marital status, health status, PWA's Katz ADL score, number of caregivers, hours of care given per week, and how long the participant had been giving care to the PWA.

Further investigation of anticipated response to caregiving was made. It was decided that a comparison of anticipated response versus actual response to the revelation of care to a PWA would be desirable. Additional probing of Question 7 regarding the actual response of those told about the caregiver's care for an AIDS patient was conducted. There were six different responses to this question, and these micro-categories were reduced to the following two. 1. A generally positive or neutral response including curiosity as to what it was like or wanting to know more about AIDS in general (30 responses, 71.4% of responses, 96.8% of cases). 2. Generally negative reaction, including being upset about not being told sooner. This second part was a disappointed response from relatives--but it could not be discerned if the relative was upset because of wanting to help or was afraid of AIDS exposure (12 responses, 28.6% of responses, 42.8% of cases).

Thus, almost all individual caregivers had experienced at least one case where there was a positive response to revealing that they were giving care to an AIDS patient, and almost half had experienced a negative response. Table 19 shows the comparison of these figures to the answers in the previous part of Question 7--what response was anticipated.

Table 19

Anticipated and Actual Responses of Caregiving Revelation

	Anticipated response	Actual response	N
Negative	16	12	28
Positive or neutral	6	30*	36
Total numbers	22	42	64

*X^2(df=1, n=64) = 8.81, p=.01

The Chi-Square value for this table computes to X^2(df=1, n=64) = 8.81, p=.01, a statistically significant value. Analysis of the matrix reveals that actual responses to the revelation of caregiving for a person with AIDS are likely to be more positive or neutral than anticipated.

Actual responses to the revelation of giving care to a PWA were compared to demographic variables. None of the demographic variable compared in previous answer categories proved to be statistically associated with responses caregivers received when their role as caregiver to a PWA was revealed.

Caregiver Behaviors

Question 8. The next section of questions concerned the actual duties and behaviors of giving care. Question 8 was about specific arrangements the caregiver might have made to help the PWA, whether through location, training, or scheduling. Ten separate categories of answers were coded into the following four macro-categories. 1. THP buddy or hospice training was taken (21 responses, 41.2% of responses, 67.8% of cases). 2. The PWA or caregiver moved closer together or in with each other at some point in the illness (14 responses, 27.5% or responses, 45.2% of cases). 3. No special training or arrangements were made (8 responses, 15.7% of responses, 25.8% of cases). 4. The caregiver's employment changed or work was scheduled around the PWA's needs (8 responses, 15.7% of responses, 25.8% of cases).

A large number of caregivers came to give care through a formal training process. These would include family and nonfamily members. Almost one-half of the caregivers experienced a change in their or the PWA's living arrangements which included the PWA and caregiver living together.

Special arrangements to give care were compared to the caregiver demographic variables discussed in previous questions. None of the demographic variables proved to be statistically associated with special arrangements made to become a caregiver.

Question 9. The ninth question concerned the actual duties and responsibilities of the caregiver to the PWA. This proved to be a difficult quantity to obtain, as many caregivers do tasks too numerous to delineate, or so basic that the lists of detailed tasks would be cumbersome. Still, an attempt was made to get the flavor of the involvement. Initial responses yielded 26 separate categories (167 responses). They were reduced to the following five macro-categories. 1. Emotional support is given through visits, discussions, and other types of emotional support (64 responses, 38.4% of responses, 206.5% of cases). 2. Transportation, the caregiver takes the PWA places such as the doctor's office, grocery shopping, or to run errands (38 responses, 24% of responses, 129% of cases). 3. Physical support is given, which might include help with feeding, bathing, clothing or dressing the PWA. The caregiver may help the PWA get in and out of bed or with general locomotion, or may give light physical therapy (34 responses, 20.4% of responses, 109.8% of cases). 4. The caregiver assists the PWA financially. This may include buying food, clothing, or gifts for the PWA or his/her family, helping to arrange financial dealings, or giving the PWA money (26 responses, 15.6% of responses, 83.8% of cases). 5. Information services are provided, such as interpretation of Social Security regulations, medical information on AIDS, etc. (3 responses, 1.8% of responses, 9.7% of cases).

Clearly, the most common types of duties of caregiving were emotional, transportation, and physical support behaviors. All caregivers reported doing these three types of care. Monetary help is the next most frequent type of care, followed by information services.

Further investigation of a statistical association of types of duties of caregiving with caregiver variables was made. None of the demographic variables compared in previous categories proved to be statistically associated with specific duties or behaviors of the caregivers.

Question 10. This question dealt with the caregiver's perception of what other caregivers do for their PWAs. There were 21 distinct response categories reduced to the five macro-categories. These generally followed four of the categories outlined in Question 9--transportation, financial, emotional, and physical support--with a fifth being the "general other support" category. Of the original 21 micro-categories, talking with the PWA brought 18 responses or 14.9% of responses and 58.1% of cases. Transportation in general gleaned 16 responses, 13.2% of responses, 51.6% of cases. Nonspecific other duties had 15 responses for 12.4% of responses and 48.4% of cases. Table 20 shows the breakdown of major categories of what caregivers thought other caregivers did for their PWAs.

Table 20

Duties of Other Caregivers

Duties	Responses	% Responses	% Cases
Physical	43	35.6%	138.8%
Emotional	39	32.3%	125.9%
Transportation	17	14.0%	54.8%
General other	15	12.4%	48.4%
Financial	7	5.8%	22.6%
Total numbers	121	100.1%	390.5%*

*% of Cases totals to more than 100% because respondents were allowed to choose more than one category of duties of caregiving.

Caregivers in this study see other caregivers as being involved mostly in physical and emotional support, but find themselves more involved in emotional and transportation support. The group of participant caregivers may represent PWAs who are less dependent than others that they know of or imagine to be very dependent. Their expectations of what caregiving to a more dependent PWA entails may be included in the higher degree of physical support expected in other caregivers to PWAs.

Further investigation of possible statistical associations between caregiver variables and what participants thought other caregivers to PWAs did for their care recipients was made. The participants' responses to perceived other caregiver duties were reduced to two categories--"physical and transportation duties" and "other duties", and hours per week of care was reduced to two categories--"10 hours or less", and "11 or more hours". The 2x2 matrix in Table 21 reveals a statistical relationship between perceived other caregiver duties and hours of care per week (X^2=6.92, df=1, n=82, p=.01). In this case, caregivers who do 10 or fewer hours of care per week are more likely to believe that other caregivers do physical and transportation support. None of the other demographic variables compared in previous questions proved to be statistically associated with beliefs about what other caregivers do for their PWAs.

Table 21

Perceived Other Caregiver Duties Versus Hours of Care per Week

	Types of other caregiver duties		
Hours of care per week	Physical & transportation	Other	N
10 or Fewer	33*	19	52
11 or More	10	20	30
Total numbers	43	39	82

*X^2(df=1, n=82) = 6.92, p=.01

Question 11. This question sought to reveal the caregiver's feelings about his or her care duties to the PWA. There were 11 categories of responses, with 45 total responses. These micro-categories were reduced to the four macro-categories that follow. 1. There are few expectations, the caregiver feels okay about the duties (27 responses, 60% of responses, 87.1% of cases). 2. There is a need to manage time with the PWA better or reestablish personal distance. There may be some conflict here between caregivers to a specific PWA (11 responses, 24.5% of responses, 35.5% of cases). 3. The PWA needs to take more responsibility for him or herself, and may need to stop manipulating the caregiver (5 responses, 11.1% of responses, 19.4% of cases). 4. The caregiver wants to do more but feels inadequate (2 responses, 4.4% of responses, 6.5% of cases).

Further investigation of statistical associations of caregiver feelings about duties to the PWA with participant demographic variables were made. Here the previous four categories of responses were further condensed to two--"feels good about duties or wants to do more", and "duties need some adjustment to improve". When marital status was condensed to a dichotomous variable reflecting emotional commitment and living arrangements--"married or cohabiting", and "divorced or single", the matrix in Table 22 was produced.

Table 22

Participant Feelings About Caregiving Duties Versus Marital Status

	Feelings about caregiving duties		
Marital status	Positive	Need adjustment	N
Single/divorced	12	8	20
Married/cohabiting	14	2*	16
Total numbers	26	10	36

*X^2(df=1, n=36) = 3.35, p=.08

The Chi-square for this comparison reveals a trend between feelings about caregiving duties and marital status: X^2(df=1, n=36) =

3.35, p=.08. Married and cohabiting caregivers are more likely to feel that their caregiver duties need some adjustment. None of the other demographic variables compared with previous questions proved to be associated with feelings about caregiving duties.

Answers to Question 11 were probed to further define the respondents' feelings about their duties as caregivers. They were asked to explain or describe their expectations with regard to caregiving prior to becoming a caregiver. This part of Question 11 yielded five separate micro-categories, reduced to the following three macro-categories. 1. This is pretty much what the caregiver expected (14 responses, 41.2% of responses, 51.9% of cases). 2. This is not generally what the caregiver expected to be doing (11 responses, 32.4% of responses, 40.7% of cases). 3. There are specific areas in the relationship that are different from what was expected--the PWA is not what the caregiver hoped for or specific duties are dissimilar to those expected (9 responses, 26.5% of responses, 33.3% of cases).

Further comparison of expectations with regard to caregiving and demographic variables produced the following statistical relationship. Expectations were reduced to two categories: "not what expected" and "what expected". When a 2x2 matrix was created to compare the PWA's Katz ADL score to caregiver expectations, the relation in Table 23 was revealed to be statistically significant. Here, the Katz ADL scores were reduced to a dichotomous variable--"Independent to moderately independent", and "Dependent to moderately dependent". The Chi-square for this matrix computed to X^2(df=1, n=31) = 4.47, p=.04. This reveals a tendency towards the duties of caregiving to be different than expected for caregivers to PWAs that are moderately independent to independent. None of the remaining descriptive variables compared in previous questions were found to significantly affect the caregiver expectations.

Table 23

Participant Caregiving Expectations Versus PWA's Katz ADL Score

	Caregiver's expectations		
PWA's Katz ADL scores	Not what expected	What expected	N
Independent to moderately independent	15*	4	19
Dependent to moderately dependent	5	7	12
Total numbers	20	11	31

*X^2(df=1, n=31) = 4.47, p=.04

Additional information regarding the expectations versus the realities of caregiving was obtained in Question 11. The four micro-categories produced the following three macro-categories of answers. There were only 11 responses to this probe of Question 11. 1. This has been a learning experience compared to what I expected (6 responses, 54.5% of responses and cases). 2. This was different from or more time consuming than what was expected (4 responses, 36.4% of responses and cases). 3. This has been a negative experience compared to what I expected (1 response, 9.1% of responses and cases).

Some caregivers were surprised with the differences between actual and expected duties as caregivers. In some cases they may have learned something about themselves that they did not expect to gain from the experience.

Demographic variables were compared with the reality of caregiving duties. None of the variables compared in previous questions were found to be significantly related to expectations versus reality of caregiving.

Question 12. Question 12 dealt with what the PWA's wants or needs were regarding care as the caregiver saw them. There were 15 micro-categories of responses to this question that were reduced to five macro-categories. 1. Emotional help, such as someone to talk to, a friend, or more time in general with the buddy (33 responses, 50% of responses, 123.3% of cases). 2. General help was needed by the PWA, including errands and backup in case of emergencies (17 responses, 25.8% of responses, 56.7% of cases). 3. Transportation help or help finding transportation (5 responses, 7.6% of responses, 16.6% of cases). 4. No help was wanted by the PWA of caregivers (5 responses, 7.6% of responses, 16.6% of cases). 5. Communication help was needed, on the phone or in understanding others or the disease (2 responses, 3% of responses, 6.6% of cases).

Demographic variables were compared to what the PWA's needs were as reported by the caregivers. None of the variables compared in previous questions were found to be statistically related to the PWA's needs regarding care.

In probing Question 12 the participants were asked what the differences were between what they did for the care recipient and what the care recipient wanted. This yielded four micro-categories of responses reduced to the following three. 1. The PWA expects the same of the caregiver as is given (15 responses, 53.6% of responses, 55.6% of cases). 2. The PWA expects less of the buddy than is done (9 responses, 32.1% of responses, 33.3% of cases). 3. The PWA expects more of the caregiver (4 responses, 14.3% of responses, 14.8% of cases).

Demographic variables were compared to the participants' report of differences in needs versus duties of care. None of the variables compared in previous questions were found to significantly affect the differences in what the caregiver did for the PWA and what the PWA wanted the caregiver to do.

Caregiver Coping Skills

Question 13. The next section of the questionnaire dealt with how the caregiver was coping with being a caregiver to a PWA, a person with a stigmatized, terminal disease. Question 13 dealt with how the caregiver was adjusting to the terminal nature of the disease. It yielded 12 categories of responses that were reduced to the following three macro categories. 1. This is horrible, the caregiver is upset (22 responses, 41.5% of responses, 71% of cases). 2. The terminal nature of AIDS is not an issue for the caregiver and PWA; either they are ignoring it or have dealt with it and it is all right (19 responses, 36% of responses, 61.4% of cases). 3. The caregiver and PWA are busy with other aspects of life (10 responses, 18.8% of responses, 32.3% of cases).

The most frequent of the 12 original responses was "it is difficult to think about the PWA dying", with 14 responses (26.4% of responses, 45.2% of cases). The next most frequent response was that the "caregiver was feeling all right about the issue of death and the PWA", which brought 11 responses (20.8% of responses, 35.5% of cases).

Demographic variables were compared to the caregivers' feelings about the terminal nature of the disease. When caregiver education level was reduced to "college graduate" and "not college graduate", and when caregiver feelings about he terminal nature of the disease were reduced to the dichotomy: "upset about it" and "not upset", the 2x2 matrix in Table 24 was produced.

Table 24

Participants' Feelings About Terminal Nature of AIDS Versus Education Level

Education level	Feelings about terminal nature of AIDS: Not upset	Feelings about terminal nature of AIDS: Upset about it	N
Less than college graduate	3	8	11
College graduate	21*	11	32
Total numbers	24	19	43

*X^2(df=1, n=43) = 4.88, p=.03

The Chi-square for this matrix reveals a tendency for college graduates to be less upset about the terminal nature of the disease than non-college graduates (X^2=4.88, df=1, n=43, p=.03). None of the remaining descriptive variables were significantly associated with participants' feelings about the terminal nature of the disease.

Question 14. This question dealt with how the respondent was coping with the caregiver status. There were 20 original response categories, reduced to the following five macro-categories. 1. The caregiver treats him/herself well or takes (very) good care of self outside of the caregiving experience (34 responses, 39.1% of responses, 109.7% of cases). 2. The caregiver seeks more spiritual, therapeutic, or solitude experiences to deal with the strain of caregiving (21 responses, 24.1% of responses, 67.7% of cases). 3. This is hard to do, the caregiver is not coping well with some aspects, or may be stoic about the experience (21 responses, 24.1% of responses, 67.9% of cases). 4. The overall experience is positive, therefore little coping with the negative aspects of caregiving needs to be done (6 responses, 6.9% of responses, 19.4% of cases). 5. Caregiver takes care of self during caregiving experience, takes a book to read during doctor visits, meets with friends while waiting for PWA at Social Security office, etc. (5 responses, 5.7% of responses, 16.2% of cases).

The three most frequent micro-categories of responses given to Question 14 were as follows. 1. Religious or spiritual faith is helpful in coping with the stress of the situation (13 responses, 14.9% of responses, 41.9% of cases). 2. Doing more work with or without the PWA helps in coping (11 responses, 12.6% of responses, 35.5% of cases). 3. Talking to others about the caregiving experience helps in coping with it (10 responses, 11.5% of responses, 32.3% of cases).

Demographic variables were compared to how the participants were coping with their caregiver status. When marital status was reduced to the dichotomous categories of "married or cohabiting" and "divorced or single", and coping with caregiver status was reduced to "it is hard to do" versus "coping in some positive way", Table 25 was generated. The Chi-square reveals a weak trend between marital status and coping with caregiving (X^2=2.74, df=1, n=60, p=.10). Here it appears that married and cohabiting caregivers are more likely to feel that they are coping well with their caregiver status.

Table 25

Participant Coping With Caregiver Status Versus Marital Status

Caregiver marital status	Coping status Hard to do	 Coping in some way	N
Single or divorced	9	18	27
Married or cohabiting	5	28*	33
Total numbers	14	46	60

*X^2(df=1, n=60) = 2.74, p=.10

Further, when how the caregiver was coping was compared to how long care has been given, the matrix in Table 26 was generated. Here coping is reduced to the same dichotomous categories as in Table 25. Time of care is reduced to "one year or less" and "over one year" of care. It appears that individuals giving care for less than one year may be more likely to feel that it is hard to cope with caregiving (X^2=7.94, df=1, n=60, p=.01). All other descriptive variables compared in previous questions were found to be unrelated to how the caregiver was coping with caregiver status.

Table 26

Participant Coping With Caregiving Versus Time Having Given Care

Length of time giving care	Coping status Hard to do	 Coping in some way	N
Less than 1 year	8*	21	29
One year or more	6	25	31
Total numbers	14	46	60

*X^2(df=1, n=60) = 7.94, p=.007

Question 15. Continuing on in the questionnaire, Question 15 was designed to reveal differences in actual coping versus what the caregiver thought would be expected with regard to coping. The were 12 micro-categories of responses reduced to the following three. 1. The caregiver expected a negative experience but to be able to cope with everything that might happen (23 responses, 45.1% of responses, 74.2% of cases). 2. We would be expected to recognize when we are having a hard time and to talk it out or deal with it in some way (16 responses, 331.4% of responses, 51.6% of cases). 3. The caregiver didn't know what to expect or what would be expected (12 responses, 23.5% of responses, 38.8% of cases).

Of the 12 original response categories the three most frequently raised were as follows. 1. Did not really know what to expect (12 responses, 23.5% of responses, 38.8% of cases). 2. Expected to keep silent or stoic about problems with coping or caregiving (11 responses, 21.6% of responses, 35.5% of cases). 3. Expected to be able to complain when we needed to (9 responses, 17.6% of responses, 29% of cases).

Demographic variables were compared to what the caregiver had expected with regard to coping. None of the descriptive variables compared to previous questions were found to be significantly related to coping expectations.

Question 16. In Question 16 I sought to reveal what the caregivers felt others expected of them with regard to coping with caregiving to a PWA. From the eight original micro-categories of responses, the following three were gleaned. 1. Others may feel that the caregiver is doing okay or very well under the circumstances (23 responses, 52.3% of responses, 74.2% of cases) 2. Others may feel that the caregiver need to change the way he or she is coping (15 responses, 34.1% of responses, 48.4% of cases). 3. The caregiver doesn't know what others might think about how he/she is coping (6 responses, 13.6% of responses, 19.4% of cases).

Demographic variables were compared to what the caregivers felt others expected of them with regard to coping. When caregiver education level and expectations of others were compared, the following matrix was created (Table 27). Here education is reduced to "less than a college degree" and "college degree or more", and expectations of others with regard to coping is reduced to "adjustments need to be made" and "doing okay or don't know".

Table 27

Caregiver's Report of Expectations of Others With Regard to Coping Versus Caregiver's Education Level

	Others' coping expectations		
Education level	Needs some adjustment	Doing okay/ don't know	N
Less than college degree	1	11	12
College degree or more	9	17*	26
Total numbers	10	28	38

*X^2(df=1, n=38) = 2.92, p=.09

The level of caregiver education may affect feelings regarding what others think about how the caregiver is coping. There is a tendency for caregivers with a college education to feel that others might think they are coping well with caregiving.

In Table 28 the comparison between other's expected coping and caregiver annual income is shown. Here income level was reduced to "$0 to $20,000" and "$20,001 and above", and expected coping categories were reduced to those described above.

Table 28

Caregiver's Report of Expectations of Others With Regard to Coping Versus Caregiver's Income Level

	Others' coping expectations		
Caregiver income level	Needs some adjustment	Doing okay/ don't know	N
$0 to $20,000	7	8	15
$20,001 and Above	3	20*	23
Total numbers	10	28	38

*X^2(df=1, n=38) = 5.29, p=.02

The matrix reveals a statistically significant relationship between caregiver income and what the respondents felt others would think about how they are coping (X^2=5.29, df=1, n=38, p=.02). Here it appears that higher income is associated with better feelings about what others would say with regard to the respondents' coping with caregiving to a PWA. All other descriptive variables compared in previous questions were found to be not significantly related to what the caregivers felt others expected of them with regard to coping.

Question 17. This question was designed to discern how the caregiver expected to cope before actually giving care. This has several facets. First, did the caregiver think about what might be involved that might need to be coped with? Second, did the caregiver have coping skills already developed that could be called upon to cope during the caregiving experience? Eight micro-categories of responses were given to Question 17. These micro-categories were reduced to the following three. 1. The caregiver had some reservations as to whether he or she had the necessary coping skills (27 responses, 62.8% of responses 87.2% of cases). 2. The caregiver thought he or she would cope well with giving care to the PWA (12 responses, 27.9% of responses, 38.7% of cases). 3. The caregiver did not think about coping skills before giving care (4 responses, 9.3% of responses, 12.9% of cases).

These responses indicate that a majority of the caregivers (87.2%) felt some trepidation about their abilities to cope with caregiving to a PWA. However, many of the respondents (38.7%) felt that they would cope well enough with caregiving.

Demographic variables were compared to how the respondents had expected to cope with caregiving prior to actually giving care. When gender of caregiver was compared to this category, the matrix in Table 29 was generated. Here the categories regarding coping expectations were reduced to "not sure could cope" and "did not think about it, or thought I would do well". Women were more likely to doubt that they would be able to cope with caregiving to someone with AIDS (X^2=4.82, df=1, n=36, p=.03).

Table 29

Participants' Expectations With Regard to Coping Versus Gender

	Participants' coping expectations		
Gender	Not sure could cope	Do okay/didn't think	N
Female	16*	6	22
Male	5	9	14
Total numbers	21	15	36

*X^2(df=1, n=36) = 4.8, p=.03

When caregiver expectations of ability to cope prior to caregiving were compared to marital status, the matrix in Table 30 was generated. Marital status was reduced to the two categories described above, and caregiver expectations of coping were reduced to the two categories in the previous comparison. Here we see a trend towards single or divorced individuals not being sure they could cope prior to caregiving (X^2=3.29, df=1, n=36, p=.07).

Table 30

Participants' Expectations With Regard to Coping Versus Marital Status

	Participants' coping expectations		
Marital status	Not sure could cope	Do okay/didn't think	N
Single/divorced	12*	4	16
Married/cohabit	9	11	20
Total numbers	21	15	36

*X^2(df=1, n=36) = 3.29, p=.07

When caregiver coping expectations were compared to length of time having given care, the matrix in Table 31 was generated. The time of care category was reduced to "one year or less" and "over one year" of care. Caregiver expectations were reduced to the dichotomy described above. Here we see that those caregivers giving care for less than one year were less likely to be sure of how they would cope with caregiving (X^2=5.60, df=1, n=36, p=.02). All other categories of variables compared in previous questions were not found to be significantly related to caregiver expectations of coping.

Table 31

Participants' Expectations With Regard to Coping Versus Length of Time Giving Care

Time giving care	Participants' coping expectations		
	Not sure could cope	Do okay/didn't think	N
One year or less	14*	4	18
Over one year	7	11	18
Total numbers	21	15	36

*X^2(df=1, n=36) = 5.60, p=.02

<u>Question 18.</u> Question 18 was designed to deal with coping skills and the eventuality of the PWA's worsening health or death. Caregivers whose care recipient was already near death or had passed away were instructed to answer according to their actual experience. Caregivers who would have a future experience with this issue were instructed to answer in light of how they expected to cope.

Twenty-six micro-categories of responses were given in answer to Question 18, with 76 total responses for an average of 2.45 responses per participant. The five macro-categories of responses that follow were culled from the original 26 micro-categories. 1. An adjustment of some kind will need to be made such as taking more time for self, or with PWA, getting busy, getting some support or additional buddy help (28 responses, 36.8% of responses, 90.3% of cases). 2. Generally talking more to others will help or was utilized (27 responses, 5.5% of responses, 87.1% of cases). 3. There was or will be a decrease in coping such as getting numb to the pain or not dealing with the situation (15 responses, 19.7% of responses, 48.4% of cases). 4. The caregiver expresses fear and concern regarding the prospects, expects poorer relations with others (3 responses, 3.9% or responses, 9.7% of cases). 5. The caregiver feels that somehow coping will increase or the future will get better (3 responses, 3.9% of responses, 9.7% of cases).

The three most frequent responses of the 26 original micro-categories were as follows. 1. There will be a need to adjust (9 responses, 11.8% of responses, 29% of cases). 2. The caregiver will need to talk more about his or her feelings (7 responses, 9.2% of responses, 22.6% of cases). 3. The caregiver will need to talk more with others in order to cope (6 responses, 7.9% of responses, 19.4% of cases). Clearly many of the caregivers anticipated or experienced a need to adjust their coping skills as the PWA's condition worsens.

Demographic variables were compared to how coping skills might change in the face of the PWA's death. None of the descriptive variables compared in previous questions were found to be significantly related to predicted changes in coping skills.

Question 19. The final specific question in the open-ended questionnaire was utilized to explore the source of the caregivers' coping behaviors. Eight separate categories of responses were given to this question. These eight categories were reduced to the three macro-categories of responses that follow. 1. Life experiences, religious faith, or psychotherapy had taught the caregiver to cope (49 responses, 81.7% of responses, 158% of cases). 2. A member of the caregiver's family had set a coping skills example (9 responses, 15% of responses, 29% of cases). 3. The caregiver had no idea where he or she learned to cope (2 responses, 3.3% of responses, 6.5% of cases).

Demographic variables were compared to the source of the caregivers' coping skills. None of the descriptive variables compared in previous questions were found to be associated with where the caregiver learned to cope.

Question 20. The final question was designed to allow the participants a place to cover any additional information they felt needed attention. In some cases this information was concerned with issues not covered in the interview such as the caregivers' personal grief, anger, or politics. Occasionally participants used this question to review an issue already discussed in the interview. Sixteen original answers were recorded when participants were asked "is there anything else you would like to say about your experience?" The four macro-categories of responses that follow were condensed from the original 16. 1. This has been a learning experience and the caregiver is motivated for more involvement (22 responses, 41.5% of responses, 104.5% of cases). 2. There was some negativity associated with caregiving, burn out, limited setting, difference in levels of sharing, etc. (17 responses, 32% of responses, 80.9% of cases). 3. The caregiver is upset or angry about the government and public response, there is a great need for more education about the disease to fight discrimination and denial (11 responses, 20.8% of responses, 52.4% of cases). 4. There is a cultural/communication difference that makes caregiving more difficult (3 responses, 5.7% of responses, 14.4% of cases).

Of the 53 answers given from the 21 caregivers responding to Question 20, the two most common categories of the 16 micro-categories were as follows. 1. The caregiver would do this type of care again (7 responses, 13.2% of responses, 33.3% of cases). 2. This was a learning experience in which the caregiver grew as a person (7 responses, 13.2% of responses, 33.3% of cases).

A large number of the caregivers (41.5%) responded that they felt their overall experience had been a positive one. Over one-fifth (20.8%) expressed anger or grief over the low rate of response that had been made so far to the AIDS crisis by the government.

Demographic variables were compared to statements in response to Question 20. None of the previously examined variables were significantly associated with answers to this question.

CHAPTER SIX

CONCLUSIONS AND DISCUSSION

Conclusions

The following is presented to briefly review the findings and set the format for the discussion section. Unification of theoretical concepts and the proposed structure of the research with findings will also begin in this section.

Care recipients. Eighteen PWAs were cared for by the 31 participants. Half of the care recipients were black, about one-fourth were female, and eight of the males (44.4% of total, 57.1% of men) were homosexuals. Even though some of the reports on PWAs were semi-historical (many caregivers reported on past experiences) the sample of PWAs represented here closely fits the current local population demographics. Increasing numbers of heterosexuals--black and white--have been reported as HIV+, and this change is rapidly showing up in the AIDS population. The changing face of AIDS has many implications. These will be reviewed in the discussion below.

Caregivers. The 31 caregivers in this study were chosen as a convenience sample, with some attempt at purposive sampling of caregivers to hemophiliac and female PWAs. The racial and gender ratios of the participants reflect the general local AIDS caregiver population. This is especially true with regard to race. THP has fewer than one dozen black volunteers out of several hundred.

The families of PWAs were generally responsive in some way to the care needs of their relative with AIDS. Primary caregivers were more likely to be filial caregivers. These individuals were also more likely to have given care for a longer period of time and for more hours per week than volunteers. The fact that family caregivers may often be overwhelmed with the tasks of care, especially in the later stages of the disease, was also reflected in the sample, where 10 (32.2%) caregivers were friends, seven (22.6%) were family members or homosexual spouses, but the largest portion, 14 (45.2%), were volunteers (strangers) in a caregiving team. Many family members worked as primary caregivers in the initial stages of the disease, but were members of a team of primary, secondary, and attenuated caregivers as the disease progressed. The team of caregivers is an adaptation to the multiple needs of care at the later stages of the disease.

Caregiver education level was relatively high, and this may have impacted on many areas of attitudes and coping skills. The fact that almost all of the caregivers were employed full time (26 participants, 83.9%) has implications for recruitment and training of caregivers. Fully employed individuals do not have the time to devote to intense care of a PWA in the lasts stages of the disease. Thus a team of caregivers is often constructed.

The strains of caregiving on participants' health seemed to be insignificant in that most caregivers reported themselves to be in excellent health. Several caregivers, however, were in poor health, with at least two reporting very serious, life threatening conditions (not HIV+). While the HIV status of participants was not determined in the interview, the researcher was aware that several of the participants may be HIV+, in the earliest stages of the disease.

With regard to caregiver coping skills and the progression of the disease, caregivers must deal with the potential for declining health in the PWA as the disease progresses. When actually confronted with the health decline, they may react by attempting untried coping behaviors, thus increasing the potential for attempting unsuccessful coping behaviors. Therefore, if we can measure the PWA's decrease in health as beginning with increased dependency, this may signal an important crossroad for the caregiver in testing coping skills.

The tendencies associated with numbers of caregivers and the PWA's Katz ADL score may give some support to the model of a caregiving team suggested in the sampling frame. It is logical to expect that more dependent individuals require more assistance with activities of daily living. As this disease progresses many primary caregivers find themselves involved in more care for the PWA, taking more time. Secondary caregivers may already have been recruited, may have been giving only a few hours of care per week until the PWA reaches a more critical stage of the disease. As the PWA's health decreases, care needs increase, and care behaviors increase accordingly. Secondary caregivers may be called upon to give additional care, requiring more hours of care per week. Eventually the secondary caregivers reach a limit to the amount of time they can spend assisting the primary caregiver. Attenuated caregivers, who may already have been recruited, may subsequently be called upon more frequently, and for more time-consuming activities. Numbers of caregivers, not length of time giving care, predicts level of health of the care recipient.

It is in this way that the disease drives the care. As AIDS progresses, levels of care needs increase, and numbers and types of care providers expand. We see this trend in the area of caregiving-related coping. Generally, caregivers do not utilize as many coping behaviors when they give fewer hours of care. Newly initiated caregivers may attempt more coping behaviors than would be randomly expected. This would seem in line with the natural expectation that a new and potentially stressful behavior might require adjustments in coping, and thus launch a campaign to expand coping skills. One of the coping behaviors of a new primary caregiver may be to enlist the aid of a secondary or attenuated caregiver. Logically, this would be expected to show up in the socialization behaviors of the Coping Inventory, and it does. Once again the disease drives the caregiving--in caregiving behaviors and coping skills. This fits the model for care that has been developing. Table 32 illustrates the model of the caregiving driven by the disease with variable chronicity.

Table 32

Disease Phases Corresponding to Amounts and Types of Caregiving

Progression of the disease	Caregiving behaviors
Phase I--Infection & diagnosis	Little caregiving needed or recruited. May occasionally use attenuated care such as baby sitting or transportation to and from medical procedures, or join a support group. May recruit future caregivers.
Phase II--AIDS related complex	May need help with strenuous activities. Primary caregiver may be doing only specific tasks. May still have only attenuated or secondary caregivers.
Phase III--First opportunistic infections	Has usually recruited primary caregiver for major help. May have secondary caregivers and attenuated caregivers lined up to give some respite care during medical emergencies.
Phase IV--Multiple opportunistic infections & terminal phase	At first primary and secondary caregivers may be able to handle most of care needs. Secondary caregiver(s) eventually caps out at a maximum number of hours of assistance available. Multiple secondary and attenuated caregivers take on more responsibility for PWA's care. Medical team takes over some ADL duties (feeding, bathing, elimination, and transportation). Other ADL duties may be reduced (dressing). Care team thus expands as disease progresses.

Caregiver self esteem. Participants proved to have relatively good self esteem. This is surprising in light of the fact that AIDS is a very isolating and troublesome disease for all involved. Many caregivers had witnessed the death of their PWA, and experienced a concomitant sense of failure or inevitability in the face of death. However, many expressed feelings of satisfaction with caregiving. This may be an intervening factor in the self esteem of participants.

On the other hand, participants may be predisposed to generally higher levels of self esteem, contributing to their desires to give care and participate in the study. A cross-sectional, long term study of the AIDS caregiver population may reveal one or more of such predispositions.

Coping Inventory. Caregivers participating in this study proved to be a resourceful group with regard to coping behaviors. Only one item, "I tried to put the event out of my mind", was not found to be helpful (no one selected it as "does apply and helpful", see Appendix F). All of the 33 items were tried by at least seven individuals. The descriptive variables of participant age, gender, education level, annual income level, marital status, health, Katz ADL score of care recipient, numbers of caregivers, hours of care, and length of time giving care did not seem to impact coping behaviors. There were slight, nonsignificant trends reported in several of these variables. A larger sample size may reveal statistically significant relationships.

The Coping Inventory is divided into three areas or types of behaviors. The type of behavior of "changing attitudes and activities" was utilized the least and also was the category listed least frequently as helpful. "Working through the event" behaviors, or doing something active in response to the need to cope, were reported as the most frequently successful. Socialization behaviors were also generally successful. Caregivers to PWAs do not find coping to be enhanced by changing their attitudes or activities as much as working through the meaning of the caregiving or spending more time with friends. This is somewhat surprising as many participants reported drawing on spiritual values as a form of coping. Others seemed to be processing their worries and concerns about caregiving by returning to nature, hobbies, or work. The results here may conflict with some of the ideas expressed in other parts of the interview. This conflict of results may also be the result of a weakness in the Coping Inventory. Further investigation of coping skills and behaviors needs to be done.

Caregiver attitudes. Answers to questions about how the caregiver came to give care and overcame fears of contagion, stigma, death, and helplessness were used to operationalize caregiver attitudes. In many cases feelings of filial responsibility, mixed with a desire to volunteer, were responsible for the participant becoming a caregiver to a PWA. Feelings of anger or grief about the disease seemed to motivate only a few participants. When the reasons for giving care were condensed to volunteer versus filial, the Chi-square test revealed that volunteer and other non-family reasons for giving care were related to fewer hours of care. All but two of the non-family caregivers were secondary or attenuated caregivers, and this factor alone may account for the fewer hours of care. The remaining two non-family caregivers were listed as primary caregivers only because their PWAs were so isolated from friends and families that no other care was available. However, these two primary volunteer caregivers did not give care to a critically ill PWA; thus, their hours of care were very few. Family and friends were also more likely to give care for a longer period of time (though not statistically significantly so).

Many caregivers were concerned about the decreasing physical and mental health of their PWAs. Surprisingly few (one) were worried about contracting AIDS, and few (one) were worried about AIDS phobia affecting the PWA's health care. Obviously, a well educated, strongly motivated caregiver can make a decision to learn more about a stigmatized disease and how to avoid contracting it. But worries about AIDS phobia affecting the PWA's care deal more with symbols of external sanctions as found in the medical community. Fortunately, this area of North Carolina has a dedicated community of health care workers. Many of these health care professionals have made an extra effort to educate themselves about AIDS and AIDS phobia. This effort has paid off with decreased fears of AIDS in the medical community. This in turn has helped PWAs and their caregivers feel less anxious about AIDS phobia affecting health care.

Fortunately for PWAs and their caregivers, most participants reported excellent relationships with their care recipients. Unfortunately for the researcher this prevented a factor analysis of successful versus unsuccessful relationship variables. A larger sample, perhaps with purposive representation of caregivers with less than happy relationships with their PWAs, would be useful in analyzing quality of relationship variables.

The quality of the relationship between the caregiver and the PWA seemed to be related to caregiver income level, marital status, hours of care per week, and the PWA's Katz ADL score. Higher income level was shown to be associated with better relationships, as was being married or cohabiting. In many cases the financial strains of caregiving can be ameliorated with higher income. Emotional strains of caregiving may be reduced by having an active primary relationship outside of the caregiver role.

The disease seems to affect the relationship between caregiver and PWA. As PWA Katz ADL scores become more dependent, the relationships seem to decrease in quality. As hours of care increase, the relationship seems to decrease. This may reflect a growing AIDS dementia interfering with the personality of the PWA (Holland & Tross, 1985). It may also reflect a general deterioration of the relationship over time due to a number of other intervening variables. Scenarios for the intervening variables include such things as the increased likelihood of interpersonal strains over time in the caregiver-PWA dyad. This may be accomplished by the reduction of denial in the dyad, depletion of financial or emotional resources of the dyad, or increased number of needs of the caregiver and PWA over time interacting in their relationship in a negative way.

Further investigation of feelings about giving care revealed a generally positive feeling among participants. Income level was the only variable that seemed to be significantly related to feelings about caring for a PWA. Participants with annual incomes of over $20,000 had a tendency to report better feelings about giving care. AIDS is an expensive disease to care for. Having adequate personal income as a caregiver may help with incidental contributions to the PWA's comfort or medical care. In several cases of parental caregivers, large sums were expended seeking alternative care regimes. The ability that adequate income provided for these family members to seek additional care for their sons, may have helped them feel less powerless in the face of the disease. This may in turn have translated into better overall feelings about caregiving.

The symbolism inherent in perceptions of others' feelings about the participants' caregiving was operationalized through answers to several questions about others' opinions. Many caregivers expressed a fear of sanction from others, but hope for appreciation by others of what they were doing. Further definition of why the participant became a caregiver revealed that most felt the need to "do for others". These feelings of altruism, charity, and self worth through contribution were major influences on the decision to give care. Many volunteers or family members could have opted to do other types of work with or outside of AIDS. This could have included such work as attenuated care, office work at THP, AIDS prevention education, general hospice volunteering, or volunteering in other community programs. They chose, however, to give care to a loved one or stranger. This reflects a deep cultural value of "giving of oneself". The positive symbolism of a charitable act can seem to enhance self esteem, coping mechanisms, role performance, and feelings of acceptance in society. This may in part help explain the participants' relative lack of concern for societal sanctions against caregivers of PWAs. With general feelings of the rightness of the care overriding the risks and stigmas, it is not surprising that many caregivers expressed an interest in continuing current care or reestablishing a caregiver relationship in the future (even in light of the recent death of their PWA).

Many caregivers were very visible in their caregiver status. This may be surprising in light of possible risks of stigma that revelation of caring for a PWA might provide. However, there seemed to be a trend to tell either complete strangers or close friends and family. Telling neighbors, clergy, or medical personnel was conspicuously low in the hierarchy of informed acquaintances. Many participants were able to tell others of their caregiving status even when they anticipated negative responses. However, an investigation of anticipated versus actual responses revealed that actual responses to the revelation of caregiving to a PWA were generally more positive than expected. Thus perceptions of public stigma against the disease may be greater than the actual presence of the stigma. On the other hand, caregivers may tell individuals they feel are predisposed to give a positive or neutral response.

Caregiver behaviors. An attempt was made to document the role of caregiver as operationalized by caregiver duties and preparation for the role. Over two-thirds of the caregivers had some formal training with regard to caring for a terminally ill person. In many cases, the PWA or caregiver moved closer to each other, and in others (25%) there was an effect of caregiving on the care provider's employment.

All caregivers experienced giving emotional, transportation, and physical support to their PWAs. When questioned about what kinds of care the participants thought other caregivers gave to their PWAs, physical and emotional care were named by all participants. Clearly participants felt their duties were in line with those of other caregivers.

Generally, care providers in this study felt positive about their duties as caregivers to PWAs. However, married and cohabiting caregivers were more likely to feel that their duties needed some adjustment. In many cases this included doing less for the PWA. It would seem logical that participants who are involved in a primary relationship at home may feel the need to do less for a PWA as they may simply have less time to devote to caregiving outside the primary relationship.

For the most part the duties of giving care were as expected, or in some cases where different, it was felt that specific changes were needed. The tendency to feel that duties were not as expected was significantly related to independence of activities of daily life (Katz ADL) in the PWA. Family and volunteers expect caregiving to be difficult and thus when the PWA is relatively healthy duties are less than expected. Many caregivers reported that the experience had been one in which they learned more about themselves, and only one reported that the experience had been more negative than what had been expected.

The researcher sought to document the perceived needs of the PWA as reported by the caregiver. Emotional and general backup physical help were the two main needs of the PWAs as reported by the participants. This is in line with what caregivers report as their duties to PWAs, in that most reported a general agreement between caregiver and PWA on care duties.

Coping skills. The Coping Inventory revealed some of the behaviors participants utilized in coping with their role as caregiver to a PWA. The final section of the open-ended questionnaire dealt with how the caregiver felt about his or her coping, and what they thought others might think about their coping. Most caregivers felt that being a care provider to a PWA was a horrible situation to have to deal with. Higher educated caregivers had a tendency to be less upset about the terminal nature of the disease. All caregivers reported that they do something specific to deal with their caregiver status. Two-thirds revealed that they gain strength from spiritual, therapeutic, or solitary experiences. Two-thirds also felt that they were not coping well with their caregiver status. Caregiving to a PWA is difficult and provides an opportunity for personal examination and growth. This may reflect a societal expectation that hard times can produce individual growth. Armed with this presupposition, many caregivers seek the meaning of their experience and to utilize their pain and uncertainty to expand their own self actualization. Future studies should attempt to further operationalize the concepts of personal growth and learning through hard times to reveal the symbolism alluded to here.

Cohabiting or married individuals showed a tendency toward feeling they were coping well with their caregiver status. This may reflect the opportunities that a primary relationship provides for venting of frustrations and receiving compliments on charitable work. Much like results of studies on caregivers to the elderly, those participants giving care for less than one year showed a tendency to feel they were coping less well than those with more experience, and reported that they were less likely to be sure they could cope prior to the caregiving experiences.

Almost three-fourths of the caregivers reported that they felt they would be able to cope in their role as care provider to a PWA with whatever happened, even though most had reservations. This, in turn, corresponded to feelings that others would think that the caregiver was doing well (under the circumstances). There was also a tendency for caregivers with a college degree to feel that others might think they were coping well with caregiving. This was also the tendency among caregivers with higher incomes. Women and single or divorced individuals were less likely to feel that they would be able to cope with caregiving to a PWA prior to the actual caregiving experience.

It was felt that investigating predicted coping with future events would help define feelings about overall coping skills. Almost all of the participants reported that they felt an adjustment in their coping behaviors would have to be made to accommodate the future decline of their PWA's health. These additional coping behaviors included talking to others more about the experience. Many feared a decrease in their coping skills as the PWA's health decreased.

Once coping skills and needs to adjust coping were documented, it was felt that documentation of models for coping in the caregivers' lives would be necessary to help define caregiver training and recruitment. Almost all caregivers reported that life experiences of some kind had helped prepare them to give care. Only two participants had no idea where they learned to cope. In almost one-third of the cases caregivers learned to cope with this situation from examples set by family members (usually their mothers) during their youth.

One of the more memorable aspects of the information provided by the participants was that all of the caregivers reported at some time during the interviews that, knowing what they do about AIDS and PWAs, they would give care again if the opportunity arose. In spite of all the fears of stigma, contagion, burn out, and lack of ability in the face of the disease, all participants reported that they had a positive experience with caregiving to a PWA.

Discussion

Caregiver attitudes, behaviors, and coping, and the theoretical framework. The findings with regard to caregiver attitudes towards giving care to a person with AIDS were of note. This was generally a group rather free of fear of contracting the disease. In that sense, they had rejected many of the medical myths about the disease that have been associated with AIDS phobia. This may mean that these individuals were able to give care because they could override the AIDS hysteria. It may be that their generally high levels of education armed them with information and skills to make their own unbiased opinions. Whatever the factors that contributed to this medical awareness, this calls on "I" self or individual behaviors rather than "me" self or societal values.

In terms of symbolic interactionism, these caregivers exhibited all three types of role taking delineated at the onset of the study--basic, reflexive, and appropriative. In basic role taking the caregivers anticipated what society expected of them, and in many cases potentially sacrificed time, money, feelings, and relationships with others to take on the basic role of caregiver to a terminally ill friend or relative.

There was a general awareness of what stigma society had assigned to AIDS. This reflexive role or anticipation of what others' reactions to caregiving to a PWA would be was also tempered by the basic role-taking task of anticipating what society expects from family and friends. In American culture it is a generally recognized role to assist family and friends who are faced with problems. Roles pertaining to caring for a terminally ill friend or family member include sacrificing one's personal time to care for this person before they die. Often financial and emotional strains are present in completing this task. This group of caregivers accepted the tasks involved in this role of sacrificing time, etc. Feelings of civic responsibility drove many to volunteer as caregivers in an extension of the role of helper to someone who is facing problems.

The fact that many respondents feared censure from society for their association with a PWA speaks to the issues of reflexive role-taking. How did they overcome these fears of sanction, stigma, and disenfranchisement? Highly educated individuals can also conclude that the stigma, etc., may be unwarranted. They may be more willing to perform an altruistic act if the overriding senses of filial responsibility or civic duty are stronger than their fears of sanction. Once again the "me" self societal values of filial and civic responsibility have been stronger in these individuals than fear of sanction. The appropriative role-taking that has occurred here has been that of appropriating the attitudes of AIDS care workers who have already overcome fears of contagion and stigma to give care and train other caregivers. Evidently, the "I" self of personal values and behaviors is very strong in these individuals as they have been able to create the role of "caregiver to a PWA" with no societal role models to speak of. This adaptive behavior has produced changes in all participants on many levels. One of the most memorable is the willingness to resume AIDS community or caregiving work soon after the death of the PWA. Once having overcome fears of stigma and contagion, these individuals have responded to the great needs of a small segment of society. This is rather phenomenal given the small size, moderately conservative attitudes, and limited resources of the community from which the sample was drawn. How did these caregivers perform their myriad duties?

Behaviors associated with caregiving ran the gamut from social and emotional to physical and financial. Much can be said for the variety of caregiving opportunities available for primary, secondary, and attenuated caregivers. Almost no job was too small. Nor did any job seem too large. When caregiving became too complex and time consuming, caregivers generally were able to ask for and find assistance from relatives, friends, and volunteers. This overall group was so dedicated to assistance for PWAs, that no PWA who wanted housing lacked for it in this small community. Almost all orphaned or abandoned pediatric AIDS cases have been placed in foster care or adopted by friends and family. All surviving children of AIDS patients have been absorbed into their families or the community. Thus some of the caregiving behaviors are performed after the death of the PWA. This study did not attempt to investigate these posthumous duties. A long term, cross sectional study would be ideal for documenting pre- and post-death caregiving behaviors, attitudes, and coping skills.

Caregivers revealed themselves to have a veritable cornucopia of coping skills. Coping with death and dying is a cultural role. In America, we are alternately stoic and businesslike or highly emotional and unable to cope. Here we found a group of individuals who took on the role of compassionate capable caregiver.

There were many emotions associated with the telling of the caregivers' stories. Great admiration, joy, dread, fear, love, grief, and resolve were evidenced in the face of the powerlessness that the disease produces. Yet, empowerment of caregivers and care recipients was evident as is recommended in the literature (Haney, 1988).

There was a sense of needing to cope better--that somehow feeling powerless or feeling bad about the eventual death of the PWA was unacceptable (powerlessness as unacceptable is perhaps a societal value) and that new coping skills needed to be learned to empower the caregiver to new levels of acceptance, competence, and understanding. This may be a transitional state. It may be that coping may have a component of anticipatory grief that allows for recognition of the inevitable with empowerment to do a multitude of behaviors. However, doing something or anything seemed to be the overarching theme of coping. These were not people who could sit back and watch the media presentations on AIDS and do nothing. Either by circumstances of relation or friendship, or by civic or spiritual duty, these people got involved. This may be the most important coping skill. In the end, caregiving was how they coped with caregiving.

Caregiving and the disease. Caregivers' behaviors, and to some extent attitudes and coping, were driven by the disease. The health of the PWA gradually declined, causing caregiving behaviors to increase. This impacted attitudes towards the care recipient by the caregiver and also affected coping. The model in Table 32 illustrated this disease-driven phenomena. This has multiple implications for recruitment, training, and retention of caregivers to PWAs. This also has implications for the changing face of AIDS. In the past, the disease was the primary problem. With new types of PWAs, some heavily involved in addictive health-antagonistic behaviors, there will be a multiplicity of problems to be attended to. This has already complicated AIDS caregiving. In this study, the only caregivers who reported less than very good relations with their PWAs were those who were giving care to a substance abuser. Often there was an associated mental instability present in the PWA. This is not to say that the gay male population of PWAs was totally free of substance abuse or mental illness. However, the relative frequency of these antisocial elements was rather low. The increase in pediatric AIDS cases, often offspring of drug abusers abandoned or orphaned, brings yet another level of problems with seemingly exponentially detrimental effects on the caregiving community.

Implications for recruitment and training. How does what we have learned about caregiving to PWAs impact recruitment of caregivers? First, we must recognize that successful care does not mean beating the disease. Successful care means providing necessary services to the PWAs to help them live life to the fullest for as long as they can. This period of time may be relatively short--less than one year--or with new drug regimens, relatively long--five to ten years. Recruitment of caregivers to PWAs needs to include individuals who are flexible, intelligent, resourceful, dedicated, and compassionate.

Second, a family member, friend or acquaintance serving as a primary caregiver seems more likely to succeed for longer, more intense periods of time than others. They can be successfully augmented by secondary and attenuated care providers. Recruitment of family, friends, and acquaintances may best be accomplished through the PWA, perhaps assisted by medical care or AIDS service organization personnel.

Recruitment of volunteer caregivers can generally be accomplished by AIDS service organizations and PWAs.

Third, some training of caregivers is required due to the variant nature of the disease, needs of reducing fear of contagion, needs of decreasing susceptibility of infection, and requirements of coordinating care. Training need not be overly extensive. The local AIDS service organization provides what amounts to a 12 hour general training and an additional 20 hours of intensive training for all caregivers who are interested. Additional, specific medical procedures can be taught in a matter of minutes. Prevention education, outside of training, is essentially a one hour session.

Thus in recruiting and training caregivers, some above-average intelligence is needed, with a moderate sense of self esteem, and the ability and resources to deal with the variant nature of the disease. The successful recruitment candidate will need to be able to cope with the multitude of emotions associated with caregiving. Training of caregivers requires the ability to discern areas of needed information both by the trainer and the potential caregiver.

All of this suits the caregiving needs of the past face of AIDS. With the ever increasing presence of drug abusers with AIDS, many more complications arise. In some cases gay men with AIDS were rejected by their families for their lifestyles. Usually the rejected gay man built a new network of resources and fictive kin. Drug abusers are known for their decreased kin and resource networks. Most of their families and friends have long ago given up trying to help them. Many relatives of the drug user may tell stories of being robbed, cheated, manipulated, and lied to by the addict. They no longer trust the individual, and often warn others away from him or her. Recruitment of caregivers from this population will be very difficult, if not impossible. Retention of caregivers, volunteer or family, has already been shown to be difficult. The addict must be able to maintain sobriety, and even in the face of that accomplishment, may still have a long way to go in being able to maintain healthy interpersonal relationships. The recidivism rate for this population of recovering substance abusers has yet to be determined. Common sense would indicate that it would be very hard for a former addict to maintain sobriety and learn new interpersonal skills over the short period of time between diagnosis and recruitment of caregivers.

Recruiting caregivers for pediatric AIDS patients may be easier than for gay men or (former) drug addicts. There is a certain societal value in helping the defenseless, especially children. There is a notion in society that these AIDS patients are the "blameless victims" of the disease (along with hemophiliacs). However, the multitude of needs of the pediatric AIDS population--their total dependency on adult care--complicates the issues of recruitment, training, and retention of caregivers. How then to address this issue? The use of numerous attenuated caregivers to assist the primary and secondary caregivers (often foster or adoptive family), seems a logical solution. Few people have the enormous amount of time it takes to care for an infant or toddler full time. However, shifts of respite caregivers can be established to baby-sit the child and allow mothers and families time for normal, necessary tasks. Complicating the caregiving process is the fact that the only pediatric AIDS treatment clinic in the area is in Durham, North Carolina, at Duke University Hospital, which is a day's trip of travel time and clinic activities. This may necessitate that the primary caregiver not be employed full time.

Implications for retention. Retaining caregivers calls upon increasing coping skills and reinforcement of positive attitudes towards the PWA. Respite care provided by attenuated caregivers to primary and secondary care providers is generally essential in the later stages of the disease. There is a strong potential for caregiver burnout with a disease that produces a sense of powerlessness. Burnout prevention, then, would be a major component in retention of caregivers.

Lowering the effects of financial distress often visited on the PWA families and their primary caregivers is another important goal. Public assistance (federal and state) coupled with the contributions of a local AIDS service organization can do much to allay financial ruin. Hospice organizations provide low cost or free nursing assistance to terminally ill patients. However, much needs to be done to assist caregivers and PWAs by reducing the red tape of government regulations prior to receiving assistance.

Care of caregivers after the death of the PWA. Little has been done to help the caregivers after the death of the PWA. Other than support groups for grieving and adjusting caregivers, there seems to be little attention paid to these survivors. This is particularly disturbing in light of this group's professed desire to return to some form of AIDS caregiving after the death of the PWA. These experienced caregivers could well be utilized in what is essentially a small pool of human resources associated with AIDS.

This disease allows some time for anticipatory grief among care providers. This may help the care provider adjust to the death of the

PWA, or it may interfere with the level of care provided. A further investigation of this variable (anticipatory grief) is needed. The study of coping and adjustment of caregivers after the death of the PWA is also needed.

AIDS service organizations--their future and roles. One of the focal points in caregiving for a PWA is the availability of local assistance groups in training and supporting caregivers. Indeed, this study could not have been accomplished without the aid of the local organization. The cost to society of a governmental agency to provide this type of care would be prohibitive. Thus these grass-roots volunteer agencies provide irreplaceable services.

Thousands of hours of care are funneled through these agencies, with a substantial savings to the public over real costs in personal time, employment, emotional strain, and health care (Sisk, 1987). Much can be done to assist them. Zoning regulations should be modified to allow for group homes for AIDS patients unable to find appropriate housing. Business communities can assist with contributions of time, services, and money to bolster the donations of private citizens. The media can illustrate for their audiences the dedication of the volunteers and the needs for additional attenuated caregivers. The media continuing its participation in helping to educate the public about AIDS, and thus reducing AIDS phobia, is essential. The religious community can make contributions of goods and services in addition to fostering a renewed value in volunteerism and helping those in need. Much can be done by religious leaders in reducing the stigma of AIDS. This is especially true in the black community, where the church is the focal point of community strength and individual moral values.

Much effort is needed in minority sectors of the society to improve living conditions and economic opportunities. Thus, AIDS education is essential in preserving health in populations afflicted by poverty, drug abuse, and despair. The previous insularity of the heterosexual, mainstream and minority, population regarding AIDS has served to increase the spread of the disease across all segments of society. Private, non-profit, AIDS service organizations are the only groups actively responding to the disease in the United States.

One of the problems AIDS service organizations face, stemming from the demographics of the disease, is the homophobia associated with AIDS. Not only does this have implications for the face of AIDS, it also speaks to the face of the AIDS caregivers and organizations. Many AIDS service organizations were founded by the gay community in response to the disease. Thus many potential volunteers were discouraged from becoming involved for fear of association with "gay" organizations. As these individuals dealt with their homophobia and AIDS phobia they have been able to respond to the crisis. Much of this change in attitudes has been as a direct result of educational interventions produced by the AIDS service organizations.

With the increasing sensitivity of heterosexuals to the needs of the AIDS population, many non-gay volunteers and family members have become involved with care and in running the organizations. This has manifested a seeming backlash in the gay community, where heterophobia has been evident. Gay community leaders have begun to question the direction of AIDS service organizations that now treat heterosexual clients or have numerous heterosexual volunteers or employees. Their reactions may not be so surprising in light of the homophobia that they have suffered under all of their lives. Questions about the sincerity and intent of heterosexuals in charge of homosexual health care are then not as reactionary as they may seem at first glance. AIDS service organizations experiencing this transition from primarily gay-oriented groups to a more heterogeneous mix will have to address these concerns and resolve the conflicts.

In the end, with the changing face of AIDS, these may be the "good old days of AIDS". This is because resourceless addicts with AIDS pull very little sympathy from the general public, and thus little financial or caregiving response. Even some gay community AIDS policy advocates find little room for "wasting" precious resources on the abusing population. This attitude, in addition to all of the other financial and medical constraints, will have to be overcome if all AIDS patients are to receive caregiving assistance.

Future research. This study sought to provide a basis for future theoretical and research design. Nothing was known of the caregivers to people with AIDS. The ethnographic design with primarily qualitative data, and theory based elements of the study provide one way to look at this population. Clearly a larger sample size is necessary if we are to understand this phenomenon. The implications for clinical intervention with this population in assisting in adjustment to caregiving, coping, and grief have broad applications to other caregiving populations. This researcher would like to see a long term, cross sectional study with a large randomly chosen sample of caregivers to PWAs as a follow-up to this preliminary study. Clearly some of the instruments used in the research design fell short of their intended purpose. The Coping Inventory has only recently been developed and is not yet in a final form. Thus there were some questions as to whether it had true subscales or not, and whether the wording of some of the coping behaviors was clear. The Culture Free Self Esteem Inventory was more developed but the researcher felt that some of the instructions and the wording of some of the questions were at odds with each other. In addition, there is a "lie" subscale that is not explained thoroughly in the instructions available to the researcher. Additional research will be needed to enhance the measurement of attitudes, behaviors and coping skills in caregivers. Instruments for use in nonclinical adult populations need to be developed for general use.

In another light, future researchers on caregivers to PWAs should be aware of the impact this type of research has on the researcher. There are many inherent problems associated with studying a stigmatized and invisible population. It is difficult to obtain funding for research on this disease, whether or not it is being conducted for a dissertation or through an AIDS service organization. When the researcher contacted the Centers for Disease Control in Atlanta, Georgia (CDC), no funding source was given for psychosocial research on AIDS. All funds for research are channeled into medical prevention, treatment, and education. General support funding for the project such as computer time and interlibrary access was provided by the University of North Carolina at Greensboro in general accordance with the assistance of a doctoral student's dissertation. Funding to assist with the costs of transportation, audio equipment, and transcription was eventually provided by private local citizens. In short, the researcher was basically alone in much of the financial responsibility for the project. Larger studies of this population would be even more costly. This might be prohibitive in light of the lack of funding for AIDS caregiver research.

The psychosocial effect of the research on the researcher must also be taken into account. This researcher has worked with at-risk populations for over 15 years in a clinical setting, yet the multiple tragedies associated with the disease took a toll on the amount of interviewing that could be accomplished. It is not recommended that researchers who cannot deal with the topic of death and dying undertake research in this field. In addition, professionals familiar with this topic should be advised that there are increased risks to the researcher with this area of research.

Further, it is believed that interviewers with few clinical skills and little experience would not have been able to elicit the wealth of responses from participants that a more mature researcher could accomplish. It is not recommended that researchers recruit interviewers with few clinical skills or experience. Indeed, training requirements for participation in a project such as this may almost be prohibitive in light of the potential for emotional disturbance of the interviewer and interviewees.

Finally, in light of the stigmatization of this almost invisible group, entrance into the population is very difficult. Future researchers must be able to establish their sincerity and awareness of multiple issues of confidentiality. Not only does the researcher need to guarantee the usual measures of participant protection, but it is recommended that they consider possible harm to the caregiver-PWA dyad when recruiting and obtaining informed consent from participants. Thus a multiple level informed consent process is needed. This may have the benefit of helping to insure the participation of more caregivers when the cooperation of the PWA is obtained, since it recognizes the need for preserving the precious resources of the PWA. Generally when these consent precautions are taken, PWAs and caregivers are enthusiastic in their support of the research and participation is high.

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APPENDIX A

OPEN-ENDED QUESTIONNAIRE AND DEMOGRAPHIC INFORMATION SHEET

Open-ended Questionnaire

After all standardized inventories were administered, the following oral questionnaire was administered and tape recorded.

A. Caregiver attitudes:

1. How did you come to decide that you would help the PWA?
2. What worries, if any, do you have about the health of the PWA?
3. How well do you and the PWA get along?
4. How do you feel about being a caregiver to someone with AIDS?
5. What do you think other people would say to your being a caregiver to a PWA?
6. Tell me about what has brought you to be a caregiver?
7. Have you told anyone (who doesn't know the PWA) that you are giving care to someone with AIDS? Who did you tell? What did you think they would say? What was their reaction?

B. Caregiver behaviors:

8. Were any special arrangements made to become a caregiver? Did you change employment in any way? Did you and the PWA move closer to each other?

9. What are the duties and behaviors of the caregiver to the PWA? Is the PWA disabled in any way (see Katz ADL)? How many caregivers are there?
10. What do you think other caregivers do for their care recipients?
11. How do you feel about your duties as a caregiver. Is this what you expected it would be?
12. What do you believe your PWA wants you to do? Are the PWA's expectations of you different from your own?

C. Coping skills:

13. How are you adjusting to the terminal nature of the PWA's disease?
14. How are you coping with your caregiving status?
15. What do you think is expected of you with regard to coping?
16. What do you think other people might say to how you are coping?
17. How did you think you would cope with caregiving prior to becoming a caregiver?
18. What do you think will happen to your coping skills as the PWA gets more seriously ill?
19. When did you learn your coping skills? Is this something you were taught to do in the past?

Demographic data. The brief demographic information sheet included the following:

Demographic Data

1. Participant code #.
2. Date of interview.
3. Time of interview.
4. Age of participant (date of birth).
5. Educational level.
6. Employment.
7. Income level.
8. Marital Status.
9. Physical health--on a scale of 1 (low) to 10 (high).

APPENDIX B

KATZ INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

The Index of Independence in Activities of Daily Living is based on an evaluation of the functional independence or dependence of patients in bathing, dressing, going to the toilet, transferring, continence, and feeding. Specific definitions of functional independence and dependence appear below the index.

A. Independent in feeding, continence, transferring, going to the toilet, dressing, and bathing.

B. Independent in all but one of these functions.

C. Independent in all but bathing and one additional function.

D. Independent in all but bathing, dressing, and one additional function.

E. Independent in all but bathing, dressing, going to the toilet, and one additional function.

F. Independent in all but bathing, dressing, going to the toilet, transferring, and one additional function.

G. Dependent in all six functions.

Other Dependent in at least two functions, but not classifiable as C, D, E, or F.

Independent means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he is deemed able.

BATHING (Sponge, shower, or tub)

Independent: assistance only in bathing a single part (as back or disabled extremity) or bathes self completely.

Dependent: assistance in bathing more than one part of body; assistance in getting in or out of tub or does not bathe self.

DRESSING

Independent: gets clothes from closets and drawers; puts on clothes, outer garments, braces; manages fasteners; act of tying shoes is excluded.

Dependent: does not dress self or remains partly undressed.

GOING TO TOILET

Independent: gets to toilet; gets on and off toilet, arranges clothes, cleans organs of excretion; (may manage own bedpan used at night only and may or may not be using mechanical supports).

Dependent: uses bedpan or commode or receives assistance in getting to and using toilet.

TRANSFER

Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports).

Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers.

CONTINENCE

Independent: urination and defecation entirely self-controlled.

Dependent: partial or total incontinence in urination or defecation, partial or total control by enemas, catheters, or regulated use of urinals and/or bedpans.

FEEDING

Independent: gets food from plate or its equivalent into mouth; (precutting of meat and preparation of food, as buttering bread, are excluded from evaluation.

Dependent: assistance in act of feeding (see above); does not eat at all or parenteral feeding.

Source: S. Katz, A. B. Ford, R. W. Moskowitz, B. A. Jackson, and M. W. Jaffee, "Studies of Illness in the Aged. The Index of ADL: A Standardized Measure of Biological and Psychosocial Function," Journal of the American Medical Association, 185 (1963): 94ff.

APPENDIX E

CODEBOOK

Question 1. How did you come to decide that you would help the PWA?

I-1 Friend is HIV+ or PWA.

I-2G Needed to deal with emotions regarding AIDS.

I-2A Needed to deal with anger regarding AIDS.

I-3 Wanted to do volunteer work.

I-4L Long time decision.

I-4S Short time decision.

I-BA Buddy assignment.

Question 2. What worries, if any, do you have about the health of the PWA?

II-DHG Decreased health, in general.

II-DHS Decreased health, soon.

II-DHL Decreased health, longtime.

II-WTI Worried due to terminal nature of the illness.

II-WP Worried about the pain the PWA might go through.

II-WA Worried about AIDS phobia and how it will affect the PWA/PWA's health.

II-PDM Felt PWA could do more on his/her own.

II-LW Losing weight.

II-NHA Non-handicapped access housing will/does make it difficult for the PWA to get out to appointments, etc.

II-NM PWA lacks financial resources, no money.

II-VN PWA is very needy in many areas.

II-A PWA is very physically active and might get injured.

Question 3. How well do you and the PWA get along?

III-VW Very well.

III-W Well, pretty well.

III-OK Okay, good enough.

III-NW Not well.

III-P Poorly.

4. How do you feel about being a caregiver to someone with AIDS?

IV-W Want to do it.

IV-H Hard to do.

IV-NA Not afraid.

IV-U Used to be afraid of AIDS, now know more about it.

IV-T Was afraid I wouldn't have the time.

IV-RC Was afraid racial/cultural differences might be a problem.

5. What do you think other people would say to your being a caregiver to a PWA?

V-H Hesitant in general to tell others.

V-AP Others might express AIDS phobia.

V-C Others might fear contagion.

V-DC Doesn't care, hasn't really thought about what others might say.

V-N Others might be generally negative.

V-P Others might be generally positive, or not really care.

V-HP Might express homophobia.

V-O Others might be interested in knowing more about AIDS/caregiving.

V-W Others might want to know why I was doing it.

V-T Others might be worried about the time consideration, they would have less time with me.

6. Tell me about what has brought you to be a caregiver.

VI-M Wanted to meet other people.

VI-PP People person, with people skills, this seemed a logical choice.

VI-CI To get involved in the community (Gay).

VI-F Friend had/has AIDS, doing it for him/her (is the caregiver).

VI-FH Person I know (Friend) has AIDS, doing it to honor him/her.

VI-R Relative has/had AIDS, did it to take care of him/her.

VI-RH Relative has/had AIDS, did it to honor him/her.

VI-W Was working in medical community and got to know PWAs.

VI-C Compassion, a general feeling of having to do something about this terrible disease.

7. Have you told anyone (who doesn't know the PWA) that you are giving care to someone with AIDS? Who did you tell? (B4VII) What did you think they would say? (AVII) What was their reaction?

VII-Yes Yes, in general, told others.

VII-No No, have not told anyone else.

VII-N Have told neighbors.

VII-CW Have told coworkers.

VII-R Have told relatives.

VII-F Have told friends.

VII-MP Have told medical personnel (own personal).

VII-C Have told personal clergy.

VII-L Have lectured on the subject, or told of experience to group.

B4VII-NS Not sure what they would say.

B4VII-Q They questioned why I would get involved with that particular disease/group.

B4VII-AR They were fearful that I would be at risk for AIDS.

B4VII-TC They were afraid it would take all of my time, or some of my time away from them.

B4VII-AP Was afraid they would express AIDS phobia.

B4VII-DC Didn't care what others might say.

AVII-PO A generally positive or neutral reaction.

AVII-N A generally negative reaction.

AVII-NC Thought it was a nice thing to do.

AVII-GV Thought it was a good idea to volunteer.

AVII-I Thought it was an interesting thing to do.

8. Were any special arrangements made to become a caregiver? Did you change employment in any way? Did you and the PWA move closer to each other?

VIII-BT Buddy training with THP

VIII-HT Hospice training with Hospice of the Piedmont or other such group.

VIII-MIW The PWA moved in with the Buddy, temporarily.

VIII-LT The PWA moved in with the buddy, permanently.

VIII-MC The buddy moved closer to the PWA.

VIII-PC The PWA moved closer to the buddy.

VIII-EC The buddy changed or didn't consider another type of employment due to the caregiving status.

VIII-BOL Buddy has offered to let a friend or relative live with him/her.

9. What are the duties and behaviors of the caregiver to the PWA? Is the PWA disabled in any way (see Katz ADL)? How many caregivers are there?

IX-T Transportation in general.

IX-TD Transportation to doctors' appointments.

IX-TE Transportation on errands.

IX-TF Transportation for food shopping.

IX-TC Transportation for clothes shopping.

IX-V Buddy visits (socially) the PWA.

IX-L Buddy listens to PWA, serves as sounding board.

IX-ES Buddy gives PWA emotional support.

IX-M Buddy occasionally gives PWA money.

IX-BF Buddy occasionally buys food for the PWA.

IX-SO Buddy takes PWA on social outings.

IX-F Feeds the PWA.

IX-B Bathes the PWA.

IX-C Cleans house/apartment for the PWA.

IX-RC Is respite care for the primary caregiver.

IX-PS Is physical support (combination of feeding, bathing, cleaning, etc.).

IX-P Answers the telephone for the PWA.

IX-RX Administers medicine for the PWA.

IX-D Dresses the PWA.

IX-BR Helps PWA get to bathroom

Record Katz ADL according to numerical value given.

Record number of caregivers according to numerical value given.

Record number of hours per week that Buddy gives care to PWA.

Record number of weeks/years Buddy has been giving care/gave care in weeks only, as given.

10. What do you think other caregivers do for their care recipients?

X-S Sit with, while PWA is in bed, or very frail.

X-TK Talk with PWA.

X-CH Clean house for PWA.

X-CM Cook meals for the PWA.

X-TR Transportation of PWA.

X-O Other things, not specified.

X-SH Go shopping for PWA.

X-RE Run errands for PWA.

X-C Clean house for PWA.

X-B Help bathe PWA.

X-RC Respite care for primary caregiver.

X-L Locomotion, helps PWA get up and around.

X-Rx Helps PWA with medications.

X-BR Helps PWA to get to the bathroom.

X-HF Helps PWA have fun.

X-CF Buddy is close friend with PWA, give emotional support.

X-SAL Expected to solve all problems.

11. How do you feel about your duties as a caregiver? (EXI)Is this what you expected? ((RXI) What is the reality?)

XI-TM Need more time, or to improve time management. This is indicated when the buddy feels that there isn't enough time to do what is needed for the PWA.

XI-TS Buddy needs more time for self, the job is too intrusive on personal life, or buddy work takes too much time.

XI-BPC There is a buddy versus a primary caregiver issue. This is indicated when the buddy did not sign up to be primary caregiver but has turned into the PC.

XI-PD The buddy feels the need to keep a personal distance.

XI-AOD The buddy wants the PWA to avoid overdependence.

XI-OK The buddy feels okay about what he/she does.

XI-N The buddy does not feel good about the duties.

XI-M Buddy feels manipulated by PWA.

XI-CGC There is conflict among other caregivers and buddy is in middle.

EXI-NE This is not what the buddy expected.

EXI-S Buddy expected PWA to be more seriously ill/sicker.

EXI-C Expected a PWA more culturally like self (this PWA is from a different culture than the buddy).

EXI-M Expected a PWA more mentally or intellectually like self (this PWA is different intellectually than the buddy, but not necessarily less intelligent than buddy).

EXI-ES Expected the PWA to need more emotional support.

EXI-WE This is pretty much what was expected.

RXI-SW The buddy is more like a social worker (problem solver) to the PWA than what was expected.

RXI-TC More time consuming than had first thought it would be.

12. What do you believe your PWA wants you to do? (PEXII) Are the PWA's expectations of you different form your own? (Caregiver expectations=CGEXII)

XII-ES PWA wants emotional support.

XII-H PWA wants help, generally.

XII-TK PWA wants someone to talk to.

XII-L PWA wants someone to listen to him/her.

XII-F PWA wants someone like a friend.

XII-T PWA wants transportation.

XII-HT PWA wants help with finding transportation.

XII-HE PWA wants emergency help.

XII-TI PWA wants telephone intervention--liaison with SS agencies, and medical personnel, etc.

XII-HUO PWA wants help in understanding others--social support and liaison.

XII-ER PWA wants help with errands.

XII-BU PWA wants backup help, in case he can't do something that he usually has no trouble with.

XII-MT PWA wants more time from buddy.

PEXII-L PWA expects less of buddy.

PEXII-M PWA expects more of buddy.

PEXII-S PWA expects the same of the buddy.

CGEXII-SP CG expects to solve all the PWA's problems.

13. How are you adjusting to the terminal nature of the PWA's disease?

XIII-NI This is not an issue for the CG.

XIII-NS The PWA is not sick enough yet to notice the illness.

XIII-I The CG is generally ignoring this issue (denial).

XIII-PI The CG is ignoring this issue because the PWA is ignoring it.

XIII-NT The CG and PWA haven't talked much about death.

XIII-D Difficult for buddy to think about.

14. How are you coping with your caregiving status?

XIV-T This is troublesome, a pain in the neck.

XIV-N This is sometimes a nice experience.

XIV-P The CG calls on reserves of patience.

XIV-TCB The CG takes care of own needs (avoids boredom waiting at doctors' offices, etc.) by planning ahead.

XIV-AT/XT The CG takes care of own needs by anticipating the amount of time spent on errands, etc, and planning extra time so as not to be in a hurry. The CG takes care of own needs by planning on spending extra time with the buddy, thus avoiding a pinch on his/her time.

XIV-TS Treats self to something nice, like a little trip or buys something nice.

XIV-DTM Trying not to do too much.

XIV-GO Grieving openly.

XIV-OE Overeating (decompensating).

XIV-TA Caregiver talks to others about the experience.

XIV-F Religious faith has been helpful.

XIV-YW Yardwork has been helpful.

XIV-S Solitude, alone time is helpful.

XIV-MW Getting involved in more work, either with PWA or other work in general.

15. What do you think is expected of you with regard to coping?

XV-C We are expected to complain when we need to.

XV-S We are expected to keep silent about caregiving burden, be stoic.

XV-DK Don't really know what is expected.

XV-D Expected to be depressed, sad.

Who expects coping?

WXV-THP THP expects us to cope with just about every aspect of being a buddy.

What is expected of you with regard to coping?

XVW-CB We are expected to continue being a buddy.

XVW-NDO We are expected to not drop out from being a buddy.

XVW-H We are expected to help the PWA.

XVW-C We are expected to communicate with THP, etc.

XVW-DK Don't know what is expected.

16. What do you think other people might say to how you are coping?

XVI-CHS Others would criticize me as too hard on myself.

XVI-TK Others would expect me to talk about my experience.

XVI-OKC Others would say I am doing okay under the circumstances.

XVI-TH They might want me to think about what I am doing, etc., what is happening to the PWA, and how I feel about it.

XVI-CW Coping well.

XVI-DK Don't know what others might say.

17. How did you think you would cope with caregiving prior to becoming a caregiver?

XVII-NS Not sure could cope.

XVII-AMP Was afraid of meeting the PWA.

XVII-TC Was afraid it would be too time consuming.

XVII-WA Went ahead because wanted to do it even though had some reservations that I could be a successful caregiver.

XVII-SS Spiritual strength.

XVII-B Thought I'd be better at it than I am.

18. What do you think will happen to your coping skills as the PWA gets more seriously ill?

XVIII-MTPS Will need more personal time for self.

XVIII-MTPP Will need more personal time with PWA.

XVIII-TKG Will need to talk more, generally.

XVIII-TKO Will need to talk more, generally with others.

XVIII-TKT Will need to talk more with a psychotherapist/counselor.

XVIII-CG Will need to talk more with another caregiver.

XVIII-TAF Will need to talk more about feelings.

XVIII-TAE Will need to talk more about the experience.

XVIII-TAP Will need to talk more with the PWA.

XVIII-AB An additional buddy will need to be assigned.

XVIII-CGF Caregiver expresses general fear about the prospects.

XVIII-OF Caregiver expresses general concern about other people's fears of the PWA (AIDS phobia).

XVIII-OS Caregiver expresses concern about not enough support from other people in the PWA's life.

XVIII-POR Poorer other relationships.

XVIII-CD Coping decreased.

XVIII-LTS Less time for self.

XVIII-A Got angry.

XVIII-DM Doing more for PWA.

XVIII-WC Will cry, get more emotional.

XVIII-GB Will get busy, get a more intense schedule either with PWA or others.

19. When did you learn your coping skills? Is this something you were taught to do in the past?

XIX-NI No idea where learned them.

XIX-D Deal with the issue on a daily basis.

XIX-P Parents/family set good example.

XIX-T Took training in coping.

XIX-VW Did volunteer work over the years and learned to cope then.

XIX-PT Psychotherapy has taught me how.

XIX-LE Life experiences have been educational.

20. Anything else?

Code as applies. You may refer some of these ideas back to the 19 questions above in order to fill in blanks in information.

XX-C Communication between PWA and buddy is difficult.

XX-CP Communication between PWA and buddy is difficult due to the difference in pronunciation of words between the two.

XX-CG Communication between PWA and buddy is difficult because of differences in grammar usage.

XX-BL PWA's behavior is less polite than what the buddy expected.

XX-WDA Would do again.

XX-LE It has been a learning experience.

XX-GE It has been a good experience.

XX-BO Buddy is burned out, questioning whether to continue or not.

XX-SL Buddy needs to learn to set limits.

APPENDIX F

HELPFUL COPING INVENTORY CATEGORIES

The following list is of the 33 Coping Inventory categories in order of their reported use in the "does apply and helpful" choice.

Category	Count	% Responses	% Cases
1. I tried to think through the meaning of the event for my life at present.	21	6.0	70.0
2. I tried to experience all of my feelings and work them through.	19	5.4	63.3
3. I welcomed some time alone to think about what happened.	18	5.1	60.0
4. I tried to talk about the event with others.	17	4.9	56.7
5. I tried to develop an attitude toward the event which would help me to deal with it.	17	4.9	56.7
6. I sought increased emotional support from others.	16	4.6	53.3
7. I tried to clarify the choices I have in adjusting my present life to the effects of the event.	15	4.3	50.0
8. I tried to revise my expectations of the future.	14	4.0	46.7
9. I spent more time in nature, listening to music, with art or writing.	14	4.0	46.7
10. I tried to be more useful to others.	14	4.0	46.7
11. I tried to concentrate on other things in my life.	13	3.7	43.3
12. I tried to work out how the event related to things in my past.	13	3.7	43.3

13. I tried to figure out why the event made me feel the way it did.	13	3.7	43.3
14. I tried not to withdraw from other people.	12	3.4	40.0
15. I tried to look at my present situation as realistically as possible.	12	3.4	40.0
16. I tried to think about the good things that had happened in my life and weigh what had happened against them, for a better perspective.	11	3.1	36.7
17. I tried to find a funny element in the event or in life in general.	10	2.9	33.3
18. I tried to separate the rational from the irrational in my responses.	10	2.9	33.3
19. I sought consolation in religion and philosophy.	10	2.9	33.3
20. I tried to find some other outlets, like sports, cooking, or gardening, to relieve some of the feelings I had.	10	2.9	33.3
21. I thought about events in my past life which might help me to deal better with the present.	9	2.6	30.0
22. I tried to find people who had experienced the same kind of event to see how they dealt with it.	9	2.6	30.0
23. I tried to figure out what would happen in the future if I behaved in one way, and what would happen if I behaved another.	9	2.6	30.0
24. I tried to find new interests.	8	2.3	26.7
25. I tried to devote myself to work.	6	1.7	20.0
26. I tried not to be bothered by conflicting feelings in my reactions to the event.	6	1.7	20.0

27. I looked for a person who could provide direction for me.	6	1.7	20.0
28. I tried to separate the possible from the unlikely consequences that occurred to me.	5	1.4	16.7
29. I tried not to make any decisions about the future until I was sure I was seeing things more clearly.	4	1.1	13.3
30. I tried to remind myself that what happened could have been worse.	4	1.1	13.3
31. I tried to face my feelings sometimes, but put them out of my mind at other times.	3	.9	10.0
32. I tried to do things impulsively, that I might have thought about before, if they made me feel better and didn't bother anyone else.	2	.6	6.7
33. I tried to put the event out of my mind and just go on with my life.	0	0.0	0.0

APPENDIX G

COPING BEHAVIORS THAT WERE TRIED

Category	Count	% Responses	% Cases
1. I tried to separate the possible from the unlikely consequences that occurred to me.	18	4.8	58.1
2. I tried to experience feelings sometimes. but put them out of mind at others.	17	4.5	54.8
3. I tried to look at my present situation as realistically possible.	17	4.5	54.8
4. I tried not to be bothered by conflicting feelings in my reactions to the event.	16	4.2	51.6
5. I tried to think about the good things that had happened in my life and weigh what had happened against them, for a better perspective.	15	4.0	48.4
6. I tried to separate the rational from the irrational in my responses.	15	4.0	48.4
7. I tried not to withdraw from other people.	15	4.0	48.4
8. I tried to develop an attitude toward the event which would help me to deal with it.	14	3.7	45.2
9. I tried to concentrate on other things in my life.	13	3.4	41.9
10. I tried to devote myself to my work.	13	3.4	41.9
11. I tried not to make any decisions about the future until I was sure I was seeing things more clearly.	13	3.4	41.9

12. I worked to revise my expectations of the future.	12	3.2	38.7
13. I sought increased emotional support from others.	12	3.2	38.7
14. I tried to figure out why the event evoked the feelings it did.	12	3.2	38.7
15. I tried to find some other outlets, like sports, cooking, or gardening, to relieve some of the feelings I had.	12	3.2	38.7
16. I welcomed some time alone to think about what had happened.	11	2.9	35.5
17. I tried to clarify the choices I have in adjusting my present life to the effects of the event.	11	2.9	35.5
18. I thought about events in my past life which might help me to deal better with the present.	11	2.9	35.5
19. I tried to remind myself that what has happened could have been worse.	11	2.9	35.5
20. I tried to be more useful to others.	10	2.7	32.3
21. I tried to do things impulsively, that I might have thought about before, if they made me fell better and didn't bother anyone else.	10	2.7	32.3
22. I tried to talk about the event with others.	10	2.7	32.3
23. I tried to find a humorous or even tragi-comic element in the event or in life in general.	10	2.7	32.3
24. I tried to work out how the event related to things in my past.	9	2.4	29.0
25. I tried to find people who had experienced the same kind of event to see how they dealt with it.	9	2.4	29.0

26. I tried to figure out what would happen in the future if I behaved one way, and what would happen if I behaved another way.	9	2.4	29.0
27. I looked for a person who could provide direction for me.	8	2.1	25.8
28. I sought consolation in philosophy or religion.	8	2.1	25.8
29. I spent more time in nature, listening to music, with art or writing.	8	2.1	25.8
30. I tried to experience all my feelings and work them through.	8	2.1	25.8
31. I tried to think through the meanings of the event for my life at present.	7	1.9	22.6
32. I tried to put the event out of my mind and just go on with life.	7	1.9	22.6
33. I tried to find new interests.	6	1.6	19.3