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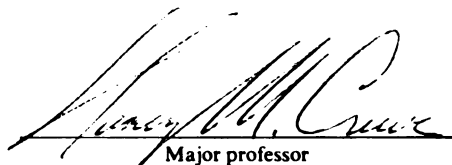


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PERSONAL, FAMILIAL, AND SOCIAL PREDICTORS
OF BURDEN IN HIV/AIDS INFORMAL CAREGIVERS
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Richard D. Hanson

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**PERSONAL, FAMILIAL, AND SOCIAL PREDICTORS
OF BURDEN IN HIV/AIDS INFORMAL CAREGIVERS**

By

Richard Hanson

A DISSERTATION

**Submitted to
Michigan State University
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PERSONAL, FAMILIAL, AND SOCIAL PREDICTORS OF BURDEN IN HIV/AIDS INFORMAL CAREGIVERS

By

Richard D. Hanson

Abstract

This study examined how personal, familial, and social variables contribute to the experience of burden for informal caregivers to persons with HIV/AIDS (PWA).

Utilizing AIDS clinics in the Kansas City area, the study targeted caregivers who were identified by PWAs as someone who is a primary source of support. The 38 participants included both traditional caregivers (parents, spouse, siblings) and nontraditional caregivers (long-time friends, partners). Using cross-sectional survey methodology, participants completed measures assessing sociodemographic variables, level of instrumental need expressed by the PWA, personal level of extroversion, family environment, fears associated with the potential loss of social support, and burden. The results suggest increased risk for burden is associated with the following: controlling family environments that emphasize following rules and set procedures; increased instrumental needs on the part of the person with HIV/AIDS; and a level of involvement characterized by providing about 50% of any caregiving needs. The results highlight the importance of working with caregivers in three areas: 1) managing their own needs as the instrumental demands of the PWA increase; 2) navigating family relationships regarding the opportunity to direct one's own coping process; and 3) accurately assessing the risks and benefits associated with social disclosure and the possible loss of social support.

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I would like to express my sincere appreciation to my wife Kim. Her support, encouragement, and motivation enabled me to persist in this long and sometimes consuming task. Thank you for sharing my dream, shouldering my burden, and most of all for believing in me when I was unsure I would ever see the end. Although my name is on the cover, it was truly a team effort in completing this dissertation.

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I deeply value the ongoing input, throughout this project, of my advisor, Dr. Nancy Crewe. This task has been one of the most frustrating that I have been involved with, either personally or professionally. The numerous setbacks and obstacles challenged my resolve and belief that this research project actually could be completed. You challenged me to keep going. You helped me step back, see the big picture, and redesign the data collection and analysis procedures when it was apparent that the previous plans were not going to be successful. Through the trials, challenges, and failures of this project, I have deepened my understanding of, and appreciation for, quality community-based research.

Thanks to the three other committee members, Dr. Fred Lopez, Dr. Marty Ewing, and Dr. Barbara Ames. From the beginning stages of this dissertation, as a research design course project, Dr. Lopez provided probing and insightful feedback. His knowledge of research design and statistical analysis issues were invaluable. A special

thanks to Drs. Ewing and Ames, who willingly joined the committee late in the process. I believe that some of the encountered obstacles could have been avoided or minimized if I had found Dr. Ames earlier in this process. Her knowledge and experience with this type of research were very helpful in drafting the final copy of this manuscript. When I invited Dr. Ewing to participate in this project, I knew she would provide a fair and critical reading. I was not disappointed. Thank you Marty for expanding my professional horizons and mentoring me in the beginning stages of my work as a consultant. I will always view you as a mentor.

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Chapter 1

Introduction

The crisis generated by acquired immune deficiency syndrome (AIDS) has been widely reported in both the popular and professional literature. Since being first diagnosed in the early 1980's, AIDS spread rapidly through our society. AIDS has affected many areas of society, including medical, social services, psychological, familial and interpersonal relationships. The financial and emotional costs to the infected individuals, their families, and society as a whole have been considerable.

The number of persons identified as being either HIV+ or having AIDS has greatly increased over the past decade. As of January, 1990, the CDC reported 121,645 cases of AIDS within the United States (Centers for Disease Control, 1990). Within five years that number had almost quadrupled. By June, 1995, the number of cases diagnosed with AIDS had increased to approximately 476,000 (Centers for Disease Control, 1995). The past several years have seen a decrease in the numbers of persons diagnosed with HIV/AIDS. By December, 1998, the total number of persons diagnosed with HIV/AIDS had decreased to 393,045 (Centers for Disease Control, 1998). It is estimated that nearly one million more people in the United States do not yet have AIDS, but are infected with the human immunodeficiency virus (HIV) that causes AIDS. As this disease has continued to spread, the number of persons directly and indirectly affected by the disease has continued to rise. Each person infected with the AIDS virus represents a family system and social network. This means that nearly 1.4

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million families in the United States are, or soon will be, personally affected by the AIDS pandemic.

Improved medical care and symptom control is allowing patients to live longer and spend more time out of the hospital. This raises issues of care for long-term survivors and their families, specifically, who will provide care and where. Trends in insurance cost containment have contributed to decreased reliance on fully trained medical professionals. With the large number of persons infected with the AIDS virus and the trend toward more home based care, it is clear that informal caregivers will play a more significant role in the fight against AIDS.

Initial research in the area of AIDS focused primarily on the medical and psychological needs of persons with AIDS (PWA) (Benjamin, 1990). A tremendous amount of energy was directed at understanding the illness, its causes, modes of transmission, and progression. The focus then broadened to explore the social and emotional ramifications of the disease on the person infected. Only within the past five to seven years have researchers begun exploring the effect of AIDS on spouses, partners, and families. What has emerged from the preliminary work on the families and caregivers of PWAs is a realization that this is a group of people who are experiencing considerable distress and whose coping abilities and resources are being greatly taxed.

This chapter will provide an overview of consequences of caring for a person with AIDS. Theoretical models will then be introduced, followed by a discussion of the variables contributing to caregiver distress. The significance and purpose of this study

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will then be explained and key variables defined. The chapter will conclude with a statement regarding this study's relevance to counseling psychology and a list of research questions.

Consequences of Caring For Someone With AIDS

Informal (nonprofessional) caregivers are frequently unprepared and untrained for the responsibilities they assume. They may be asked to monitor medications and symptoms, interact with medical and social services professionals, assume responsibilities for daily living tasks such as cleaning, shopping, and preparing nutritionally balanced meals, providing basic nursing and hygiene functions such as changing dressings, administering shots, diapering, and bathing. These demands are superimposed on their own issues of emotional adjustment to a loved ones' diagnosis of a terminal illness.

A consequence of assuming a caregiving role is the likelihood that one will experience physical, social, and emotional distress. Previous research indicates that regardless of care receiver characteristics, caregivers are likely to be confronted with anxiety, depression, anger, social isolation, physical fatigue, guilt, shame, feeling of helplessness, and increased objective and subjective burden (Frierson, Lippmann, & Johnson, 1987; Grief & Porembske, 1988; McDonnel, Abell, & Miller, 1991; Williams & Stafford, 1991). These consequences of caregiving affect not only the caregivers' quality of life, but also threatens their basic physiological, safety, social, and self-esteem needs (Braithwaite, 1992).

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In the literature, distress associated with the caregiving role has been referred to as caregiver stress, caregiving problems, and burden (Montgomery, Gonyea, & Hooyman, 1985). This study will focus on the concept of burden. Although relatively little research has been conducted on the experience of burden among AIDS caregivers, the general caregiving literature indicates that it is common and that it provides a useful index of caregiver well-being. A central element of burden is the perception of disruption in one's own life as a result of assuming a caregiving role (Folkman, Chesney, Cooke, Boccillari, & Collette, 1994). Differences in perception, as a result of how one appraises the situation and available resources, provides an explanation for how the same experiences result in differing levels of distress for caregivers.

Theoretical Models

This study draws on two theoretical models to understand the experience of distress associated with HIV/AIDS. The specific focus of this study is on the distress associated with the social disclosure process for HIV/AIDS caregivers. Stress and coping theory (Lazarus & Folkman, 1984) emphasizes the individual's appraisal of both the disruptions associated with caregiving and the available resources. This theory provides the overall conceptualization which underlies this study. Cognitive dissonance theory (Festinger, 1957) is utilized to further explain the distress associated with social disclosure.

Stress and Coping Theory

According to the stress and coping theory proposed by Lazarus and Folkman (1984), situations are experienced as stressful when they are perceived as taxing or

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exceeding one's resources. Stress is a complex psychological process consisting of three major elements: stressors, perceptions (appraisals), and emotional reactions/adaptational outcomes. Stressors are situations or circumstances that are characterized by some degree of physical or psychological threat. A situation is perceived as threatening when the individual appraises the situation as potentially dangerous. The appraisal process can be divided into primary and secondary processes. In primary appraisal, the individual assesses the threat to his or her well being. If a situation is perceived as relevant, or threatening, the secondary appraisal process is activated. During secondary appraisal, the individual assesses two things: the availability of resources, and the probability that the resources can be employed successfully. The result of this appraisal process dictates the resulting level of distress experienced by the individual (see Figure 1).

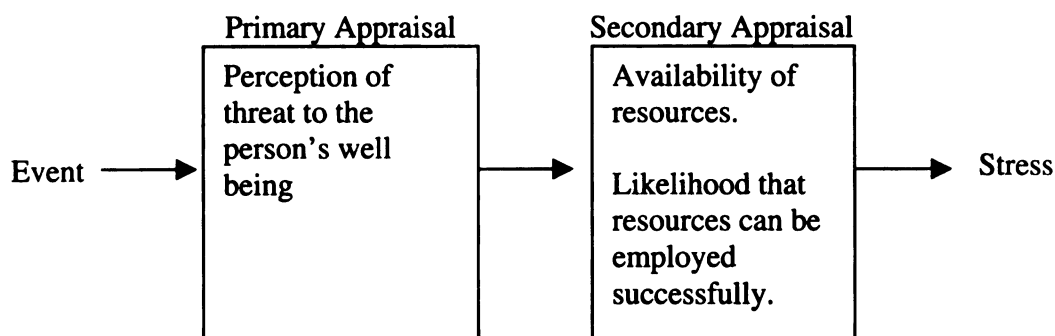
If the individual encounters a stressor, but does not appraise it as threatening, then there will be minimal emotional reaction, or distress. On the other hand, no matter how minimal the stressor, if it is appraised as potentially threatening and exceeding one's resources, then the individual will experience distress.

Lazarus and Folkman (1984) suggest that the more important something is to a person (level of commitment), the more stressful threats are to that area. For instance, failing to get into medical school will be perceived as much more threatening for a student whose central life ambition is to be a medical doctor, than for a student who is vacillating between several career options. Likewise, when aspects that are central to how one identifies him or herself (such as having social status) are threatened, the

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Figure 1

Stress Model: Primary and Secondary Appraisal



individual responds with greater physical and psychological vigilance. On the positive end, this can be interpreted as challenge. However, if the individual does not perceive that he or she can adequately deal with the threat, then the result is distress.

Cognitive dissonance theory

Distress associated with AIDS caregiving can be further conceptualized as arising, in part, from dissonance between conflicting beliefs or conflict between beliefs and behaviors. Cognitive dissonance theory (Festinger, 1957) suggests that when inconsistency exists between two theories, or between a belief and a behavior, a state of tension and discomfort is created which motivates the individual to resolve the discrepancy. Cognitions vary in the extent to which they are resistant to change. Cognitions, elements of knowledge, that are viewed as clearly based on “reality” are generally considered facts and are quite resistant to change (i.e., the grass is green). On

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the other end of this continuum are events and cognitions that are highly ambiguous (outcome of future events) and represent lower resistance to change.

Regarding decisions about publicly disclosing, caregivers may be caught between the desire to mobilize their own social support network (social disclosure) and fear of possible consequences (perceived risk). The desire to both disclose and not disclose creates a state of tension because one can not satisfy both options simultaneously.

Dissonance also may arise when there is a discrepancy between what a person believes and current behaviors. For caregivers, this may take the form of believing one should be open with others (family, friends, coworkers) but at the same time lying about the nature or status of the disease. It may also be expressed as a belief that one should not be ashamed of a loved one with AIDS, but publicly acting as if one were not an AIDS caregiver ("passing").

The resistance to change of AIDS related cognitions plays an important role in how individuals attempt to dissipate the cognitive tension. Early in the disease, before symptoms appear, it may be easier to deny the existence or importance of HIV/AIDS. Related social components, such as disclosure, may be less important because, by denying the existence of HIV/AIDS, the tension or dissonance is reduced. As the disease progresses and the "reality" of the disease can not be denied, the only way to reduce the dissonance is by addressing the cognitions associated with what will happen when others find out.

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Contributing Variables

Caregivers differ in the degree to which they experience distress. Some experience relatively little increased burden associated with their caregiving role while others report high levels. The anecdotal and clinical literature indicate that many things may be contributing to caregiver distress. Only recently have researchers begun systematically exploring these variables to establish their prevalence and influence. One aspect noticeably absent in the literature is distress associated with disclosure. Some of the variables associated with increased distress or burden can be considered environmental while others are more personological and familial.

Environmental Variables Associated with Caregiver Distress

In AIDS caregiving, social stigma and fear of contagion are important environmental sources of stress. Although AIDS shares many things in common with other terminal illnesses, there are several unique aspects that merit special consideration. AIDS carries a strong social stigma. This is true both for the persons infected and for those who care for them (Green, 1995; Perse, 1987; Powell-Cope & Brown, 1992). Because of its socially unacceptable modes of transmission, AIDS is frequently viewed as disgraceful and those infected as shameful. As a result of public attitudes toward AIDS, social support is often withdrawn if it is known that one has AIDS or is caring for someone with AIDS.

A second unique aspect of AIDS is the public fear of contagion. Since the beginning of the epidemic, the public has demonstrated both ignorance and fear about how the disease is spread. There has been a tendency both to overreact and to create

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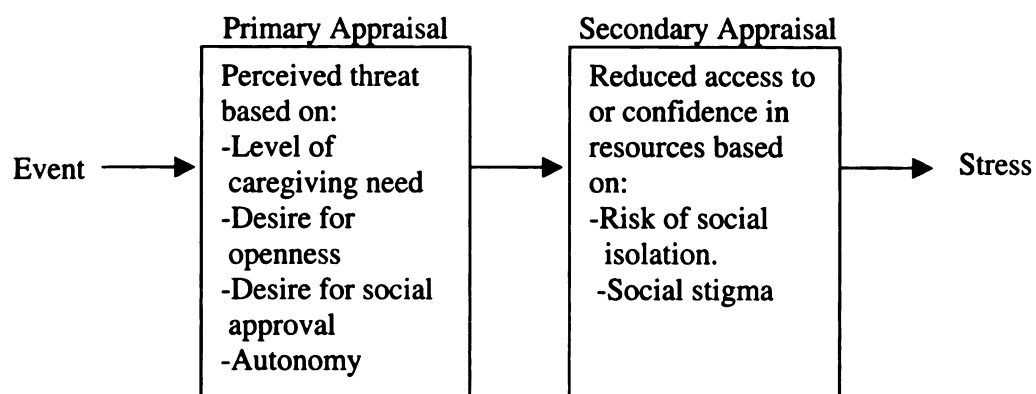
physical separation from the disease. Given the social stigma and fear of contagion, caregivers must carefully decide who and when to tell others about their caregiving.

In addition to the social factors influencing caregivers, previous research indicates that the needs and symptoms of the PWA also influence caregiver distress (Folkman et al., 1994; Pakenham, Dadds, & Terry, 1995). Both studies found a positive relationship between the instrumental needs of the PWA and caregiver burden. This indicates that the more instrumental concerns and health complaints a patient reported, the more likely his caregiver was to experience high levels of burden. Contrary to expectations however, Pakenham et al. (1995) found that patients' illness stage was not significantly related to caregivers' adjustment or burden. The results indicated that whether a person was caring for someone who was symptomatic or asymptomatic was not significantly related to the experience of burden. In attempting to reconcile these seemingly conflicting findings, the authors report that high levels of burden were present across all groups of caregivers and that the psychological aspect of caregiving may be more burdensome than the physical aspect. In this conceptualization, the instrumental and physical demands of caregiving may be an important contributor to burden during the later stages of the disease when instrumental needs are high. During the earlier stages, while instrumental needs are typically lighter, emotional and existential needs may be more pronounced. Over time, the emotional and existential adjustment issues may diminish in intensity and become increasingly replaced by instrumental demands.

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Figure 2

Stress Model with HIV/AIDS Variables



Within the stress model, social stigma and fears about contagion are viewed as possible barriers to adaptive coping by influencing the perception of risk in primary appraisal and the availability and accessibility of resources in secondary appraisal (see Figure 2). In primary appraisal, when the caregiver is assessing the risks associated with others knowing that he or she is associated with someone with HIV/AIDS, the issues of social stigma and possible social alienation may be very relevant and threatening. Regarding secondary appraisal, fears associated with contagion and social stigma sometimes cause social support systems to withdraw, thereby making it less accessible and the probability of utilizing it in a positive manner diminished. The uncertainty associated with predicting how others will actually respond increases the stressfulness of the situation.

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Personological Variables Associated with Caregiver Distress

The process of going public was explored through in-depth interviews with 53 AIDS caregivers (Powell-Cope & Brown, 1992). Participants reported that the disclosure process occurred over an extended period of time and was stressful. The process of going public included selecting appropriate people and audiences to tell, formulating approaches to communicating information, and considering the risks and benefits of the possible choices. Two themes emerged from the interviews: balancing secrecy with assertiveness, and balancing risks and benefits of going public. The qualitative research design limited the ability to explore relationships among the variables. Although caregivers reported the process as stressful, as of now the relationship between disclosure variables and a psychological construct such as burden has not been established.

A personal characteristic that may influence caregiver distress associated with going public is the preferred level of social openness. Some people prefer to be open (or "out") about their caregiving in all spheres of their life (Powell-Cope & Brown, 1992). They may be comfortable with family, friends, and co-workers knowing that they are involved in caring for someone with AIDS. They may speak publicly about AIDS and become politically active. Other caregivers may desire less openness, or want to restrict their disclosure to limited groups. For this study, the construct of social extroversion will be used to indicate the preferred level of openness and desire for social support.

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Another personal characteristic that may influence caregiver's level of distress is the importance placed on social approval. Caregivers who place a high value on maintaining social approval may be at increased risk for distress. Due to the social stigma associated with AIDS, many caregivers face rejection or isolation simply by their association with the disease.

Within the stress model, desires for openness and social approval are viewed as influencing primary appraisal. Building on Lazarus and Folkman's (1984) concept of commitment, the more important openness and/or social approval is, the more stress will be experienced when these are threatened. Given the presence of stigma and the possible social isolation, threat will be perceived as greater for those who place more emphasis on interacting openly with those around them. Caregivers who have higher levels of fear associated with losing social approval also would share this threat.

Familial Variables Associated with Caregiver Distress

On the family level, two characteristics appear relevant to caregiver distress and the process of seeking and accessing one's social support network: rules regarding communication and the degree of autonomy to make one's own decisions. First, Atkins and Amenta (1991) found that families of PWAs who were associated with an AIDS organization, compared with general hospice, had significantly more prohibitions against emotional expression. This reflected the degree of comfort within the family to openly discuss the current health related situation. Families caring for someone with AIDS were less comfortable discussing the illness and factors associated with it. Powell-Cope and Brown (1992) found that decisions about who and when to publicly

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disclose created considerable distress for both the PWA and the caregiver. In some situations the PWA was not ready to publicly disclose his/her status and therefore “mandated” that the caregiver not disclose either. In these cases the freedom for the caregiver to access his or her social support network is externally restricted. Although the caregiver can go against the PWAs wishes, this creates other sources of conflict. For instance, if the PWA held a public office, he may disclose his HIV status to his partner, but insist that the partner tell no one out of fear that public knowledge would ruin his reputation. In other cases the PWA was ready to disclose, but the caregiver was not yet prepared. In these situations, the caregivers reported feeling rushed into dealing with the illness on a social level before they were comfortable with it on a personal level. In both scenarios, the caregivers experience less control and decreased ability to direct their own coping process. For this study, the Family Environment Scale: Control and Independence, will be used to assess these variables. These subscales are not AIDS specific, but do reflect the general social climate of the relationship.

Purpose

The purpose of this study is to further the understanding of AIDS caregiving by specifically addressing issues associated with social disclosure and caregiver burden. The degree to which family caregivers are successful at managing the tasks associated with caregiving is related to their experience of burden. One of the primary ways many people attempt to cope is by accessing and drawing on their social support network. It is hypothesized that variables that increase social isolation and /or decrease the ability to access one’s own social support network in a self-directed way will increase the

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experience of burden among HIV/AIDS caregivers. This study examines the influence of personal, familial, and social variables on the experience of burden.

Key Variables

1. **Disclosure:** For this study disclosure refers to the process of going public with the information that one is acting as an AIDS caregiver. It is not limited simply to the act of informing others that one is an AIDS caregiver. Rather, it is conceptualized more broadly as the process of thinking about and making decisions about who should know, when and how they should be told, and by whom they should be informed. Letting others know about one's involvement with AIDS applies to a range of relationships from the most intimate to the most public. The types of information disclosed range from superficial generalities to details of the PWAs health status and personal reactions.
2. **Burden:** In general, burden refers to the distress or disruption resulting from caring for someone who is ill. It consists of two components: objective and subjective burden. Objective burden refers to the potentially observable caregiving related disruptions in family life, finances, relationships, and employment. Subjective burden involves caregiver feelings, attitudes and emotions, such as guilt, resentment, and overload associated with the caregiving experience.
3. **Caregivers:** For this study caregivers refers to individuals who are not medical or social service professionals, but who are directly involved in supporting the PWA. This may include parents, partners, or friends. The literature frequently refers to

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these individuals as "informal" caregivers. To be included in the caregiver group, the person needed to have personal contact with the PWA. This criterion was used to exclude family and friends whose only contact with the person is by telephone.

4. **Family unit.** For this study, a family includes the relationship between two partners, whether the same or opposite sex, and the relationship among members of a traditional nuclear family – parents and siblings. Although friends and extended family are included in this study, their responses to the family environment scales will be excluded in the analysis and discussion.
5. **Family environment.** Family environment refers to the social climate, or environment, of the family. The social climate of the family is its “personality” (Moos, 1989). Each family has a unique social climate. Like individuals, some families are friendlier than others; some are more competitive; and some are more restrictive and controlling.
6. **Extroversion:** Extroversion is one end of a personality trait continuum characterizing sociability and impulsivity. At the other end of the continuum is introversion. Extroverts are described as sociable, having many friends, needing to have people to talk to, and not liking to be by themselves. They also crave excitement, take chances, like change, and tend to be care-free. Feelings, for extroverts, are generally not kept under tight control (Eysenck & Eysenck, 1975).
7. **Demographic variables:** Previous research indicates that several personal characteristics may be significantly related to the experience of burden among

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caregivers. These include age, sex, relationship to the patient, living arrangements, employment status, income, and types of tasks provided.

Significance

There are several reasons this study needs to be done. First, caregivers represent a distressed population in need of social support and psychological intervention. The decision to assume a caregiving role brings with it the likelihood that one will experience emotional, social and physical consequences. If caregivers are to sustain their caregiving over an extended period of time, they must have access to, or develop appropriate resources. They may not necessarily require ongoing professional services or interventions, but clinical and social service providers must become aware of important issues and themes for AIDS caregivers.

Second, the larger context includes not only the caregivers but also the one who is currently ill or dying. Caregivers typically involve themselves because they care about the well-being of another, whether that person is their child, spouse, partner, or close friend. The needs of caregivers must be understood so that they can be helped to provide compassionate care for the loved one who is dying. The affect of the caregiver is important to the person receiving care. Because of the close relationship between caregiver and receiver, the well-being of the caregiver can have a significant influence on the well-being of the patient (Grief & Porembski, 1988). Pakenham, Dadds, and Terry (1995) found support for reciprocal determinism in their study of 34 Australian caregivers. Specifically, they found that patients' and caregivers' level of adjustment were positively correlated. Within this model the authors suggest that the PWA's illness

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influences the caregiver, and the caregiver's response in turn influences the PWA. In the broader scope of AIDS, the needs of caregivers are significant both for their own sake as well as for the person for whom they are caring.

Third, although burden has been established as a significant consequence of caregiving for both the general population and persons with AIDS, researchers are only beginning to systematically explore the variables that significantly contribute to the experience of burden for AIDS caregivers. Although our understanding of caregiver burden has increased significantly, many questions remain unanswered. To this point, studies exploring burden among AIDS caregivers have excluded important components unique to AIDS caregiving. None of the quantitative studies looking at burden in AIDS caregivers have included variables associated with publicly disclosing versus remaining secretive. Due to the social stigma and fear of contagion, decisions about publicly disclosing are significant.

Relevance to Counseling Psychology

Helping people adapt to change is a traditional area of interest to counseling psychologists. Counseling psychologists have also been interested in the role personal characteristics play in interpersonal relationships. In addition, counseling psychology has been interested in exploring ways to intervene in a preventive manner to maximize healthy adjustment. Within the past decade, counseling psychology has taken an active role in bringing to the forefront issues important to oppressed groups: racial and ethnic minorities, women, gay/lesbian, and people with disabilities. As the AIDS epidemic

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continues to grow, counseling psychologists will undoubtedly be called upon to play an important role in the lives of those directly affected by AIDS.

Research Questions

1. Do caregivers who prefer using social support as a means of coping experience higher levels of burden?
2. Are caregivers who perceive greater risk associated with disclosing more likely to experience increased burden?
3. Do caregivers who perceive higher levels of personal independence within their family experience lower levels of burden?

Hypotheses

By influencing decisions about accessing social support, it is anticipated that personal, familial, and social influences will be significantly related to the experience of burden.

1. There will be a positive relationship between extroversion and Burden.
2. There will be a positive relationship between family environments that exhibit high levels of control over family members and Burden.
3. There will be a negative relationship between family environments that encourage individual independence and Burden.
4. There will be a positive relationship between fear of negative evaluation and Burden.

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The primary focus of this study is to further clarify the role of personal, familial and social factors on the experience of burden among family members providing support for persons with HIV/AIDS. Although burden has been identified as a relevant variable for HIV/AIDS caregivers, only minimal investigation has extended beyond the role of demographic variables. This proposal attempts to clarify and extend this body of research.

Chapter 2

Literature Review

This review is divided into four main sections. The first section places AIDS in the context of chronic and terminal illnesses and highlights common themes for caregivers. The second section deals specifically with caring for persons with AIDS and reviews the current status of the literature, conceptualizations of AIDS progression, and the affect of AIDS on informal caregivers. The third section reviews the concept of burden as a consequence of caregiving and explores variables contributing to perceptions of burden. The fourth section explores aspects unique to AIDS that are hypothesized to contribute to perceptions of burden. These unique aspects include: social stigma, fear of contagion, emotional expression, and public disclosure.

Caring For Chronic and Terminally Ill Patients

Chronic illnesses have been defined as illnesses that cause anatomical or physiological changes and persist over time. They are characterized by alternating periods of stability and crisis, alterations in life style and need for care, low probability of improvement and either the possibility or the certainty to a decreased life span (Koch-Hattem, 1987). AIDS certainly meets these criteria. This section briefly highlights common themes in caregiving for the chronic and terminally ill.

One common theme among all terminal illness caregivers is grief. Grief is most commonly an ongoing, long-term process rather than a crisis that is simply mastered

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or resolved over a circumscribed period of time (Zisook & Shuchter, 1986). Over the past decade, research in the area of bereavement and grief indicate that the emotions and behaviors most related to poor coping several years into bereavement include feeling confused, crying, taking prescription tranquilizers, and wanting to die (Lund, Diamond, Caserta, Hohnson, Poulton, & Connelly, 1985).

Social isolation is another common experience for terminally ill persons and their significant others. In part, isolation is due to this culture's fear of death and the accompanying sense of contagion, and in part due to the inability of caregivers to exert the energy necessary to reach out to others (Sanders, 1983). As caregivers spend increasing amounts of time absorbed in caregiving, they have less time available to interact with others. The physical isolation experienced by many caregivers when friends withdraw is exacerbated by the accompanying emotional isolation.

Research indicates that emotional and physical consequences are a common result of caregiving. Emotionally, caregivers may experience depression, anger, anxiety, and mental exhaustion (Rabins, Mace, & Lucas, 1982). Physical consequences include chronic fatigue, exhaustion, and deterioration in personal health (Seitz, 1987).

Although sharing commonalties with other illnesses, each subgroup (Alzheimer's, frail elderly, stroke victims, mentally ill, AIDS) experiences some unique psychosocial stressors (Brown & Powell-Cope, 1991). AIDS is no exception. To better understand the effect of AIDS on caregivers and to design

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appropriate interventions, it is important to explore the variables that are important in the AIDS caregiving process.

Caring For Persons With AIDS

Status of AIDS Caregiving Literature

The trend toward increased community and home based care for HIV infected persons means that caregivers are likely to assume greater responsibility and their needs greater priority (Pakenham, Dadd, & Terry, 1995). At this point, there is limited knowledge of the affect of HIV on caregivers. Relatively few research studies have specifically addressed the issues of AIDS caregivers. The articles selected for this review address in some way the experience of caregiving or dynamics of the coping process for spouses, partners, or families of PWAs.

Quantitative studies that used instruments with established measures of reliability and validity are unfortunately rare in the AIDS caregiving literature. The majority of studies reported in the area of AIDS caregiving have been descriptive and employed an unstructured interview format with relatively few subjects.

Additionally, much of the information is presented by clinicians as experiential summaries with little or no quantitative data. As a result, it was necessary to include studies with varying degrees of rigor and control. There is a need in this line of inquiry to begin structuring research and systematically investigating the constructs of interest.

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Conceptualizations of AIDS Progression

From the time of infection, individuals are considered HIV+ and the virus is actively attacking their immune system. Since many people do not get tested or learn of their status immediately, the virus may go undetected for months or years. At some point however, individuals learn they are infected, and this brings about an intense period of adjustment (Nokes, 1991; Walker, 1991). If detection occurs fairly early in the disease's progression, it may be several years before they begin to experience any HIV related symptoms (Macklin, 1988). When symptoms do begin to occur, the criteria for the formal diagnosis of AIDS is usually not yet met. Criteria for the diagnosis of AIDS have been established by the CDC (1992) and include a CD4 (t-cell) count of less than 200/cubic mm, or the onset of any of a number of specific illnesses.

Using chronic illness models, HIV progression over time has been conceptualized as proceeding through early, middle and late stages. Nokes (1991) applied the chronic illness trajectory model developed by Corbin and Strauss (1988) to HIV/AIDS. The illness trajectory model was developed to help those involved in practice, teaching, and research better predict the course of the illness. This model identifies three stages of HIV infection: the early or acute phase, the middle or chronic phase, and the final or crisis phase. The acute phase generally lasts between six weeks and six months from the time individuals are infected with HIV+ until they develop antibodies against the virus. The chronic phase lasts years and is characterized by minimal but measurable pathologic changes. It begins following

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the acute phase and proceeds until the diagnosis of AIDS. The crisis phase begins with the formal diagnosis of AIDS and may last months or years before death occurs.

McDonell, Abell, and Miller, (1991) noted the applicability of Mailick's (1979) model which proposed focusing on caregiver coping at three phases of chronic illness progression: (1) onset or diagnosis (of HIV), (2) adaptation to long-term and debilitating effects of the illness, and (3) ending the illness through cure, remission, or death. This model may be considered more of a crisis point conceptualization of illness progression. It is intended to alert professional caregivers (therapists, social workers, nurses) to points at which families are likely to need additional support.

Both models indicate that PWAs and their caregivers are likely to experience distress associated with three aspects of the terminal illness: 1) the initial notification of infection status; 2) confronting deteriorating health which limits their ability to function at a previous level; and 3) the final stages when limitations are severe and death becomes imminent. The focus of this proposal will be on caregivers for PWAs that are in the chronic or crisis phases.

Families as AIDS caregivers

This section includes discussion of the consequences of AIDS on families and highlights the prominent issues of double disclosure and uncertainty. The effects of AIDS extend beyond those who are formally diagnosed with the illness. For each person with AIDS, numerous family members and close friends are touched by the disease. As a progressively debilitating disease, AIDS places severe demands on

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the infected individual's social network (Raveis & Siegel, 1989). Aranda-Naranjo (1993) indicates that all family members are affected either directly or indirectly. Those who are infected with HIV/AIDS experience physical deterioration and emotional upheaval. Family members are likely to experience varying degrees of emotional and social burden as they watch and support their loved one. These families must be regarded as high risk for emotional and psychological difficulties because of the likely feelings of shame, guilt, and possible alienation from neighbors, friends, and extended family (Maloney, 1988).

Those associated with a PWA, and on whom caregiving frequently falls, have typically been divided into three categories: biological family, lover/partner, and professionals. Perlin et al. (1988) describe these categories as either formal (professional) or informal (family and friends) caregivers. It is likely that all groups will be involved at some point in providing care for the patient. The primary responsibility will shift between formal and informal caregivers at various points in the illness.

Advances in medical care have made it possible for PWAs to live longer. With extended life expectancy comes the need to understand and address the issues of long term survivors. One issue revolves around where and how PWAs will receive treatment. With the medical advances and more effective symptom control, patients who might previously have been institutionalized or received long term hospital care are now allowed (or forced) to live at home (Koch-Hattem, 1987). Recent

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developments in insurance cost containment have also contributed to this trend.

Much of the responsibility for ongoing care thus falls on informal caregivers.

Families play an important role in the lives of PWAs. Due to the close connection between caregiver and patient, the well-being of the caregiver can have a major influence on the emotional and possibly physical well-being of the PWA (Grief & Porembski, 1988; Pakenham et al., 1995). Whether providing direct physical care or emotional support, informal caregivers have an important influence on the PWA.

Double disclosure

Many families are simultaneously confronted by the pronouncement that their loved one has a terminal illness, and informed for the first time that he is gay, bisexual, or an intravenous drug user. Raveis and Siegel (1990) refer to this as a double disclosure that increases both the number of stressors and their intensity, especially for spouses. The dilemma was articulated by one wife who stated: "At first I wanted to kill him, then I realized he was already dying" (Frierson et. al, 1987, p.66). In these situations, the caregivers often find themselves unable to express feelings of anger without also experiencing guilt.

Uncertainty

Brown and Powell-Cope (1991) indicate that a problem central to AIDS caregiving is dealing with uncertainty. The nature of the disease is such that it is very difficult to predict its course and plan for the future. Though caregivers expressed increasing confidence in their caregiving abilities and their ability to

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predict outcomes over time, the issue of uncertainty always remained. Additionally, the multiple crises associated with AIDS progression may contribute to the caregiver's sense of chaos, loss and vulnerability (Nichols, 1985). This combination of factors places heavy demands on the coping abilities and resources of caregivers.

The Affect of AIDS on Family Caregivers

In addition to meeting the needs of the person with AIDS, family members have many needs of their own. These can be grouped into three broad sources of stress: emotional, social, and personal.

Emotional Consequences

Emotionally, caregiving has been associated with increased reports of anger and guilt (Murphy & Perry, 1988; Rinella & Dubin, 1988; Tiblier, Walker & Rolland, 1989; Williams & Stafford, 1991; Frierson, Lippmann & Johnson, 1987); depression (Tiblier et al., 1989; Williams & Stafford, 1991); shame (Murphy & Perry, 1988; Williams and Stafford, 1991); helplessness (Frierson et al., 1987; Tiebler et al., 1989); a sense of being emotionally overwhelmed (Rinella & Dubin, 1988); loneliness, anxiety, and unpredictable mood swings (Williams & Stafford, 1991). Horowitz (1985) stated that the emotional burdens associated with caregiving are the most pervasive and difficult to manage. Though some individuals experience all of the emotional reactions mentioned, many experience different combinations at various points in the AIDS process.

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Grief is experienced both in terms of anticipating the eventual death of the PWA, as well as the actual loss of health, relationship, and well-being (Murphy & Perry, 1988). The grieving process frequently begins shortly after the diagnosis is disclosed and continues at different levels of intensity throughout the illness. Identification with the PWA is particularly powerful for gay partners as they have often been exposed to the same risk factors, and may experience both anticipatory grief and anxiety (Perlin et. al, 1989). As caregiving partners look into the future they see the possibility of their own fate. In addition, they may experience anxiety as they consider who, if anyone, will be there to provide the care for them that they now give to another.

Anger is another common reaction (Macklin, 1988). Spouses and partners may be angry that information was withheld from them and that they were put at risk without being informed. Parents' anger may be associated with a perception that their son or daughter made choices that are causing a premature death. Parents also experience anger with themselves for having done, or not done things that contributed to the behaviors that put their child at risk. This perception may also lead to feelings of guilt.

Depression and anxiety are common reactions to the diagnosis of HIV. It is easy to feel overwhelmed at the diagnosis, and to experience a sense of helplessness and hopelessness. This is compounded when social support withdraws or when attempts to reach out are met with rejection or scorn.

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Social Consequences

Socially, many families experience both isolation and stigmatization. Because AIDS initially struck the gay community, it became known as the "gay disease" (Geis, Fuller, & Rush, 1986). Thus, anyone diagnosed with AIDS was assumed to be gay. The gay lifestyle has been historically viewed in our society as unacceptable and those associated with it as disgraceful. The other predominant population of persons infected with the AIDS virus are intravenous drug users. This is also a stigmatized group, although possibly not to the same degree.

Based on clinical experience, Maloney (1988) suggests that many of the normal social support systems withdraw because of difficulty acknowledging and talking about sexual orientation and substance abuse. In addition, family members and caregivers frequently avoid their traditional support networks because of feelings of embarrassment and guilt (Perse, 1987). Rather than reach out and risk becoming identified with the AIDS population, some caregivers choose to keep their caregiving secret. Based on clinical experience, Aramda-Naranjo (1993) suggests that this adds an additional stressor as caregivers must always monitor what they say and to whom.

Personal Consequences

Personal sources of stress come from several areas. For those assuming a caregiving role, the emotional and physical demands are ever increasing. In addition, caregivers must balance multiple roles. They may serve as nurse, friend, lover, housekeeper, and liaison with family and doctors (Pearlin, Semple, & Turner,

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1989). Not only do roles with the PWA change, but frequently they conflict. For example, the caregiver may be in a position of trying to provide emotional support and understanding while simultaneously pushing the patient to maintain a rigorous medical regimen. In addition to the changing role with the PWA, caregivers frequently experience life strain associated with trying to continue other life roles in the areas of work, social activities, and family (Perlin et al., 1989).

In summarizing the consequences of caring for someone with AIDS, it is clear that the increasingly important role caregivers play in AIDS care comes with a cost. Due to the reciprocal nature of the relationship, it is important to help caregivers successfully adapt to the demands of caregiving so they in turn can better assist the person for whom they are caring. There are several obstacles, however, that need to be addressed, including the uncertain course of the illness, the need to adapt to new revelations about the person, and the emotional, social, and personal consequences of caregiving.

Burden

The consequences of caregiving have been referred to in the literature as caregiver stress, problems, and burden (Montgomery, Gonyea, & Hooyman, 1985). This study will focus on the concept of burden. Burden has been a key concept in family caregiving research over the past twenty years (Braithwaite, 1992). Most generally it refers to the consequences of providing care to another person. A precise and consistent definition of burden, however, is lacking. George and Gwyther (1986) defined it as: "the physical, psychological or emotional, social, and

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financial problems that can be experienced by family members caring for impaired older adults" (p.253). Others define burden as distress arising from dealing with the care receivers' physical dependence and mental incapacity (Poulshock & Deimling, 1984). Folkman et al.'s (1994) conception of burden centered around caregiving related disruptions. They defined burden as: "the extent to which the caregiver is bothered by caregiving related disruptions having to do with work, community activities, finances, or personal goals (p. 746)."

Other researchers proposed multidimensional conceptualizations of burden including objective and subjective components (Hoenig & Hamilton, 1966; Thompson & Doll, 1984; Montgomery et al. 1985; Reinhard, Gubman, Howowitz, & Minsky, 1994). From this perspective, burden incorporates two separate but related components, objective and subjective burden. The need to separate objective and subjective perceptions of caregiver burden was first proposed by Hoenig and Hamilton (1966). These ideas were explicated some time later by Thompson and Doll (1982). Although defined somewhat differently by different researchers, objective burden generally refers to events, happenings, and activities carried out by the caregiver which are associated with negative caregiving experience and are potentially observable. Subjective burden involves caregiver feelings, attitudes and emotions associated with the caregiving experience (Montgomery et al., 1985). It is important to distinguish between the two aspects of burden. Although related, subjective burden involves a personal component which may or may not be directly related to the caregiving activities. Differences have

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been reported in both the incidence and correlates of the two types of burden (Miller & Montgomery, 1990; Montgomery et al., 1985).

The relationship between burden and caregiving has received significant attention in the gerontological and mental illness literature, but minimal attention related to AIDS caregiving.

Variables Contributing To Burden

Caregiver Characteristics

The experience of burden may be influenced by characteristics of the caregiver, care receiver, types of tasks conducted, or social environment. Caregivers vary along several dimensions that have been found to influence their experience of burden. Research on caregivers for the elderly and mentally ill indicates that caregiver age, sex, employment status, family income, relationship to one receiving caregiving (i.e., mother, partner), living arrangements, types of tasks provided, availability of social support, and perceptions of control were all related to perceptions of burden (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994; Drinka, Smith, & Drinka, 1987; Lutzky & Knight, 1994; Miller & Montgomery, 1990; Montgomery et al., 1985; Pratt, Schmall, Wright, & Cleveland, 1985). When age differences have been found, they generally indicate that higher levels of burden or strain are associated with being a younger caregiver. Women, who most commonly assume caregiving roles, are more likely than men to experience higher levels of burden. Although the findings are mixed, those who must balance a full-time job with primary caregiving are more likely to experience burden. Families

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with lower levels of income, and therefore fewer resources, are also more likely to experience burden. Caregivers who are in good health are less likely to experience burden. Parents, spouses, and daughters are all more likely than sons to experience burden, primarily because sons tend to be less involved in caregiving responsibilities. Unfortunately, a consistent pattern of results across studies is lacking. The above mentioned variables are commonly, but not always significantly, related to burden.

Carerecipient Characteristics

Characteristics of the care receiver also have been associated with perceptions of burden. Specifically, the type of illness, attitudes, and types of troublesome behaviors are related to burden. For instance, public embarrassment, being kept up all night, and dealing with suicidality were all found to increase perceptions of burden when caring for someone who is mentally ill (Jones, Roth, & Jones, 1995). With Alzheimer's patients, asocial and disoriented behavior were associated with perceptions of burden (Talkington-Boyer & Snyder, 1994).

Social Support

Types and amount of social support have been an important influence on burden. When more than one person shares responsibility for caregiving, perceptions of burden are generally lower (Montgomery et al., 1985; Reinhard et al., 1994). Caregivers who were involved with support groups also reported lower levels of burden. The examination of social support in the two referenced studies did not include any control or manipulation of social support. Rather it examined

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differences between previously intact groups. It is premature therefore to say whether observed differences represent the affect of social support (shared responsibility or support group) or of the individuals who tend to share responsibilities or attend support groups.

Variables Contributing to Burden for AIDS Caregivers

Although several authors have discussed the stressors and consequences associated with AIDS caregiving, only two articles could be located which explored the correlates of caregiving burden. These studies revealed that some of the variables in AIDS caregiving are similar to those in other types of caregiving, while others were not. Specifically, Folkman et al. (1994) found that income, ethnicity, and perceived social support were significantly correlated with burden. Age, education, and employment status, however, were not significantly related. In a study of 34 Australian caregivers, living arrangements and instrumental needs of care receiver were significantly correlated with caregiver burden, but duration of caring, age, sex, and education level of the caregiver were not significantly related to burden (Pakenham, Dadds, & Terry, 1995). To gain a clearer understanding of the variables associated with AIDS caregiving it is important to continue exploring the relationship between caregiver characteristics and burden.

Unique aspects of AIDS

Although AIDS caregiving shares many things in common with caring for other populations, there are some factors that set AIDS apart and merit special

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consideration. Specifically, important variables include the social stigma associated with AIDS, the fear of contagion, and rules regarding emotional expression. These variables have been reported in the anecdotal literature, but the specific relationship to burden has not been explored. These three aspects would appear to combine to increase the stress associated with going public, or disclosing that one is acting as an AIDS caregiver. Of particular interest for this proposal is the experience of publicly disclosing that one is acting as an AIDS caregiver.

Social stigma

Unlike most other terminal illnesses, AIDS carries with it a strong social stigma. Based on interviews and clinical experience, several authors have noted that this decreases the likelihood of social support (Frierson et al., 1987; Geis, Fuller, & Rush, 1986; Maloney, 1988; Williams & Stafford, 1991). Diminished social support can be a problem for both the caregiver as well as the PWA. Although AIDS is not exclusively a gay or IV drug user disease, these are the largest populations affected by AIDS (CDC, 1998). As a result of the negative social stigma associated with these lifestyles, many choose to keep their lifestyle secret. Perse (1987) noted that caregivers of people with AIDS risk a "spoiled identity" by association, and that the potential for discrimination and rejection combines with other burdens of caregiving. She also noted that the fear of stigmatization might reduce the likelihood that caregivers will discuss with others the fact that they are caring for a friend or relative with AIDS. Powell-Cope and Brown (1992) in a study of 53 caregivers, noted a similar phenomenon they referred to as guilt by

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association. Persons with AIDS were stigmatized because they had the disease, caregivers were "tainted" because they associated with someone with AIDS.

Fear of Contagion

Since its emergence as a public health concern in 1981, AIDS has been associated with tremendous social fears of contagion. As a communicable disease, AIDS adds an element of risk not present when providing care to persons with other chronic illnesses (Wardlaw, 1994). Family members are likely to experience the same fears regarding contagion as other people, and such fears may be present even when relatives know rationally that there is no basis for concern (Maklin, 1988). Raveis and Siegel (1990) reported that of 47 individuals caring for gay men, 60% were somewhat worried they might get AIDS, and 16% were very worried. Associated with their fear of contagion, relatives frequently develop obsessive concerns with cleanliness (Frierson et al., 1987). Additionally, based on interviews with 53 family caregivers, some reported rejection or isolation due to public fear that the caregiver might also be infected and thus a threat (Powell-Cope & Brown, 1992).

Restricted Emotional Expression

Social support frequently includes the opportunity to talk about the experience of caregiving with others. In a comparison of 26 AIDS caregivers who were associated with an AIDS organization and 26 families of hospice patients, Atkins and Amenta (1991) found that families of PWAs had significantly fewer people in their social networks and significantly more rules prohibiting emotional expression. Koch-Hattem (1987) notes that as prohibitions against emotional expression

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increase, effective adaptation decreases. No studies were found that explored the effect of prohibitions against emotional expression. The relationship between limited emotional expression and burden is an area that needs further exploration.

Social Disclosure

Due to the fears about contagion and the social stigma associated with the disease, secrecy has frequently been noted in the anecdotal literature as a protective stance against rejection and discrimination. Unfortunately secrecy also diminishes opportunities to gain social support.

In qualitative interviews, Powell-Cope and Brown (1992) found that decisions about going public created considerable distress. The authors noted that in a society which values individualism, the right to privacy, self-reliance, secrecy, and deception are all considered acceptable strategies to protect oneself from other's judgements. Two themes emerged from the interviews: balancing secrecy and assertiveness, and balancing the risks and benefits of going public. Due to the potential negative effects of going public, many caregivers choose to keep their caregiving a secret. In order to keep their caregiving a secret, respondents often tried to "pass," that is, to act as if they were not involved with AIDS while remaining actively involved in caregiving. This frequently involved using deception and dishonesty. For some caregivers it meant changing jobs or residences.

The other major theme involved the perceived risks of disclosing (Powell-Cope & Brown, 1992). Frequently cited fears included negative judgements of others,

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public shame, harassment, loss of friends or jobs, and fear that the information would be used to discredit them. For gay partners who were less open about their sexual orientation, disclosure of their caregiving would inadvertently reveal their sexual orientation. A final risk in deciding to disclose involved increased interpersonal conflict between the PWA and caregiver over who should know. When disagreements occurred, it was frequently the PWA who wanted to remain secretive or significantly restrict the circle of people informed. Caregivers on the other hand, commonly wanted to tell others to gain social support.

Besides clinical reports and studies using an interview format, none were found that explored the affect of disclosure related variables. No instruments could be found that adequately assess stressors associated with publicly disclosing. The most commonly used instrument, Family Adaptation to Medical Stressors (Koch, 1983), includes a four question scale on rules prohibiting emotional expression. Rather than rules prohibiting emoting, it appears to measure level of discomfort when someone is expressing emotion laden content. Although this is certainly a part of what is experienced by AIDS caregivers, it does not adequately cover the scope of factors influencing caregivers' decisions about going public.

Taken together, perception of public fears regarding contagiousness, negative social stigma, and rules prohibiting emotional expression would appear to combine to create a potentially potent stressor for caregivers. A common element in each of these variables includes decisions about publicly disclosing. From this perspective, caregivers would be expected to vary in their perceptions of the risk involved in

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disclosing, amount of distress associated with disclosing, and perceptions of control over disclosure. It is believed that these variables significantly contribute to perceptions of burden among caregivers. By directly exploring these variables, it is hoped that the results of this study will clarify and extend previous research in the area of AIDS caregivers.

Chapter 3

METHODOLOGY

This study employed a correlational research design utilizing cross-sectional survey methodology and included several survey instruments. The purpose of the design was to correlate scores on personal, familial, and social variables with an index of caregiver burden. Multiple regression was also utilized to explore which independent variables function as predictors of burden among HIV/AIDS informal caregivers. This chapter begins by describing the participants in this study. The measures employed are then described, followed by an outline of the procedures. Due to an inadequate response in the initial recruitment effort, a second revised recruitment procedure was necessary.

Participants

A nonrandom convenience sample of informal caregivers for persons with HIV/AIDS (PWA) was used for this study. This design was necessary because of the limited number of HIV/AIDS caregivers from which to draw and the difficulty accessing this population. Family and friends play a wide variety of roles in supporting persons with AIDS. For inclusion in this study, participants must have personal contact with the PWA. This criterion excluded informal caregivers whose primary role was limited to emotional support via the telephone or financial support. The sample represented caregivers across the time spectrum of HIV/AIDS. It included participants in the early stages when instrumental activity is light through the later stages when caregivers typically assume increasingly larger responsibility for care.

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It was expected that the caregivers would vary in age, relationship to the PWA, living arrangements, work status, income, and sex. This sample is different from most reported in the literature in that the participants are from mid-sized mid-west cities rather than from large urban cities on the East or West Coast.

Contacting caregivers for PWAs presents several challenges. First, there are no formal associations or service agencies that directly service this population. This makes direct access difficult. Second, informal caregivers represent a secondary level of care. Primary care can be thought of as the relationship between the PWAs and their doctors or social service representatives. Informal caregivers are frequently involved in these relationships, but the ability of doctors and agencies to contact them may be limited by confidentiality and incomplete or outdated address and phone numbers. Third, some caregivers have not yet reached the point where they are willing to be associated with professional AIDS organizations. As a result they may prefer to remain isolated. With these challenges in mind, participants were recruited through two primary avenues: AIDS service agencies and the Internet. This is described in more detail in the procedure section of this chapter.

The original target sample size was 200 participants. When it became apparent that the sample size was going to be markedly less, the research questions were revised in accordance with new sample size estimates. The sample for this study included 38 informal caregivers, consisting of parents, siblings, spouses/partners, extended family, and friends.

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Measures

Seven instruments were used for data collection: a demographic questionnaire, an instrumental needs checklist, a disclosure questionnaire, the Fear of Negative Evaluation, the Eysenck Personality Questionnaire extroversion scale, the Family Environment Scale: Independence and Control scales, and the Burden Assessment Scale. The demographic questionnaire collected information on participant's age, sex, relationship to PWA, work status, living arrangements, income level, duration of care, and current health status (see appendix A).

Burden Assessment Scale

The Burden Assessment Scale (Reinhard, Gubman, Horwitz, & Minsky, 1994) was selected because the items and structure of the inventory most closely match the purpose and goals of this study. It was developed to assess burden among those caring for the severely mentally ill. Like AIDS, severe mental illness is likely to carry a social stigma and therefore shares a common aspect of burden not commonly accounted for in inventories targeting the gerontological populations. Additionally, the BAS uses a multidimensional definition of burden including both objective and subjective components.

The BAS contains 19 items that capture both objective and subjective consequences of providing ongoing care. It was developed and tested on caregivers for the severely mentally ill. This scale excludes measurement of the ill relative's (care recipient) disruptive behaviors and the family's caregiving activities which are viewed as predictors of burden rather than aspects of burden.

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Ten items assess the degree to which caregivers experience objective burden as a consequence of their caregiving responsibilities. Objective burden refers to potentially observable behavioral effects of caregiving. This includes such things as financial problems, limitations on personal activity, household disruptions, and social interactions.

Nine items measure aspects of subjective burden including feelings, attitudes, and emotions expressed about the caregiving experiences. Specific aspects of subjective burden assessed by this instrument include shame, stigma, guilt, resentment, grief, and worry. One subjective burden item was removed and replaced with a statement more closely related to AIDS caregiving. The item removed was: to what extent have you become embarrassed because of (name's) behavior. This item was replaced with: to what extent have you worried that you might become infected with HIV.

Respondents indicate on a four point Likert type scale the degree to which each of the 19 statements relate to them. The items all reflect negative consequences of caregiving and are structured in the same direction so that responses can be summed with higher scores indicating greater levels of burden. It can be self-administered or administered by an interviewer.

The BAS is sensitive to changes in burden level over time. As such, test-retest measures of reliability are inappropriate. Instead, internal consistency was used to estimate reliability. Two studies were reported by the authors (Reinhard et al., 1994)

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with corresponding Cronbach's alpha levels of .91 and .89. This represents acceptable internal consistency. For the sample in this study, the observed alpha level was .84.

The authors (Reinhard et al., 1994) report two ways in which the validity of the instrument was established. To establish content validity, the set of items was reviewed by a caregiver advisory group consisting of six family members of long-term mentally ill adults. Their feedback supported the content, and suggestions for clarity were incorporated into the final instrument. Additionally, the authors indicate that the instrument appropriately distinguished between two sample groups. They predicted that the sample which had requested mental health services would report higher levels of burden than those that were recruited who did not request services. The magnitude of burden varied in the predicted direction.

Instrumental Needs Checklist

The instrumental needs of the care recipient were assessed by having caregivers indicate whether the care recipient needed help with each of seven daily tasks. The instrument was used by Folkman et al. (1994) for their study of gay-partner caregivers and consists of seven items indicating how frequently help is needed with each task (never, sometimes, or always). If the respondent indicates that the care recipient needs help sometimes or always there is a follow up question indicating how often the respondent is the one who provides help or arranges for the help (never, sometimes, almost all of the time, all of the time).

The instrument provides an index of both the needs of the care recipient as well as how often the respondent is involved in meeting the needs. The checklist can be self-

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administered and the responses summed to create a composite score. This provides opportunity to assess how much someone (or multiple people) other than the respondent is contributing to the caregiving. In the Folkman et al. (1994) study, the reported range of scores was 0-16. No information about the psychometric properties was reported in the Folkman et al. (1994) study, nor was any included with the instrument when it was received from the authors.

Brief Fear of Negative Evaluation Scale (FNE)

Watson and Friend (1969) developed the FNE scale to assess ones' "apprehension about other's evaluations, distress over their negative evaluations, and the expectation that others would evaluate oneself negatively (p.449)." The original FNE scale consisted of 30 true-false items. The revised, brief version (Leary, 1983a) which was used for this study, contains 12 of the original items. Respondents indicate on five-point scales the degree to which each statement is characteristic of oneself. Scores for the brief version range from 12-60. The opposite of high FNE is the lack of apprehension about other's evaluations, but not necessarily a desire or need to be evaluated positively.

Internal consistency estimates for the Brief FNE include item-total correlations ranging from .43 to .75, and a Cronbach's alpha coefficient of .90 (Leary, 1983a). The four week test-retest yielded a correlation of .75. Original and brief versions correlate .96. A Cronbach's alpha level of .89 was observed for the sample in this study.

Convergent validity was estimated by comparison with other measures of apprehension in social situations (Leary, 1983a). FNE correlated .51 with the Social

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Avoidance and Distress Scale, and .32 with Interaction Anxiousness Scale. In a test of discriminant validity, the FNE correlated slightly negatively ($r = -.25$) with the Marlowe-Crowne Social Desirability Scale.

Family Environment Scale: Independence and Control scales

The Family Environment Scale (FES) has been used extensively by researchers to assess various aspects related to family functioning. Form R consists of 10 subscales assessing three underlying dimensions: relationship dimensions, personal growth dimensions, and system maintenance dimensions (Moos & Moos, 1994). The Real Form (Form R) measures people's perceptions of their current family environment. The Family Environment Scales are appropriate for use with both conjugal relationships and nuclear family relationships. Two scales, Independence and Control, are being utilized for this study.

Independence is categorized as a relationship dimension that indicates the extent to which family members are assertive, are self-sufficient, and make their own decisions. Control is categorized as a system maintenance dimension that indicates how much set rules and procedures are used to run family living. These two scales were selected because they may shed light on the degree of freedom caregivers experience in directing their own social disclosure process.

Both subscales (independence and control) contain nine statements about families. Respondents indicate whether each item is True or False for their family. Because this study employed a broader definition of family, participants were directed

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to interpret each statement in terms of the “family system” that included the PWA. For both scales, five items are keyed True and four items are keyed False.

The FES manual (Moos & Moos, 1994) describes several ways by which the validity of the instrument was established. After conceptually defining each construct (i.e., control), items were prepared that fit the construct definition. Empirical criteria, such as intercorrelations, item-subscale correlations and internal consistency, were used in the final selection of items for each scale. To increase conceptual clarity, each item is only used for one dimension.

Additional support for construct validity was indicated in that families that evidenced more structure and regular routines scored higher on the control and organization scales (Fiese & Kline, 1993; Jensen, James, Boyce & Hartnett, 1983). Convergent and discriminant validity were reported in several studies cited in the manual. The FES control scale correlated significantly with the control scale of the Family Assessment Device (Dickerson & Coyne, 1987), the adaptability scale of the Family Adaptability and Cohesion Evaluation Scales (FACES-III), and the dyadic power scale of the Family Systems Test. Discriminant validity was demonstrated by the lack of correlation between FES control scale and the Family System Test (FAST) cohesion scale (Gehring & Feldman, 1988), and the lack of correlation between FES control and cohesion scales (Dickerson & Coyne, 1987). No specific information regarding the validity of the independence scale was provided in the manual.

The manual also includes a substantial review of research involving the FES. The FES has been used to describe families of youth with behavioral, emotional, or

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developmental disabilities; families with a physically ill child; families with psychiatric patients, families of medical patients, and how understanding family environment can help predict and measure treatment outcome.

Reliability estimates for the independence and control scales were calculated using test-retest and internal consistency (Moos & Moos, 1994). The 2-month test-retest reliabilites were .68 for independence and .77 for control. Internal consistency estimates, using Cronbach's Alpha, were .61 for independence and .67 for control. Although not substantial, according to the manual (Moos & Moos, 1994), these reliability estimates are in the acceptable range. The Cronbach's alpha levels for this study were .46 for independence and .71 for control.

Eysenck Personality Questionnaire: Extroversion scale

The EPQ is an established instrument that has been used frequently by researchers as an index of neuroticism and extroversion. Originally developed in 1963 as the Eysenck Personality Inventory, the instrument was revised in 1985. The extroversion scale consists of 21 items that are answered in a yes / no format. Item statements reflect common behavioral characteristics of either extroverted or introverted individuals. Respondents indicate whether or not the statement describes them. Eighteen of the 21 items are keyed for the "yes" response, three for the "no" response. The manual reports that the conceptualization of extroversion is similar with, but not identical to, that developed by Jung (1921/1960). Seventeen of the 21 items are drawn from the earlier EPI-E scales. Minor revision in the scale reflects greater emphasis being placed on the sociability aspect of extroversion, and less on the impulsivity

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component (Block, 1988). Extroverts are described as sociable, having many friends, needing to have others to talk to, desiring excitement and risk, tending to be impulsive, and always having a ready answer.

Test-retest reliability coefficients are reported as .94 at nine months and .88 at one year (Eysenck & Eysenck, 1975). Using the split-half method, internal consistency is reported to be .855. For the sample in this study, a split-half estimate of .67 was obtained. Using Cronbach's alpha, a .77 coefficient was obtained.

The EPQ extroversion-introversion scale was selected because it is an inventory that has been widely used, represents an independent scale within the EPQ, is relatively brief, and places more emphasis on the sociability aspect of extroversion. The EPQ was selected instead of the NEO (neuroticism, extroversion, openness), despite the fact that the NEO is superior psychometrically, because it more closely taps the desire for social interaction theme.

Procedure

In compliance with University protocol, approval for this study was sought through the Michigan State University Committee for Research Involving Human Subjects. Initial approval for this study was granted in October, 1996. In obtaining approval from the university committee, it was necessary to demonstrate that the rights of the participants in this study were being safeguarded. In an effort to provide informed consent for the participants in this study, a cover letter was included with the research questionnaires. The cover letter outlined the purpose of the study, the criteria

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for participation, highlighted that participation was voluntary, and described the process for disseminating the results (see Appendix B).

When the first data collection attempt failed to yield an adequately sized sample, a revised procedure was designed and resubmitted to the human subjects committee. Approval for the revised data collection procedure was obtained in July, 1998.

First Sample Recruitment

There is no way to directly access caregivers for PWAs. No organizations could be identified that specifically targeted HIV/AIDS caregivers. It was therefore necessary to work through less direct routes. Participants for this study were recruited through two avenues: AIDS service agencies and the Internet.

AIDS service agencies

Agencies that provide direct support services represent contact with the largest number of persons with AIDS and therefore their caregivers. Six agencies within the mid-Michigan and the Kansas City area were identified and contacted to solicit their support and participation. Agencies were identified through a list of those providing services to PWAs.

In order to minimize the amount of work required by agency personnel, a one page recruitment letter outlining the nature and purpose of the study and confidentiality was prepared (see Appendix C). In discussion with organization representatives, it was decided that the most efficient way to disseminate information about the research project was to include the recruitment letter in their newsletters. The newsletters are typically distributed to everyone on the agencies' mailing lists. This includes clients

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with HIV/AIDS, volunteers, community activists, and others interested in the organization. In the letter, interested caregivers were instructed to contact the researcher by e-mail or a toll-free number if they wanted more information or were interested in participating.

Questionnaire packets also were sent to four of the sites to distribute through their offices. These were sites that indicated they had support group meetings available for family and friends. Attendance at these support groups tends to be sporadic and unpredictable. Approximately 100 surveys were distributed to the agencies to make available through the support groups and their office lobby.

Internet

As not all PWAs and their caregivers are associated with AIDS organizations, attempts were made to notify and recruit caregivers through the Internet. The Internet was selected because it provides individuals anonymity as they search for resources related to an AIDS care. It was anticipated that caregivers who were not prepared to publicly identify themselves with AIDS organization might be using the Internet as a source of information. Two Internet sites were identified that provided information about HIV/AIDS and targeted caregivers. Both had electronic bulletin boards on their web pages on which it was possible to post the recruitment letter. One site included a specific section titled “research opportunities.”

Those who indicated a willingness to participate by responding to one of the above mentioned strategies were mailed a packet consisting of an introductory letter and the seven questionnaires. Letter sized envelopes were hand addressed and first class

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postage stamps affixed. A stamped return envelope addressed to the researcher was included with the packet. The recruitment process began in January of 1998 and concluded in August of 1998.

Response to First Sample Recruitment

The recruitment efforts outlined above generated a very minimal response. Five requests for research packets were received by phone. No inquiries were made by email. At the end of August, 1998, the toll-free number was discontinued. Eight completed research packets were returned. All of these came through the AIDS service agencies. As a result it was necessary to design a second sample recruitment plan.

Second Sample Recruitment

A more direct approach to sample recruitment was attempted in the second recruitment effort. After consulting with personnel in the AIDS organizations, it was decided to distribute the questionnaires directly to the HIV infected clients and ask them to forward the packet to someone who was an important source of support for them. Four AIDS organizations in Kansas City originally agreed to participate. Two organizations were AIDS/Infectious Disease clinics within Kansas City area hospitals. One was a free health clinic with an AIDS clinic. The fourth was a social service agency exclusively dedicated to those with HIV/AIDS. The packets were the same as those distributed in the first recruitment effort with the exception that the cover letter included the directions to pass the packet on to someone who was an important source of support (see Appendix B). The packets included a return stamped envelope that had the researcher's name printed above a stamped address. All research materials were

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returned directly to the researcher by mail. The second recruitment effort began in March 1999 and ended in August 1999.

To protect the confidentiality of potential participants, the researcher never has access to the client or caregiver names. The health clinic agreed to mail the research packet to all 225 of their HIV/AIDS clients. Packets were mailed in the agency's letterhead envelopes to ensure that any undeliverable addresses would be returned to the agency and not the researcher.

The two hospitals chose to distribute the research packets through their clinics when patients came in for check-ups or for clinic days. Each of the hospitals was given 50 packets to distribute. The fourth agency decided not to participate citing that they had just concluded their own survey and did not want to burden their clients.

Both hospitals were concerned that mailing the packets might offend their clients. There were three primary concerns. First, they feared that clients might perceive participation as a prerequisite for continuing to receive services. Second, there was concern that clients would believe their confidentiality had been compromised. Third, they wanted to limit the amount of mail clients received from them, so as not to burden the clients. As a result they chose to hand out the packets in the clinic rather than mail them out.

A total of 304 packets were distributed to persons with HIV/AIDS in the second recruitment effort. It is unknown how many of these were then passed on to a caregiver. Thirty completed packets were returned. The total number of completed packets from the two data collection procedures was 38.

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As the completed packets were returned, they were removed from the return envelopes and assigned an identification number. The return envelopes were then disposed of and the questionnaires scored. The demographic information and questionnaire scores were entered into the statistics computer software program SPSS for analysis.

Chapter 4

RESULTS

The sample for this study consisted of 38 informal caregivers for persons with HIV/AIDS (PWA). Caregiver ages ranged from 20 to 68 years with a mean age of 44 ($SD = 12.13$). Approximately 10 percent of the caregivers were under 30 years old and 10 percent were over 60 years of age. Sixty-eight percent ($N = 26$) of the participants were male. Twenty percent ($N = 8$) were parents and siblings of the PWA. Fifty-nine percent ($N = 22$) identified themselves as partners, and 21 percent ($N = 8$) were extended family or friends. Eighty-six percent ($N = 31$) of the caregivers identified their race as White. Due to sample size, the other racial groups were collapsed into one group comprising approximately 14 percent. Sixty-seven percent ($N = 22$) indicated they share a residence with the person with HIV/AIDS. In 21 percent ($N = 7$) of the cases, the PWA lived alone, while 10 percent ($N = 4$) share a residence with someone else. None of the participants were caring for someone in hospice. Sixty-four percent ($N = 21$) of the participants indicated that they are the primary caregiver for the PWA. Twenty percent ($N = 7$) indicated they provide about one-half of the caregiving responsibilities, while the remaining 15 percent ($N = 5$) reported that someone else provides more than 50 percent of the caregiving responsibilities. The duration of caregiving ranged from three months to 16 years, with a mean of 60 months ($SD = 44$) of providing care. The number of hours per week caregivers worked ranged from 0 to 55 with a mean of 25 ($SD = 21$). Family income ranged from 0 to \$200,000 with a mean of \$35,000 ($SD=34,830$). Regarding the highest level of education, 21% ($N = 8$) reported high school, 3% trade school ($N = 1$), 26% some college ($N = 10$), 13% ($N =$

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5) associate of arts degree, 21% (N = 8) a bachelor's degree, and 13% (N = 5) a graduate degree. Due to only one subject being in the trade school category, it was removed for the analysis. Forty percent (N = 15) identified their religious affiliation as Protestant, 13% Catholic (N = 5), 3% Jewish (N = 1), 31% none (N = 12), and 8% (N = 3) indicated Other.

Summary of Personal, Familial, and Social Variables

An alpha level of .10 was used as the cut off level for the analyses in this study. This alpha level was selected due to the exploratory nature of this study.

Caregiving tasks are identified as common areas of support often required by those with medical conditions. Based on the Instrumental Needs Checklist, scores for caregiving needs ranged from 0 to 22 out of a total possible score of 28 with a mean score of 8.5 (SD = 6.81).

The extroversion/introversion scale measured the degree to which caregivers see themselves as sociable, having many friends, needing to have others to talk to, desiring excitement and risk, tending to be impulsive, and always having a ready answer. Higher scores indicate greater levels of extroversion. Out of a total possible score of 21, scores ranged between 0 and 21 with an observed mean of 12.4. This compares with a norm of 13.19 for all ages listed in the manual (Eysenck & Eysenck, 1975). The norm for 30-40 years is 12.8 and for 40-50 years the norm is 12.38 (See Table 1).

Two family environment scales, independence and control, were used to explore the effect of family variables on caregivers. The family environment scale for

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Table 1
Comparison of Caregiver Mean Scores with Normative Means

	Range	Mean	SD	Norm mean	t
Caregiving needs	0-22	7.90	6.81	7.15	.11
Extroversion	0-21	12.40	5.23	13.19	.15
Family environment-independence	2-8	6.08	1.58	6.03 ^a 6.66 ^b	.03
Family environment-control	0-9	3.63	2.23	4.61 ^a 4.26 ^b	.50
Fear of negative evaluation	16-60	36.60	11.52	35.70	.08
Burden	23-62	38.50	10.96	32.10	.58

*all observed mean differences were nonsignificant at $\alpha=.05$

^aFamily Environment norm using "distressed families."

^bFamily Environment norm using "normal population."

independence measured the extent to which caregivers are self-sufficient and autonomous within the family. Scores ranged between two and eight out of a total possible score of nine. Higher scores indicated greater levels of independence. The mean of 6.08 compares with a mean score of 6.66 reported in the manual for a normal population and 6.03 for distressed families, indicating that this sample is more comparable to the distressed families. Scores between 5.5 and 6.0 are considered below average and scores between 6.5 and 7.0 are considered average.

The family environment scale - control, measures the extent to which set rules and procedures are used to run family living. Scores ranged between zero and nine out of a total possible score of nine, with higher scores indicating higher levels of control.

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Table 2

Correlation Matrix for Burden, Personal, Familial, and Social Variables

	1	2	3	4	5
1. Burden (N)	-				
2. Extroversion (N)	.11 (38)	-			
3. FES Control (N)	.56** (30)	.35 (30)	-		
4. FES Independence (N)	-.26 (30)	-.07 (30)	-.57** (30)	-	
5. Fear of Neg. Evaluation (N)	.21 (38)	-.21 (38)	.04 (38)	.06 (38)	-

Note: * $p < .05$, ** $p < .01$

The observed mean of 3.63 reflects below average levels of control and is slightly lower than the reported mean of 4.26 for normal families and 4.61 for distressed families.

For the social variable, the Brief Fear of Negative Evaluation Scale was used.

The observed scores ranged between 16 and 60 out of a total possible score of 60.

Higher scores indicated greater levels of fear of negative evaluation. The observed mean of 36.6 ($SD = 11.52$) represents an average level of FNE and compares with a norm of 35.7 ($SD = 8.1$) reported in the manual (Leary, 1983).

As can be seen in Table 1, none of the mean scores for the questionnaires used in this study differed significantly from the national norms. This indicates that, for the variables in this study, the current sample is similar to other groups, and the observed differences in statistical results are not an artifact of a skewed sample.

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Burden

The level of caregiver distress was assessed using the construct of burden and the Burden Assessment Scale. Because this instrument includes both an objective and subjective component, it was possible to derive three scores: overall burden, objective burden, and subjective burden. Objective burden refers to the potentially observable effects of caregiving, such as missed days at work or neglecting other family members' needs. Subjective burden refers to the feeling, attitudes, and emotions expressed about the caregiving experience. The overall burden scores ranged from 23 to 62 out of a total possible score of 76. Higher scores indicate higher levels of burden. There are two mean scores reported in the manual (Reinhard et al., 1994). A mean score of 55.3 was observed for a group of caregivers that sought services for themselves, related to the demands of caring for a seriously mentally ill relative. The other group for whom normative data is available represents those who did not seek services for themselves, but were identified as the primary caregiver for a person who was receiving services. The mean score for this second group was 32.1. It is this second group that is most like the sample in this study. The observed mean for this sample was 38.5.

For objective burden, the scores ranged from 10 to 34 out of 40, with a mean of 19.84 ($SD = 8.13$). For subjective burden the scores ranged from 11 to 36 out of 36, with a mean of 18.63 ($SD = 5.61$). Thus, the caregivers in this sample were experiencing a moderate level of burden. The results also suggest that caregivers in this sample were experiencing both objective and subjective burden.

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Relationship Between Burden and the Personal, Familial, and Social Variables

The relationship between burden and the Family Environment Scale for control was positive and statistically significant $r(30) = .56, p < .01$ (see Table 2). This supports hypothesis number two and suggests that burden is higher in families that exert higher degrees of control over their members and place more emphasis on following set rules and procedures.

The relationship between burden and independence was negative but not statistically significant $r(30) = -.26, p = .17$. This fails to support hypothesis number three. It can also be observed that the relationship between independence and control is negative and statistically significant ($r(37), -.56, p < .01$). This compares with $r = -.24$ reported in the manual (Eysenck & Eysenck, 1975).

The relationship between burden and extroversion was nonsignificant $r(37) = .11, p = .51$. This fails to support hypothesis number one. The relationship between the social variable, Fear of Negative Evaluation, and burden was also nonsignificant $r(38) = .21, p = .21$. This fails to support hypothesis number four.

Relationship Among Other Variables

Caregiving needs were significantly correlated with both overall burden $r(37) = .32, p < .05$ and objective burden $r(37) = .46, p < .01$. As the needs of the PWA increase and the caregiver is involved in meeting those needs, the caregiver is more likely to experience distress associated with the observable behavioral effects of caregiving. This would include such things as having the household routine upset, experiencing financial problems, having to change personal plans like taking a new job or going on

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Table 3

Univariate Analysis of Variance for Demographic Variables by Burden

	df	MS	F
Model	7	7798.12	87.47**
Level of caregiving	2	398.02	4.46*
Sex	1	77.51	.87
Relationship	2	3.49	.04
Living Arrangements	1	20.49	.23
Error	28	86.18	
Total	34		

* $p < .05$, ** $p < .01$

vacation, or experiencing family friction and arguments. Caregiving needs were uncorrelated, however, with subjective burden $r(37) = -.04$, $p = .83$. Examples of subjective burden include: feeling guilty because you were not doing enough to help, resenting the demand made on you, feeling trapped by the caregiving role, and worried about what the future holds for the other person.

Univariate ANOVA was used to explore the relationship between categorical variables and burden (see Table 3). Four variables were entered into the model that accounted for multiple assessments. A statistically significant difference on burden existed between groups based on how much care the individual was providing. Caregivers who indicated that they provide about 50% of any caregiving needs reported more burden ($M = 51.14$, $SD = 8.67$) than those who identified themselves as the primary caregiver ($M = 37.64$, $SD = 9.68$), and those who indicated that someone else provided more than 50% of the caregiving responsibilities ($M = 31.60$, $SD = 5.22$). These differences were statistically significant $F(2,34) = 4.94$, $p < .05$. The observed

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Table 4
Regression Coefficients for Predictors of Burden

Variables	B	Beta	t
Caregiving needs	.50	.29	1.84*
Family environment-control	2.35	.51	3.30**
R=.61, Rsq =.38, Adj Rsq =.33 $F(2,28) = 7.96^{**}$			

* $p < .10$, ** $p < .01$,

effect size, using eta squared, was .22. There were no differences observed on the basis of sex, level of education, relationship, or living arrangements.

Predictors Of Burden

Multiple regression analysis was used to explore the degree to which variables combined to explain caregiver burden. Based on the results of the previous analyses, two variables, FES control and caregiving needs, were entered into the equation with overall burden as the dependent variable (see Table 4). Both FES control and caregiving needs significantly contributed to caregiver burden and accounted for 38% of the variance.

Post hoc analysis was conducted to further explore FES control. A univariate ANOVA model was used to test the relationship between FES control and three categorical variables. It was hypothesized that differences in FES control might be associated the caregiver age, sex, or relationship status. No statistically significant differences were found based on age, $F(27,35) = .99$, $p = .57$; sex, $F(1,35) = .27$, $p = .62$; or relationship, $F(2,35) = .64$, $p = .57$.

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Summary

This study explored the relationship between burden and personal, familial, and social variables using correlation and ANOVA models. The following research questions guided the development of this study.

1. Do caregivers who prefer using social support as a means of coping experience higher levels of burden?
2. Are caregivers who perceive greater risk associated with disclosing more likely to experience increased burden?
3. Do caregivers who perceive higher levels of personal independence within their family experience lower levels of burden?

The following four hypotheses were tested:

1. There will be a positive relationship between extroversion and Burden.
Not supported by the analysis.
2. There will be a positive relationship between family environments that exhibit high levels of control over family members and Burden.
Supported by the analysis.
3. There will be a negative relationship between family environments that encourage individual independence and Burden.
Not supported by the analysis.
4. There will be a positive relationship between fear of negative evaluation and Burden.
Not supported by the analysis.

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Two other variables were found to be statistically related to caregiver burden. As the needs of the care recipient increased, caregivers reported greater burden. The level of involvement on the part of the caregiver was also significant. Caregivers who reported that they provide about 50% of caregiving needs reported greater burden than those who identified themselves as either the primary caregiver, or as providing less than 50% of any caregiving needs.

Chapter 5

Discussion

The purpose of this study was to further the understanding of AIDS caregiving by examining issues associated with social disclosure and caregiver burden. I proposed that certain personal, familial, and social variables would provide additional insight into the process of caregiving and specifically the experience of caregiver burden. This chapter will provide a more thorough discussion of the findings from this study, as well as implications for practitioners and future research.

Overall, burden continues to be a relevant variable in understanding HIV/AIDS caregiving. Caregivers in this sample expressed a wide range of scores in the area of burden, indicating that many are experiencing distress associated with fulfilling the tasks of providing care and managing their own emotions in the process. Several variables were found to be predictive of overall burden.

Burden

Family Climate

Results of the analysis indicate that family climate plays an important role in how caregivers manage the demands associated with providing care for someone with HIV/AIDS. Family climate refers to the general social environment of the family. According to the FES manual (Moos & Moos, 1994), the scales are appropriate both for conjugal dyads and nuclear family structures. The results suggest that families that rely more on set rules and procedures to run family life are likely to experience higher levels of burden. In families that are more restrictive or controlling, family members are often

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expected to follow highly prescribed ways of doing things. There is less flexibility for independent decisions and actions on the part of family members. In these situations, caregivers' ability to determine for themselves what would be most beneficial is often limited.

Stress theory (Lazarus & Folkman, 1984) suggests that if caregivers appraise their access to coping resources as being restricted, they will perceive the stressor as a greater threat and respond with more distress. For the caregivers in this study, it could be that family environments characterized by higher levels of control represent less flexible relationship patterns. If this is the case, then important decisions about socially disclosing are likely to involve more conflict and distress.

This is consistent with interviews conducted by Powell-Cope and Brown (1992) which found that caregivers reported increased stress when there was disagreement and conflict with the PWA about who should know, when they should be informed, and what specifically they should be told. Most often the caregivers in these situations felt compelled to modify their wishes or needs to comply with the demands of the person with AIDS or with an authority figure within the family (usually a parent).

Additionally, in family environments characterized by higher levels of control, caregivers may perceive that access to coping resources is restricted. Whether it actually is or not, if caregivers perceive that they are not able to utilize important coping resources (social support), they will interpret the stressors as more threatening and are likely to respond with greater distress or burden.

From this study, it is not possible to determine, for certain, where power differentials

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exist, and who in the family manages the control. However, the FES manual (Moos & Moos, 1994) suggests that it is the one who is not “in control” that usually reports higher levels of perceived control. For instance, adolescents frequently perceive the family environment to be more controlling than do the parents. Likewise, when couples complete the FES, the woman frequently perceives the climate in the relationship to be more controlling than does the man. From this, it may be inferred that the caregivers who characterized their family environments as more controlling, were not the ones in the position of power. As a result, they are less likely to be making the decisions about how the disclosure and coping process will be managed.

From the results of this study it is not possible to determine whether the observed family environments existed prior to the illness and resulted in the observed level of burden, or whether they are a result of families adapting to the illness. Families may attempt to manage the uncertainty and unpredictability associated with AIDS by becoming more controlled within family life. Establishing set ways of doing things and simplifying the chain of command may give family members less about which to worry.

Fear of Negative Evaluation

Having a general apprehension about receiving negative evaluations from others was not significantly related to the experience of caregiver burden. This social variable essentially measured a fear of losing social approval. All of the items referred to the caregivers' general level of social apprehension. This was not an AIDS specific index, but it was anticipated that those who have elevated general apprehension would have heightened distress when the topic carries potential social stigma. The wide range

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of scores on this variable indicates that caregivers differ in the degree to which they are concerned about how others perceive them. Although caregivers varied in their perception of the importance of social approval, higher levels were not associated with increased burden.

One interpretation of these findings is that social stigma may no longer be as important for HIV/AIDS caregivers. If disclosing one's caregiving status is not perceived as a threat, then according to stress theory (Lazarus & Folkman, 1984), there should be little distress generated. It may be that caregivers anticipate minimal negative social repercussions as a result of their caregiving role.

Over the last 10 years considerable effort has been put forth to educate the general population about AIDS and to encourage a compassionate response. As a result, caregivers may be more confident in their ability to access and utilize social support. The results of previous research, however, indicate that the social stigma of the disease decreases the likelihood of social support (Frierson et al. 1987; Gies et al., 1986; Maloney, 1988; Perse, 1987; Powell-Cope & Brown, 1992; Williams & Stafford, 1991). This was true not only in the 1980's and early 1990's, but also within the past five years (Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996; Turner, Pearlin, & Mullan, 1998). As a result of the educational efforts, some caregivers may overestimate the sensitivity and responsiveness of their support network. When this occurs, caregivers will experience less distress initially because they perceive their resources to be accessible and adequate. They may, however, be caught off guard if people react negatively. Given that research continues to indicate that social stigma and social

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isolation are relevant, it may be valuable to remind caregivers to be thoughtful in their social disclosure decisions.

A second consideration involved the questionnaire utilized for this study. It may be that the broad, general measurement of fears associated with negative evaluation and social approval do not adequately reflect the AIDS caregiving experience. A questionnaire more specifically addressing aspects germane to AIDS caregiving, such as stereotypes, discomfort with sexual or substance use topics, religious beliefs, and the ignorance of the disease process, may more precisely delineate the relationship between caregivers' perceptions and distress.

Extroversion

The personal variable of extroversion proved to be an ineffective predictor of caregiver burden. It was hypothesized that because extroverts desire higher levels of social support and interaction, they would be at greater risk to experience burden. This was not supported by the results. In fact, knowing about a caregiver's level of extroversion told virtually nothing about his or her level of burden. There are two possible explanations for this finding. The broad construct of extroversion includes several aspects in addition to the desire for social support and interaction. The most relevant aspect for this study, desire for social openness, may need to be measured more precisely.

A second possibility is that those higher in extroversion may still be able to utilize their social support or some other means of coping. It may be that those higher in extroversion perceive less threat in the environment. This idea was supported by the

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finding that, in general, those higher in extroversion expressed less fear about how others perceived and evaluated them.

Level of Involvement and Instrumental Needs

Other variables that were important predictors of burden included the level of involvement by the caregiver, and the level of caregiving needs expressed by the PWA. An unexpected finding was that caregivers who reported providing about 50% of the caregiving responsibilities experienced higher levels of burden than those who indicated they were either the primary caregiver or that someone else provided more than 50% of any caregiving responsibilities. It was anticipated that primary caregivers would be the most affected. The results suggest that caregivers who split responsibilities may actually experience greater burden.

Primary caregivers may experience more predictability and therefore more control over the process, thereby reducing burden. As a primary caregiver, the activities and responsibilities may become a natural part of one's schedule. When responsibilities are split, it may be that in addition to any caregiving tasks, there is additional stress associated with organizing, dividing responsibilities, and maintaining communication.

Another possible interpretation of this finding is that the group reporting that they provide about fifty percent of caregiving responsibilities may include many caregivers who have already divided their caregiving due to the demands and distress. Although they have reduced their level of involvement, the disruption continues at such a level that they continue to experience burden. The general caregiving literature (Montgomery et al., 1985; Reinhard et al., 1994), and common sense, suggest that

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sharing the load should be an adaptive response to increased burden. Whether these results represent a characteristic unique to AIDS caregiving or simply a spurious finding needs further clarification. Due to the small sample size, the representativeness in each of the three cells is limited. Only seven individuals comprise the group of caregivers who provide about 50% of the caregiving. Caution, therefore, should be exercised when interpreting these findings.

The instrumental needs of the PWA were significantly related to caregiver burden. When PWAs required greater assistance for their basic needs, the caregiver was likely to experience higher levels of burden. This is consistent with other research on AIDS caregivers (Folkman et al., 1994; Pakenham et al., 1995, Turner et al., 1997; Turner et al., 1998). It is therefore important to recognize that as persons with AIDS experience decreased health and independence, the individuals caring for them are likely to experience more distress. Although advances in healthcare over the past five years are allowing PWAs to maintain better health and sustained independence, medical interventions do not work for everyone. A substantial number of PWAs still require extensive support on an intermittent basis.

Implications

For professionals working with persons with HIV/AIDS or their families, it is important to explore variables that might influence caregiver well being. When conducting an assessment, as well as at various points in ongoing treatment, it is valuable to assess the level of assistance required by the PWA and how those needs are being met. As need for assistance increases, attention and support should be broadened

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to include the caregiver. Previous research suggests that caregivers may feel guilty about their own needs. Given the importance of the caregiving relationship, however, it is critical to ensure that they are adjusting well to the changes.

It also appears valuable to explore relationship dynamics related to individual autonomy and flexibility. Caregiver distress appears to be lower when there is more flexibility and autonomy within the relationships. It may be valuable to ask questions concerning: how decisions are made, how much flexibility exists in family routines, and how much emphasis is placed on doing things in prescribed ways. When it becomes evident that autonomy is low, or that caregivers are feeling restricted in how they deal with the illness, it may be beneficial to assist the family in exploring more adaptive options.

Given the potential consequences of personally identifying with AIDS, it is important to assess perceptions about the disclosure process. This may include exploring the perceived risks of disclosing and the anticipated response of others. Identifying safe persons with whom to disclose, and clarifying myths or misperceptions may also be beneficial. For some caregivers it may be valuable to assess and challenge cognitive distortions in terms of fears of disclosing. Due to the social context and realistic fears associated with loss of social support, caregivers may benefit from assistance in weighing the options and developing a strategy. Pomeroy, Rubin, and Walker (1996) reported positive benefits for caregivers that participated in a psychoeducational group intervention. Participants completed eight group therapy

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sessions focused on alleviating the social and emotional burdens confronting family members.

Limitations

Several factors that limit the generalizability of these findings need to be considered. First is sample size. As is common with most studies of HIV/AIDS caregivers, the limited size of the sample limits the robustness of the findings. A larger sample would allow for more sophisticated analysis and greater confidence in the reliability of the results.

Self-Selection

A second limitation related to the sample involves self-selection on the part of the person identified with HIV/AIDS and the caregivers. The design of this study called for the questionnaire to be distributed to HIV infected persons and for them to pass it on to someone who is an important source of support for them. This required a decision on the part of the person with HIV/AIDS as to whether he or she wanted to participate. Of those who did pass it on to a caregiver, it is impossible to determine what percentage of caregivers responded.

Given this, there are several things that need to be considered. First, some PWAs may not forward the packet on because there is no one they identify as a primary source of support. In fact, one packet was returned with a comment from the PWA that he was healthy and independent and did not feel that he needed support from anyone. Other PWAs may not have anyone on an informal basis that is actively involved in their care. One of the social service professionals from a participating clinic indicated that

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some clients who are healthy have not disclosed their HIV status to anyone. These persons simply use the medical and social service professionals as needed to monitor their health and well being.

A second potentially important aspect of self-selection has to do with the quality of the relationship between the PWA and the caregiver. Because PWAs were allowed to select to whom they wanted to give the packet, it is more likely representative of supportive relationships rather than conflicted relationships or even general family members. It is doubtful that the PWA would intentionally select someone with whom there was considerable conflict, as is sometimes the case in family relationships. For instance, an infected man may select to give the packet to his sister rather than his mother, even though the mother provides more tangible care.

In deciding to whom the packets should be forwarded, the patients who received them may also try to anticipate who is likely to be interested in completing the packet. As they consider their social network, if one member is more interested in AIDS research, or more active with the AIDS community, they may pass it on to them thinking this person is more likely to complete the packet. This would likely result in caregivers who are more socially active and comfortable with their caregiving role. This may influence scores on variables important for this study, namely, fear of negative evaluation, extroversion, and family environment. However, the scores for caregivers in this sample were all similar to the national norms, indicating at least in part, that the sample was not biased toward an extreme on any of these variables.

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Probably the most significant barrier to higher rates of participation is that caregivers may already feel overwhelmed. If they feel like they are over-committed and have too little time, then it is unlikely that they will be motivated to complete a research packet. It was hoped that their commitment to providing care for someone with HIV/AIDS would carry over into involvement with this study. However, given the response rate this was not the case.

Because there are very few studies of HIV/AIDS caregivers reporting demographic data, particularly in the Midwest, it is difficult to determine how representative this sample is.

Changes in Social Context

Over the past five years notable changes have occurred in the area of AIDS care. Due to advances in medical treatment, many PWAs are able to remain healthier longer, if not indefinitely. This means that they have lower need for substantial nursing care. They are able to remain virtually independent and maintain normal social relationships. Instead of intensive and prolonged nursing care, many require only a strict medication regime. For many, this represents a shift from viewing HIV/AIDS as a terminal disease to a chronic disease.

In the past, it was essential that someone with AIDS have one or more identified caregivers. With medical advances this is no longer the case. The demands placed on caregivers may therefore be more intermittent and more social and emotional in nature. Unfortunately the medical treatment options do not work for everyone. A smaller, but substantial number of PWAs do not respond to the medical treatments and become ill

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and succumb to an opportunistic illness. For these persons, more traditional caregiving is necessary.

Along with the medical advances, there has also been increased social awareness of the disease. Tremendous effort has been put forth to educate the public in terms of the risk factors and resources available. As a result there is less hysteria about contagion and unrealistic infection risks. Several recent studies, however, indicate that social stigma and social alienation continue to be important issues for informal HIV/AIDS caregivers (Jankowski et al., 1996; Reynolds & Alonzo, 1998; Turner et al., 1998).

Instruments

The survey questionnaires used in this study were originally intended to serve as general indicators of social variables with which to establish the validity of an AIDS specific questionnaire. When the response was inadequate to proceed with the development of the questionnaire, these instruments became the primary focus of the analysis. A particular limitation therefore is that they are not AIDS specific. The personal, familial, and social questionnaires all assess the caregivers' general style rather than specifically related to their HIV/AIDS caregiving relationship. This is particularly true for the Fear of Negative Evaluation questionnaire. It may be assumed that someone with a higher level of fear and apprehension in general would also have elevated fear of negative evaluation related to HIV/AIDS. However, it is possible that someone who has a relatively low level of social apprehension in general may have quite a different reaction concerning AIDS. Due to the social stigma and possible

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alienation, caregivers' fear of losing social support may be exacerbated. Addressing this in an AIDS specific way may be more beneficial.

An element of the Extroversion scale, desire for social openness and social support, was of particular interest for this study. However, the construct of extroversion is broader and contains elements that are not as relevant to this study. This may have diluted the potency of this variable in this study. Recent research continues to highlight the importance of social support for HIV/AIDS caregivers, and the possible social isolation that accompanies HIV/AIDS caregiving. (Jankowski et al., 1996; Turner et al., 1998). More clearly measuring how personal characteristics among HIV/AIDS caregivers, such as the desire for openness and social interaction, relate to the social climate surrounding AIDS, may be beneficial.

The Family Environment Scale was used in this study to assess the overall climate, or environment, of the family. Because several different family relationships were represented in this study, including partners, parents, and siblings (extended family and friends responses were excluded), the directions were slightly modified. Participants were directed to respond to the items in reference to the family system including the PWA. Although this is only a slight modification, it is a change nonetheless. Additionally, a substantial portion of the sample for this study was male partners. The FES manual (Moos & Moos, 1984) reports that the instrument can be used to assess family environments for couples, as well as more traditional nuclear families. There are no norms listed for same sex couples, and it is unclear whether

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substantial differences exist regarding family climate. No differences in this study, however, were found in family environment on the basis of relationship status.

Recommendations for Future Research

This study extends our understanding of the stresses associated with caring for someone with HIV/AIDS by examining family environment and social fears. If issues around social disclosure create distress for caregivers, it may be beneficial to explore the characteristics of those who do it well. Instead of focusing exclusively on the negative impact for those who do not manage the transitions well, future studies would do well to identify and explore important variables that enable other caregivers to successfully manage.

A second recommendation relates to family environments. The cross sectional design of this study only allowed for a comparison of current family environments. It was therefore impossible to determine whether observed difference in burden were associated with preexisting family environments or were in fact adaptations the family was making in response to the illness. A repeated measures longitudinal design would clarify the role of family environment and allow exploration of whether certain family environments are predictive of adjustment and well being further into the illness.

Although tremendous strides have been made in the treatment of HIV/AIDS, as of yet, there are no cures, and more people are infected daily. It is prudent to continue improving our understanding of the disease and developing the most effective strategies to maximize the well being of all involved.

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APPENDIX A

Questionnaires

HIV/AIDS FAMILY SUPPORT RESEARCH PROJECT

ABOUT YOU:

- | | | | | | | | | | | |
|---|--|--|------------------------------|------------------------------|-------------------------------|-----------------------------|------------------------------|-------------------------------|---------------------------------------|------------------------------|
| <p>1. Age _____</p> | <p>2. Sex _____</p> | <p>3. How long have you been providing direct support for the person with HIV/AIDS _____</p> | | | | | | | | |
| <p>4. On average, how many hours per week do you work? _____</p> | <p>5. Estimated total annual family income? _____</p> | <p>6. Your relationship to the person with HIV/AIDS</p> <table border="0" style="width: 100%;"> <tr> <td><input type="radio"/> father</td> <td><input type="radio"/> mother</td> </tr> <tr> <td><input type="radio"/> sibling</td> <td><input type="radio"/> child</td> </tr> <tr> <td><input type="radio"/> spouse</td> <td><input type="radio"/> partner</td> </tr> <tr> <td><input type="radio"/> extended family</td> <td><input type="radio"/> friend</td> </tr> </table> | <input type="radio"/> father | <input type="radio"/> mother | <input type="radio"/> sibling | <input type="radio"/> child | <input type="radio"/> spouse | <input type="radio"/> partner | <input type="radio"/> extended family | <input type="radio"/> friend |
| <input type="radio"/> father | <input type="radio"/> mother | | | | | | | | | |
| <input type="radio"/> sibling | <input type="radio"/> child | | | | | | | | | |
| <input type="radio"/> spouse | <input type="radio"/> partner | | | | | | | | | |
| <input type="radio"/> extended family | <input type="radio"/> friend | | | | | | | | | |
| <p>7. What is your highest level of education?</p> <p><input type="radio"/> none</p> <p><input type="radio"/> Grade school</p> <p><input type="radio"/> High school</p> <p><input type="radio"/> Trade school</p> <p><input type="radio"/> Some college</p> <p><input type="radio"/> Associate degree</p> <p><input type="radio"/> Bachelor's degree</p> <p><input type="radio"/> Graduate degree</p> | <p>8. Caregiving responsibilities In addition to the person with HIV/AIDS?</p> <p><input type="radio"/> none</p> <p><input type="radio"/> children</p> <p>→how many _____</p> <p><input type="radio"/> spouse (other than the person with HIV/AIDS)</p> <p><input type="radio"/> parent</p> | <p>9. Current living arrangements?</p> <p><input type="radio"/> The person with HIV/AIDS shares my residence</p> <p><input type="radio"/> The person with HIV/AIDS lives alone</p> <p><input type="radio"/> The person with HIV/AIDS shares a residence with someone else</p> <p><input type="radio"/> The person with HIV/AIDS is in hospice</p> | | | | | | | | |
| <p>10. What is your religious affiliation?</p> <p><input type="radio"/> Protestant</p> <p><input type="radio"/> Catholic</p> <p><input type="radio"/> Jewish</p> <p><input type="radio"/> Islamic</p> <p><input type="radio"/> None</p> <p><input type="radio"/> Other _____</p> | <p>11. Ethnicity</p> <p><input type="radio"/> Black or Afro-American</p> <p><input type="radio"/> White</p> <p><input type="radio"/> Hispanic</p> <p><input type="radio"/> Asian or Pacific Islander</p> <p><input type="radio"/> Native American</p> <p><input type="radio"/> Other _____</p> | <p>12. Caregiving responsibilities</p> <p><input type="radio"/> I am the primary caregiver for (name)</p> <p><input type="radio"/> I provide about 50% of any caregiving needs</p> <p><input type="radio"/> Someone else provides more than 50% of any caregiving responsibilities</p> | | | | | | | | |

CAREGIVING NEEDS

The following questions have to do with the help the person you are caring for needs in day-to-day tasks. By "needs help", I mean that he/she cannot do the task without help because he/she is either physically or emotionally unable to do so. For each item please indicate whether or not the person you are caring for needs help.

- 1a. Does _____ need help with day to day grocery shopping?
- ☐ Never → skip to question #2a
 - ☐ Sometimes
 - ☐ Always
- 1b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always
- 2a. Does _____ need help preparing meals – planning for fixing them?
- ☐ Never → skip to question #3a
 - ☐ Sometimes
 - ☐ Always
- 2b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always
- 3a. Does _____ need help with housekeeping – doing the dishes, vacuuming, cleaning the bathroom, or doing the laundry?
- ☐ Never → skip to question #4a
 - ☐ Sometimes
 - ☐ Always
- 3b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always

- 4a. Does _____ need help with physical tasks such as lifting things, carrying packages, going up stairs, or moving furniture?
- ☐ Never → skip to #5a
 - ☐ Sometimes
 - ☐ Always
- 4b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always
- 5a. Does _____ need help with transportation – to the doctor, the store, or other places?
- ☐ Never → skip to #6a
 - ☐ Sometimes
 - ☐ Always
- 5b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always
- 6a. Does _____ need help with any type of medical application at home? By that I mean, do you help him/her take medicine, with injections, a catheter or any other medical device?
- ☐ Never → skip to #7a
 - ☐ Sometimes
 - ☐ Always
- 6b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always
- 7a. Do you find that _____ needs help managing his/her money and finances – checkbook, paying bills, or handling insurance?
- ☐ Never → go on to next page
 - ☐ Sometimes
 - ☐ Always
- 7b. (IF "Sometimes" or "Always"), How much of the time are you the one who helps him/her or arranges for that help?
- ☐ Never
 - ☐ Sometimes
 - ☐ Always

Impact of Caregiving Scale (Burden)

The following items are a list of things which other people have found to happen to them because of their relative's illness. Please indicate to what extent you have had any of the following experiences in the past six months.

1	2	3	4	9
Not at all	a little	some	a lot	NA

Because of (name's) illness, to what extent have you:

1. Had financial problems 1 2 3 4 9
2. Missed days at work (or school) 1 2 3 4 9
3. Found it difficult to concentrate on you own activities 1 2 3 4 9
4. Had to change your personal plans like taking a new job
or going on vacation..... 1 2 3 4 9
5. Cut down on leisure time..... 1 2 3 4 9
6. Found the household routine was upset 1 2 3 4 9
7. Had less time to spend with friends..... 1 2 3 4 9
8. Neglected other family member's needs..... 1 2 3 4 9
9. Experienced family frictions and arguments 1 2 3 4 9
10. Experienced friction with neighbors, friends, or relatives
outside the home 1 2 3 4 9
11. Worried that you might become infected with HIV 1 2 3 4 9
12. Felt guilty because you were not doing enough to help 1 2 3 4 9
13. Felt guilty because you felt responsible for causing
(name's) illness 1 2 3 4 9
14. Resented (name) because he/she made too many demands
on you..... 1 2 3 4 9
15. Felt trapped by your caregiving role 1 2 3 4 9
16. Were upset about how much (name) had changed from his/her
former self..... 1 2 3 4 9
17. Found it painful to watch (name's) physical deterioration 1 2 3 4 9
18. Worried about what the future holds for (name) 1 2 3 4 9
19. Found the stigma of the illness upsetting..... 1 2 3 4 9

Family Environment Scales

The following are 18 statements about families. You are to decide which of these statements are true of your family and which are false. In responding to the questions, please refer to the family system involving the person with HIV/AIDS. If you think the statement is True or mostly True of your family, make an X in the box labeled T. If you think the statement is False or mostly False of your family, make an X in the box labeled F.

T F

- ☐ ☐ 1. We don't do things on our own very often.
- ☐ ☐ 2. Family members are rarely ordered around.
- ☐ ☐ 3. In our family, we are strongly encouraged to be independent.
- ☐ ☐ 4. There are very few rules to follow in our family.
- ☐ ☐ 5. We think things out for ourselves in our family.
- ☐ ☐ 6. There is one family member who makes most of the decisions.
- ☐ ☐ 7. We come and go as we want to in our family.
- ☐ ☐ 8. There are set ways of doing thing at home.
- ☐ ☐ 9. There is very little privacy in our home.
- ☐ ☐ 10. There is a strong emphasis on following rules in our family.
- ☐ ☐ 11. Family members almost always rely on themselves when a problem comes up.
- ☐ ☐ 12. Everyone has an equal say in family decisions.
- ☐ ☐ 13. Family members strongly encourage each other to stand up for their rights.
- ☐ ☐ 14. We can do whatever we want to in our family.
- ☐ ☐ 15. It's hard to be by yourself without hurting someone's feeling in our household.
- ☐ ☐ 16. Rules are pretty inflexible in our household.
- ☐ ☐ 17. We are not really encouraged to speak up for ourselves in our family.
- ☐ ☐ 18. You can't get away with much in our family.

Extroversion

Please answer each question by marking an "X" beside the "YES" or "NO" following the question. There are no right or wrong answers, and no trick questions. Work quickly and do not think too long about the exact meaning of the question.

1. Are you a talkative person? YES ☐ NO ☐
2. Do you have many different hobbies? YES ☐ NO ☐
3. Are you rather lively? YES ☐ NO ☐
4. Can you usually let yourself go and enjoy yourself at a lively party? YES ☐ NO ☐
5. Do you enjoy meeting new people? YES ☐ NO ☐
6. Do you tend to keep in the background on social occasions? YES ☐ NO ☐
7. Do you like going out a lot? YES ☐ NO ☐
8. Do you prefer reading to meeting people? YES ☐ NO ☐
9. Do you have many friends? YES ☐ NO ☐
10. Would you call yourself happy-go-lucky? YES ☐ NO ☐
11. Do you usually take the initiative in making new friends? YES ☐ NO ☐
12. Are you mostly quiet when you are with other people? YES ☐ NO ☐
13. Can you easily get some life into a rather dull party? YES ☐ NO ☐
14. Do you like telling jokes and funny stories to your friends? YES ☐ NO ☐
15. Do you like mixing with people? YES ☐ NO ☐
16. Do you nearly always have a "ready answer" when people
talk to you? YES ☐ NO ☐
17. Do you like doing things in which you have to act quickly? YES ☐ NO ☐
18. Do you often take on more activities than you have time for? YES ☐ NO ☐
19. Can you get a party going? YES ☐ NO ☐
20. Do you like plenty of bustle and excitement around you? YES ☐ NO ☐
21. Do others think of you as being very lively? YES ☐ NO ☐

APPENDIX B

Cover Letters

Cover / Consent Letter
First Sample Recruitment

The purpose of this study is to gain a better understanding of those providing support to someone with HIV/AIDS. To accomplish this, a questionnaire is being developed to assess how individuals make decisions about telling others that they are providing support for a person with HIV/AIDS. To ensure that the questionnaire is an accurate reflection of social disclosure variables, participants are asked to complete several related brief questionnaires. Total time to complete the packet should be between 15-20 minutes. It is possible that reflecting on the process of providing support for someone with HIV/AIDS may be uncomfortable for you at times. Your participation in this project is completely voluntary and you are free to stop at any point. All results will be strictly confidential and participants will remain anonymous in all reports of the research findings. When the study is completed, a summary of the results will be mailed to all participating AIDS organizations. You indicate your voluntary agreement to participate by completing and returning this questionnaire. Although I am currently working at Rockhurst College, this project is being conducted as my dissertation research through Michigan State University.

Thank you,

Rick Hanson
Principle investigator
Michigan State University

Dr. Nancy Crewe
Supervising faculty

Cover / Consent Letter
Second Sample Recruitment

The purpose of this study is to gain a better understanding of those providing support to someone with HIV/AIDS. To accomplish this, a questionnaire is being developed to assess how individuals make decisions about telling others that they are providing support for a person with HIV/AIDS. If you are HIV+, please pass this on to a family member (parent, sibling, spouse/partner, long-time friend) who is a primary source of support for you. To ensure that the questionnaire is an accurate reflection of social disclosure variables, participants are asked to complete several related brief questionnaires. Total time to complete the packet should be between 15-20 minutes. It is possible that reflecting on the process of providing support for someone with HIV/AIDS may be uncomfortable for you at times. Your participation in this project is completely voluntary and you are free to stop at any point. All results will be strictly confidential and participants will remain anonymous in all reports of the research findings. When the study is completed, a summary of the results will be mailed to all participating AIDS organizations. You indicate your voluntary agreement to participate by completing and returning this questionnaire. Although I am currently working at Rockhurst College, this project is being conducted as my dissertation research through Michigan State University.

Thank you,

Rick Hanson
Principle investigator
Michigan State University

Dr. Nancy Crewe
Supervising faculty

APPENDIX C

Recruiting Letter

Recruitment letter

Friends and family members play an enormous role in a person's response to HIV/AIDS. They are on the front lines providing support emotionally, physically, and financially. As care for those with HIV/AIDS has shifted from hospital-based to community-based and in-home care, informal caregivers have assumed greater responsibility and made the shift possible. Unlike professional care providers, informal caregivers are often on-call 24 hours a day and are not protected by a limited work day or professional distance. Many informal caregivers have never cared for a seriously ill person, nor have they been asked to provide medical care or monitor medications. The process of providing care can at times be exhausting and overwhelming. As a support group co-facilitator, I have noticed that a common source of stress among caregivers involves the social stigma associated with AIDS which remains prevalent in our society. In addition, people greatly affected by AIDS are often already stigmatized populations: gay men, injection drug users, African-Americans and Latinos. Caregivers may fear social rejection, loss of job and /or housing and may thus conceal their caregiving status from family, friends, and co-workers. Decisions about who to tell, if anyone, and at what point, become significant. Unfortunately, very little has been written about how we can be most helpful to caregivers at different points in the illness.

I am currently finishing my doctorate in counseling psychology from Michigan State University and have elected to focus my dissertation research project in the area of informal HIV/AIDS caregivers. I am currently inviting individuals who are involved in providing direct support for someone with HIV/AIDS to participate in the research project. Eligible participants include those who have personal contact (not just by phone) on at least a twice a month basis. The goal of the research is to better understand how caregivers find and utilize support at various points in the illness. Better programs and resources can then be developed to assist in this process, but I need your help.

Individuals who choose to participate will be mailed a packet containing several brief questionnaires to be filled out and returned. It is important to have caregivers representing different points across the stages of the illness. This includes those who have only recently been informed of a loved ones HIV/AIDS status through those who have been involved in providing support for many years.

Participation will be confidential and your name will not be associated with questionnaire packet you return. If you, or someone you know would be interested in participating or receiving more information, please call 1-800-203-7717 or e-mail me at r_hanson@vax1.rockhurst.edu. I will be happy to provide additional information or forward a research packet to you. Please provide a mailing address.

Thank you,

Rick Hanson

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