MICHIGAN STATE UNIVERSITY LIBRARIES
3 1293 00916 3357

This is to certify that the

dissertation entitled

Toward a Theory of Care Partnering: The Role of Third-Party Carers in the Illness Management Systems of AIDS Patients

presented by

Eric George Zook

has been accepted towards fulfillment
of the requirements for

Ph.D. degree in Communication

Katherine Miller
Major professor

Date 4/19/91

MSU is an Affirmative Action/Equal Opportunity Institution

O-12771

LIBRARY
Michigan State
University

PLACE IN RETURN BOX to remove this checkout from your record.
TO AVOID FINES return on or before date due.

DATE DUE	DATE DUE	DATE DUE
[illegible] NOV 1 [illegible]		

MSU Is An Affirmative Action/Equal Opportunity Institution
c:\circ\datedue.pm3-p.1

Toward a Theory of Care Partnering: The Role of Third-Party Carers in the Illness Management Systems of AIDS Patients

By

Eric George Zook

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

DOCTOR OF PHILOSOPHY

Department of Communication

ABSTRACT

Toward a Theory of Care Partnering: The Role of Third-Party Carers in the Illness Management Systems of AIDS Patients

By

Eric George Zook

An examination of the role played by third-party persons in the context of AIDS was conducted through a focus on what is termed the "care partner" (CP). Following a review of the literature which revealed the second class status of third parties in the relational dynamics associated with acquiring medical care in the face of illness, a grounded theory investigation of the CP's role for persons with AIDS was undertaken. Using a sample of 22 CPs for persons with HIV infection/AIDS, the core construct of <u>CP involvement</u> was identified. This was conceptualized as a multidimensional variable encompassing CP selection from a range (100) of potential activities: hospital care, home care, medical appointments, medical regimen compliance, information search, and emotional support. It was shown that a extensive variation exists among CPs in terms of both the nature and degree of involvement with the patient's illness. This variation in involvement was linked to differences in the CP interaction with medical professionals, and on the degree of perceived uncertainty about the patient's illness as reported by CPs. Factors which influence CP choice among involvement possibilities were also identified: patient health status, CP life philosophy/personality, CP motivation to care, prior CP experience, CP-patient relational history, and structural limitations. CP involvement was examined as a bridge construct that links individual CP desires with actual involvement established through "negotiations" with the patient and medical staff. Finally, quantitative analysis revealed a strong discrepancy between perceived and objective knowledge about HIV infection and patient prognosis. Consequently, CPs who perceived themselves as knowledgeable were less likely to report suffering from psychological and physical problems than were CPs who actually had greater objective knowledge. The theoretical implications of these findings were then applied to work in illness management, social support and empathy.

Copyright by

ERIC GEORGE ZOOK

1991

To the Critical Spirit,

upon which alone rests the fate of humanity

ACKNOWLEDGEMENTS

My deepest gratitude is extended to Katherine Miller who has nurtured me from naive neophyte into sensitive scientist. We took the plunge into qualitative research together, an approach which helped me grow both analytically and spiritually. Her understanding, concern and intelligence nourished this project through many a last-minute deadline and other rough terrain.

Heartfelt appreciation as well goes to the rest of my committee: Jim Stiff, Alicia Wilson, Rebecca Henry, and Mary McCormack. Thanks for all the criticism and support which forced this into a more complete and satisfying shape.

Unpayable debts are owed Marge Barkman for guiding me safely through the bureaucratic jungle, and for just being a safe haven during the rough storms in my personal life.

Finally, I wish to thank Stacy Stelter, my dearest friend and playmate. She likely suffered more than I in the course of being near me throughout this project. Her enthusiasm and drive to live a life worth living has been a constant source of enjoyment; I look forward to achieving all our dreams.

TABLE OF CONTENTS

Chapter Page

Chapter Page

LIST OF TABLES

Table Page

LIST OF FIGURES

CHAPTER ONE: LITERATURE REVIEW

> "The sick are better cared for [in hospitals] with less waste of energy, their presence in the home does not interrupt the occupations and exhaust the means of wage earners...The day of the general home care of the sick can never return," (Hurd, 1913).

Eighty years later, this statement appears staggeringly naive. General home care of the ill is back--with a vengeance. The increasingly chronic nature of illness in the United States has rendered inadequate much of our current medical system with its acute-illness orientation (Strauss & Corbin, 1988). And as chronic illnesses have created pressure for new forms of general institutional care, attempts to control the burgeoning cost of health care have reduced the allowable institutionalization for even standard acute ailments. The mixture of chronicity and health care finance reform has yielded individuals with recurrent health problems that must be handled primarily via out-patient treatment and limited hospital stays. Thus, the nature of illness treated in the home has increased in both quantity and quality; more hands-on care for a wider variety of illnesses is being provided in non-institutional settings than perhaps ever before in our history.

Despite the existence of community agencies (e.g., hospice, visiting nurse associations, respite care centers) the bulk of home health services are provided by the family.

Estimates of family involvement in home health care range from 75% to 90% (Brody, 1985; Brody, Poulshock, & Masciocchi, 1978). Such statistics have led Strauss and Corbin (1988) to argue that "the home should [now] be at the very center of care. All other facilities and services should be oriented toward supplementing and facilitating the work done at home," (p. 150, emphasis in original).

Given these societal changes in the locus of health care, it is important to examine the health partnership of family care providers and medical personnel. This is the aim of the current study. The home care partner is viewed as the primary provider of care; the medical staff is presented as one element of a support universe available to assist care partners in illness management. This universe also includes family and friends, support groups, and community agencies. While much research has examined interactions between care partners and other members of the support universe, little emphasis has been directed to the medical professional/home care partner relationship.

The theme developed here is that medical professionals play a crucial role in the care partner's ability to cope effectively with stress, provide quality care, and generally care for their own health. However, the health care system has traditionally emphasized the physician-patient relationship to the general exclusion of any third party carer. An investigation of the grounds for this tradition points up its inadequacy for today's health problems.

Accordingly, the following sections explore the unique dimensions of AIDS as a chronic illness and the stresses experienced by care partners for persons with AIDS (PWAs). Implications for both the patient and care partner are discussed. Potential matches between care partner needs and resources existing in their support universe are presented, with particular emphasis on the relationships with medical personnel. A number of specific communication themes are examined for their impact on care partner well-being and function. These are: availability of medical staff, clarity and completeness of information exchanged, expressed empathy of medical providers. Information sources and stragies of information seeking are also investigated.

CARE PARTNER VS. CAREGIVER: AN IMPORTANT DISTINCTION

Research on the role of third-party, lay care assistants (typically family members) has generally referred to them as "caregivers." This term is exchanged in the current research for the more appropriate referent of "care partner." This latter term places greater emphasis on the shared nature of most illness situations. That is, patient care is achieved through a <u>sharing</u> of the required tasks. Caregiving, on the other hand, more adequately describes the nature of involvement during times when the patient is fully unable to participate in his/her care (i.e., through lack of consciousness or impaired mental function).

The shift toward viewing care as a shared experience grows out of research on alterations of relational reciprocity during illness (Brown). This view argues that in most relationships, individuals seek to maintain a balance between giving and receiving. Illness generally creates an imbalance by simultaneously lowering the patient's ability to repay assistance and necessitating greater dependence on an other or others for various forms of assistance. However, it is increasingly recognized that normalizing a strongly imbalanced relationship between care assistants and patients has potential detrimental effects for both parties: patients become overly dependent and more detached from life, and care assistants become burned-out as a result of trying to do "everything" for the patient in addition to meeting other daily responsibilities. Thus, patients are encouraged to be involved and as independent as possible, while care assistants are urged to restrict their tendency to continually "do" for the patient.

The emphasis on shared care is also more consonant with changing perceptions of how care is provided within medical institutions as well. In opposition to the model of a passive patient recipient, Strauss, Fagerhaugh, Suczek, and Weiner (1985) have illustrated the various forms of "patient work" required to sustain the interdependency between patients and medical staff.

To greater reflect the changes occuring both in formal medical care institutions and home care, "care partner" is used herein to refer to the primary non-medical assistant utilized by a patient in the care and management of his/her illness.

AIDS: PAST AND PRESENT

As with most avalanches, it began small. In late 1979 and early 1980, young gay men on the coasts of America began to succumb to a series of inexplicable illnesses. Each was seemingly immune to the curative efforts of medical personnel. The diagnoses made in these cases provided little further explanation: toxoplasmosis (a mild illness which may cause fever and swollen lymph nodes in healthy adults), cytomegalovirus (typically mild and unnoticeable), oral thrush (also known as candida, a generally mild yeast infection), pnuemocystis carinii pneumonia (found only among people with marked immunosuppression), and Kaposi's sarcoma (a rare form of cancer found primarily in elderly men and people with lowered immunity). Though clear that all the patients suffered severe immune suppression, it was far from clear as to why.

By 1985, Drs. Luc Montaigner and Robert Gallo had supplied the probable answer--a retrovirus which came to be known as HIV (human immunodeficiency virus). It was transmissible through body fluid exchange, predominantly sexual intercourse and blood. The growing spread of infection occurred specifically among those with high risk exposure to such exchanges: gay males with promiscuous sexual histories, partners of infected persons, intravenous (IV) drug users, and those receiving blood product transfusions, particularly hemophiliacs.

At the close of 1990, 63 percent of the 161,073 cases of AIDS diagnosed since June 1981, had died (NYT, 1/25/91). With another 1 to 1.5 million additional Americans predicted to be infected with HIV, the Centers for Disease Control predicts that another 215,000 Americans will die from AIDS in the next three years. One study predicts that over half of all HIV-infected patients will develop AIDS, and another 25 percent will develop AIDS-related complex within nine years of infection (Eckholm, 1989). In fact, individuals may remain asymptomatic for seven to eight years following infection. Upon diagnosis of full-blown AIDS, the majority die within two to three years (though 10 percent live at least five years).

AIDS is a medical designation which refers to the latter stages of HIV infection. It is typically diagnosed through the presence of the opportunistic infections which first alerted researchers to the problem: pnuemocystis, Kaposi's sarcoma, cytomegalovirus, chronic lymphadenopathy, and diffuse, undifferentiated non-Hodgkin's lymphoma. Prior to contracting one or more of these identifying opportunistic infections, persons with AIDS (PWAs) often experience what is by now a familiar litany of symptoms: wasting syndrome, fatigue, night sweats, vomiting, and diarrhea. This is commonly referred to as ARC, or AIDS-related complex.

The course of illness is generally slow, progressing through a continual weakening of the immune system with a concomitant limitation of function. This corresponds to what Strauss and Corbin (1988) term a "downward illness trajectory." That is, the patient experiences a slow, steady progression toward death. This path usually carries the PWA through a series of acute crises such as recurrent pnuemocystis or the development of additional infections. Each new illness episode further weakens the immune system, creating the rapid, negative spiral toward death which typically follows the diagnosis of AIDS.

Though the downward trajectory remains a generally accurate description of HIV infection, its slope has grown less steep. This is the result of better treatment protocols for the opportunistic infections that resulted in the deaths of many PWAs during the early stages of the epidemic, the implementation of AZT to treat the depletion of the immune system, and the more recent extension of AZT treatment to all those testing HIV+ (Friedland, 1990; Volberding, et al., 1990).

Pnuemocystis has long been the primary cause of death for PWAs. However, the increasing preventative use of aerosol pentamidine, in combination with AZT and Bactrim, has proved effective (Altman, 1990). Acting more directly on the underlying mechanism by which the immune system is weakened, AZT slows the replication and spread of HIV. However, the drug has severe side effects which eventually require abandonment of the drug. Experimental trials of a treatment protocol whereby patients alternate between AZT and a second antiviral drug with equally severe but different side-effects, ddI, shows promise as a method for overcoming toxicity effects of constant AZT therapy. Finally, in what is at last a strong incentive for people to determine their HIV status, a recent study has found that AZT treatment for asymptomatic HIV+ individuals delays the onset of AIDS (Volberding, et al., 1990). While such patients can better handle the toxicity of AZT, the longer treatment time makes the development of better alternatives imperative. Whatever the promise of AZT and ddI, neither drug alone or together, represents a cure. As of yet, the course of the illness may only be slowed, staving off the end.

The added years of life afforded PWAs through these advances, however, are not all pleasant. In fact, this the bitter parody of the extension of life expectancies in industrialized countries during the last century, people now succumb to a wider range of more chronic ailments. With AIDS, however, the process has occurred in a mere decade. As pneumocystis declines, increases are being noted in cancers such as Kaposi's sarcoma and a host of other secondary infections such as wasting syndrome and cytomegalovirus retinitis (Altman, 1990). Medical regimens for treating this widening array of viral, fungal and bacterial infections are increasingly complex and may somewhat reverse the trend toward shorter hospital stays and greater outpatient treatment for PWAs. According to Dr. Merle Sande, chief of medicine at San Francisco General Hospital, "AIDS is a different disease than it was last year," (Altman, 1990).

Stigma and Discrimination

One thing which does not appear to have changed, however, is the stigma and discrimination (Goffman, 1963) many HIV+ persons and PWAs experience as a result of their infection. A recent study by the American Civil Liberties Union found that despite greater knowledge that casual contact does not put one at risk for AIDS, discrimination increased from less than 400 reported cases in 1984 to 92,548 in 1988 (Hilts, 1990). This can be partially attributed to the greater number of infected individuals and

PWAs, but it also reveals that the abatement of the AIDS hysteria which gripped the country in the early 80s has not caused automatic acceptance of affected persons. Employment discrimination was the most frequently cited, followed by housing, public accommodations like nursing homes, insurance, access to government services such as Medicare, access to health care services, and violence.

From the onset of the epidemic, discrimination was driven by both the transmissibility of a recognized terminal illness, and the already stigmatized nature of the main transmission methods (Siegel, 1986). Very few people infected with HIV were seen as innocent, a view which likely holds true still today. Such attitudes exist even among the medical professionals to whom PWAs must turn for care.

Basically, professional health care providers have been motivated by the same concerns with personal well-being and moral approbation as the general population. Blumenfield, et al. (1987) found that 59 percent of nurses in their sample believed AIDS could be transmitted despite infection control precautions and a similar number feared AIDS more than viral hepatitis which also passes through body fluids. Kelly, et al. (1987) found that physicians made harsher judgments of a patient with AIDS when compared with a leukemia patient, including greater responsibility for illness, more deserving of the pain and suffering accompanying the illness, and less deserving of sympathy and understanding. There was also lower willingness to socialize with an AIDS patient. Other reactions include preoccupations and nightmares about giving AIDS to one's family and reporting symptoms of AIDS (Gerbert, Maguire, Badner, Altman & Stone, 1988).

Pomerance and Shield (1988) present findings which suggest that greater contact and transmission knowledge can increase interaction comfort as well as reducing perceptions of stress and risk. All employees had had some contact with PWAs. Those with greater patient contact experienced less discomfort but still reported high stress and greater perceptions of risk. Employees with more accurate transmission knowledge experienced greater comfort and reduced perceptions of stress and risk. Despite these positive signs, however, doctors reported greater vulnerability to stress and lower levels of comfort, while nurses and technicians reported higher perceptions of risk based on their greater exposure to body fluids.

The consequences of negative medical staff attitudes regarding care of the HIV+/AIDS patient are illustrated by Gerbert, et al., (1988). Their review of the literature on staff attitudes revealed potential reductions in job performance and enthusiasm, lessened ability to respond to PWAs' psychological needs. Such negative attitudinal outcomes have clear implications for the quality of patient care (Siegler, 1979). Gerbert, et al. (1988) also report that physicians engage in persistent referrals to others for reasons of a purposely maintained lack of knowledge, as well as more directly refusing to treat patients with AIDS. Such care avoidance may be positive to the extent that patients are encouraged to find more willing, empathic providers. However, this avoidance is contributing to the critically shrinking pool of medical personnel available to patients in two ways. First, as greater numbers of HIV+/AIDS patients seek treatment from a proportionately small number of physicians, case loads become unmanageable to the point that quality of care must be compromised and/or the physicians become overly stressed and burnout. Second, when stress-related departures from the pool occur, negative attitudes in other physicians restrains the influx of "replacement" personnel. Thus, lack of a critical mass of providers to shared case demand is creating a potential for demand to greatly outstrip supply, with the burden falling once more upon the formally invisible care partner.

In sum, the picture presented of AIDS is far from uplifting. The future holds an increase in AIDS diagnoses despite slowing infection rates as those already infected worsen, a worsening patient/physician ratio, greater restrictions of funding, a continued lack of appropriate institutional care options, and longer life spans characterized by more troubling, complex illnesses. This stark view and the stigmatized nature of HIV+/AIDS is a driving factor behind Tiblier, Walker, & Rolland's (1989) emphasis on the importance of family members for AIDS patient care:

> 'Business as usual,' focusing solely on the patient and utilizing only the traditional service model, will not meet the enormous pressures AIDS puts on the entire family and health care system. Professionals who work with persons with AIDS will be unable to provide adequate care without the help of the client's family, friends, and significant others. (p.82).

THE CASE FOR FORMAL INVOLVEMENT OF CARE PARTNERS

The case for more formal recognition and inclusion of care partners in the system of health care delivery can be made on a number of points: (1) the large number of *de facto* care partners currently assisting an ill partner, (2) the increasing complexity of care requirements associated with providing care in the home as well as negotiating the health care system at the community level, and (3) the known stress involved in home care provision. As greater numbers of care partners provide a wider range of assistance to patients, their efforts cannot be ignored by the medical community. Rather, by providing *formal* recognition and creating a role for the care partner on the patient's care team, the expended efforts can be shaped and guided by medical professionals for the better care of the patient and the greater well-being of the care partner and medical staff.

By sheer dint of numbers involved, third party carers are making themselves felt in the American health care system. This system increasingly relies on the patient's ability to involve others, typically one primary other, in the maintenance of function and survival. Several factors over the past 60 years have intensified the importance of the willing involvement of care partners: (1) the increasingly chronic nature of illness in the United States and other industrial nations which have succeeded in extending life via technological and medical breakthroughs, and (2) the efforts of health care finance reform to control burgeoning expenditures in a time of increasing fiscal restraint. These forces, which combine to exert tremendous pressure on our health care institutions, are examined in the following sections.

Increases in Chronic Illness

The increase in chronic illness is the outcome of two major social trends. First and foremost, changes in public health (e.g., public sanitation, improved nutrition) and the conquest of infectious diseases through the use of vaccines and antibiotics produced a sharp decrease in common forms of illness and death (Callahan, 1990). Second, the improvements in public health and curative means for viral illness combined with a large birth rate following World War II to yield a burgeoning elderly population in the United States. Each of these developments is explored below.

Prior to the 1930s, disease and death were the result of viral causes and poor public health (Strauss & Corbin, 1988; Callahan, 1990). Common virus-induced diseases were streptococcal infections, epidemic meningitis, whooping cough, and polio (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, 1984). These infectious diseases spread widely due to inadequate public health standards and were often deadly due to a lack of knowledge about viral causes. The development of vaccines to combat viruses and improvements in public health systems resulted in the extension of the average human life span, currently placed at 75.4 years (though that of blacks is at a lower 69.4; Callahan, 1990). Whatever the benefits, both real and supposed, of this longer life span, it has yielded, as one negative result, a significant increase in the development of chronic illness. Callahan (1990) reports that comparison of chronic illness figures for the periods of 1969-1970 and 1979-1980, reveals a 21.8 percent increase for the total United States population. And these chronic illnesses are increasingly the major causes of death in our country as seen by the placement of heart disease, cancer, stroke, and various dementias in the top ten causes of death (Callahan, 1990).

The second trend producing greater chronicity is the aging American population. By the end of this century, persons over 65 are expected to represent 13 percent of the population. By the year 2050, this figure is projected to rise to 20 percent (Stone, 1987). The largest projected increase is a 53 percent rise among those 75 and older by this century's end (Steinmetz, 1981). Clearly, this latter group is the most vulnerable group to physical and mental crises that will require the assistance of family and other societal segments.

Overall statistics on the significance of chronic illness in the United States are even more staggering (Cluff, 1981). Eighty percent of resources for health care in the United States are devoted to chronic illness (Somers, 1971). Over 30 million Americans suffer some chronic dysfunction and over half are limited in or unable to carry on major life activities such as work, maintaining a household, and achievement of other common survival needs (Rice & Hodgson, 1978). Sixty percent of patient days in hospitals are for acute episodes derived from chronic illness. Finally, chronic ailments account for 52 percent of visits to doctors for diagnosis and treatment.

These two forms of increasing chronicity in American health care are symbolically represented by AIDS--which has become the second leading cause of death among men 25 to 40 years of age (NYT, 1/25/91)--and Alzheimer's, which has emerged as the fourth leading killer of adults (especially those over 65), taking more than 100,000 lives annually and predicted to affect more than 4 million people currently

(Gelman, Hager & Quade, 1989). Thus, young and old alike are suffering from chronic/terminal illnesses in greater and greater numbers.

This greater chronicity has created a host of problems for traditional health care delivery systems. These problems derive primarily from the fact that increasing numbers of people are suffering some form of impairment for greater amounts of time. This has created a greater demand for palliative rather than curative care (Corbin & Strauss, 1989; Cluff, 1981), an area traditionally outside the domain of the physician's role, and only partially built into that of the nurse. This shift has also carried illness beyond the structural design of hospitals which focused heretofore on short-term medical assistance for acute ailments.

And while the American medical system struggles to reorient their care toward the chronic patient, it must do so with fewer fiscal resources. Thus, the crisis in health-care financing and attempts by private and public insurers to reduce costs are creating the conditions by which care partners will bear the brunt of demands presented by the chronic/terminal patient.

Health Care Finance Reform

In 1989, about $600 billion was spent on American health care (Egan, 1990). This amounts to an an average of $2,200 per citizen, and represents a greater portion of the gross national product than any other major industrialized country in the world (Culhane, 1990). Of this total expenditure, 72 percent is paid by private insurance, business, philanthropists and the government. Efforts are under way in each of these sectors to control the burgeoning cost of American health care. Most notable and far-reaching, however, is the government adoption of the reimbursement format of diagnostically related groups (DRGs) (Fischer & Eustis, 1988).

In 1983, Congress reorganized the reimbursement system by which care provided for Medicare and Medicaid patients was compensated. Related diagnoses were grouped into 470 DRG categories, each grouping receiving a specified maximum reimbursement fee. Because profit can only be garnered by spending less than the total reimbursement, the system provides incentives to hospitals and physicians to reduce reliance on expensive procedures and lengthy hospital stays. The program appears to have achieved some level of success on this latter goals. The length of stay for Medicare patients reveals sharp decreases in both 1984 and 1985 (Fischer & Eustis, 1988). This corresponded with an increase in the use of nursing homes and health care agencies. As predicted, patients are released earlier and thus in need of longer recuperation at home.

A more recent national study of the impact of DRGs on the quality of medical care for the elderly reports conflicting results (Kosecoff, et al., 1990). In general, researchers found little evidence for a decline in care quality during hospitalization, citing that doctors and nurses appeared to be providing better physical exams, diagnostic tests and treatment. Estimates of poor quality care declined from 25 percent to 12 percent, despite a reduction in length of hospital stays from 10 days in 1983 to 8.5 days in 1989. Further, the researchers report a 1.1 percent drop in death rates for the five most serious diseases covered by Medicare during the critical 30-day period following admission when most deaths occur. <u>However</u>, the study also found that patients discharged in a medically unstable condition rose from 10.3 percent to 14.7 percent. When compared with medically stable discharges, the unstable patients were 50 percent more likely to die within 180 days of being discharged. Investigation of nursing home stays following discharge revealed no significant increase, suggesting that the majority of patients, both stable and unstable are returning to their own or their family's home.

This contention is supported in the statistics on home health care for the elderly. Of this population, only one in five reside in nursing homes (Stone, 1987). Three quarters of the non-institutionalized disabled elderly rely solely on informal sources for care provision (Stone, 1987). The main informal care source is families, who provide approximately 80 percent of all home health care for those who need it (National Center for Health Statistics, 1972; Brody, 1985).

Such numbers are less readily available for AIDS patients. Due to the cyclical nature of their condition AIDS patients are more apt to shuttle between hospital and home, as well as stays in long-term care facilities such as nursing homes. Calculating the numbers who receive home care is thus almost impossible. Emotional, illustrative case examples, however, are provided by Monette (1988) and Peabody (1986).

It is clear then that developments in the United States regarding both the nature of illness and methods for funding medical care have yielded what may realistically be labeled a crisis in modern medicine. What keeps the medical system afloat in the face of contradictory demands for greater care with fewer dollars is the existence of care partners who have been required to take on greater care responsibilities. As part of the solution to the crisis in health care, however, care partners have not typically been included in formal policy statements, despite increasing documentation of the difficult role played by such individuals (Stone, 1987; Brody, 1985). And it is more the detrimental quality of care partner experiences than the sheer number of care partners that gives weight to calls for greater formal recognition of and attention to their efforts. Of particular concern is the stressful nature of care assistance which both harms the care partner and impacts the quality of care they are able to provide the patient.

CARE PARTNERING STRESS

Stress experienced by care partners is determined to a large degree by the amount of impairment suffered by the patient (Silliman & Sternberg, 1988). Care partners of PWAs face are placed in the problematic situation of facing stressors specific to HIV+/AIDS in addition to those associated with other terminal, chronic illness (Tiblier, Walker, & Rolland, 1989).

Patient Impairment and Care Partner Stress

The stress of care partnering for someone with a terminal, chronic illness like AIDS is based on the direct relationship between the patient's <u>level of impairment</u> and <u>care partner burden</u> (Goldstein, Regnery & Wellin, 1981). Impairment consists of the degree to which a person can act independently to meet his or her needs for survival. Impairment may arise from either physical or mental dysfunctions, and range from no impairment (e.g., a typically healthy adult) to full impairment (e.g., paralysis victims or the severely mentally disabled). Impairment may be tracked on illness trajectories (Strauss & Corbin, 1988) which map the length and degree of impairment. In some instances, the trajectory is primarily stable, punctuated by acute episodes (e.g., asthma, arthritis, diabetes). In illnesses such as Alzheimer's and AIDS, the illness trajectory is one of steady gradual decline with ever increasing levels of impairment until death.

Increases in patient impairment are associated with a concomitant rise in care partner burden, which is defined as negative perceptions with regard to patient involvement (Ellis, Miller, & Given, 1989; Given, Stommel, et al, 1988). Lower levels of burden are associated with situations where required assistance focuses on instrumental activities of daily living (IADL). These involve various transportation issues such as getting to and from appointments (medical, beauty, etc.), buying groceries and doing yard work. Impairment is not severe; the patient is able to care for him or herself, and can usually live independently. Higher levels of burden occur when assistance is required for activities of daily living (ADL). These involve more personal aspects of care such as bathing, dressing, feeding and toileting. Impairment at this level is quite severe, often requiring 24-hour contact with a care partner who can provide assistance necessary for survival.

While the underlying connection between patient impairment and care partner burden has more recently been designated as the central phenomenon in home care, the mental and physical strain of being a care partner has long been recognized (Goldstein, Regnery, & Wellin, 1981). The connection to impairment focuses attention on the patient's illness trajectory which may be used to rationalize treatment and assessment of care partner strain and/or ability to meet demands of care. As patients move through the course of chronic illness, the care partner burden-patient impairment link translates into a variety of stressors.

General Stressors

A number of stresses involved with care partnering the person with AIDS are common to other terminal, chronic illnesses. Initial diagnosis, many times accompanied by an acute crisis, is inherently stressful. While patients may experience some relief from the legitimization of symptoms by the medical community, this is offset by the substantial ambiguity remaining. The patient and his or her family typically lack knowledge regarding the illness, its prognoses and treatment, and the specialized care needs necessary for maintaining the patient at home (Nichols, 1987; Greif & Porembski, 1988; Speedling, 1982). Particular difficulty may be experienced in learning to operate medical equipment in the home (Nichols, 1984; Black, Hersher, & Steinschneider, 1978).

As the illness advances, the patient often experiences changes in body image and functioning (Corbin & Strauss, 1988; Teusink & Mahler, 1984). This may lead the patient to strike out, both verbally and physically, against the care partner, venting personal frustrations at the illness-

imposed limitations (Peck, 1983; Turk, 1979). In addition to coping with such outbursts, care partners must also deal with their personal grief over the loss of the loved one and life as it once was. Dreams, hopes, perhaps the very foundation upon which life was constructed, are altered in the face of chronic illness. What was once important may now seem worthless or, more negatively, impossible to achieve despite strong remaining desires.

The unique demands of the chronically ill individual compete with the normal requirements of work and family, creating yet an additional source of stress. The result is often a curtailment of leisure activities as personal time gets absorbed by duties involving demanding others (Nichols, 1987, Teusink & Mahler, 1984). Such role conflict is a key element in care partner fatigue (Goldstein, Regnery & Wellin, 1981).

Clearly, the development of a successful illness management system is necessary to help care partners balance significant role demands. To the extent that this is not achieved, additional stressors accrue. One of the greatest is family conflicts over negotiation of care (Teusink & Mahler, 1984). To the extent that issues of care responsibility are not satisfactorily resolved, the potential strength of the family system dissolves into a deeply frustrating irritant.

The care partner is often assailed by these various stressors in relative social isolation. Family abandonment can occur in subtle ways once other family members are confident that someone is providing care (Grieco & Kowalski, 1987). Time to interact with friends is restricted as impairment worsens and care requirements increase. As social resources are cut off, the care partner has less chance for respite and ventilation of frustrations and grief. Research by Ellis, et. al., (1989) reveal the importance of perceived social support and available social resources for helping care partners cope with care provision stressors.

Several researchers have noted the potential of family systems to become closer in response to such pressures (Corbin & Strauss, 1988; Longo & Bond, 1984). However, the potential for division, strife, hopelessness and collapse are very real.

AIDS-Specific Stressors

In addition to the "common" stressors associated with caring for the chronical/terminally ill, care partners for individuals with AIDS or HIV infection face additional stressors. First and foremost among these is the leakage of stigma from patient to care partner. The ACLU study of AIDS discrimination cited earlier reported that 30 percent of all reported incidents were directed at people <u>linked</u> to someone with AIDS (Hilts, 1990). Though noted in other terminal illnesses such as cancer (Sontag, 1978) the impact of stigma has been seen most strongly in association with AIDS since

the nature of the disease and its transmission is still in many ways unknown (Tiebler, Walker, & Rolland, 1989). Many people remain unconvinced that the virus is borne only through blood and semen, thereby creating a scenario in which infected persons are to be avoided at all costs.

Care partners too may have concerns about transmission, especially if they do not have much knowledge of or involvement with AIDS prior to assuming care responsibilities (Karolynn, 1986). This is most likely to occur in situations where a life style containing high risk behaviors has either been hidden or ignored by a family of natural origin. The diagnosis and increasing impairment of HIV infection eventually brings the lifestyle to light with resulting stressors of its own. At minimum, however, the care partner, as well as other family members, would typically benefit from a refresher course on transmission routes and precautions when HIV infects someone close to them.

The youth of AIDS patients is another unique stress. Over 90 percent of PWAs are between the ages of 21 and 48 (NYT, 1/25/91). The unfairness of youthful death can elicit strong negative emotions for both patient and care partner. When the care partner is a parent, the pain of outliving a child--an "unnatural" occurrence--exacerbates the situation.

For unrelated care partners, particularly those in gay relationships, lack of legal recognition may create further antagonism. In the worst cases, families of origin who view the gay lover as the cause of their son's death obstruct his involvement in care decisions. Other frustrations include non-recognition or outright discrimination by medical professionals.

Finally, as AIDS becomes more chronic in nature, the complications associated with it have grown, requiring matching complexity of medical regimens. As such, the knowledge and abilities required of care partners, particularly for home care, have increased. Grieco & Kowalski (1987) note a growing list of care requirements that can be transferred to the care partner in home care settings:

> "keeping a record of the amount of urine passed and of bowel movements; obtaining urine specimens and testing them for glucose, acetone, or blood; taking oral or rectal temperature; giving medications; observing the rate, regularity, and ease of respiration; taking the pulse rate, and noting its rhythm variations; changing wound or surgical dressings; giving injections; giving enemas; regulating the rate of flow of home intravenous fluids; and taking blood pressure," (p.79).

Additional tasks include providing physical assistance to the patient, and operating technical equipment (Katoff, 1989). Among patients with AIDS, care partners typically will need to help administer aerosol pentamidine as a preventative for pnuemocystis. Given the greater medical instability of persons being cared for at home and the more complex regimens thereby required, failure to adequately prepare the care partner can create additional stress.

Communication-Related Stressors

While care situations will always be inherently stressful, emotional stress can be directly linked to information deficits arising through problematic communication. Lack of knowledge about the illness in general, the patient's status and prognosis, care needs at home, and the skills necessary to fulfill them all undermine the care partner's confidence in his/her ability to meet all the demands created by the illness (Greif & Porembski, 1988; Nichols, 1987). Such knowledge deficits operate at both existential and practical levels.

At the existential level, the advent of a chronic/terminal illness such as AIDS presents the family system with a strong shock of ambiguity concerning how long the patient will live and in what condition. Mishler (1984) reports that the uncertainty associated with suffering more serious illnesses is strongly related to patient's stress, with clear implications for care partner reactions. Most troublesome is the uncertainty that remains even after complete knowledge of the illness is achieved. The course of a serious illness like AIDS is uncertain and volatile. No cure seems eminent. Hence, full, up-to-date knowledge may still prove ineffective for protecting the PWA from renewed infections and illnesses. The uncertain course of a serious illness such as AIDS, combined with the lack of a cure, creates a highly stressful experience for both the patient and care partner.

To deal with this stress, care partners attempt to construct meaning both cognitively and emotionally (Leventhal, Nerenz & Steele, 1989). At the cognitive level, there is a gathering of information about the patients prognosis and treatment, as well as general information about HIV infection. This produces a more or less accurate and complete picture of the physiological dysfunction. At an emotional level, however, care partners and patients seek to build an illness meaning which retains hope and emphasis on the quality of remaining life (Kleinman, 1988). Lack of information at the cognitive level may inhibit the ability of care partners to work with patients on the task of reconstructing a personal meaning of life.

More specifically, though not necessarily of greater importance, deficits of patient-specific information works to reduce care partners confidence in their ability to care for their ailing partner. Greif and Porembski (1988) reported that families of persons with AIDS (PWAs) expressed difficulty in coping due to lack of information regarding disease process, dietary restrictions, and transmission issues. Those involved in home care believed they were inadequately trained and found themselves under tremendous emotional strain. This is consistent with Nichols' (1987) finding that even after an intensive training period, 23 percent of care partners involved in renal dialysis reported being very tense and worried about the venipuncture procedure. Thirty-one percent complained of added stress and frustration associated with inconsistent and poor training which undermined already low confidence levels.

Information exchange in the face of chronic/terminal illness serves thus as an important stressor to the extent that its potential function as a stress reducer is not met. That is, appropriate information can ideally serve to help develop competence in both patient and care partner to meet the demands of the illness, both at the pragmatic and existential levels. If it is not forthcoming, as implied in the findings of the above studies, it serves to embellish rather than reduce problems of care.

Whether stress derives from general issues associated with chronic/terminal illness, AIDS-specific issues, or information deficits, it has clear implications on outcomes of care partner health. Stress is rarely something which is perceived without influencing function. Thus, it is important to consider how the stress faced by care partners plays out in the course of illness assistance to their partner.

Outcomes of Care Partnering Stress

Lazarus (1974) links perceptions of stress to situations in which personal coping resources are deemed insufficient to meet environmental demands. It has been argued above that unresolved uncertainty and rejection or abandonment by health care professionals will create a stressful situation. This will express itself through the care partner's negative reaction to care assistance (Given, et al., 1988). Such negative reactions have been shown to play a central role in creating emotional maladjustment in illness situations (Ellis, et. al., 1989):

> "...the care partner feels the negative effects of providing care to a large extent because he or she cannot participate in outside activities and has had responsibility for the patient thrust upon him/her by other family members. This social isolation and scheduling burden produces a cycle of health problems, negative reactions, decreased positive well-being, and depression," (p. 223).

When the perception of family abandonment is combined with the heavy demands exacted by care partner involvement in patient ADL, the ability to meet other life responsibilities is strained. This may ultimately lead to care partner fatigue, which influences negative reactions to the care situation.

Sustained negative reactions to care partnering displays itself in both the physical and psychological well-being of the care partner. Psychologically, the care partner may experience bouts of depression. In Nichols (1987) study of renal dialysis care partners, 61 percent felt depressed over spouse changes, 54 percent felt exhausted, many felt trapped and resentful, and 25 percent believed their own health to be deteriorating. Thompson and Haran (1985) conducted a study of 109 "key helpers" of amputees, and found 40 percent to be at psychological risk. Overall, they revealed a pattern of strain, emotional deterioration, isolation and a life beset with difficulties. Studies of care partners for dementia patients have identified depressive symptoms in 45% of the spouses sampled (Fiore, Becker, & Coppel, 1983; Haley, Levine, Brown, Berry, & Hughes, 1987). Further support is provided by Tyler, Harper, Davies, & Newcomb (1983) who studied 92 families of patients suffering from Huntington's chorea. Of the primary care partners in this sample, 82 percent reported being distressed, 39.5 percent were depressed and 21 percent were taking sedatives.

In relation to physical outcomes, care partners may engage in harmful self-medication habits (e.g., increased reliance on tranquilizers, alcohol, etc.) as they attempt to cope with stress. Nichols (1987) also found perceptions of health deterioration among care partners for renal dialysis patients. In a study of spouses of chronically ill patients, the highest complaint from the care partners was of increased fatigue and chronic tiredness (Klein, Dean, and

Bogdonoff, 1966). Finally, Quist (1989) cites a number of health problems faced by home care partners: sleep disturbances, insomnia, anorexia or an increase in appetite causing weight fluctuations, gastrointestinal problems, and headaches and backaches severe enough to warrant prescription pain relievers.

In one of the few published accounts of stress outcomes associated with AIDS care partners Trice (1988) reports the existence of "post-traumatic stress syndrome-like symptoms" a group of mothers whose sons had died of AIDS. This rather awkward but appropriate label refers to existence of both physical and psychological problems in the sample. Specifically, mothers who had provided extensive care during their sons' illness were twice as likely as mothers who did not provide care to have experienced divorce/separation, job turnover, night terrors and episodes of uncharacteristic violence. Care partner mothers also reported greater amounts of panic attacks and psychosomatic complaints. While the mere knowledge that a child has or is dying from AIDS is stressful, this study makes clear that actual involvement in caring for an AIDS patient has stronger deleterious effects.

When care partners are allowed to reach extreme levels of stress without adequate assistance, it is little wonder that their physical and psychological stability wears thin. As front line employees in the battle for health, medical professionals can play a significant role in care partner stress reduction. This can primarily be achieved through the transfer of requisite skills and information, combined with acceptance and encouragement (Strauss & Corbin, 1988).

The mandate for such interaction with medical staff is strongly stated in the advent of negative health outcomes for care partners. To this concern, Nichols (1987) adds a moral imperative: "...if the hospital staff simply conscript family members as ill-prepared, poorly informed, unsupported medical auxiliaries and abandon them in such a position, then they are fostering neglect which inevitably risks secondary illness in the form of psychological disorder, alcohol or drug problems, stress effects and psychosomatic illnesses" (p. 77). These are clearly potential harms to both the care partner and patient arising through dysfunctional relationships with medical professionals.

For purposes of the present study then, it is important to examine in what manner care partners' relationships with medical professionals influence their ability to successfully negotiate the demanding tasks of illness assistance. Specifically, the development of strong, positive relationships on both informational and emotional levels should reduce negative reactions by providing the care partner with a sense of competency and acceptance (Monette, 1988). Prior to a more explicit examination of the literature on medical staff interaction with third-parties in the illness situation, however, it is important to contextualize the role of medical personnel in the care partner's potential support system.

THE CARE PARTNER'S SUPPORT SYSTEM

A variety of support resources are available to aid the care partner in coping with the stressors of home care provision (Evashwick, 1987). These can be categorized into four general groups: (1) family and friends, (2) community agencies, (3) support groups and (4) medical professionals (see Figure 1). The effective provision of home care requires that care partners construct an illness management system which capitalizes on the differential expertise of these sources for dealing with specific problems. Needs and services can be matched for the mutual care and benefit of both care partner and patient.

As portrayed in Figure 1, however, stress and support flow along the same pathways (Thoits, 1986; Hobfoll, 1986). Social interaction, especially in stressful situations of need and crisis, is never fully positive and accepting. One's support system must therefore possess the capability of absorbing or deflecting negative interactions. An individual's overall level of support then can be conceptualized as the proportion of positive to negative interactions with others. Given this more balanced view of social support, the following section discusses the role of each general support source in assisting home care partners.

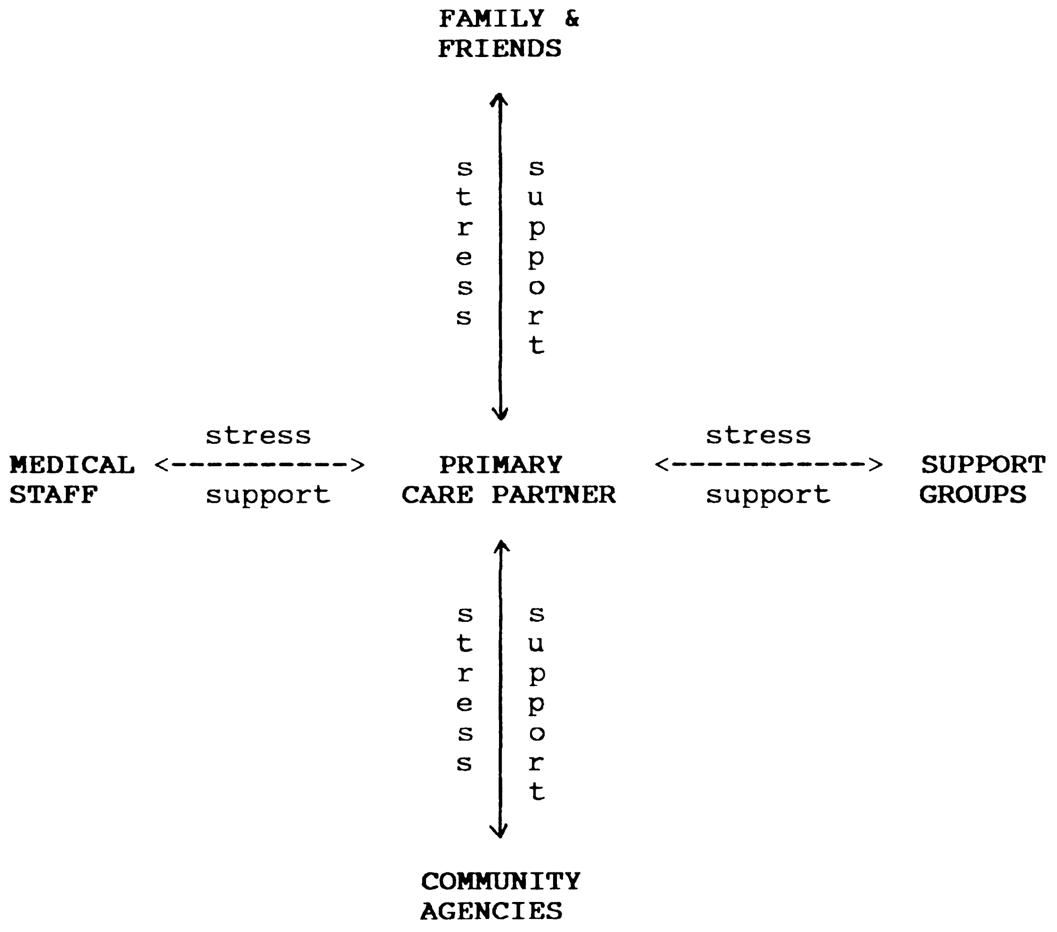

Figure 1. Care Partners' General Support System

Family and Friends

As a family member steps into the role of care partner for an ill person, he or she relies for assistance on the extended family and friendship network (Kazak & Wilcox, 1984; Kazak & Marvin, 1984). The emotional attachment and relational history associated with such relationships warrants their primacy in helping the care partner establish a system of illness management (Brody, Poulshock, & Masciocchi, 1978). These relationships provide a number of essential supports for the care partner.

Family and friends provide a great repository of emotional sustenance for the caretaker. They provide a basis of acceptance, respect and love which can form a strong line of defense against the many stresses of care provision which assail one's self-esteem (Tiblier, Walker & Rolland, 1989; DiMatteo & Hays, 1981).

Family members and friends may also help the care partner secure assistance from formal institutions (Brody, Poulshock, & Masciocchi, 1978; Litman, 1974). This support may range from information on where to locate specific forms of help to instrumental assistance such as transporting the patient to appointments or pursuing Medicare coverage problems (Torrens, 1987).

Family and friends can also provide much needed respite from care partnering duties. Zarit, Reever, and Bach-Peterson (1980) report a study in which the greatest impact on care partner perceptions of burden was the extent to which other relatives visited the impaired individual. This is consistent with more recent findings by Ellis, et. al., (1989) who found negative health consequences associated with perceptions of family abandonment.

Perceptions of abandonment can be tied to the real social isolation patients and care partners experience. Over time, chronic illness is associated with shrunken networks. Changes are particularly acute at the friendship level, and networks typically stabilize as smaller, denser, family-oriented entities (Kazak & Wilcox, 1984; Kazak & Marvin, 1984). As an early response, smaller, denser networks are functional for acquiring direct care assistance from friends and family (Kazak & Marvin, 1984), However, as the illness wears on, impairment grows, and the remaining friends and family are called upon to provide greater and greater levels of assistance (Orford, O'Reilly, & Goonatil, 1987). While this might suggest an increased reliance on assistance from outside agencies, smaller networks may decrease the care partner's knowledge of available services. Due to the restricted number of contacts, the information pool whereby care partners may hear of and access various community services is more shallow (Finlayson, 1976; Granovetter, 1975).

Community Agencies

Community agencies (e.g., Visiting Nurse Association, hospice, mental health facilities, government agencies) can also provide much needed assistance to care partners. This may consist of referrals to or provision of self-help/support groups, formal respite care services, individual or family counseling, and financial assistance (Linsk, Osterbusch, Simon-Rusinowitz, & Keigher, 1988; Crossman, London, & Barry, 1981). Unfortunately, the array of available services is often complex or uncertain; hence these health care services are typically underutilized (Strauss & Corbin, 1988). In an effort to bring diverse elements of assistance together, many communities have begun moving toward case management in which a social worker or hospital discharge planner coordinate needs and services for clients (Loomis, 1988).

Support Groups

Though support groups are often seen as part of the community services network, the nature and function of such groups is unique enough to warrant special concern. Gottlieb (1981) emphasizes that a support group "brings to bear a new set of ties that supplements the natural network's resources or compensates for deficiencies in its psychosocial provisions, offering participants a specialized person community composed of people with common problems, life experiences or misfortunes," (p.28).

Of all the functions served by support groups, perhaps none is so valuable as normalizing the care partner's experience (Arntson & Droge, 1987; Crossman, London, & Barry, 1981). The ability to share one's fears, frustrations, problems and depressions with others in similar situations can be a great boon to care partners. Many care partners experience feelings of restriction on personal freedom which may result in anger and resentment of the patient and/or the illness (Thompson & Doll, 1982). To learn this is not uncommon and to work through it with others experiencing the same struggle may be an important coping mechanism.

Support groups also serve as continuing education sources. This function may take the form of visiting speakers, or more informal sharing of problems and concerns based on member experience. Information is primarily of two types: (1) that aimed at helping caretakers better understand their loved one's ailment, current research and expected course of development (Arntson & Droge, 1987; Dzau & Boehme, 1978), and (2) advice on solving specific problems (Arntson & Droge, 1987). The information value of support groups is particularly useful as a method for counteracting care partners' shrinking informal support networks (Kazak & Wilcox, 1984).

Support groups often go beyond the provision of information to help members develop new skills as well.

For example, Schilling, Gilchrist, & Schinke (1984) describe a program used in teaching members of a support group for disabled children how to build and tap necessary social resrouces during times of need.

Medical Professionals

Family, friends, community agencies and support groups offer a great deal of assistance to the home care partner. Though these support sources possess functional redundancy, variations exist in the formality, cost, and nature of the aid. This allows care partners to construct a system which conforms to their specific wants and needs. Successful illness management systems will likely draw resources from each category.

No illness management system can be complete however, without the involvement of medical personnel. It might be argued that physicians and nurses are charged with the physical care of the _patient_. This would place many _care partner_ stressors beyond the domain of medical expertise (Dzau & Boehme, 1978). Such an approach is an outgrowth of the acute-care philosophy underlying American health care (Corbin & Strauss, 1988). However, when an illness is chronic, both patient _and_ family must acquire a strong working knowledge of the illness, its prognosis, treatment and care requirements (Strauss & Corbin, 1988; Strauss, et al., 1975). Such assistance is clearly within the realm of the health care professional. Health care professionals have expertise regarding the patient's diagnosis, treatment and prognosis. They also possess knowledge regarding the patient's care needs at home, especially pertaining to medical regimens and technical equipment.

If patient health is to be maintained at home, clear and open lines of communication between the care partner and medical professionals are mandated. Some would argue that the care partner actually be incorporated as a full member of the medical team responsible for care (Nichols, 1984; Rew, Fields, LeVee, Russell, & Leake, 1987; Mechanic, 1977). Physicians as well are beginning to argue for family systems perspectives in providing patient care (Glen, 1987; Sawa, 1985; Hofling & Lewis, 1980). Collaborative models of nursing have also been more recently emphasized (Rew, et. al., 1987; Monsen, 1986). However, it remains to be seen whether relationships between medical professionals and the growing numbers of home care partners are any better today than those discussed by Mechanic (1977): "The fact is that many family members feel excluded from the care process, have difficulty obtaining needed information, and rarely receive adequate instruction as to what they might do and how to do it" (p. 83).

To understand the development of such problems, it is necessary to examine the traditional model of medical care provision, with its emphasis on the patient-physician dyad.

The justification of this model and the manner in which it downplays the involvement of a care partner is detailed in the following section. Following this, an investigation of more recent research on the state of third-party interaction with medical professionals concerning patient care is presented.

THE INTERACTION ARENA

This section examines the traditional model of health care interaction which gives precedence to--indeed is constructed around--the doctor-patient relationship. The implications of this model for current health care delivery are examined, with emphasis on its growing inadequacy in light of greater illness chronicity. A new model of health care is then posited which argues for a widening of legitimized interaction to include care partners on a wider, more formal scale of involvement. Given the increasing level of involvement among lay persons (typically family members), there must be a commensurate rise in care partner consideration, knowledge and abilities to offset the burden of care involvement.

The Traditional Care Model

Whatever the size of institutions, communities, or nations, work is fundamentally accomplished through interlocked dyads with varying degrees of centrality, power, influence, structure and scope. This principle is clearly prevalent in the traditional health care model which focuses primary attention on the physician-patient relationship, despite the existence of a variety of allied health professionals (nurses, lab techs, orderlies) and the patient's friends and families (Cassell & Siegel, 1979). This primacy is based on several factors: (1) the expertise of patient and physician regarding the illness, and (2) the confidentiality requirement derived from the stigma attached to illness.

Expertise. Regarding the illness, arguments for the possession of expertise can be made for both patient and physician, albeit in different forms (Siegel, 1979). The patient's role is clear. He or she carries the illness and is thus naturally the focus of curative measures. Furthermore, the patient possesses the most intimate knowledge concerning changing symptoms and developments, and is therefore viewed as the most reliable source of diagnostic information. The physician, on the other hand, has the formal training and expertise to gather symptom information, make a diagnosis and generate a plan of treatment.

Due to this "expert" status, patient and physician are primary players, an alliance founded for resolution of the illness and a return to a state of health. To be sure, neither is typically divorced from the social systems in which they are embedded. Rather, these diverse systems are stimulated at the behest of the patient-physician dyad for appropriate and necessary help in achieving treatment goals. The physician requires results of diagnostic tests from lab technicians, careful monitoring and maintenance of patient status by trained nursing staff, drugs from pharmacists, structures for accessing all these in convenient manner (i.e., hospitals), to name but a few. The patient also relies on the immediate family and friends for various forms of assistance ranging from transportation to and from medical facilities to broader forms of emotional and physical support and care during illness.

Confidentiality. Illness has long been seen as unnatural. In its extreme, it was viewed as the result of a moral failing on the part of the patient, God's retribution for a hidden sin (Sontag, 1978). Even with the advent of a biological understanding of illness, disease maintains its associations with personal character defects: unclean, slovenly, impure, immoral. A moral taint thus remains, particularly for sexually transmitted diseases such as AIDS which are seen as avoidable (Brandt, 1986). In this context, flagrant irresponsibility replaces sin as the construct on which condemnation is based, and conceptions of guilt and innocence are maintained within the biological model of health.

The religious imagery which yet informs our conceptions of illness extends to the patient-physician relationship as well, the physician playing father confessor to the wayward, penitent patient. The situation is less morally charged only in the case of the <u>innocent</u> patient who must simply seek competent, professional "exorcism" of the disease which has possessed him or her; perceptions of irresponsibility may be avoided through seeking legitimized forms of help (i.e., modern medical practice). Patients deemed responsible for their illness connect most strongly with the confessional metaphor. Such a patient must admit the error of past behavior and forswear its continuance.

The physician's role in the "confession" of illness is to receive intimate information from the penitent and absolve him from the illness. To promote the exchange of private information necessary for absolution, the physician is bound by an oath of confidentiality that carries legal backing. In short, information about the illness, and thereby its diagnosis, prognosis and treatment, are deemed proprietary and thus carefully guarded. This is especially true for an illness like AIDS where stigma and discrimination may result from breaches of confidentiality (Katoff, 1989). Unlike the priestly confessor, however, the physician cannot so easily absolve the patient independently, and must often involve others. Still, patient and physician retain control over who should receive information about medical findings, passing it through their respective networks on a need-to-know basis.

Information control is not exactly equal, however; the patient has greater liberty since the illness is a personal possession. The physician is typically not allowed to communicate information directly to the patient's network without the latter's express consent. This extends in large part even into the difficult area of infectious or contagious illness; the physician must generally be satisfied with patient assurances that either appropriate precautions will be taken or that others will be informed of his/her illness status. The patient has no such restrictions. He/she can communicate information about the disease to whomever he/she wants, within the doctor's, as well as his/her own, network.

As a result of the illness expertise of patient and physician, and the potential stigma associated with the illness, primacy of the physician-patient relationship is justifiable. Patient deficiencies in mental functioning is the only exception which specifically mandates the inclusion of some third party to serve as a patient surrogate.

The lack of recognition of accorded care partners in the traditional model of health care is clear. As such, the patient's network accesses the illness through more indirect, bystander perspectives. At best, a patient's family is deemed important as the environment to which the patient will return when well. At worst, the patient's family and wider network is seen as thwarting medical curative efforts, particularly in the hospital. Hence, the restriction on number of visitors at any one time, limited visiting hours, limited activity when with the patient. In contrast, involvement of the physician's broader support system (nurses, technicians and other allied health professionals) is deemed necessary and normal.

It can be said of this model that the rights of all are generally protected. The primacy of patient control over information concerning his or her health is necessary to prevent undue public censure and discrimination. And in most situations, the patient will be a viable conduit of information to his social network. After all, he/she needs the help and assistance of those close to him/her. Even in instances of asymptomatic infection where lack of outward manifestations make it easier to hide the illness, the emotional support of loved ones is invaluable.

However, a situation in which the patient serves as the lone conduit of information is far from ideal. Specifically, a number of problems can and do occur if care partners are excluded from communicating directly with the physician. First, the patient presents second-hand information to the care partner. If the patient and care partner have different concerns, the latter's may not be addressed to the physician and adequate information thus gathered. Or the patient may merely attend less to such information and thus relate it insufficiently. Patient filtering may also result in information loss. The patient's interpretation of the information given him/her by the medical staff necessarily rearranges and condenses it. At best then, the patient's report is a rough summary of the actual content. This may or may not provide adequate information that keeps the care partner apprised of the situation.

Such winnowing of information, however, is not always so unconscious. That is, the patient in such a situation may knowingly withhold information from the care partner. This is likely with patient's in denial or those who don't wish to burden the care partner with knowledge of worsening health or approaching death.

At minimum, the care partner benefits from direct communication then because he or she gets the information first hand. There is also opportunity for physician and care partner to evaluate the extent to which the patient is accurately relating information regarding illness developments; care partners may compare the physician's information with that given by the patient, while physicians can inquire about symptoms and behavior exhibited at home which the patient may not be relating to the medical staff.

Direct contact with medical staff in itself may be an emotional support to the care partner as he or she interacts with the patient's medical care providers.

Widened care partner involvement contains far greater potential than that offered under the traditional medical model. The latter does nothing more than create a substitute patient, foregoing any assistance prior to the near complete incapacitation of the patient. Though clearly necessary during end-stage illness, this approach fails to capitalize on the advantages of care partner involvement earlier in the illness. Such advantages include the ability the development of stronger relationships between the care partner and medical personnel which can aid in the difficult decisions that may be required as patient health worsens. Also, the patient is able to have a formal ally from his social network involved in the care process, something which may be both emotionally and instrumentally valuable. Finally, and likely most important, more adequate treatment and better quality care is afforded by making sure more information is forthcoming which yields a clearer picture of illness developments for all concerned.

The value of greater care partner involvement has been demonstrated at this point. However, its ability to overcome the traditional medical model is uncertain. To determine its level of usage in current medical practice, it is necessary to examine more closely the existing research on relationships between medical professionals and care partners.

AN INVESTIGATION OF CARE PARTNER INVOLVEMENT

Third party surrogates have traditionally interacted with medical staff insofar as children (Barbarin & Chesler, 1984), the mentally and/or physically disabled (Longo & Bond, 1984), the mentally ill (Grad & Sainsbury, 1968), and patients near death are concerned. Increasingly, they are also involved in the chronic illnesses which reflect the difficulties inherent in the traditional model of health care delivery, particularly with the elderly suffering a variety of disabling illnesses (Stone, 1987) and persons with AIDS (Tiblier, Walker & Rolland, 1989). From these situations, it is possible to construct an understanding of the nature of care partner interaction with an eye toward functions served and/or underserved. The following section is organized around the three identified stages of illness (Corbin & Strauss, 1988). The medical staff interaction needs of care partners within each stage are presented, followed by an examination of the possible role communication problems play in the failure to meet those needs.

COMMUNICATION BETWEEN HEALTH PROFESSIONALS AND CARE PARTNERS

Most of the research focusing on the relationship between health professionals and families does not identify a primary care partner. Research that does consider a primary care partner typically identifies the care partner as the patient's spouse. The following review concentrates on these studies.

To fully excavate the domain of medical professional-care partner communication, it is necessary to understand the contexts in which such exchanges are grounded. Contexts may be differentiated on the basis of illness stage and treatment location (Corbin & Strauss, 1988). Since treatment location is dependent on illness stage, the following section focuses on issues related to three basic phases: (1) diagnosis/acute phases, (2) stable phases, and (3) deterioration and death phases.

Diagnosis Phase

Illness diagnosis is both a welcome and painful event. If one has been suffering recurrent symptoms and impaired function without explanation, diagnosis represents a legitimization of experience, an affirmation that a real physical problem exists. This relief is offset when the diagnosis is a chronic illness and thus describes a future which is uncertain and perhaps radically altered to incorporate the impairments brought about by the disease.

At the point of diagnosis, the uncertainty of unknown symptoms is exchanged for the uncertainty of illness ramifications. Patients and their family members require information regarding the specific illness: cause, prognosis, and treatment. This information must be integrated with the specifics of the patient's case. If the diagnosis is for long-term impairment, the early and direct involvement of family members is crucial.

To identify specific family needs in hospital settings, Hampe (1973) conducted a series of focus group interviews with the spouses of terminally ill patients. This process yielded a list of eight needs. Five of these were needs related to the terminally ill partner: (1) to be with the dying/sick person, (2) to be helpful to the dying/sick person, (3) to be assured of the comfort of the dying/sick person, (4) to be informed of the physical condition, medical plan, and expected course of events, and (5) to be informed of the impending death of the partner. Three additional needs related to self: (1) the need to discharge emotion with other people, (2) the need for comfort and support by family/friends, and (3) the need for acceptance, support and comfort by health care professionals. Medical professionals are implicated in all but the first two self-related needs. Thus, interaction with a recalcitrant staff could result in a great deal of frustrated need fulfillment for care partners.

To examine how well these needs were met, Hampe (1975) interviewed the spouses of 27 terminally ill patients. The findings revealed a number of major deficits. Fifty-five percent of the spouses reported unmet needs for acceptance, support and comfort from health professionals. An additional 26 percent had this only partially met. Information regarding their partner's prognosis as well as daily physical condition was also lacking. Eighty-eight percent were unsatisfied with explanations regarding prognosis whereas 45 percent mentioned dissatisfactory information on daily physical condition. Regarding assurance of partner's physical comfort, 67 percent reported unmet need. Finally, while 74 percent were informed about impending death, 81 percent of these complained of the lack of privacy available for this discussion; most often these talks took place in the hallway.

Many of the problems Hampe (1975, 1973) addresses in her research are placed within a long-term hospital stay. However, evidence exists as well emphasizing the importance of early family involvement. Krant and Johnston's (1978) study of the relatives of terminal patients found that members who did not interact with the physician during early diagnosis felt inhibited about interacting at later stages in the illness. Bunn and Clarke (1979) also report on the value of brief counseling sessions to reduce anxiety among family members of patients admitted to the hospital for a serious injury or illness. Sessions focused on information about the problem and its prognosis, as well as discussion of emotional reactions, and took place as soon as the patient was admitted. Family members who received no counseling actually experienced <u>increased</u> cognitive anxiety over time. This can be expected to impair information processing at the point when patient diagnosis is finally shared with them.

Despite the potential value, diagnostic contexts often mitigate against immediate care partner involvement. If a patient is diagnosed during an acute crisis, immediate concern focuses on stabilizing the patient's condition. Distraught family members who might interfere with life-saving medical treatment are thus separated. However, as Bunn and Clarke (1979) illustrated, abandoning care partners in a waiting room with no information is not the only option.

Family information deficits are problematic for later stages of illness as well. That is, the longer family members are excluded from patient-relevant information, the more likely their illness meanings are to diverge from those of patients and medical personnel. As discussed above, illness meanings refer to the psychological adaptation to and understanding of the life impact associated with a particular illness (Kleinman, 1988; Nerenz & Leventhal, 1983). Without open dialogue, each party in the care relationship can nurture discrepant meanings, leading to family conflict in later stages of illness.

Speedling (1982) provides important insights into this process in his investigation of eight families' experience with heart attack. The near total focus on the patient, the seclusion of the patient in the intensive care unit, severely limited visiting rights for family, and the lack of communication between the medical staff and family all led to sharp discrepancies between family members' and patients' perceptions of illness severity and meaning. These discrepancies then resulted in family attempts to interfere with the medical regimen assigned to the patient by medical personnel.

Stable Phase

As the patient enters a stable phase, he or she is able to return home. Adjustment and coping will depend on the extent to which family care partners are prepared for this transition through information regarding home care provision and their ability to contact appropriate medical professionals as needed. The increasing chronicity of illness produces large numbers of people who will traverse the road between home and hospital a number of times prior to death. The success with which these transitions are negotiated can play a large role in the reduction of care partner stress and patient relapse. However, such transitions are not easily accomplished.

Speedling (1982) records a deeply troubling lack of preparation for hospital departure among families of heart attack victims. Patients and their families were not prepared for the changes required by the illness, and specifically were inadequately informed about the regimen to be followed due to vague instructions as well as lack of a formal conference to discuss such issues. Particularly, Speedling (1982) illustrates how discrepant illness meanings continue to frustrate interactions family members have with both patient and medical staff. In relation to skills training, Nichols (1984) study of home dialysis, care partners who received training on dialysis procedures rated the training as poor and insufficient for the early days in the home environment. Spouses still felt incapable and frightened by the new responsibilities of providing care. Thus, the information poor state of care partners developed during hospitalization may prove inadequate for carrying the full burden of care.

The move home also brings about changes in the health professionals providing one’s care. Visiting nurses and primary care physicians take over for hospital-based specialists. An increasing reliance on family practitioners as a gatekeepers to the more knowledgeable specialist is seen in the insistence of patients and their family on continuing to work with the specialist in continuing stages of the illness (Speedling, 1982). There is a resistance to turning the illness over to the control and discretion of the family physician who was not in charge of the acute phase of the illness. This problem is associated with AIDS as well, such that following HIV+ diagnosis, patients and their loved ones want to deal only with infectious disease specialists for any and all ailments, regardless of the specific link to AIDS (Gulick, 1990, personal communication; Bernstein, 1987).

This lack of smooth passage from hospital care to home care calls to mind the metaphor used to explain the traditional manufacturing process: the route from research and development to actual production and sale of a product consists of a series of high-walled boxes. Each area's role is clearly defined and internal quality may be very high. However, integration is near zero with each department performing their role and then throwing it over the wall to the next function. Such is the acute care experience of many with chronic illness.

Deterioration and Death

In the final stages of illness, family members' primary needs are acceptance and support of the medical staff, and knowledge of when the patient will die. Since many people return to the hospital at this stage or receive care from hospice, other needs discussed by Hampe (1975) are applicable as well (e.g., need to be with the patient, to be involved with patient care).

Since little can be done at this point beyond strictly palliative care, the care partner and other family need to work through grief over the approaching death. Medical staff, particularly those who have had a close working relationship with the care partner, can be a great boon in this process. Much of the literature, however, suggests that emotional closeness to dying patients and family is very stressful for medical professionals (Nichols, 1984, Lief & Fox, 1969). As noted earlier, medical professionals' expertise lies more in the physical than emotional realm; psychologists, counselors and support groups are more appropriate for in-depth work on issues of grieving and loss. Still, medical professionals can set the tone for acceptance on the part of the care partner. Research on how the medical staff communicates during the terminal phase of illness suggests that their role is less than exemplary.

The tendency for medical staff to withdraw emotionally as the patient approaches death has been noted in several studies (Field & Howells, 1986; Redding, 1980). Dying patients are often placed at the end of hallways away from the nursing station (Watson, 1973), their calls are answered more slowly (LeShan, Bowers & Jackson, 1969), and less time is spent in the room with them. These tendencies are likely to result in the abandonment of family members as well, exacerbating relationships that may have already become strained over the course of illness. Availability of medical staff may be desired at this stage primarily from an emotional standpoint. However, information about the patient's status, particularly assurances that suffering is minimal and knowledge of when he or she will die, is still desired. Since the content of such communication is less complex, emphasis is on the manner in which information is communicated. Thus, empathic concern may eclipse issues of clarity and completeness.

In summarizing the findings of the limited research on care partner/family interactions with medical staff across the three contexts of acute crises, stable phases, and death and deterioration, specific needs of the care partner can be identified. Additionally, a number of specific communication variables appear relevant. These are the degree to which the medical staff is <u>available</u> for discussion, provides <u>clear</u> and <u>complete</u> information, and is able to communicate empathically with care partners. These issues are explored more fully below.

KEY COMMUNICATION ISSUES FOR CARE PARTNERS

Research has established fairly clearly the importance of social support received by care partners for ill persons from three major resources: family and friends, support groups, community agencies. The present study, however, seeks to redress the lack of knowledge about the role of medical professionals in supporting the care partner. The importance of accessing medical professionals is apparent given the importance of social and communicative support specifically during times of uncertainty and stress. As Albrecht & Adelman (1987) noted:

> The experience of uncertainty and ambiguity is ... an impetus for communication as a way through the helplessness and hopelessness. Individuals who need to communicate during these situations are subject to influence by those who offer messages of clarity and explanation, affecting not only how those individuals assign meaning to their stressors, but also how they see themselves and interpret similar or pertinent future events. (p.26)

The potential for uncertainty of the home health care situation is clear in the lack of preparation for the new role (Getzel, 1981) and the lack of information and training to develop necessary care partnering skills (Silverman & Brahce, 1979). Furthermore, all illnesses carry some degree of uncertainty with regard to impact on future life, prognosis for survival, and treatment efficacy. The relevant expertise for coping with the uncertainty lies most directly in the realm of medical professionals, whose communication with care partners and other family members should be explored to understand how care partner stress and strain might be alleviated.

Nichols (1984) suggests a number of variables which may explain why care partner information deficits, uncertainty and doubt are left intact by medical professionals. These are: (1) unavailability of health care professionals, (2) lack of clear communication, (3) lack of complete communication, and (4) lack of empathic concern from medical staff.

First, medical personnel are often unavailable for questioning. Physicians often make rounds prior to visiting hours, thereby assuring their absence when family members are present (Nichols, 1984; Speedling, 1982). Hawker (1983) noted this among nurses as well. When on the floor, other forms of "non-availability" are evidenced: family attempts to gain attention are ignored, or an air of being too busy to stop and talk is presented (Hawker, 1983). However, the extent to which families initiate communication with the medical staff is itself questionable (Brey & Dracup, 1978). A number of researchers have called for a more proactive stance whereby health professionals strive to anticipate and fulfill the likely information needs of care partners (Rew, et al., 1988; Nichols, 1984). Otherwise, it is all too likely that a conspiracy of silence may arise wherein each side of the medical professional-care partner dyad assigns responsibility for communication to the other party (Speedling, 1982). Care partners assume that the physician will tell them anything important, that "no news is good news." Physicians and nurses, however, may assume that if the patient or family has any questions they will ask them (Wright & Dyck, 1984; Breu & Dracup, 1978). The situation thus becomes one where both parties are willing to dance but are waiting for the other to lead.

Lack of medical staff availability restricts care partner information in a direct manner with influence on both constructed illness meanings and objective understanding of the disease. This <u>lack of availability</u> plays a strong role in the creation of information deficits in family care partners.

The problems of clarity and completeness of communication assumes contact with the medical staff, and turns attention toward interaction dynamics which may interfere with the education and training of care partners (Thompson, 1990; Speedling, 1982). Common complaints regarding discussions with medical professionals include the heavy use of technical jargon (Nichols, 1984; Strauss & Corbin, 1988), and vague responses to questions about treatment and/or regimens (Speedling, 1982).

Problems of clarity derive from the need for specific, "complex" terminology in the scientific approach to medicine. The precision afforded through finer distinctions in a mutually-shared, specialized language paves the way for advancement as well as increasing communication efficiency, producing in effect medical shorthand which conveys a wealth of information, but only if one possesses sound medical training. It is the inability to set aside this language when interacting with lay populations which creates confusion and misunderstanding (Thompson, 1990). Ley (1982) reports findings in which approximately 50 percent of people interviewed after receiving medical information did not understand what was said about diagnosis, aetiology, or prognosis of the symptoms involved. It is a logical conclusion then that the degree of medical professionals' communication clarity will strongly influence care partners' knowledge both about the illness in general and about their patient's current status and care requirements.

A somewhat opposing complaint centers around the vague or incomplete information given to patients and care partners by medical personnel (Mechanic, 1977). Family members may be told of the importance of maintaining the patient on a low sodium diet without an explanation of what such a diet entails or why it is important (Speedling, 1982). Additionally, family members may not be adequately prepared for specific side effects of the illness or treatment.

If health care professionals do not offer information in a preemptive manner, care partners will have to acquire it through questioning. Given a lack of care partner knowledge, however, it is unlikely that he or she can extract all relevant information. Care partners may thus maintain ignorance in specific aspects of the illness without being conscious of that very ignorance. Even for the knowledgeable care partner, however, medical staff responses to questions may still suffer from incompleteness (Wright & Dyck, 1984).

A final issue relating to medical professional interaction with family members has to do with the acceptance and respect. As was noted in Hampe's (1975) research, spouses desire to be accepted and valued by the medical staff. The feeling that he/she is part of the medical team providing care for the patient can go a long way toward soothing the family care partner's anxiety. Such involvement can also provide a useful context for medical professionals to educate the care partner (Rosenthal, Marshall, MacPherson, & French, 1980).

However, research reveals consistently low levels of empathic concern among physicians in relation to families (Greif & Porembski, 1988; Speedling, 1982; Hampe, 1975). Nichols (1984) argues that this is an extension of the detached concern (Lief & Fox, 1963) health professionals practice to avoid overexposure to the extreme emotional stress of their work. The lack of this detachment in family members or other loved ones is, in fact, one reason Parsons and Fox (1952) argue that family members should not provide care. However, family members <u>are</u> providing care today and expansion of concern with burnout must be widened to care partners. To fail in this regard is to abandon the care partner and thus, indirectly, the patient, thereby failing to fulfill the medical mandate for patient care (Nichols, 1984; Cluff, 1981).

SUMMARY

While much of the literature reviewed above does not focus specifically on care partners as defined in this study, it does suggest that the role of care partners in illness management systems is ill-defined, non-legitimized, and therefore, problematic. Such an interpretation is consistent with findings that reveal potential shortcomings in the communication between medical staff and family members. Specifically, these would appear to include problems of availability, completeness and clarity of information exchange, and empathic concern. When linked to research on caregiving stress and strain, it seems probable that such difficulties in information exchange run the risk of restricting the resources (cognitive, affective, and behavioral) care partners can bring to bear on the potentially stressful experience of involvement in patient care. Under such circumstances, care partners may be left with a number of inadequacies which hinder effective intervention in patient illness trajectories: inadequate understanding of the patient's illness, lack of necessary skills for adequate care involvement at home, and a lack of confidence in personal ability to meet the varying demands of patient care. In short, communication difficulties undermine the potential value of information and support to ameliorate the effects of stress (Sutton & Kahn, 1987).

While the review of literature is thus suggestive of hypotheses about the nature of medical staff-care partner communication, and its impact on care partner stress and strain, a number of factors intimate that formal statement and testing of these relationships may be premature. First, as noted above, much of the literature focuses on "family" responses to situations of illness. While family may be operationalized in a manner consistent with the current study's focus on "care partners," previous research cannot be said to represent a direct examination of the experiences of individuals who possess primary responsibility for patient care. We have generated extensive knowledge in the area of caregiving stress and strain, but we have yet to specifically examine the relationships between care partners and medical staff.

Second, by "family," much of the caregiving literature has focused on the patient's spouse or other biological family members. In the context of AIDS, the "family of birth" concept must be exchanged for a focus on the "family of choice." Given the lack of research on the role of care partners in non-traditional couples (i.e., homosexual relationships), ambivalence in applying past research is warranted. This is especially true since the inability of homosexual couples to establish legal ties may inhibit the homosexual care partner from establishing legitimacy in the eyes of the medical staff, thereby further hindering the quality of interaction.

Finally, while care partners are playing an increasing role in the care of patients in the United States, the role is still in its infancy. It has emerged only in recent years in the face of increased chronic illness and national attempts (however minimal at the moment) to limit our dependence on centralized care in high-technology institutions.

Given these conditions, it would thus be both naive and counter-productive to approach the phenomenon of care partnering with a preconceived framework of expectations and hypotheses. If we are to develop a true understanding of the role care partners are playing in American health care today, and the effects involvement has on their own personal health and well-being, it is necessary to investigate the phenomenon from an inductive stance. This does not mean a complete rejection of implications entailed in the review of literature; rather, such an approach seeks to place primacy on the data of actual care partner experience. While the study is structured to allow for testing of the implications tentatively outlined above, it is designed to resist the temptation to prematurely define the central constructs in a theory of care partnering.

In sum, the goal is to construct a theory firmly grounded (Glaser & Strauss, 1965) in the present experiences of care partners for patients with AIDS. Accordingly, the following general questions are explored: (1) To what extent is the care partner accepted by the medical staff? (2) What is the nature of communication between medical staff and care partner? (3) How does communication help or hinder the care partner's provision of assistance to the patient? (4) What is the impact of medical staff communication on care partners' understanding of the illness situation, and in turn, on care partner's physical and mental health.

CHAPTER TWO: METHODS

Data for this project were gathered with the assistance of a case management system located in a large Midwestern city. Created in 1988, the agency employs a staff of 13 and services approximately 450 clients. The client population is predominantly black (64%) or white (33%), between the ages of 20-49 (93%), male (77%), and at moderate (49%) to severe (44%) levels of difficulty in dealing with their infection (from asymptomatic HIV+ to full-blown AIDS, in the traditional nomenclature).

Funded primarily by state and local government, the agency is designed to assess client needs, develop care plans, and provide or arrange for services through referral to appropriate community resources. Focusing on economic, medical and social work models of case management, the agency seeks to establish a continuum of care to include tertiary, primary, extended nursing, home-based and hospice care integrated with psychosocial and volunteer support services available for the person with HIV through appropriate financing and payment systems. The majority of agency services are provided by four case management teams, each consisting of a registered nurse and a social worker.

SAMPLE DEVELOPMENT

Given the sensitive nature of the research, extreme care was exercised to protect the anonymity and confidentiality of all study participants. A two-step procedure for sample development was used to insure protection from the possible repercussions of being identified as an AIDS patient or a provider of care for someone with AIDS. Throughout the entire sample development process, the purely voluntary nature of participation was stressed.

In the first phase of sample development, the case management agency publicizing the research aim. Using existing client records, a mailing list was compiled of individuals listed as primary care partners by an agency client. This process yielded a total of 195 care partners. However, these ranged from being an emergency contact only to being a full partner in care. People in the former group were typically unaware of the client's HIV+ diagnosis, a situation the clients spelled out specifically and wished to maintain. As such, the mailing list was pared to exclude 49 care partners who were unaware of the client's HIV+ status, yielding a total of 146 who received the initial letter.

This letter, written by the agency's supervisor in consultation with the primary investigator, was then mailed to each care partner. The letter (see appendix A) briefly explained the nature of the research, encouraging all willing care partners to apply, regardless of their current level of involvement with the patient's medical care and regimen. At this stage in the research, concern focused on generating the largest sample possible so a strong effort was made to avoid any unwarranted self-selection on the part of care partners. Furthermore, inclusion of care partners for patients at various stages of HIV infection allowed investigation of the full range of issues involved in care for those suffering an illness with a downward trajectory. The letter closed by asking recipients to return an enclosed release form if they wished to receive further information from the primary investigator. These release forms were returned directly to the primary investigator in a pre-addressed, stamped envelope which accompanied the letter.

Two weeks following the initial mailing by the agency, 18 responses were received for a response rate of 12 percent. Given this low rate, the agency agreed to have a volunteer place follow-up phone calls to those care partners who had not responded. This was deemed a worthwhile step to counteract the possibility of illiteracy within the overall sample.

An additional 34 verbal agreements to receive the second follow-up letter were garnered in this fashion. In all, 41 persons could not be reached during the two week phone follow-up; 27 because of inadequate information in the agency's records, and 14 who did not answer the phone. Another 26 who were contacted declined to receive further contact for a variety of reasons: nonspecific reason (11), too busy (6), moving or recently moved (3), care partner sick (2), patient deceased (2), too hard on care partner (1), and "disgusted" by the nature of the research (1).

Thus, a mailing list of 52 care partners (36% of the initial mailing) was compiled for a second letter generated by the primary investigator. This letter explained the specifics of the study, with special emphasis on what would be required from participants. All care partners wishing to participate at this point were asked to return an enclosed form, noting the participation option they desired (see below). If respondents selected the interview option, they were asked to select times and days appropriate for arranging the interview.

PARTICIPATION OPTIONS

Care partners for persons with AIDS all exist in a stressful situation. For some, the life-threatening disease itself is the sole (albeit great) source of stress. For others, stress is the outcome of years of poverty, powerlessness and addictive habits. These social, economic and political gulfs create a situation in which AIDS is yet another burden.

The cautious sample development process described above was used to avoid imposing further hardships on care partners. Anyone uncomfortable with being contacted or having their name released to outside investigators was able to opt out during the first mailing. If further information was requested, care partners were still not committed in any way. _Only_ those who returned the second release form were contacted regarding actual research participation. Finally, after selecting themselves into the final sample, several options were developed to allow care partners to tailor their participation according to individual levels of comfort.

The study contained both an interview and a survey. constructed to provide full information as a combined unit. However, partial information seemed better than no information at all. As such, participants were offered the following choices: (1) survey only, (2) interview only, (3) both survey and interview -- _personal interview_ (4) both survey and interview -- _written responses_ through mail.

The survey portion required approximately 30 minutes to complete. Due to its non-interactive nature, it could be conducted through the mail, and was thus only moderately invasive (see full description below). The interview portion required approximately two hours (see full description below). Clearly, the interview option was much more invasive. If participants wished to participate in the interview portion of the research but were unwilling to meet personally with an interviewer, the protocol was offered for written responses.

Six months after the interview phase of the study, a second mailing was conducted. This mailing had two components. First, the original survey was included for all participants who had not yet returned it. The second component was sent to all participants, and consisted of new scales whose need became apparent during the interviews and data analysis. Specifically, the second survey contained an HIV knowledge test, several scales on CP motivations to seek information, perceptions of control in the illness situation and tolerance for ambiguity. The specific scales and items are discussed in more detail below.

SAMPLE DESCRIPTION

Twenty-five people agreed to participate in both components of the study, and an additional eight agreed to complete the survey-only portion. Due to scheduling conflicts and missed appointments, only 21 of the scheduled interviews were conducted in person. Two of these missed interviews were conducted over the phone three months after the first wave of interviews, in the latter stages of data analysis.

Of those care partners who completed both the interview and survey, the majority were mothers (45%), followed by lovers (23%), siblings (18%), an aunt, an ex-wife, and a friend. Half the sample were or had been involved in caring for a patient with full-blown AIDS (of which 55% had already died at the time of the interview), 39% with asymptomatic HIV+, and 4% with ARC. Eight percent of the sample cared for patients suffering an illness other than AIDS. Fifty-nine percent of the patients were black compared to 41% white, and predominantly male (91%; given the dominance of males in the current sample, the male pronoun will be used throughout the results section). The primary route of transmission was IV drug use (32%) followed closely by sexual transmission through homosexual relations (30%). Other forms included unknown (14%), heterosexual sex (8%), and multiple risks (8%).

Only eight participants completed the second survey, so interviews were conducted over the phone. This yielded an additional nine completed responses, for a total of 17 completed survey sets. These formed the basis for the quantitative analyses described below.

INSTRUMENTATION

In order to provide a complete picture of the interaction home care partners for PWAs experience with medical professionals, two forms of data collection were used. Each is fully explained below.

Interview Component

This component consisted of a semi-structured interview addressing the degree and nature of care partner involvement with the patient, care partner burden, professionals involved in patient care, and communication patterns between care partners and medical personnel.

Initially, care partners were asked to provide a brief history of their patient's experience, particularly noting the crisis periods of illness and medical contacts. Participants were then asked about interactions with each individual providing medical care to the patient, focusing on those who participated regularly in the care. The distinction between institution-based professionals and those working in an outreach capacity was maintained.

Following the unstructured commentary, a series of directed questions was asked which focused on the a priori constructs of interest (i.e., completeness, clarity, availability, empathic concern). Additional theoretical variables uncovered during the unstructured portions of initial interviews were built into subsequent interviews. This was in keeping with the iterative process advocated by Glaser and Strauss (1967) in their work on grounded theory. Added variables included such issues as physician acceptance of the care partner as a legitimate participant in the care process, and the impact of institutional visitation policies (e.g., hospitals, nursing homes).

Survey Component

This research component focuses on the care partner's interaction with the one person self-identified as the primary medical contact. Measures were designed to assess the impact of the primary medical contact on care partner stress and negative outcomes. The survey measures were used to supplement and corroborate the broader and more detailed information gathered in the interview process.

Because of the limitations of previous research, it was necessary to develop original scales for most of the survey instrument. Seven items were developed to tap availability of the primary health professional contact. Clarity and completeness of communication were both assessed with five-item scales. Eight items measure the degree of perceived empathic concern. Perceived knowledge constructs were measured in with six items for knowledge of AIDS in general, eight items for knowledge of AIDS in its specific case, and six items for knowledge of the care partnering role. Perceived satisfaction with overall contact with the primary medical contact was assessed using a six-item scale.
All of the above scale items were measured using a 5-point response scale ranging from strongly disagree to strongly agree.

Existing scales were used to assess the outcome variables in this study. Care partner depression was assessed with the Depression Scale from the Center for Epidemiologic Studies (CESD; Radloff, 1977). This 20-item scale asks care partners about feelings of depression using a four-point response scale ranging from almost all the time to rarely or none of the time. Negative health outcome was measured using a physical symptoms index (Miller, Ellis, Zook, & Lyles, 1988). This 15-item scale asks care partners to rate their experience of a range of physical aches and pains on a five-point scale ranging from always (5) to never (1).

A second survey was constructed after concluding the interview phase and during analysis of the qualitative information. It seemed likely during interviews that CPs were distorting their perceived level of knowledge. Specifically, CPs who could talk quite expertly about HIV issues, rated themselves quite low in overall knowledge, citing awareness of a great amount of information they did not know. CPs whose knowledge focused primarily on issues of HIV transmission, however, rated themselves quite highly on overall knowledge. While this may simply reflect the awareness of greater complexity among knowledgeable CPs, it seemed important to assess knowledge through an objective test in order to compare perceived knowledge with actual knowledge. Thus, a 29-item measure of HIV knowledge constructed by the AIDS Education Project of Michigan State University was sent to all applicants.

A second objective knowledge variable was also constructed to assess the extent to which CPs had knowledge of the various treatments, whether widely used or in experimental phases. Fifteen common drugs used to treat either underlying HIV infection or various complications of infection were presented and participants were asked to check all those about which they had knowledge.

In addition, early analyses indicated that CPs differed greatly in the information search activity with clear implication for medical staff interaction. Thus, several scales were also included to assess potential motivations for seeking information. One was a 16-item measure of tolerance for ambiguity. The other measures were constructed by the researcher and included: a 4-item measure of CP perceptions of control, a 3-item measure of CP perceptions of the usefulness of AIDS information, a 2-item measure CPs' perceived need to talk with medical staff, and a 3-item measure of CP motivation to seek information.

Though the qualitative data were emphasized in this study, the quantitative data played two crucial roles. First, these data enabled partitioning of the qualitative data by tapping variables of differentiation: knowledge, burden, involvement, depression. A second function for the quantitative scales was to provide a limited test of relationships between various communication dimensions and CP perceptions of knowledge, burden and depression.

DATA PREPARATION

All interviews were recorded and transcribed by a team of seven research assistants. Each assistant was informed about the nature and purpose of the study and trained in simple transcription. All statements by the interviewer and interviewee were transcribed, but no specific markings were made to illustrate inflection, interruptions, etc. While clearly important for more specific investigation of the process through which communication exchanges are constructed, such detail was deemed unnecessary here.

The average interview lasted approximately 150 minutes and resulted in 30 pages of transcript. Finished transcripts were sampled for accuracy by the primary investigator. This was accomplished through transcript-recording comparisons of selected portions of the initial transcript generated by each transcriber. Accuracy levels for each transcriber were thus established and used as a basis for selecting further accuracy checks as the transcribing proceeded. In general, accuracy did not present a problem beyond occasional portions of the interviews which were unintelligible.

DATA ANALYSIS

Quantitative Analysis

Due to the small sample size, complex statistical analysis was not advisable. Confirmation of the measurement instruments was accomplished by investigating inter-item correlations generated by the correlation routine of SPSS. Items lacking sufficient correlation with the other items in a scale was excluded in an effort to approximate internal consistency. Generally, the cutoff point was any item having a majority of non-significant correlations with the other items, though exceptions were made to this rule if cutting items significantly compromised the face validity of the scale. Though clearly weaker than a full confirmatory factor analysis (Hunter & Gerbing, 1982), this method roughly matched the first two of Hunter's (1980) three criteria for assessing the unidimensionality of scales: homogeneity of item content, internal consistency, and parallelism with outside variables. All scales were tested using these two criteria. Following correlational cleansing of the scales, the reliabilities subroutine of SPSS was used to generate reliabilities on all scales except the objective HIV knowledge test and measurement of IADL and ADL.

As a result of such analyses, a number of items were deleted from the scales. The revised scales are presented in Table 1. (Means and standard deviations for each construct are presented in Table 2). With regard to the communication variables, five items were retained to measure availability, five items for clarity, six items for empathic concern, and six items for overall communication satisfaction. The items meant to assess completeness of

Table 1: Final Measurement Scales.

Availability of Primary Medical Contact (Alpha = .86)

1. It is easy for me to contact _____ when necessary.
2. _____ takes time to talk with me.
3. I feel like I'm imposing when I talk with _____ about my loved one's illness. (R)
4. _____ goes out of his or her way to make sure I don't have any unanswered questions.
5. Sometimes I feel _____ is avoiding me. (R)

Clarity of Primary Medical Contact (Alpha = .92)

1. It is easy to understand the information given by _____.
2. _____ is clear in his/her instructions and presentation of information.
3. _____ often speaks in complex, medical terms. (R)
4. I often experience confusion about what exactly is being told to me by _____. (R)
5. I get frustrated with the lack of clarity present when communicating with _____. (R)

Completeness of Primary Medical Contact (Alpha = .43)

1. _____ gives complete and satisfactory responses to my questions.
2. I am satisfied with the <u>amount</u> of information _____ presents when answering my questions.

Full Disclosure of Patient-Specific Information (Alpha=.82)

1. It seems _____ is reluctant to provide me with information. (R)
2. I sometimes feel that _____ is holding back information. (R)
3. I am sure _____ knows things about my patient's situation that he/she is not telling me. (R)

Table 1 (cont'd).

Empathic Concern of Primary Medical Contact (Alpha = .89)

1. _____ cares about me as a person.
2. I feel accepted by _____.
3. _____ is warm and caring in his/her interactions with me.
4. I feel supported by _____.
5. I feel respected by _____.
6. I feel _____ includes me as part of the care team.

General Communication Satisfaction with Primary Medical Contact (Alpha = .96)

1. In general, I am satisfied with _____'s communication.
2. There is little I would change about the nature of my communication with _____.
3. I have some real problems communicating with _____. (R)
4. I wish I could communicate better with _____. (R)
5. I am rarely dissatisfied with the communication between _____ and myself.
6. I have real concerns about my ability to communicate with _____. (R)

Perceived Level of Knowledge about General HIV Issues (Alpha = .79)

1. I feel comfortable with my level of knowledge about AIDS.
2. I know quite a lot about HIV infection.
3. I understand how HIV infection works.
4. I know pretty much everything there is to know about AIDS.
5. Other than those which researchers have yet to answer, I have very few questions about AIDS.

Table 1 (cont'd).

Perceived Level of Knowledge about Patient-Specific HIV Issues (Alpha = .83)

1 - I know the treatments for the specific opportunistic disease(s) _____ suffers.

2 - I am uncertain of the chances for recovery from the specific diseases _____ suffers. (R)

3 - I understand the physical impact each opportunistic disease(s) will have on _____.

4 - It's unclear to me why certain treatments are performed with _____. (R)

5 - I know all the current information about each of the diseases _____ has experienced.

6 - I understand the current medications prescribed for _____.

Perceived Level of Knowledge about Home Care Requirements (Alpha = .80)

1 - I understand _____'s needs when he/she is not in the hospital.

2 - I feel capable of taking care of _____ during his/her times at home.

3 - I am <u>unsure</u> of my ability to help _____ follow his/her prescribed medical regimen.

4 - I know what needs to be done to make _____'s life at home more comfortable and enjoyable.

Table 1 (cont'd).

Care Partner Burden (Alpha = .84)

1. Somedays I just don't know where to begin in providing care for my _____ at home.
2. I feel overwhelmed by the problems I have caring for _____.
3. I <u>seldom</u> get discouraged caring for _____. (R)
4. Since caring for _____, sometimes I hate the way my life has turned out.
5. I often feel frustrated in my attempts to care for _____.
6. At times I feel I just can't continue to care for _____.
7. I get great satisfaction from caring for _____. (R)
8. Caring for _____ has been a very rewarding experience. (R)
9. I feel I was forced into caring for _____.
10. I feel trapped by my caregiving role.
11. Just when I thought times were going to be easier for me, I have to be a caregiver.

Involvement in Instrumental Activities of Daily Living

How often during a typical <u>week</u> does ____ need help with each of the following?

1. Shopping?
2. Housework?
3. Laundry?
4. Cooking?
5. Handling his/her own money?
6. Arranging his/her own transportation?

Table 1 (cont'd).

Involvement in Activities of Daily Living

How often during a typical day does ____ need help with each of the following? Enter "0" if you do not provide assistance.

1 - Eating?

2 - Dressing/undressing?

3 - Combing hair or shaving?

4 - Taking a shower or bath?

5 - Using toilet, bedpan?

6 - Walking?

7 - Getting around the house?

8 - Getting in and out of bed?

9 - Cleaning because of incontinence of urine?

10 - Cleaning because of incontinence of stool?

Physical Symptoms (Alpha = .86)

How often do you experience the following:

1 - Tightness of heaviness in your chest.

2 - Trouble falling asleep.

3 - Feeling nervous or fidgety and tense.

4 - Cramps in your legs.

5 - Pains in your stomach.

6 - Trouble staying asleep.

7 - Becoming very tired in a short time.

8 - Poor appetite.

9 - Coughing or heavy chest.

10 - Feeling your heart pounding or racing.

Table 1 (cont'd).

Care Partner Depression (Alpha = .82)

How often have you felt the following:

1 - Were you bothered by things that usually don't bother you?

2 - Have you not felt like eating; had a poor appetite?

3 - Have you felt that you could not shake off the blues, even with the help of family or friends?

4 - Have you felt depressed?

5 - Have you felt tearful?

6 - Has your sleep been restless?

7 - Were you happy? (R)

8 - Have you talked less than usual?

9 - Have you felt lonely?

10 - Were people unfriendly?

11 - Have you had crying spells?

12 - Have you enjoyed life? (R)

13 - Have you felt sad?

14 - Have you thought your life has been a failure?

Care Partner Perceptions of Control (Alpha = .90)

1 - There is very little I can do to make sure _____ gets good medical care.

2 - The only people who can really have a strong impact on _____ regarding AIDS are medical professionals. (R)

Table 1 (cont'd).

Care Partner Perceptions of Knowledge Usefulness (Alpha=.67)

1 - There is a lot I can do for _____ beyond waiting and hoping for a cure.

2 - As a caregiver for someone with AIDS, I really don't need to know more than the basic information about how it can be transmitted. (R)

Perceived Value of Talking With Medical Staff (Alpha = .75)

1 - It is not necessary for me to talk with _____'s doctors and nurses in order to provide good care. (R)

2 - I believe that greater communication with _____'s doctors and nurses would significantly change the way I provide care.

Perceived Motivation to Acquire HIV Information (Alpha=.96)

1 - I want to know everything I can about AIDS in order to provide the best care possible.

2 - I really believe that the more I know about AIDS, the better care I can give.

Table 1 (cont'd).

Care Partner Tolerance For Ambiguity (Alpha = .81)

1 - An expert who doesn't come up with a definite answer probably doesn't know too much. (R)

2 - I would like to live in a foreign country.

3 - There is really no such things as a problem that can't be solved.

4 - A good job is on where what is to be done and how it is to be done are always clear. (R)

5 - In the long run, it is possible to get more done by tackling small, simple problems rather large complicated ones. (R)

6 - Often the most interesting people are those who don't mind being different and original.

7 - People who insist on a yes or no answer just don't know how complicated things are.

8 - What we are used to is always preferable to what is unfamiliar. (R)

9 - Teachers or supervisors who hand out vague assignments give a chance to show originality and creativity.

10 - The sooner we all learn to see the world the same way, the better. (R)

11 - A person who lives an even, regular life in which few surprises or unexpected happenings arise, really has a lot to be grateful for. (R)

12 - A good teacher is one who makes you wonder about the way you look at things.

Table 1 (cont'd).

HIV Epidemiology: Objective Test Items

1 - The HIV can grow outside a living cell. (F)

2 - The AIDS virus has been found in breast milk. (T)

3 - HIV typically destroys T-4 lymphocyte cells. (T)

4 - In HIV+ persons, the number of T-cells destroyed is the main reason why health declines. (T)

5 - About 99% of persons infected with HIV will test positive by week 12 <u>after</u> infection. (T)

6 - Most patients with HIV infection have symptoms. (F)

7 - More of the AIDS virus can be found in blood and semen than in other body fluids. (T)

8 - In addition to damaging the immune system, the AIDS virus may also attack the central nervous system. (T)

HIV Transmission: Objective Test Items

1 - The AIDS virus is easily killed by ordinary bleach or detergent. (T)

2 - Proper use of condoms reduces the risk of HIV infection. (T)

3 - An HIV+ person who has no symptoms can transmit the virus. (T)

4 - A needle stick injury involving an HIV+ individual leads to HIV infection in less than 1% of the cases. (T)

5 - Spermicides containing nonoxynol-9 have proven to be highly effective in killing the AIDS virus. (T)

6 - A person who shares IV drug needles with someone who has the virus is at <u>low</u> risk for HIV infection. (F)

7 - A pregnant woman who is HIV+ may transmit the virus to her fetus. (T)

8 - A person is less likely to get infected with HIV through oral sex than through sexual intercourse. (T)

Table 1 (cont'd).

HIV Transmission: Objective Test Items (Cont.)

9. The AIDS virus can be spread by coughing or sneezing. (F)

10. It has definitely been established that females can pass the AIDS virus to their male sex partners. (T)

11. HIV may be transmitted by infected blood. (T)

12. HIV may be transmitted by insects such as mosquitos.(F)

HIV Treatment: Objective Test Items

1. The AIDS virus can be inactivated by substances that occur naturally in saliva. (T)

2. AZT inhibits reverse transcriptase. (T)

3. AZT is a cure for AIDS. (F)

4. AZT has very few side effects. (F)

5. One of the newest treatment developments is to combine AZT with other antivirals like ddC. (T)

6. HIV infection is now considered to be a long-term chronic illness. (T)

7. Asymptomatic individuals who are HIV+ need regular medical evaluations. (T)

HIV Symptomology: Objective Test Items

1. Diffuse lymphadenopathy can be a sign of HIV infection. (T)

2. Oral candidiasis (thrush) is a common infection among AIDS patients. (T)

3. Pnuemocystis carinii pneumonia is a common initial infection among people with AIDS. (T)

4. Infections of the central nervous system are common among people with AIDS. (T)

5. Patients with ARC may have fever, diarrhea, weight loss, lymphadenopathy, and/or thrush. (T)

Ta

HI

6.

7.

HI

1.

2.

3.

HI

1.
2.
3.
4.
5.
6.
7.
8.
9.

Table 1 (cont'd).

HIV Symptomology: Objective Test Items (Cont.)

6 - The diagnosis of AIDS can be made if a patient has wasting syndrome or dementia. (T)

7 - Kaposi's sarcoma is a common initial diagnosis for people with AIDS. (T)

HIV Total Test & Additional Items: Objective Knowledge

1 - Many health care workers have become infected as a result of treating AIDS patients. (F)

2 - The ELISA and Western Blot tests for HIV are interchangeable. (F)

3 - The Western Blot test is more sensitive than the ELISA test. (F)

HIV Drug Therapy Knowledge

Please mark a check by each of the following drug therapies that you have knowledge about.

1 - AZT
2 - AL-721
3 - AS-101
4 - Ampligen
5 - CD4
6 - ddC
7 - ddI
8 - Dextran Sulfate
9 - Forscanet
10 - Interleukin-2
11 - Interferons
12 - Imreg-1
13 - Isoprinosine
14 - Pentamadine
15 - Ribavirin

Ta

--
Co

Table 2. Construct Means and Standard Deviations

Construct	Mean	Standard Deviation	Range
Availability	18.68	4.79	5-25
Clarity of Communication	19.87	4.56	5-25
Completeness of Communication	7.69	2.21	2-10
Empathic Concern	22.63	5.81	6-30
Full Disclosure	11.50	3.29	3-15
General Communication Satisfaction	22.44	5.83	6-30
Perceived General HIV Knowledge	16.88	4.43	5-25
Perceived Patient-Specific HIV Knowledge	18.00	3.57	6-30
Perceived Home Care Knowledge CP	15.73	2.98	4-20
Perceived Care Burden	19.27	6.54	11-55
CP Physical Symptoms Index	24.00	9.72	10-50
CP Depression	30.50	7.48	14-70
Tolerance for Ambiguity	42.14	6.23	12-60
Perceived Control in Illness	7.13	2.36	2-10
Perceived Usefulness of HIV Knowledge	7.25	2.26	2-10
Perceived Need to Talk with Medical Staff	7.69	1.62	2-10
Perceived Motivation to Gather Information	9.19	1.38	2-10

Table 2 (cont'd).

Construct	Mean	Standard Deviation	Range
HIV Knowledge Test	29.31	4.73	0-38
HIV Transmission Knowledge	8.71	2.73	0-12
HIV Treatment Knowledge	3.29	1.65	0-7
HIV Epidemiology Knowledge	5.24	2.25	0-8
HIV Symptomology	4.12	2.14	0-7
Knowledge of HIV Drug Therapies	3.88	3.41	0-15

communication split into two scales, with two items focusing on completeness, and three assessing what is best interpreted as full-disclosure of patient-specific illness information. In relation to perceived knowledge outcomes, five items were retained to assess perceptions of general HIV knowledge, five items for perceptions of patient-specific HIV knowledge, and four items for perceptions of home-care requirements knowledge. Eleven items were retained to assess perceptions of CP burden, 10 items for measuring physical symptoms, and 14 items for CP depression. CP perceptions of control, knowledge usefulness, value of talking with medical staff and perceived motivation to acquire HIV information were all assessed with two-item scales. CP tolerance for ambiguity retained 12 items.

Data generated from the cleaned scales were used in two ways. The relations between primary medical contact communication and the care partner perceptions of knowledge, burden, involvement, depression and negative health outcomes were examined through a zero-order correlation matrix. Responses to the second survey were used to examine the motivations for seeking information and ability to deal with ambiguous outcomes, as well as to test the relationship between perceived knowledge and objective knowledge. While greatly limited by restricted sample size, such analysis provides an initial assessment of the relationships between care partners and medical providers. The statistical findings are incorporated with the qualitative data throughout the results section to better explain and map out CP involvement in the illness situation.

Interview Coding

The methodology of grounded theory (Glaser & Strauss, 1967; Glaser, 1978) was used to code the data generated through the semi-structured interviews. This procedure integrates data collection, observation, coding and categorizing of data, and theory development into a series of steps leading away from first-hand empirical observation to theoretical abstraction.

Analysis begins with the first interview, as the researcher pursues investigation of the research question(s). The observations and hypotheses thus generated serve to guide the evolution of further data collection. The researcher is attempting to discover the categories of behavior and thought that seem to define or aid in management of the situation under study. This is done through the abstract naming of behavioral similarities and patterns, and then developing these categories by relevant properties (e.g., intensity, duration, frequency). Once a catalog of the important categories (constructs) is generated, their interrelationships are examined. This is accomplished by identifying the conditions, interactions,

strategies and tactics, and consequences associated with each category. A hierarchy of relationships is thus established with the ultimate aim of selecting a core category and its attendant constructs. The theory yielded in this manner explains a specific phenomenon (e.g., pregnancy management) by selecting a primary construct (e.g., compliance with physician) and revealing the orbit of constructs which explain how the situation is accomplished (e.g., assessments of risk and medical regimen efficacy).

The process of theory construction thus involves an iterative exchange between data collection and analysis, with emphasis on extracting the primary constructs that define and operate in the situation under study. This means the researcher has to rather quickly escalate to more abstract levels in preparation for elaborating the theory. Throughout the research, the investigator should remain attuned to the potential need of gathering further data.

Memos containing category descriptions, interrelationships (both supported and hypothesized), as well as general theoretical developments are the staple of grounded theory. As analysis progresses, the researcher moves away from the actual data and deeper into the abstractions captured in these memos.

This description of the methodology is necessarily brief. More adequate descriptions and in-depth examples illustrating its use in the generation of theory are readily available (Strauss & Corbin, 1990; Strauss, 1987; Glaser, 1978; Glaser & Strauss, 1967). However, additional clarity can be gained through an examination of the major distinctions between the grounded theory approach and its quantitative counterpart.

Both approaches share a common interest in rigorous "scientific" analysis. That is, grounded theory seeks to remain answerable to the fundamental tenets of the scientific approach (i.e., significance, theory-observation compatibility, generalizability, reproducibility, precision, rigor and verification). However, it departs significantly from the quantitative approach in terms of the <u>process</u> by which research meets these criteria.

Fundamentally, grounded theory opts for an inductive rather than deductive approach. By giving emphasis to the data (i.e., the lived experience of participants) rather than to preconceived theoretical constructs and explanations derived from existing research, grounded theory seeks to encourage a rigorous creativity--to allow the dissembling of untested assumptions and acquire a fresh, more accurate interpretation of the phenomena under study.

One of the strongest methodolical differences between grounded theory and quantitative research, concerns the issue of sampling. Rather than requiring large numbers of participants for purposes of stability and generalizability, grounded theory concentrates on a <u>purposive</u> sampling technique which allows the research to fully encompass the phenomenon under study. Thus, the departure of the sample in this research from the agency's client population and its small size are not automatically negative. Rather, it was necessary to ensure discussion with a full array of care partners (parents, lovers, siblings, friends) in a variety of situations (patient living with care partner, patient living with other family, patient living out of state) and dealing with patients at various illness stages (asymptomatic HIV+, full-blown AIDS, death). In such manner, the method aims to explore the full scope of the phenomenon through theoretical sampling of conditions in which the emerging theory may be predicted to apply and those in which it would not. Through such clear demarcation of theoretical boundaries, the theory is effectively "grounded."

Charmaz (1990) categorizes further criticisms of grounded theory as one of two types: misunderstandings and misapplications. One important misunderstanding is that the approach advocates a tabula rasa ideology in arguing for researchers to distantiate themselves from relevant, existing literature. As Charmaz (1990) points out, however, grounded theory seeks not to *ignore* previous work, but rather to allow new perspectives to emerge as necessary by not being overly immersed in the conceptual world of other theorists. It is *after* working upward from the data that the grounded theorist seeks to engage in integrating the generated theory into the existing literature. Clearly, no researcher can fully succeed in setting aside the knowledge generated through active participation in research and reading on their areas of interest. However, the point of grounded theory is to inject some ambivalence to this personal body of knowledge in order to better balance the tension between preconceived and emergent realities.

A second misunderstanding of grounded theory is the claim that it lacks scientific rigor. Charmaz's (1990) response to this is that grounded theory lacks rigor only if assessed with the criteria used in doing quantitative research. Application of such criteria to the qualitative data which lies at the heart of any grounded theory research is unjustified, and must be exchanged for more appropriately defined criteria. Failure to understand the criteria by which a grounded theory should be designed and judged, leads to the misapplications identified by Charmaz (1990): premature commitment to a set of analytical categories, unnecessary jargon, and lack of clarity about key terms. In seeking to avoid such misuses of the method, and to provide a clear basis for assessment of the theory presented in the following pages, it is important to conclude this discussion of grounded theory with an identification of relevant criteria.

Strauss and Corbin (1990) identify four criteria for assessing grounded theories. These are: fit, understanding, generality, and control. More specifically, the generated theory should have a close fit to the data; the links between the concrete world of experience and the abstract world of theory should be clearly identifiable and reasonable. A grounded theory should also be understandable to persons whose experience is being interpreted, who have been or are actively living with and/or through the phenomenon. Further, the theory should strive to be general, to apply to more than simple the sample being studied. And finally, the theory must provide the means whereby human intervention can be enacted as a means of controlling the phenomenon.

Those desiring greater specificity of criteria can refer to Strauss and Corbin (1990). These authors focus on the specific issues necessary for the purposes of establishing the validity, reliability, and credibility of the data, the adequacy of the research process, and the strength of the empirical grounding contained in the theory. Full explication beyond the overview in the above paragraph is beyond the scope of the current monograph.

Two final notes are required. One concerns the balance between qualitative and quantitative data as used in this study. Stress is placed on generating a grounded theory, and accordingly then, on the qualitative data. The

quantitative data is used in a secondary role to assess the relationships derived from the qualitative analysis.

The second note of information concerns the selection of the supporting quotes presented throughout the results section. While the themes presented and discussed occurred in varying numbers (usually the majority) of the interviews analyzed, lack of space and concern for continuity of the text prohibits the presentation of all relevant quotes. Furthermore, such concern represents a more quantitative interpretation of generalizability than that used in grounded theory. In selecting quotes then, the main criteria was the clarity with which CPs were able to relate their experience. This yielded some bias toward the more literate CPs, however, care was taken to not silence the voice of those to whom standard, grammatically correct English is not second-nature.

CHAPTER THREE: RESULTS

This section details the results of intensive interviews with care partners (CPs) for persons with terminal chronic illness, predominantly HIV infection or full-blown AIDS. Data analysis began with a focus on those constructs which seemed of central importance in the initial interviews. These included physician acceptance of the CP legitimacy, structural restrictions on CP involvement (nature and hours of work, hospital visitation policies, transportation access), and CP motivation to search for information which was useful in allaying CPs' fears or providing some sense of control in the situation. This progression of thought ultimately revealed strong differences in the level of involvement CPs exhibited in the care situation. CP involvement is defined here as the nature and degree of assistance provided by the care partner.

It is clear from the interviews conducted that CP involvement springs neither simply nor fully formed with the advent of illness. Rather, it is the outcome of predominantly informal negotiations between patient, physician, and CP. These negotiations are influenced by a number of factors, including patient health status, CP philosophy and personality, prior care partnering experience, motivation to care, and prior patient-CP relationship.

Of all these precursive factors, CP involvement appeared to hinge most strongly on patient health status. That is, as health ebbs and flows, CP involvement tended to change in parallel fashion. In fact, this study revealed the continuance of the traditional medical model of physician-patient interaction (Siegler, 1979) throughout the early stages of HIV infection, with CPs willingly playing a limited role when patient health supported independent functioning, including the intervals separating acute health crises.

The focus of the following section then is on the manner in which CP involvement evolves in relation to disease progression, and its role in structuring and/or fulfilling patient case management needs. First, the involvement options within which CPs operate are presented, with emphasis on the construction of overall involvement packages. Second, precursors which influence CP involvement are examined, with special attention to the impact of these factors and resulting involvement levels on information gathering dimensions (e.g., sources utilized, mechanisms for cross-checking information accuracy, and the functions of information for the CP). This is followed by a presentation of outcomes associated with varying levels of CP involvement. Finally, this chapter closes with a specific examination of CPs' interaction with medical staff and the impact of information thus garnered on CP knowledge levels, perceived burden and personal health outcomes.

CP INVOLVEMENT

As noted earlier, CP involvement refers to the nature and degree of assistance provided by the CP within the care situation. Involvement opportunities range from simple participation in to outright assumption of a variety of tasks required for managing illness. Though variant across the full trajectory of illness, these involvement options include the following: search for information regarding illness and/or treatment options, medical appointments, hospital care, home care, medical regimen compliance, and community service provision arrangements. As choices are made within these categories, a CP's overall involvement emerges, defining the exact character of his or her participation in the illness spectrum. Before examining the nature of involvement packages constructed from this opportunity menu, however, each option is described more completely.

Information Search Involvement

Involvement in the search for information about HIV infection (including how the virus is transmitted and how it works to diminish health, associated common diseases, and existing treatments) occurred at several levels: no involvement, passive gathering, moderate, and full search activity. Characterizing involvement at the passive level, CPs for patients who had acquired HIV through IV drug use were unlikely to search for information. Rather, these passive information gatherers acquired information through attention to media presentations (e.g., newspaper coverage, programs on radio and television) in a relative fashion. Such individuals were more attuned to articles, programs and broadcasts concerning HIV but did not consistently exhibit active search behavior. These CPs were dependent upon external sources of information which may or may not have provided information adequate to answer their questions.

> "[I don't feel comfortable with my level of knowledge about AIDS at this point]. I now I need to brush up and hear more. It's just a point of doing it. Everytime I ride past the [AIDS service agency] I want to stop, but I don't. I know they're going to ask me about Robert [the patient]. They'll try to convince me to get Robert to come...I want to learn more about symptoms, cause I only know some of them. I only know the one's that's happened to him. It's just taking time to do it." (#11, pp.19-20).

CPs engaging in moderate search activities not only gathered general media information, but also tapped into the variety of local services available through support groups and community agencies. Such CPs expended greater effort in constructing an information network in their community that could provide updates on HIV infection.

> "[My initial knowledge] was pretty nill. I mean I didn't know that much. Then being in the situation it's been a real learning process. [My main learning sources have been] literature from that we received from the AIDS Consortium, that [the patient] picked up from the doctor's office, articles in the newspaper. I'm much more aware of it now." (#12, p.32).

> "[My knowledge] came from both reading and talking. And then I had enough sense to go and find literature. Like I said, the AIDS Consortium, they were very supportive and if there was anything I wanted to know, they would tell me if I asked them and everything, and anything I wanted to know, I mean they was real, they are very helpful and so it made me understand you know that AIDS is a very dangerous disease, you know, and to have respect for it. So if you don't have to come in contact, you know if you don't have to have sex, don't. You know, they let you know, so I was aware of it and I left it alone. I took that and I let that idea [of sexual relations] go right out of my head." (#17, p.34).

Finally, full-information search activity was distinguished by a driving urge to learn about all aspects of HIV and maintain "state-of-the-art" knowledge. Such a drive was typically expressed through the construction of an elaborate information network, reaching beyond the local community to draw on newsletters and resources offered from AIDS-related groups and agencies located on the coasts of the United States where HIV infection is more widespread, and knowledge more extensive and expanding.

> "<u>It's just a question of keeping appraised of horrendous [amounts of] literature that continues to turn out from research...It requires total immersion into any and all that I can try and get my hands on</u>. Like any kind of graduate school course, you need to

> end up knowledgeable about this subject and how you go about it is up to you. It's just like basically reading and absorbing... calling different support groups and organizations that would have access to information or could channel me to other sources of information...So just networking basically to get my hands on whatever state of the art literature is published," (#1, pp.18,21).

> "When I was in California, I was like an antenna. It was like, 'Why does that work? Why doesn't it?" This and that, and [the medical staff] was telling me...I think my outlook contributed to how I perceived the information that I was getting. That helped with the whole picture. The fact that everything I did was unconditionally and it was just like a vacuum sucking in information. And so whenever I got a reference or a lead, I just kept following it...Because it's something that's not like a part-time job. It's like when you wake up in the morning, you're actually opening up your brain and your body and you mind and everything to perceive everything everybody's giving you. Well, of course, you need to be informed," (#10, pp.18,30).

> "[I got information] from everywhere. From C-HAG [a local AIDS organization], from the hospital's, the doctor's office. Everywhere I could. From the AIDS Consortium, from the papers, T.V. Everytime I saw a special on it, I would take the T.V. into the other room. Any way that I could get it. Shanti [a California agency] got me a lot of literature on it and I would sit and read it, and she [the patient] would sit and read it. We'd even sit and read it together." (#16, p.19).

Medical Appointment Involvement

As with information search, CP involvement in medical appointments played out at different levels. It is important to distinguish, however, between involvement which is direct (i.e., the CP physically present and involved during the actual appointment) and that which is indirect (i.e., the CP participating through assessment and critique of appointment proceedings and developments as recounted by the patient).

Most CPs played a very limited direct role in patient-physician interaction except during hospitalizations. At the lowest level, CPs had no involvement whatsoever with such appointments; the patient handled everything including scheduling, transportation, and filling prescriptions or other assigned treatment tasks. This was so even for fairly extensive treatment procedures:

> "For a while in January, February, March, April, he was on pretty steady treatment of chemo. It was about every three weeks. He'd drive himself; take his bag and drive over. He would go get his chemo Thursday night and drive himself home Friday." (#3, p.11).

CPs at this minimal involvement level occasionally confirmed or set up an appointment at the patient's request, but did little else.

Slightly more involving was the provision of transportation for the patient. The CP did not always stay for the full appointment, and even if he or she did, it was in the waiting room with little to no staff interaction. On occasion, the CPs would accompany the patient into the examining room, again primarily at the request of the patient. Here, he or she would play a predominantly non-participatory role, serving as an emotional support for the patient.

Only three CPs progressed to full, direct participation in routine, medical examinations; two did so because the patients suffered limited mental function prior to their HIV infection. The third CP insisted on direct participation when the patient's ability to pursue his medical care independently broke down.

In terms of indirect involvement, CPs ranged from no or minor discussion with the patient to full partnership. Some CPs pursued full disclosure of the interaction following each appointment. This took the form of both coaxing information out of the patient and coaching him for future interactions.

> "I'll say 'What do they say?" That's why I wish I had direct access because even if AL did answer questions, I'm fairly good at attacking the situation analytically and quickly. 'Did you ask him this? What about that? What about this eventuality?' And more what ifs and what abouts. He may have failed to get the information, which may impact your reaction, your decision and how you'll respond to the situation...<u>I sit here and basically logic test everything that they say. I mean he's presented with options. He reviews them with me. It's kind of like I'm his board of directors, or at least his sounding board</u>." (#1, pp.18,21).

CPs involved at this level used the patient as a resource for gathering information desired by the CP by pointing out the need to get relevant answers at subsequent appointments. One CP (#12) who worked as social worker providing assistance to the elderly, had his partner write down all his questions prior to each appointment so that nothing would be forgotten. Because the CP helped develop this list, the method assured answers to questions he thought important.

Other CPs were relatively inactive in discussing patient appointments. This appears to have been related to health status in that asymptomatic infection typically yielded standard treatment protocols. Thus, there were no major events associated with each appointment. While the monitoring of T-cell ratios provides an indication of immune system strength and thus an indication of risk for an acute episode, the monitoring of T-cell counts was not typically cited by CPs who were uninvolved with the appointment aspects of patient care.

Hospital Involvement

The minimal level of CPs' hospital involvement related by those interviewed was the provision of companionship and emotional support through visiting the patient during hospitalizations. This was standard practice from the outset of involvement with the patient's HIV infection, and was generally included hope sustaining messages, entertainment, and general distraction of the patient from his physical condition. Here too, though, CP involvement ranged widely in both quantity and quality. Some CPs visited only occasionally or for limited amounts of time during evening visitation hours, while others essentially moved into the hospital with the patient.

> "If I decided to stay the night, if there was a vacant room they would ask [if I wanted to sleep there] but I said 'No, I'll stay right here [with my sister].' I just needed a pillow and something to sleep on the floor with...[The staff] got used to me coming up and taking a shower, reading the paper, [watching TV with her]," (#16, p.5).

> "When he first when in I would stay to maybe 11:30 p.m. or 12:00 and then go home to sleep, but he had one particularly brusk conversation with [a gastrointestinal technician who strongly upset the patient]...and then after that I didn't leave [until the patient was released]." (#7, pp.15-16).

Most CPs who did not visit as frequently were constrained from doing so due to employment demands or lack of transportation. Conversation during hospital visits ranged from sharing news of life events in personal networks to more emotionally-charged topics such as thoughts concerning death.

CPs also engaged in many small comfort tasks. At the lowest level, the CP would serve as the patient's mobility: fetching water, helping them to the bathroom, calling the nurses.

> "It got to the point, if he needed something like water or ice cream or towels, I would just go get the stuff. I knew where everything was. It was on the floor we were on. I would just go get it; not even bother [the staff] really." (#3, p.17).

Such lower effort involvement is contrasted with CPs who took on more complex tasks which required greater staff interaction and use of hospital supplies (i.e., bathing the patient, cleaning incontinence).

> "So, when I was there I almost always gave him his bath, and I requested and ordered up a bed tray, so that I could wash his hair. I would wash and cut his hair, shave him, you know, I took care of him while he was in the hospital." (#7, p.13).

Patient care monitoring and advocacy were related tasks in which all CPs engaged to the extent possible. Some aspects of this monitoring were typical of all institutional illness care, including watching for oversights (e.g., backed-up IVs, spiking fevers) and outright errors (e.g., mixing incompatible medications, routing medication through veins in danger of collapse).

> "There was always things I would find out by being there with her all the time. The only thing I can tell you to sum it up is the first year I went through hell with her. It was almost like I had the disease myself," (CP#16, p.7).

Unique to CP monitoring of the HIV+ patient was a deep concern with the attitude of hospital personnel toward the patient. There was a great deal of expressed sensitivity about any action on the part of staff which might be interpreted as shunning the patient. This sensitivity was attributed to fears that the patient might feel tainted and demoralized as a result of such behavior.

> "Some of [the nurses] he didn't care for because he could feel their reaction and he

> would just say anything to them...you know, and when he would see them in this yellow [protective garb] and stuff, you know, he really put them on the shelf, because he knows that this person is leery and he would say 'I don't want her coming in here' because he could feel it and he resented that. He wanted to be treated like anybody else," (CP#17, p.24).

Generally, CPs tended to hold a relatively relaxed monitoring stance until a specific mistake or attitude presented itself. Following such incidents, monitoring became more intensive and thorough.

Monitoring was rarely passive, however. Whether originating from staff attitudes or the quality of services, perceived problems in care provision generally led to CP involvement in <u>patient advocacy</u>. This ranged from calling a current problem to the attention of the staff for immediate correction to informing staff superiors with the aim of preventing recurrence. Both increased monitoring activity following an initially discovered error and vigorous advocacy are revealed by the CP in the following example:

> "I would spend like hours with him, sometimes I would stay all day, because he was in where you could go see him anytime and one night I was out and my mind thought of him and I just went to him at about three o'clock in the morning and I had my buddy drop me off at Ford Hospital and I just went on up there to his room and I 'm glad I did, he said he was burning up with fever and his blood stopped going back into his IV and he started foaming at the mouth, this is three o'clock in the morning, and she come and asks me what are you doing here and I said good thing I'm here or he'd been dead, you know because the IV had run out and the blood had started going back into the IV, so I think she was mostly

> mad because I reported that, you know, by him being in intensive care unit they had let that happen, and I'm glad I did because I believe he really would have died. <u>So after that I started going more regularly, I would go like every day and sometimes I would be there four to eight hours and go home and come back, go home and come back, that's what I did for the three months that he was in the hospital</u>," (CP#17, p.7).

Home Care Involvement

The level of involvement with patient care in the home was strongly contingent on patient health and included the simple continuation of relational responsibilities existing prior to infection, involvement in instrumental activities of daily living (IADL), or involvement in activities of daily living (ADL). The majority of patients in the present sample were capable of independent function which obviated the need for intensive CP assistance. However, it is informative to see how one CP(#2) whose patient is also a sever diabetic, describes a typical day's involvement:

> "I will start at the morning and giving him his medication in bed. Then we get up and get to the bathroom and he gets his bath and he gets dressed. Then we come downstairs. I prepare his breakfast and more pills. Then I do around the house what I have to do then it's more pills and lunch and taking him to and from the doctors. We pick up his medicine from the drugstore. I take him out every other day. I'll take him out for a ride or to go visit my son in Southfield. We'll visit him for one day and then we'll come home. The next day we'll stay home and then the next day we'll visit one of my other sons and spend the day there. But I take him out at least every other day. That's just over and over and over. And of course Sundays we go to church. Some days we'll run

> out and pick up some fast food. Maybe ride out to Belle Isle and sit out there. Whatever hits my mind, because sitting around the house he gets bored and it's very tiring. You just take medicine and sit, take medicine and sit. I like to get him out of the house to change his environment. And his washing of course, I have to do his washing and ironing, I do washing about twice a week, iron once a week," (CP#2, p.5)

For patients who were bed-bound or too weak for extensive trips outside the home, employed CPs faced the task of providing them with company during working hours.

> "[I would arrange for] someone to come over so he wouldn't be alone. I would leave some money to go order pizza or if he's up to it take him out to dinner or watch a movie or something, just so he isn't alone. Not so much I thought he was going to get hurt, cause I think everyone's greatest fear is dying and being alone." (#3, p.9)

In both home and hospital contexts, CPs tended to do whatever was seen as necessary. CPs often spoke of rising to the occasion and developing the requisite knowledge and skills as new developments arose, even when they had strong doubts about their ability:

> "[In being a CP for my brother] I got a chance to test myself, see who I was. I had no doubt that I loved him; I was sure about that. But all the other things that I came in contact with, I would just assume not knowing that it would just kill me--dead. All the things I saw. Although they were shocking--quite revealing--it was just a settling feeling that you had to go to step number 18, step 20. Whatever, another step you gotta make it to, get through the next day. It was just like a step thing. I just kept stepping," (CP#10, p.33).

Skills Training for Home Care

Only four of the CPs interviewed found it necessary to learn specific medical skills in order to care for the patient at home. Training was usually performed by the home infusion company who provided the equipment and related emergency support once the patient was at home. Training sessions typically consisted of showing the CP how to perform the tasks once, and then having him or her perform under observation several times. There were little to no reported difficulties with skill training.

> "[I was trained in the hospital] by the pharmacist and a representative of the [home infusion company] who actually teaches the people...She was actually a registered nurse. They showed me how to use the pumps, the needles, [and emphasized] cleanliness and the time factor because...the tubes had to be changed at a certain time, the bag had to be changed at a certain time. He had a dehydration bag and the food bag also...I wrote it all out on paper just like I do at work, everything that has to be done. I studied it for three nights until he came home...It was just like they gave me a rule book from 1 to 10 and left it up to me to learn all 10 of them. They just [left] no room for doubt." (CP#10, pp.5-6).

It was important during the training for CPs to learn not only the skills required for operating the machinery at home, but also to acquire confidence both in themselves and the home infusion company. The professionalism of the trainers went a long way in establishing both of these latter elements.

> "They came in so professional and they came in so willing; I mean it was just like I was

> so impressed, I just sort of--[doubt] sort of left my mind. I stopped thinking about whether they were actually the right company to serve him or if they were going to not bring over the stuff on time...They just came in eliminating [doubt]. And I know it's been said that presentation is everything, and I commended them a number of time during the process that they had themselves together." (CP#10, p.6).

The CPs willingness to learn also played a role in their skill acquisition during training. Most CPs had no former technical experience with medical treatment and the task appeared daunting at the outset. However, CP motivation to fulfill the patient's desire to go home often provided the impetus to overcome personal fears of complexity and uncertainty.

> "I mean...I literally did surprise myself because I'm not fond of anything pertaining to needles or anything like that. It's just like, give me a typewriter, I'll compose that letter. [But] Gary says 'This is the only way I'm going to get to go home. You're going to have to learn how to do this.'... [The nurse] was quite amazed as to how I picked it up. It was just like I had made up in my mind [the night before training], if they asked me could I do it, and when they came in the next day to start teaching me, <u>I had made up in my mind that I was going to learn it regardless. It didn't matter. He wanted to come home and I wanted to do whatever I had to do</u>." (CP#10, pp.4-5).

Not all of the CPs' technical knowledge was derived from the formal training sessions however. What appeared more significant was the opportunity to observe medical staff at the hospital performing the tasks which would be required of the CP at home.

> "[I have relied on the formal training] maybe 50%, maybe less. But all of the hospital he's been in, I observed all the things that the nurses and doctors did and I held it all. So mine has mostly come from seeing what they did and doing it. (CP#2, p.10).

Methods for accomplishing other non-technical care tasks were also discovered during hospital visits with the patient. One CP (#7) learned the value of using a drop sheet to more easily move a bed-ridden patient when he observed nurses doing it in the hospital. Others brought with them prior care experience with physical management tasks which meshed with instructions received in the current situation. One CP (#2) discussed the translation of bed-bathing techniques she learned as a young girl to the current care for her son:

> "I learned to do a lot of these things while I was [at the hospital]. How to bathe a person--I always knew how to bathe a person. I learned that when I was about 16 years old. I had a sister-in-law that was sick. I was the only one available to take care of her. And I was told [again at the hospital] to turn him on his side, on his back, then turn him back over. You do the same thing as your changing the sheet, you roll him over on that side of the bed, put the sheet on, tuck it in as good as you could then you roll him back over on this side. I learned all that actually as a teen-ager. These things I call common sense, things that you don't have to go to school to learn. Just some things you pick up on common sense. So I learned how to care for sick people even then and of course I've had a lot of experience being around a lot of sick people and caring for them. I really do it with pleasure because I'm helping someone so that's how I do it." (#2, p.10-11)

Prior knowledge was not always viewed as a plus by medical staff, however, especially in the technical skill realm. One CP (#16) had worked in the military as a medic and had extensive experience in surgery procedures. However the medical staff typically undertook any technical training as thought he knew nothing about the procedures, an approach he found perfectly acceptable: "That's one of the things they say, 'A little knowledge can be too much,'" (p.12).

Medical Regimen Compliance Involvement

Involvement opportunities were less complex in the area of patient compliance with his medical regimen. The majority of CPs had limited, if any, involvement with patient medication. CP #3's experience was typical for CPs at this level of involvement: "As far as medical, giving him IVs or drugs, he pretty much took care of everything," (p.6). Others helped by developing and maintaining a checklist which ordered the medicine to be taken at various intervals throughout the day, and assuring that medications were kept in stock. Such behavior was typically part of organizing responsibilities adopted by the CP which involved him or her outside direct contact with medical personnel:

> [I took care of] getting him to appointments and keeping a calendar of when those appointments are. <u>Making sure he takes his medications. Making sure he has the medications</u>." (CP#18, p.10).

Only a few CPs were involved at the level of having full responsibility for patient compliance with the medication regimen.

> "[He takes diabetes medication] five times a day. Seven a.m., 11 a.m., 3 p.m., 7 p.m., and 11 p.m. That's five times a day. [Other medication must be taken at 8 a.m., noon, 4 p.m., 6 p.m., and 8 p.m.]...I don't know if he doesn't think he's depending on me to take the medicine. I don't think Bobby would forget, but I think he thinks 'Why should I? Mama will give it to me at 12:00.' That's my belief. I don't want him to lean on that, 'I just can't remember' [excuse]...I keep the chart up on the refrigerator and all he has to do is look up there and see and check the clock. Just check it out, "O.K., I took my 12:00 medicine, now I'll have to take it at 3." That would be a lot of help to your mom, my darling. Help save these 71 year old legs. It's not a lot of work for me. If I'm sitting down there knitting, I'll look at the clock, "Bobby, it's time for your medicine. Bring me your chart. I'll keep the chart. You go back to the kitchen. I'll tell you what to take. I'll call them out to you." We have a little thing on the table we put them in. Now he'll take them like that, I won't have to get up." (#2, pp.6-7)

While most regimens were not as complex as that described above, even complex schedules became habituated knowledge. While the checklist remained in close reach, it was less and less necessary to refer to it every day.

> "You see if I don't have them all written out I couldn't do it. I just wouldn't be able to handle it. But now, for the length of time I've been doing it, I don't have to look at this because I've been doing it so long now. Just to be sure I keep it." (#2, p.8).

A special case arose in the context of IVDU patients who were foregoing there prescriptions for AZT and continuing their drug use. Here, CPs would consistently advocate taking the appropriate medication and quitting the drug use. In general, however, there was resignation to the strong hold drugs had on the patient under the CP's care.

Service Development Involvement

CPs also differed with regard to their involvement in helping arrange for government agency services for the patient. This area of involvement generally required contact with AIDS-related agencies in the community, government offices to see about Medicaid, Social Security Disability Insurance, or other forms of financial support to cover patient's medical bills. Patients again did as much as possible within their physical limitations, but often CPs specialized their involvement in this area, becoming experts in the process:

> "I have file boxes of every discharge, every appointment, everything that happened, but it needs organizing. I have everything from Social Security, social services, applications for Blue Cross--just everything that would be helpful for someone in the same situation. Because, Welfare, you know, you have to get that before your Social Security is approved. But it's possible to have Social Security approved in four to five weeks, because I had it done. They tell you it's six months; that's bullshit. I got the names of everyone to cut through all the red tape," (CP#3, p.2).
> "Basically, I've done [everything in terms of arranging social services]: filling out reports and contacting social workers and other case workers...I've taken care of financial aspects...but in terms of medical aspects I don't go out of my way to interfere." (CP#18, pp.9,11).

This section has laid out the multiple opportunities available to CPs in the illness situation. These are: information search, hospital care, home care, direct and indirect medical appointment participation, medical regimen assistance, and service development tasks. Variation between CPs was observed within each of these areas. As patients moved along the illness trajectory, different involvement opportunities arose, leading the CP to make a series of choices. These choices significantly shaped the overall nature of CP involvement in relation to the entire illness management situation. Determinations of overall CP involvement--labeled "involvement packages"--are explored in the following section.

INVOLVEMENT PACKAGES

The involvement packages constructed by CPs in the present study operated in distinct ways for cognitive and behavioral involvement. Specifically, cognitive involvement was established primarily through participation in the search for new information about the epidemiological workings of HIV infection and its treatments. Established early in the illness process, cognitive involvement tended to remain stable across the full illness trajectory. CPs did not typically increase or alter search activity in the face of acute episodes. Such CP knowledge acquisition served to establish a strong bond to the patient, creating a perception that the pair was facing the illness together. Furthermore, the development of HIV expertise had potential impact on the interaction patterns CPs established with medical professionals. CPs with greater cognitive involvement engaged in more interactions with the medical staff (especially physicians) and talked in more depth about patient developments than did less involved CPs:

> "I can only remember one day not talking to the doctor in charge and that was because [the original physician] was rotating out and [a new one was replacing him]. The next day [the new physician] came in for rounds; I waited to talk to him but I never [saw] him that day. So the next day I let the nurse know to make sure he came and talked to me. Then after that he would come talk to me," (CP#20, p.8).

Such efforts were aided by prior information search activity which had generated a more complex understanding of HIV infection and its attendant complications. Thus, in addition to establishing greater access to medical staff, information rich CPs were able to receive information at level of greater complexity:

> "I just want to know every little thing I can that's within my understanding. When they started talking about blood counts, I think I surprised the doctors by wanting to know the specific counts and how bad they were. To somebody else, they'd just say he needs blood. But I would ask, 'Is the count that low?' or 'Are his white blood cells that high? Why?' When they told my husband that he needed blood, he just said, 'Ok, he needs blood.'" (#20, pp.12-13).

As well, CPs with extensive knowledge about experimental treatments were better able to assess current treatment efforts and advocate new options as seen in the following case:

> "As a matter of fact, both Al and I, on several occasions brought up things to the physicians that they were unaware of. Either nuances in the protocol or new experimental drugs that are available or a different protocol with existing drugs. It's just a question of keeping appraised of the horrendous [amount] of literature that continues to turn out from research." (#1, p.18).

Behavioral involvement, however, tended to depend more strongly on the patient's health status, and fluctuated across the course of the illness. All CPs tended to rise to the demands of the occasion in terms of what the patient needed them to do. This motivation was often a tenuous balance between the willingness to acquiesce to every patient request and a sensitivity to doing too much and making the patient overly dependent. As described in an above quote by CP#10, "It's just a step thing. I keep stepping," (p.33).

CP involvement in the current sample appeared in two major types: full involvement across all opportunities, and specialized involvement in more select areas. Much of this variation can be explained by the patient's placement on the illness trajectory of HIV infection. Full involvement CPs were generally characterized by: full information search, strong participation in medical appointments (either direct or indirect), strong medical staff interactions characterized by information exchange and patient advocacy, and heavy involvement in hospital and home care of the patient. Six CPs (#s 2,7,9,10,16,22) engaged in this complete range of involvement.

A second category was labeled specialized full involvement because CPs contributed high effort involvement within a more limited domain. At a general level, the 10 CPs in this group specialized in one of the two specific care contexts, either home care or hospital care. Two CPs (#4 & #20) received knowledge of their partner's HIV/AIDS status as a result of traumatic acute crises which centered their care situation in the hospital context. In this context, both CPs exhibited full involvement in all aspects of the patient's care, including regular interaction with medical staff, seeking of information, and patient monitoring and advocacy.

In the home context, additional variations in specialization were observed. Some CPs specialized in the cognitive arena of information procurement and care analysis. One CP (#1) specialized his involvement within the information search domain, including heavy indirect participation in his partner's medical appointments. Throughout the illness trajectory, this CP's emphasis was on critical analysis of the patient's care program based on "state-of-the-art" knowledge regarding HIV/AIDS. Another CP (#3) exhibited aggressive search activity in the treatment aspects of HIV while shunning specific epidemiological information about the virus itself. According to this CP, his one-sided search was in part due the denial he was practicing about his own HIV+ status.

Another area of specialization developed around the procurement of community service assistance. Five CPs (#3,4,5,18,20) devoted large blocks of time to dealing with government agencies on items such as filing for disability, securing Medicaid assistance, and applying for chore grants. Two CPs (#18 & 20) made extra efforts to ensure their partner had private health insurance; CP#18 back-dated an insurance application to get around a 6-week pre-existing condition clause, and CP#20 arranged for the extension of the partner's health insurance plan offered through his employer.

A consistent involvement pattern held for CPs whose partner acquired HIV through drug use: home-based, emotional support and double-edged attempts to convince patient to adhere to prescribed medication (i.e., AZT) and suspend continued use of illicit drugs. Hospital visits tended to be less frequent with lower interaction with medical staff. This pattern emerged with six of the 10 IVDU CPs (#8,11,13,15,17,19 & 21).

Three CPs fell into a category of very limited involvement due to the circumstances of the partner's illness. One CP's (#21) partner was fully asymptomatic with no real downturn in T-cell count. Given this, the CP saw no need to be involved beyond the level of providing emotional support and had never spoken with any medical staff about her son's illness. Another (CP#19) focused primarily on helping her son with his medication while at home and arranged for special food packages to be taken to him during hospitalizations. The son handled nearly all aspects of his care situation right up to his death, continuing a pattern of action in which he had often cared for his elderly parents rather than they for him. The last CP (#13) had initiated some care involvement (e.g., gathering information, joining a support group, and taking her son to medical appointments) when the patient ran away from home. As of the interview he had failed to return, yet her basic concerns and wishes parrot those which predominate among the CPs for IVDUs: get off the street, quit using drugs, take the prescribed medication, and try to live until a cure is found.

Clearly then, CPs construct variant involvement packages over the course of their partner's illness. Despite the strong influence of patient health status, it does not appear possible to fully explain involvement packages with this variable. Particularly in the area of cognitive involvement, a number of other factors influencing the nature and degree of involvement were uncovered in the current research: CP-patient relational history, CP life philosophy/personality, motivation to care, prior CP experience, and structural limitations such as employment demands which restricted the time CPs could devote to patient care. The influence of patient health status and these other factors on CP involvement packages are presented in the following section.

PRECURSORS TO CP INVOLVEMENT

Patient Status

The patient's physical and mental health provided a pervasive influence on CP involvement. The general trend was that the physician-patient dyad exhibited greater permeability during acute crises and/or following permanent decline in patient function. Across <u>all</u> cases, CPs and patients invoked a rule of "normalization" by which the existence of HIV infection was downplayed and life continued as before. The desire to normalize the viral infection was manifested in patient continuance of employment, home maintenance responsibilities, and continued management of personal health care. So pervasive was this normalization rule that the majority of patients who acquired HIV through IV drug use continued their habit. The patient's need for continued autonomy is clearly evident in the following quotes:

> "The doctor had told him a long time before he ever even went on disability that he could qualify. But he would work. I don't think that is just a characteristic of people with

> AIDS, but with anyone who is terminally ill would view that as giving in. Maybe acknowledging that death is close and so sometimes people even though they could stay at home don't really want to because of what that signifies. So <u>he worked until he knew that he couldn't anymore, and then it was pretty rapid downward progression after that</u>." (#7, p.6).

> "...I respected him because he had the courage to go on. He didn't give up. He didn't just lay there and wait for someone [to wait on him] hand and foot. He resented that. Like <u>he said I babied him too much. He resented that so I stopped and I let him do things he wanted to do</u>." (#17, p.21)

> "[If] I would call the doctor, it would be on behalf of him. Call for him. Get his appointment days and something like that. <u>But he took care of his own business</u>." (#17, p.17).

The normalization rule then applied with each situation described by the CPs. With regard to the CP's involvement in the medical aspect of patient care, this normalization amounted to the continuance of the traditional medical model. As time evolved, however, and the illness worsened, CPs would slowly acquire greater responsibilities. One CP provided an eloquent, touching account of how his care shifted to adapt to his partner's growing dependence:

> "It just kind of gradually evolved into you do this for him, you do that for him. I remember the first time that he was in the bathtub and we were afraid for him to stand up and get in and out of the tub by himself. It would just be little things that would come up like that, or we went to get something at a medical supply store, and we looked at commodes and we talked about it and decided that we better get it because the toilet seat is too low and it was too hard for him to get up. So I said, 'Why don't we

> get it now, because there is no sense in you struggling and maybe falling in the bathroom because you've got to try and get up off of the little commode.' And then pretty soon, I would help him get up and like a chicken going tottering and flying, trying to make it to the bathroom before he had to go and I would finally say, 'You know, Tom, why don't you let me just bring it in and then you don't have to go that far.' Then it was an easy step from that to, 'You really can't get up by yourself. Why don't you let me lift you? If you just kind of let me put my arms underneath you and stand up, then I can get you up and all we have to do is turn you. And then if we get to the point, he would be real stressed to go in his pants. It was just, he couldn't, so finally it got to the point where you say, 'You know, it probably would be easier on you and easier on me--it creates too much stress for you to decide if you have to go and to real quick get you up and get you on the commode and get your pants down before you wet them--why don't you just do it in the bed, because it is easier for me to clean it up that way. Let's just do it that way.' And he would, as long as you were kind of detached and kind of logical about it and things like that, he would take it very well. So then it got to the point where that's what he would do. And it's really easy...he wouldn't really fight me about things like that, and so he was fairly easy to take care of. And I think because of the closeness of our relationship, I didn't try to push him..." (CP#7, p.23).

CP Philosophy/Personality

The CP's philosophy of life, personality, and attitudes toward care and illness that existed prior to the HIV-related care impacted CP involvement, particularly in terms of scope. The CPs interviewed (like all individuals) had specific approaches to life, standard manners of addressing problems, interacting with others, and generally accomplishing the myriad tasks necessary for sustaining patient care. For some, this was expressed through personality traits. For example, a CP (#10) who described herself as "oriented to the facts" exhibited unflagging effort toward procuring information relevant to the patient's situation throughout the full course of illness. Another CP (#15) with fastidious habits worried about potential patient decline that would require cleaning incontinence or working with needles in a home care environment. Yet another CP (#12) was reserved, repeatedly emphasizing his role as an integrator and peace maker between the patient and service providers, a role which explicitly <u>excluded</u> full participative interaction with the medical staff.

Other CPs expressed such influences in terms of philosophical approaches to life. Several CPs expressed a strong belief in doing what you can and not worrying about what you can't. One in particular noted his belief in the negative impact of patient self-pity:

> "And another thing about him, he felt sorry for himself. Self pity is the worst thing anybody could have regardless if you are ill or not. Cause see self pity can destroy. When you start feeling sorry for yourself you might as well give it up because it's not going to get any better. I'm a person that has always believed that you can do anything you want to once you set your mind to doing." (#14, pp.8-9)

Another area of belief that influenced the development of CP involvement was CP perceptions of medical care. For instance, CPs with lower income mentioned the value of relying on traditional medicinal approaches. According to these CPs (#17 & 21), chafing skin, open sores, fevers, nausea and other illness symptoms can be effectively treated with home-spun remedies. One spoke strongly not only of the <u>necessity</u> of using these techniques due to lack of insurance or money, but also to the <u>greater effectiveness</u> of traditional, natural methods.

> "<u>Why keep going to the doctor, hoping that he is a miracle worker? It's all about you. You got to get in tune with yourself now</u>, you know, because doctors don't have the time. They are getting sued for malpractice and technology is taking over and we just got to go back to some of the old ways that our parents and stuff have taught us. You know, we just got to go back to old techniques. It sounds unorthodox, but really if we look at it we just got to go back into some of these old ways because medicine is all about discovery now...I mean science is just going too far. They are playing god a lot of times. I believe, so <u>it's just about finding yourself. Find out about yourself, that's my belief</u>," (#18, pp. 39-40).

Thus, CP personality and philosophy made themselves felt in the involvement level developed with medical staff. Not all aspects of personality and philosophy survived the CP experience, however. This will be dealt with in greater detail below, but the sight of a loved one struggling against the damaging effects of HIV infection at times diminished concerns over whether or not the CP was really up to various aspects of patient care. Indeed, CPs spoke of running into obstructions of prior beliefs about themselves that were overcome:

> "I mean, I was, I literally did surprise myself because I am not fond of anything pertaining to needles or anything like that...So Gary says 'This is the only way I'm gonna get to go home. You're going to have to learn how; you have to do this...He kept asking me 'Do you think you can do it?' And I was like, 'No, not really.' But, it's like you learn things about yourself in certain situations...and when they came the next day to start teaching me, I had made up my mind that I was gonna learn it regardless; it didn't matter," (#10, pp. 4-5).

CP-Patient History

CPs entered the care situation with a relational history that linked them to the patient. This personal history provided the foundation on which the care partnership was constructed. In general, non-relative CPs had known their partner for some time prior to the onset of infection and/or AIDS; CPs who were members of the patient's immediate family had a lifetime of knowing one another.

> "...he's the brother right under me; he's a year younger than I am. So <u>he's the person I had the most contact with as a child...He seemed to feel so much more comfortable that [I was his CP]</u>. I don't know why. He would be able to look at me, be able to say a certain something or make a certain gesture and it was understood what he meant, even though nobody else got it in the room...Because he knew I knew him and the way he though about things and how he can be -- bad -- sometimes." (#10, pp. 24-25).

The CP-patient relational history was not always functional. Two CPs (#5 & 15) noted that preexisting relational strains exhibited themselves during the course of the illness because involvement attempts were seen as part of a continuing pattern of dominance or control. For the most part, however, CPs reported that the relational history was beneficial. CPs who had a long-term and close relationship leapt into the care situation with little hesitation. Indeed, patient choice of a CP appeared to be based on the quality of the relationship enjoyed with the person prior to their infection. At times this took almost habitual routes: sons returned to the care of their mothers, lovers turned to one another. When families of origin were constrained from reaching out to the patient through fear of viral transmission, the patient's closest sibling filled his need (#10 & 16). Even when not mandated by family abandonment, siblings who served as CPs tended to be identified out of the strong pre-illness bond (#4 & 14). In the case of an IVDU patient who was deathly ill and had no one else to assist him, his ex-wife agreed to become his CP until his health stabilized.

CP Motivation

CPs recounted a variety of motivations which led them to accept the care partner role. The most prevalent reason was the love between patient and CP extending out of their past relational history. However, a number of additional motivations were presented. Several CPs noted that they felt it a personal calling to care for the sick and enjoyed being able to serve in that capacity:

> "...my granddaddy told me--he used to call me daughter--he said, 'Daughter you have a purpose. God got you here for a reason and you don't know what it is yet but one day you gonna find out,' and when he told me that and when I think about Bob's cancer going into remission, I know my purpose and that is to take care of the sick and the elderly and I believe that is my purpose in life is to take care of the sick. I thought it was to take care of the dying but it is to take care of the sick, because like every time I think about his cancer going into remission, I say well lord use me you know, here I am, if that's what you want me to do, that's what I'll do and I really feel in my heart that is what he wants me to do.

Several CPs possessed philosophical beliefs about life which supported involvement as a CP. These included the belief that "It is better to give than to receive," and that what one does comes back to them as a future reward in either this or a next life:

> "[I enjoy all aspects of providing care]. I really do because I believe, I know it's true that that which you send out comes back to you, whatever it be, good or bad. I would much rather prefer to be the giver than to be the receiver. So I give, I give all of me because I would rather be doing it for Bobby than have Bobby doing it for me, with that in mind - that I'm blessed to be the giver and not the receiver." (#2, p.11).

One CP (#11) who was assisting her boyfriend spoke of guilt feelings stemming from the knowledge that he could not find anyone else to help him:

> "Somedays he get up and want to walk and feel good, and somedays he don't. It's just up and down. Somedays I just want to get this over with. It's stupid to say stuff like

> that, but I know I care about him and love him as a person. I've been knowing him for almost 5 years. Just learning to accept his situation, and my situation, putting it together and working with it. <u>Knowing that if I leave or whatever, he can't find no other support, he can't. He can't live on without it, so he's got to reach back</u>. Somedays I get upset and wish he could just go on his own. Hope that he'd be Ok. Somedays I'm like <u>I know Robert needs me, that guilt feeling</u>. (#11, p.7).

Another CP (#17) filled in a similar abandonment gap when her ex-husband was suffering through a general physical collapse only part of which was due to HIV infection. For this CP, though, motivation came more in the form of <u>maintaining a long commitment</u> the two had shared during and after their marriage.

> "...it wasn't about a sexual relationship. It was just over the years we had been together so long until I just felt I had an obligation that I did this. Just <u>out of obligation from both us being together for so many years</u>. Because when he was in prison I, my kids we travelled everywhere, every prison he was in, we went. You know, I never, I didn't neglect him even though he was in jail. When my son growed up going to prisons seeing his dad and stuff and you know so why should I reject him now because he is sick." (#17, p.10).

The CP quoted above also expressed another common motivation--they simply had the ability to do it either through possession of the time and/or skills available for a successful response:

> "When my son told me that the doctor's had gave him up to die. Which I hadn't, well we was talking, but I didn't bother with him because he was living his life the way he wanted to and I was here. So I didn't you know, like when he called me, I went to him,

> he asked me to help him and I went to him and I told him he could come here and stay. By the kids being grown, I didn't really have anything else to do, so I said you can come here. And that's how he got here." (#17, pp.6-7).

While such motivational variations suggest differential routes into the role of CP, they appear to explain little of the variation within the role once adopted. In other words, it does not reveal why involvement developed in such distinct ways across the CPs in this study. To examine this internal variation, it is useful to examine the metaphors CPs use to define their involvement.

CP Metaphors of Involvement

The variety in metaphors matched the variety in involvement packages established by CPs, and a comparison suggests a strong relationship between the metaphors used and involvement. The following metaphors demonstrate this relationship.

The, Inquisitor/Board of Directors CP served primarily in the capacity of reviewing treatment proposals and options, collecting patient reports on medical interactions, and examining these reports for any weaknesses or problems. The patient was then given suggestions for follow-up questions and behaviors, as well as advice on treatment options to pursue or avoid. This CP also referred to himself as the Bystander, revealing his near total lack of interaction with the medical staff.

The Cheerleader/Morale Booster was another metaphor cited. Common among the IVDU CPs, this emphasizes involvement specialization in the area of emotional support and hope maintenance. Such sideline imagery also underscores the relative lack of interaction with medical staff.

One CP (#10) saw herself as a Stepper; the illness just kept throwing new obstacles and challenges in front of her to which she responded by stepping up to them and overcoming them one by one. The effect of this was that the ordeal of caring appeared more exhausting in retrospect than in process. It was not until after the death of her partner that the reality of her emotional toll sank in.

The Peace-Maker was how yet another CP (#12) defined his work as an interface between patient and service personnel (both medical and community). However, such peace-making took place almost fully with the patient in the form of explaining why personnel acted in manners which upset the patient. Since the patient was purported to have a quick-fire temper, this role was seen as a vital one if service was to be maintained with any regularity.

The Foot-Soldier typified CP #14 who willingly followed the directions of his generals (a social worker and nurse from the case management agency) in managing his partner's home care. Drills were conducted until he knew what the patient's medication schedule was, the side-effects of each medication, how he should handle the patient's emotional upheavals, and the necessity of self-control and patient support.

Finally, as an indicator that not all metaphors necessarily empower, one CP (#20) was referred to as Superwoman by both medical staffers and her husband. This CP had lost a young son to leukemia and then maintained a 20-day bedside vigil with a second son who eventually died of AIDS-related pneumonia. Rather than bolstering her spirit, this metaphor placed a heavier weight upon her with its expectation that she could withstand everything. There was no allowance for her to be weak, to lean, to seek out support from others because "she could take it."

The relationship between metaphors and overall involvement patterns does not address the question of causality, and it is not something which can be answered in this monograph. Clearly, though, the metaphors brought to bear on understanding one's place as a care partner within the illness influence the dynamics with which the CP's involvement unfolds across the illness trajectory.

Prior Experience in Care Partnering

Not all CPs interviewed were involved in their first experience in caring for others. Six CPs (#2,5,11,17,20,21) had provided some form of intensive care in previous situations and seven (4,8,10,12,15,16,17) had actually worked in medical occupations (i.e., nursing assistants).

For those who with direct care partnering experience, knowledge and skills developed in the earlier instance provided a valuable baseline of operation in the current situation. A mother (CP #2) providing care to her diabetic, HIV+ son cited her work with the sick which began as a child and from which she had learned aspects of physical management. Another mother (CP #20) who had already lost a son to leukemia spoke of the application of her knowledge of blood work and hospital routine to the current situation. And finally, a mother (CP #21) who had already buried her husband after a battle with cancer and another son with AIDS, was philosophical about her ability to care for a second son with asymptomatic HIV infection should the illness progress to the point of lost function.

For one CP, though, the prior care experience was not necessarily beneficial. This CP had spent much of her youth caring for an ailing aunt who died just before the time her boyfriend tested positive; she worried that she is unable to fully live her own life: "With my age, I look at it like I should be doing things like [playing basketball]. I learned just to deal [with it though]," (#11, p.19).

Structural Limitations

A number of structural limitations arose throughout the illness situation which hampered CP ability to accomplish tasks. The greatest structural inhibitor, however, was CP employment demands. CPs with full-time employment regarded the attempt to juggle the demands of patient care and work to be one of the most difficult elements of their care partnering experience:

> "...I had to do so much with him, there could have been a choregiver to do the laundry, or do anything of that sort. <u>I know it kind of sounds pathetic and I don't mean it because I was glad to do what had to be done, but it was a lot of work and there wasn't anybody to do it</u>," (#7, p.26).
>
> "<u>If I didn't have to try to work it would have been easier. And when a person is working under stress there is only so much you can do</u>. That makes it not as effective in anything you do. [Around the house] things don't get attended to like they really should because it's not a one person job. One person can't do it and when that one person is distracted by all of this caregiving there is even less time...It's a full time job really. <u>It became my full time job. It wasn't difficult. It was time consuming but it wasn't difficult...I don't need to sit and talk to somebody. My panic was having four full time jobs (maid, chauffer, cook, lawyer, barn help, and caregiver) and having only one person to do it</u>," (#18. pp.10,24,26).

In addition to the overwhelming task demands, CPs holding full-time employment noted the inability to visit the patient at the hospital until evening visiting hours. One CP (#1) was often unable to get away from work until after visiting hours were over and would have to negotiate with nurses who wanted to deny him entrance. Of perhaps greater impact, his inability to be present with the patient during repeated hospitalizations and appointments kept the medical staff from consciously identifying him as the patient's lover, and thus deserving of information:

> "*[The medical staff doesn't] really understand why I'm involved. Most of the time they don't even know I'm involved because I don't see them*. I mean he's running off the the hospital all the time and I'm not with him. When I have him there and they ask me to leave or something like that it's because they don't recognize me as a married spouse, or a parent, so they assume that I don't have any direct need to know." (#1, p. 20).

The patient's illness also invaded CPs' places of employment. The telephone became a tool of case management as arrangements with community service agencies had to be made during business hours:

> "I seem to spend a lot of time on the phone...trying to get him coordinated with different programs, with care workers. *You know, a lot of social workers we only have access to them from 9 to 5 which is what I work. It's like I have had to call them from work or they have had to call me when they are available. That's made it somewhat hard. It's like a full-time job. If you're working another job, it can really become time consuming*. I know even the effect of it on my husband--I'm always on the phone talking to this caregiver or this social worker or that one or this program. So it can get very time consuming that way." (#4, p.36)

More stressful for the CP, however, was the occasional need to leave the patient unattended at home. Here again the phone played a role as CPs used it to keep a running check on the patient's status. On good days, it was simply a matter of ensuring that the patient had something to eat. On bad days, accidents or health emergencies intervened.

This variation and the attendant stress exacted on the CP is clearly exhibited in the two cases cited below:

> "[Early on, he would stay home alone while I worked]. I packed the cooler and he stayed for awhile and <u>on several occasions he would call me at the office and maybe attempting to turn over to get the phone, twice he fell out of bed. When I came home I'd pick him up</u>. A couple of times something was going wrong and he called and they wanted him to come in Henry Ford, and I would have to leave work and come back...but that's not the problem. It eventually became a problem..." (#7, p.26).

> "I tried to be there as much as I could. It was difficult to get away to go to work. I was able to do a lot of work out of the house. But on the days that I didn't, I certainly hoped nothing would happen before I got back...<u>The biggest problem would be if he needed to go somewhere and couldn't because he couldn't drive. You can never tell what kind of emergency could come up</u>. For example, it could have been a breathing aberration emergency...I would normally be gone for four to seven hours. In other words leave after breakfast and get home in time for dinner. The <u>cooking was the other concern I had. To make sure that he ate. I didn't have a way of handling that...He's not one to eat leftovers, so I couldn't make him a sandwich beforehand and leave it for him because he wouldn't eat it. That made it a little tougher than some people might think</u>. (#18, p.3-4).

Work was not all negative, however. At times, the CP was able to take extra time off, or was offered paid leave. The CP quoted directly above had his own law practice and was able to work from home part of the time. Another CP (#3), employed on an automotive assembly line, simply took time off as he saw fit:

> "I called in sick a lot of days to work just because he was having a good day and he didn't want me to miss work but I was just at the point where I could care less if they fired me. I just had that attitude that I knew he wasn't going to be around long and I just wanted to do everything I possibly could to make him happy." (#3, p.6).

In general, CPs with full-time employment had to make do whether the patient was home or at the hospital. At home, the patient either had to spend time alone in various states of dysfunction, or the CP had to make repeated efforts at contacting friends who could stay with the patient or community agencies who could provide visiting care assistance, efforts which were not always successful.

Worries about the patient being attended to during the day were largely erased during hospitalizations, but employment demands still prevented several CPs from spending large blocks of time with the patient. This severely limited their ability to talk with the medical staff. Typically, these CPs interacted almost solely with nurses since doctors were not available in the evening when the CP could make it in to visit. And, as one CP pointed out, "They just have so much to say, you know, before you [have] to talk to the doctors," (#8, p.4).

Employed CPs were also unable to gather the specific information concerning patient care which is available to CPs who can spend the entire day with the patient and watch all that takes place. This inability furthered the CPs' dependence on the patient for information regarding daily events and developments, and limited patient-monitoring and advocacy. If informed of treatment errors or problems, however, CPs were quick to advocate on the patient's behalf with hospital administration (CP #5).

Perhaps the biggest drawback of limited visitation was that the patient and CP did not become paired in the eyes of the medical staff. One CP (#1) talked about a number of times in which staff members he had met several times were unable to recall or recognize him at later meetings. This was contrasted with CP #2 who said with all sincerity that when you talk about the patient you are talking about her too. This strong pairing had developed over 12 years of working on her son's diabetes with the family doctor. While a specialist was brought in to monitor his HIV infection, the family physician maintained a strong role in the patient's overall care, thus maintaining the mother's strong inclusion.

This range of precursors (patient health status, CP-patient history, CP philosophy/personality, CP motivation, prior CP experience, and structural limitations) significantly shaped the nature and degree of CP involvement. However, involvement levels did not simply fall under the purview of the CP. Rather, due to the primacy (hegemony) of the traditional medical model in which the CP is excluded, the patient <u>and</u> physician had to agree to any involvement from the CP. The manner in which the CP, patient and physician "negotiate" the acceptable level of CP involvement is the subject of the next section.

NEGOTIATING CP INVOLVEMENT

Four principle findings with regard to negotiated CP involvement are presented herein. First, CPs recognized the exclusive norms of the traditional medical model. Second, specific motivations for shifting to a more CP-inclusive model differed among the three members of the proposed care triad (patient, physician and CP). Third, each member utilized different strategies to produce CP inclusion. Finally, CPs were willing to excuse frustrating aspects of exclusion by the medical staff so long as it was perceived to arrive from the pressing demands of a heavy case load which absorbed copious quantities of time. Each of these findings is explored more fully below.

Negotiating the level of appropriate CP involvement typically began from an acceptance of the traditional medical model. CPs acknowledged that given an adult patient with sufficient mental faculties, no precedent existed for third-party involvement on a formal, participative basis:

> "The way [the medical staff sees] their job is they have a patient to care for. Their concern is the patient's knowledge of the patient's own situation in providing optimal health care for the patient. <u>They're really not concerned about appraising me. They feel it's the patient's responsibility to appraise those about them that he or she should be</u>

> involved. Unless the patient is legally incompetent or incapacitated and unable to communicate effectively, in which case, then it's common for medical professionals to find a relative, guardian, whatever, you know, someone that they can relay the information to, should care or understanding be necessary. But yeah, I think that's a standard assumption of our medical community about the patient regulating the information flow. As long as they're a competent adult." (#1, p. 22)

The prevalent influence of the traditional medical model yielded differential CP responses. For some it was a fact of life which they accepted with minimal frustration. CPs who desired greater access to physicians, however, found the traditional interaction norms inhibiting. This was the case whether traditional CP exclusion was practiced by the patient or the physician:

> "I think given the relationship I have with Al, [his doctor] should probably be involving me more, or just appraising me, saying 'Thought you'd like to know,' or 'You need to know this as a caregiver,' you know: (A) what's going on, (B) what are the potential outcomes, (C) what are the potential risks. No one's bothered to do that." (#1, p.12).

> "I think [if I were more involved with the medical staff] it would help me understand more of his situation. But by him freezing up, it kind of locks me out of helping him because he wants to be rebellious. If he's holding back, I don't want to go do something he don't want me to do. I don't want to go tell on him. So I nag at him, 'Did you tell the doctors what you're doing?' He say, 'Oh yea, they know.' But they don't know. If he was more open, it would help a whole lot more...I feel like if I say, "I know you ain't gonna do it, so let me go on and be the boss,' but somedays he says things to hurt my feelings, and I say, 'Forget it. It's not my problem.' He forgets that I'm the one that's

> helping him. He comes down to earth sometimes and we talk about it. If I really pushed myself into it and get feeling into it, I think [my getting more involved] would help him in the long run." (#11, p.17)

Whatever their own ideas about appropriate involvement, however, most CPs were willing to acquiesce when exclusion derived from the _patient_. But when _doctors_ were identified to be the source of exclusion, frustrations grew:

> "I've been asked to leave by some different specialists on several occasions when Al was either in the hospital or I took him there. You know, I would drive him there on an outpatient basis..._[They] refuse to recognize my role in the relationship to Al. Treating me as a non-family member that I had no business hearing medical information from the health professional_...He had no problem telling Al's parents, given that they're parents. But myself, he had a problem talking to." (#1, p.13).

Despite its normative strength, two types of illness events tended to loosen the restriction of the traditional medical model. These were the revelation and/or discussion of highly emotional topics, and the loss of independent function by the patient, whether due to acute crises or more permanent downturns. As these events occurred, the motivations of triad members for CP inclusion were revealed.

CPs expressed a standing desire to be present when potentially traumatic information was delivered to the patient. This was seen as a natural extension of their emotional support role, something in which _all_ CPs were involved whatever their level of involvement in other areas. Patients also shared the desire at times to have the CP present for important, emotionally-potent meetings. Such desires were evidenced most clearly by CPs who recounted instances where emotional bombshells were dropped on patients during CP absence. In these events, the patient was left to deal with the emotional aftermath on their own with negative psychological effect:

> "The most notable time [I was asked to leave by a doctor] was when he was hospitalized in May, I guess it was. The doctor came in I guess to tell him bad news that his vision was continuing to deteriorate... [the doctor] was explaining [that Al] had significant deterioration in his left and his right eye had been clear up to that time. Well the doctor came in after having examined him, to tell him that it was in his right eye. Well <u>that's a very emotional thing and normally you want to tell that to someone with their loved ones around them. But the doctor was insistent that I leave the room. And told Al on his own. I came back in and Al was crying. I thought that was extremely you know, poor thing, poor decision on the doctor's part</u>, (#1, p.13).

> "The biggest crisis I had or the angriest I ever got was <u>she called me on the phone and started up. She was crying and really upset. Somebody had gone over there and talked to her and said, "You've got this disease, it kills people and would you like to go on a life support system?" They just scared the shit out of her. When she called me I jumped in a cab and I went down there and raised all kinds of hell</u>...It scared her and it pissed me off...Whoever that person is I better educate them because they have no right and tell people that way. They could use some more tact. There was a better approach." (#16, p.10).

Absence was not the only factor hampering CP assistance with shocking emotional information and discussions; the mere lack of forewarning the CP about such discussions yielded similar effects. One CP (#7) was present when a technician roughly referenced the patient's eventual death, inciting a crisis for which the CP had no time to prepare:

> "I didn't know he was coming, you know, I didn't know that was going to happen and also I didn't come prepared to spend the night. So I stayed and I told him when I got ready to leave that I didn't want to leave him and I asked him if he would be alright, if everything was Ok with him and he said that it was Ok to go home. But, it was the same situation, it would take me about one hour and 15 minutes to get home from the hospital. By the time I got back home and had a glass of milk and got ready to go to bed and the phone rang and it was Tom and he said he was really scared and wanted to know if I would come back. So I got back into the car and drove down to Henry Ford and then after that I didn't leave [until Tom] did." (#7, pp.15-16).

Physicians, however, also recognized that the presence of the CP could be helpful for the patient during discussions of traumatic test results. In a few rare instances then, physicians would presage patient fears by encouraging the CP to attend such meetings.

The second motivation for moving toward greater inclusion of the CP was patient loss of independent function. Such developments rendered the traditional medical model inadequate, and clarified the ineffectiveness of continuing normalization efforts. While accepting the need for greater dependence was not always easy for patients, they became more willing to negotiate a more inclusive role for the CP.

Under the traditional medical model, physicians are also motivated to include the CP in the event of downturns in physical and mental dysfunction. The lack of dementia in the current sample yielded few physician-initiated efforts for reasons of limited mental function in the patient. However, a lack of initiation also appeared in the context of physical physical dependence as well. That is, physicians tended not to make inclusionary overtures toward the CP; they were simply more <u>willing</u> allow CPs opportunity to increase involvement in line with their desires. Even at the point of death, the majority of CPs talked more with nurses about the patient's approaching demise than they did with the physician.

CPs were more than willing to press physicians, and patients if need be, for greater acceptance in light of disease progression to an advanced stage. As one CP explained it, even though the immediate situation did not explicitly call for stepped-up involvement, he wanted to be "visible" to the medical staff in future dealings:

> "Tom went to his appointments by himself as long as he could drive. We discussed at home his condition and he never kept anything secret and he would never keep me out of that. But as long as he could drive, he went to his appointments by himself. And when it got to the point where we weren't comfortable [with him driving] and I started taking him, we talked about it, and <u>I told him at that point that I wanted to start going in with him to the appointment. Because I told him quite frankly that, 'I don't want to wait until you're in the hospital to form some</u>

> <u>kind of relationship with this person. I want to be visible, I want to see him before that happens, so I think it's time that I should go with you. And that was fine.</u> (#7,p.10).

The strategies for initiating greater CP inclusion varied from direct to indirect. The patient typically held the greatest power to initiate this and often did so through explicit statements to the physician of his willingness or desire to grant the CP greater access:

> "His earlier primary care physician--I had a little bit of dialogue with Al a couple of times, initially, to talk with [the doctor] when we were both still learning in the subject. I'd ask the doctor questions you know what about this, what about that, and he'd explain it to me. At first, he was very uncomfortable with it. Al told the doctor, 'No, there's no problem talking to Mike about anything.' (#1, p. 23).

Patients also produced inclusionary status for the CP by serving as a relational interface between the physician and CP. That is, the patient typically had established a relationship with the physician which could then be transferred or expanded to include the CP. A clear case of this occurred for CP#10 who was unable to visit her brother in California until after he had been hospitalized following a severe viral infection associated with HIV:

> "<u>[The medical staff] seemed like they knew him and it was like as if they knew me because that's all he talked about was that 'My sister's coming. My sister's coming.' Once I got there it was just like a band wagon</u>. 'Oh you finally came here, huh?' I was like 'Who the hell? Who was that? What?' People would come and pat me, 'Hey,

> you know, how you doing? My name is such and such,'...<u>[The charge physician] had known Gary from the time of his diagnosis...So he kind of knew [me]. So he talked to me like as if it were Gary</u>," (CP#10, pp.22,31).

In general, the patient was heavily influential in setting the tone of interactions with the medical staff, both for himself and the CP. CP#7 pointed out the value of caring for a patient who was liked by the staff:

> "Even though we were probably willing to do more than most patients when we went into [the hospital], <u>I think essentially that we got more attention and better service because Tom was a likeable. That wasn't the motivation for helping him, or changing his bed, but I think that resulted in a feeling like, 'Gee, they're doing everything they can.' And the nurses were more than willing to do everything they could</u>. Nobody was ever impatient with us. Not one single nurse acted like, 'I don't have time for you,'" (CP#7, p.36).

The manner in which CPs approached the medical staff also influenced the tone for negotiations and interaction. Several CPs spoke of their sensitivity to functional versus non-functional manners of treating the medical staff:

> "Again, I say presentation is everything. Once you talk to a person for the first time and you say, 'I need this, this. I'm full aware of the magnitude of this situation and that I may be asked to do things above and beyond normal things.' <u>You have to show a certain amount of confidence with that other person and let them know that you're not going to run scared on them or anything if they tell you things. Cause professionals, they have that feeling, like you're not going to be able to cut it, you know, in situations like this. They always think like you're going to crack up or whatever's going to happened to you, you're going to lose it</u>. I was like, 'I already know that. Now, what's

> going on.' So they would like look at me like, 'Okay.' And I guess they had to think well this is Gary's sister and they know Gary, so this works out. <u>I think just being able to present myself to everyone that I came in contact with and showing them honesty and sincerity they were more willing to give me information I didn't even ask for</u>," (CP#10, p.33).

> "I think patients buy a lot of their own problems because they tend to think that it's a hotel stay, and that they're paying and [staff members] owe them. And to some extent, I suppose [the staff does], but the reality of it is, you're working with people, and I think the nurses were quick to pick up that we were willing to do all that we could and they were more than willing then to do all that they could for us." (#07, p.32,36).

A last characteristic associated with the lack of formal negotiation of CP involvement concerns the extent to which CPs and patients discussed issues of physical decline and death at early stages of the illness. Despite the likelihood that persons with HIV infection will experience a marked and steady decline in health, there was little to no preparation for such an outcome. There was no rush to revise wills, specify preferences concerning the use of life-support through living wills, or to formally transfer decision-making power to the CP through power of attorney documents. In large part, this lack of preparation was used as a hope sustaining mechanism. To talk of death or possible/eventual dependence too early was seen as a dangerous flirtation with the destruction of hope:

> "Tom was kind of protective, he was open, he would tell me about things, but he wanted to be very independent. I just always made it

clear to him, if you want me to go, I will go if you want me to go, but if you can handle this, if that's the way you want to do it than that's fine and it came down to the point where it was time for me to and be around the doctor that was fine with him. When it got to that point, he really would have seen my going with him ass hovering or maybe even acknowledging before he was ready for it to, that he was going to die. Even the whole last year, as much as he would talk and as much as he was open about it, he never wanted me to talk about his dying. He would talk to other people about it, but he didn't want me to talk about that. He didn't want me to act like it was close or that it was imminent, and if I kept positive about it--if I fluffed it off--if I said 'It doesn't mean anything, we knew before the tests, we knew when we saw it that it was KS. Now we know because of the diagnosis, but we knew before you went, so what's the difference?' And if I took that kind of attitude, than took that kind of attitude and he would say, 'Yeah, so what,' and we would go on. But, he never really wanted me to acknowledge just how bad things were." (#7, p.22).

"As soon as someone's diagnosed with AIDS, [living wills, power of attorney] are things that you have to think about. But I don't see that as being anything necessary to the future." (#1, p.28).

"You know the medical staff is faced with, you know they're not God either, and they recognize that. And there's also the stand point of who can say really. I mean, how can you prepare someone, because you don't want to cut off hope, and you don't [say anything] at the inappropriate time, or too early say 'Now you know, you are going to die. You do have that firmly fixed in your mind don't you?" They don't want to do that because they don't want to take away hope, because they know if you give up, it's going to come sooner than if you don't." (#7, p.48).

INFORMATION SEARCH AND USE

Turning from a direct analysis of the variation in CP involvement, this section focuses the manner in which CPs interact with information related to HIV/AIDS, both in general and as it specifically relates to their patient. Two major issues are examined. First, the CPs examined in this study have been shown to possess widely variant levels of knowledge about HIV/AIDS. This may be partially explained by perceptions of information use-value (i.e., the impact of a given piece of knowledge on the manner of care involvement). This is presented below through a distinction between "need-to-know" and "nice-to-know" information. Of fundamental importance here is understanding how CPs make distinctions between these types of information. Second, all CPs exhibited a tendency to cross-check information whether it was received from the patient or a member of the medical staff. The patterns of such cross-checking provides an illustration of the value of redundancy, as well as indicating the CPs involvement in information gathering.

Information: Motivation to Seek

A concern with information transmission is based on the assumption that information is of <u>use</u> to the care partner. In examining care partner determinations of information use, it is necessary to clearly establish the uses to which information may be put.

Information sought by CPs included diagnoses (e.g., initial HIV infection and illness developments associated with immune system decline), prognoses (associated with each development), epidemiology (with clear links to patient prognosis), treatment options, and patient care requirements (primarily in relation to home care). Each of these information types serve a number of functions. First, information may be required to assure the safety of the patient, the CP and/or others coming into contact with the patient. A second information use is comfort for the CP through reduction of illness uncertainty and increasing feelings of competence and control. As one CP (#10) put it, "If you don't know, your fears are doubled," (p.22).

A third information use involves the ability to support the patient through knowledgeable discussion of his or her situation. This is seen in the context of the CP cited above in relation to her concerns about relating to the patient: "As time went on, I actually did start feeling like he needed me to be...as informed as possible so that when we had conversations about doctors or about people I could [talk at his level]," (CP#10, p.36).

Fourth, knowledgeable CPs were more able to participate in patient selection among treatment options, as well as to more effectively assess the quality of care being provided his or her patient:

> "As a matter of fact, both [the patient] and I on several occasions, have brought up things to the physicians that they were unaware of. Either nuances of a protocol or new experimental drugs that were available or a different protocol with existing drugs. It's just a question of keeping appraised of the horrendous [amount] of literature that continues to turn out from research," (CP#1, p.18).

Predictions of information search activity can thus be linked to expected uses of procured information. Care partners may focus on only one or two of these uses--thereby limiting both the nature and quantity of information seen as necessary--or they may attempt to cover all the usage dimensions with large requisite information needs. Another factor appears necessary, however to explain the different levels of information which existed across CPs in this study. This factor may best be expressed as the _perception of control_ held by the CP. The extent to which a CP sees him or herself having some control over the course of illness may influence both the _nature_ of information sought and the _intensity_ with which the search proceeds. In general, information was only seen as useful if it fell within the domain of CP influence.

Casting perceptions of control in this manner draws on perceptions of the general care situation. Three potential perceptions were derived from the CPs interviewed. The first category consists of CPs who felt powerless in all aspects of patient care. For the three CPs (#2, 13, 15) in this category, powerlessness was pressed upon them by the nature of the situation, most typically by patients who were persisting in IV drug use.

A second group of CPs (#3, 5, 6, 8, 11, 12, 14, 17, 19, & 21) made few distinctions between the care required by HIV infection or AIDS and that for other more minor illnesses such as fevers, flus, and colds. In other words, the defining attribute was the degree and nature of impairment rather than the underlying cause of the impairment. All but two of the CPs had some level of past care experience and brought to the current situation skills and knowledge about general care provision. Some medical involvement was observed in this group, but focused on more limited extensions of HIV infection (e.g., rashes and boils) and side effects from medication.

> "I think the [case management] agency should have someone to monitor and interact with the doctor because <u>most people, like myself, don't want to get involved as far as medications and stuff. You're going through enough and don't want to worry if they increase this dosage or forgot to give him this pill. I'm sorry, I just can't handle it</u>," (CP#3, p.24)

> "Yeah, I would not have put in a cite. <u>You know I told the agencies, I said I'm happy to do whatever I can, but I'm not a nurse. You can't expect me to do this skilled nursing stuff. I'll do what I can</u>," (#12, p.4).

The third form of care perception supports the greatest involvement and its concomitant need for large quantities of all types of information. While these CPs (#1, 2, 4, 7, 9, 10, 16, 17, 18, 22) did not perceive themselves as capable of the expert intervention provided by medical professionals, they did view themselves as capable of evaluating the treatment provided by such professionals. Heavy emphasis was placed on gathering extensive information for evaluative purposes. CPs who did not pursue direct participation with medical staff on a regular basis involved themselves with more traditional home remedies for illness side effects. Involvement with the medical aspects of patient care served not to supplant, but to supplement, CP work in emotional and instrumental support for the patient.

Survey results also attested to the relationship between control and information use (see Table 3). This table reveals that CPs with higher reported need for information were more likely to rate availability and clarity of communication as appropriate. This suggests that such CPs were managing to fulfill their information needs. However, those CPs who perceived themselves as having control in the situation were less inclined to evaluate interaction so positively. They were more likely to report that the primary medical contact was unavailable and exhibited low levels of empathy. Furthermore, these CPs were less satisfied with communication in general. This suggests that CPs desiring a more active role in patient care had interaction expectations that were not being met by the primary contact.

Table 3. Correlations between Communication Variables and Information Search Motivation and Objective HIV Knowledge Variables

	AVAIL	CLARITY	COMPL	DISC	EMPATHY	COMMSAT
TOLAMBG	.23	.72***	-.07	.14	-.10	.14
CONTROL	-.41**	-.16	-.18	-.27	-.30*	-.44**
KNOWUSE	.38**	.53***	.18	.09	.24	-.25
MEDTALK	.03	-.13	.01	-.19	.15	-.16
INFOMOT	.06	-.03	.01	.18	.03	.07
HIVTEST	.12	.49***	-.30	-.13	-.15	-.03
DRUGKNOW	.12	.49***	-.20	.27*	-.08	-.00

* $p < .15$
** $p < .10$
*** $p < .05$

AVAIL = Availability
CLARITY = Clarity of Communication
COMPL = Completeness of Communication
DISC = Full Disclosure
EMPATHY = Empathic Concern
COMMSAT = General Communication Satisfaction
TOLAMBG = Tolerance for Ambiguity
CONTROL = Perceived Control In Illness
KNOWUSE = Perceived Usefulness of HIV Knowledge
MEDTALK = Perceived Need to Talk with Medical Staff
INFOMOT = Perceived Motivation to Gather Information
HIVTEST = Objective Knowledge Test of HIV Info.
DRUGKNOW = Knowledge of Drug Therapies in Use or Under Investigation for HIV

CP tolerance for ambiguity also played an important role in CPs' rating of medical communication. Such tolerance might be expected to play a functional role given the great amount of ambiguity remaining about how HIV might be treated effectively. CPs with high tolerance were significantly more likely to rate communication with their primary medical contact as clear. Thus, the same level of information may be less apparent and understandable to the CP who has an aversion to ambiguity and needs answers of a more black-and-white nature.

It is also informative to examine the influence of the various CP motivations to acquire information on the outcome variables measured (i.e., perceptions of knowledge about general HIV issues, about patient-specific HIV issues, home care requirements, perceptions of care burden, and physical and mental strain; see Table 4). Particularly, CP desire to speak with medical staff caring for the patient was negatively correlated with knowledge about patient specific issues relating to HIV. This implies a recognition on the part of some CPs that their understanding about how their partner is faring with HIV infection is in need of further development through interaction with the medical staff. This is consistent with the finding that CPs with greater perceived care burden are are motivated to seek greater amounts of information. Physical and mental stress in the form of reported physical symptoms and depression were

Table 4. Correlations between CP Outcome Variables and Information Search Motivation Variables

	TOLAMBG	CONTROL	KNOWUSE	MEDTALK	INFOMOT
GENHIV	.17	-.02	.17	-.21	-.01
SPCHIV	.04	-.19	.05	-.26	-.32*
HOMEKNOW	-.26	-.03	-.09	-.21	-.25
CPBURD	.37*	-.21	.09	-.21	-.28*
PHYSYMPT	.01	-.14	.29*	.44***	.39**
DEPRESS	.09	-.33*	.26	.54***	.42***

*	$p < .15$
**	$p < .10$
***	$p < .05$

TOLAMBG = Tolerance for Ambiguity
CONTROL = Perceived Control In Illness
KNOWUSE = Perceived Usefulness of HIV Knowledge
MEDTALK = Perceived Need to Talk with Medical Staff
INFOMOT = Perceived Motivation to Gather Information
GENHIV = Perceived General HIV Knowledge
SPCHIV = Perceived Patient-Specific HIV Knowledge
HOMEKNOW = Perceived Home Care Knowledge
CPBURD = Perceived Care Burden
PHYSYMP = CP Physical Symptoms Index
DEPRESS = CP Depression

positively associated with the desire to talk with medical staff and to seek information. This further implies that the nature of the patient's health status influences the nature of information desired by CPs and their avenues for accessing it.

While CPs held different perceptions of control across emotional and medical aspects of patient care, all realized their ultimate powerlessness in terms of stopping HIV progression in their patient. This underlying lack of control was a source of constant frustration mentioned by nearly all CPs.

> "You know in terms of care that I provide, there's nothing that's nothing that's difficult or frustrating. I think the frustration comes from just watching the progression of the disease. And knowing that you're using state of the art medical technology and it's still not doing, it's still not arresting the disease. And for myself as a caregiver, standing by almost helplessly watching things occur," (#1, p.6). "He was basically in and out of the hospital and [it was frustrating] just to watch someone deteriorate knowing there's nothing you can do, but not wanting to admit it." (#3, p.5).

Role of Cross-Checking

Whatever their level of involvement, CPs exhibited a tendency to cross-check the information given to them by medical staff or relayed to them by the patient. In general, such cross-checking was reported by CPs as an attempt to verify the accuracy of information, or simply provide basic explanations about how to interpret specific statements about the patient's status:

> "I never called up [the patient's primary physician] right up and said 'Explain this to me.' Because I have my own physician I can ask questions like that about." (#1, p.24).

CP cross-checking techniques can roughly be broken down into two forms: comparison of information across personal sources, and comparison of personally-related information with that provided through various reading materials. Of special interest is the application of interpersonal information comparisons. Most frequent was the reliance of CPs on friends who had medical training or experience, enough if not directly related to HIV. These personal relationships could be drawn upon for more involved, time-consuming conversations about specific aspects of treatment and patient status that were difficult with busy medical professionals.

> "I'll tell you, the nurses are far better as far as telling you what will happen. My sister is an LPN, and works in the CAF-LAB at New Grace. Winnie Kerwin, who was probably, well not probably, was our best friend and our closest - Winnie and my sister were our best support through that whole thing, and Winnie is a RN and at that time was in the STD department at Maccomb County Health Department, and she was their AIDS person. Also, she was on the board with Tom at Lomus Networks and really highly involved. It was the two of them that would tell me. My sister told me before he even left Henry Ford, 'You know, watch for...he'll probably go into hepatic coma.' The doctors never mentioned that; she told me that," (#7, p.31).

CPs would also rely on their own physicians for answering specific questions of medical impact and developments. Such conversations were also at times helpful in providing the CP with a justification for using precaution techniques in patient interaction which might upset the patient. CP#8 discussed her ability to justify using gloves with her partner following a discussion with her physician:

> "They tell us to use rubber gloves. I talked to my doctor while he was my family doctor, and he said, 'Well you see what I do. And you've been coming to this office for many many years, and all these people.' But he said 'You don't come in here and these people don't come near you without gloves on. We have to do this, not that they want to do it. So you do what you want to do.' So when I think I'm doing something strange or I need that assistance, I just use my gloves." (#8, p.21)

Another often used tactic was to inquire about patient status and care with nurses from varying shifts, and also to "pop in" to visit the patient during non-visiting hours to see if the reality of care matched staff statements about it. It was often during such "unannounced visits" that problems with care were discovered.

> "I was about the most question askingest visitor they ever had in the hospital. I would always ask questions because I would sit all day and I would see different nurses as they changed shifts and I would ask the same questions I would ask the others. Then a new one would come on and I'd ask her the same question and kind of put them together. That's how I got my knowledge and experience from them, mostly from seeing what they were

i

t

a

i

r

Ph

th

di

ce

ph

pa

was

16,

phys

form

in t

> doing. And that's one reason why I took Bobby out of that nursing home because I knew that they were not doing what they should be doing and what they were being payed to do." (#2, p.10).

Finally, while all CPs had acquired some written information on HIV infection, there were those who preferred to see what they were being told in writing. Thus, when discussing aspects of patient care with medical staff, trust in the information was not always strong until appropriate reading material was found to back up the talk:

> "There was nothing anyone could tell me that I couldn't go read in a book. [In California], everything they told me they actually pointed to a book. They had a library in their hospital and said, 'Go look this up.' That was good. <u>I like that because it's kind of hard believing people. It's just hard, even though you know they're professional; they went to school to do this. We're all humans. Where's the book?</u>" (#10, p.35).

Physician Communication

The majority of CPs had limited or no interaction with the attending physicians and specialists, and for CPs who did communicate with physicians, most interaction was centered around patient hospitalizations (15 CPs spoke with physicians in this context). Prior to and following the patient's release, communication between CPs and physicians was typically nonexistent. Only six CPs (CP# 2, 3, 7, 9, 16, and 23) had any regular interaction with the attending physician(s) outside the hospital context, two of which had formalized involvement due to existing mental deficiencies in the patient.

In discussions with physicians, CPs desired three basic things: a positive, caring attitude toward the patient, acceptance/recognition of the CP's role in the situation, and information about the patient's status and treatment. The attitude portrayed by the attending physician factored largely into CPs' judgments of their performance at all these levels. While physicians typically displayed little of the fear and guarded patient interaction associated with patient stigmatization, any indication of a superior or inaccessible attitude was sharply criticized by CPs. In particular, CPs desired physicians to express a willingness to hear their concerns and take them into account in providing patient care. The difficulties inherent with poor interaction between the CP and physician was readily apparent with CP#9 who was attempting to care for her mentally-retarded daughter who had an extensive list of allergies to medication. When nurses during an initial hospitalization blatantly disregarded the information sheet left by the CP which clearly spelled out each allergy, the CP voiced strong criticism to the administration. This seemed to engender a negative relational attention that carried over to the CP's relationship with the primary physician.

> "I mean they get very ill-mannered, if you know what I mean. It's like I've done something wrong. I've done nothing wrong. I made sure everything was there for them to read, if they take the time to read it. The nurses, you call the nurses and you ask them

> questions about the condition or what's been given or all this kind of stuff because I'm concerned. And they'll say, 'Well I can't give you that kind of information.' But you'll talk to another nurse and they'll give you the information. Some of them are too lazy to pick up the book and look it up to tell you what is going on. Now I am her legal guardian. I have been her legal guardian since she was 18 years old. It's not just something that happened because of her illness. She is retarded, I have to know. It is a necessity for me to know what is going on with her at all times. But they get an attitude holier-than-thou and the same attitude her doctor has been giving me for the longest time." (#9, p.2)

The problematic nature of this attitude was further emphasized at a later point in time when the patient was suffering delusions that appeared to be a side-effect of AZT. The CP had read about the potential for this occurrence and spoke with the doctor about it. The doctor made but nominal note of the issue and pressed the CP to check her daughter into the hospital. However, the CP had already promised her daughter that she would not have to stay at the hospital, so great was her fear of this that she didn't even want to go into the emergency room. The physician then interpreted the CP's unwillingness as a sign of non-cooperation and responded in kind:

> "This Dr. was so angry and frustrated she would not cooperate. She would not give an appointment, she would not do anything...'If you can't put her in the hospital she'll just have to wait for an appointment.' Now that does not make sense, that is not cooperation...I'm trying to cooperate, but not to the extent that I'm going to lock this girl up. She's already emotionally crippled because she is retarded. She's not fully

> retarded, but it's enough so that she cannot function for herself. And to lock her back in the hospital after she just got out, I will not do!" (CP#9, p.3-4).

Once established, this attitude continued to interfere with the CP's access to information, which resulted in greater efforts to secure it. This appeared to set in motion a cycle of negative interaction which sustained interpretations of non-cooperation on both sides in a self-fulfilling fashion:

Other CPs lacked the mandate for interaction which existed for CP#9 through her daughter's mental retardation. Their problem was often the inability to access the physicians at all. CP#1 was completely shut out of interactions with his partner's medical staff, being at times directly asked to leave in the rare instance that he was able to get time off work and attend appointments with his partner. This lack of acceptance was a constant source of irritation to the CP.

> "I would like to be appraised on a periodic basis by the two physicians that would be most knowledgeable on his case. Just given a periodic update even if it's just every 4 weeks or something like that. Yeah, I'd like them to recognize the position I'm in, my relationship with Al and that being here to care for him and living with him. And they should let me know where he stands and say just you know, "I'm sure he's told you this but, I just want you to hear it from me and do you have any questions?" I think that would be appropriate and that would be very nice, but they don't do that...The information I get is little to none. The

> information I'd like would be diagnosis, prognosis, and protocol. It should be in the order of diagnosis, protocol, and prognosis." (#1, pp.15-16)

Other CPs were able to establish significant relationships with the attending physician(s) which, while not perfect, were at least functional for the purposes of sharing information. This took negotiation and insistence at times on the part of the CP. In one instance, the fact that the CP had power of attorney was helpful in getting the physician to open up and share information with the CP:

> "[The primary physician was kind of reluctant in giving any information at first, but after a month or two he'd call and ask for me instead of John, asking 'What's this? What's that? Is he showing any signs of this?', etc. <u>After a while I think he understood what the relationship was. After showing him the power of attorney, he was pretty good at giving information...It took a month after seeing him for him to answer questions</u>. He'd walk by or avoid me, so I'd have to track him down or go in the doctor's lounge and grab him. Then <u>he kind of realized he had best talk to me because I'd follow him to his car if necessary</u>. I'd go to the hospital or call him. I have to admit if I ever called and left a message, he would return my call. He had an office for outpatients and was very good about returning calls. <u>But then again, he was short on the phone. I had to be very specific</u>," (#3, pp.10,14).

In addition to desiring a positive attitude from physicians and information related to the patient's status, CPs expressed a need for the support and sanction of physicians with regard to decisions about patient care. For some CPs, this was readily forthcoming; their activities on behalf of the patient both in and out of the hospital were

not only recognized, but highly praised by the attending physicians:

> "[The doctor and the social worker] just praised me to high heaven. And it really made me feel good because I went through hell with her, almost to the point of--her and I were like Siamese twins...At one point--I will never forget it--[the patient and I] walked into the doctor's office one day and he looked at her and said, 'This is not Gloria. We were all ready to autograph your coffin.'...Then he grabbed me and embraced me and said, 'I don't know what you did for your sister, but whatever it is we've got to bottle it.' This brought tears to my eyes," (CP#16, p.8).

Not all were so lucky, however. The importance of such positive feedback was underscored for one CP when he was abandoned by his partner's physician at the time of the partner's death. The patient had been discharged in an unstable state because of his strong desire to go home. A breathing emergency at home engendered a situation in which the patient was admitted to a different hospital than that where his care had been centered for the past two and a half years. The patient never regained enough stability to move to the hospital where his primary physician was located, but the CP asked permission for this physician to receive visiting privileges. Despite the privilege being advanced, the primary physician neither came nor called. The CP was thus forced to accept the statement by a physician new to his partner's case that nothing more could be done to save the patient. Despite "knowing" the truth of the statement, the CP was besieged by doubt and numerous questions: should he have refused to allow the patient to come home in the first place, should he have insisted on moving the patient to his regular hospital, might there be some treatment known by someone with more knowledge about the case?

> "You know it's a big responsibility when someone goes in and the doctor doesn't know that patient, for you to accept their word that 'Well, there is nothing more we can do,' and essentially decide to let that man die. I think that's what upset me more than anything. If his doctor had even called and just said, "I'm really sorry, there's nothing more we can do, but you've done the right thing,' it would have eased my mind. I was pretty confident that I had done the right thing, but there was always that nagging in the back of my mind, I would have felt better if someone from Henry Ford would have had some contact with us." (#7, p.19-21).

These various experiences emphasize the direct influence physician acceptance of the CP's involvement has on the nature of the involvement. For those able to access physicians for information, three of the primary communication variables discussed in the first chapter appeared relevant: <u>availability</u>, communication <u>clarity</u>, and <u>completeness</u>.

Many of the CPs expressed difficulty tracking down physicians, having to rely instead on waiting for the doctors to return phone calls, or using the nurses as go-betweens to procure information. Availability was particularly tough for CPs who worked during the day.

Physicians were reportedly prompt in returning CP phone calls or getting back to them with requested information.

But when conversation was presented over the phone, problems with completeness arose. Such conversations tended to be brief and to the point, usually answering a specific question raised by the CP earlier. If further information was desired, CPs found it necessary to be specific and direct in order to get the full information desired.

> "I didn't stay on the phone long enough [to get a complete answer to my questions], we didn't conversate too long. I think had I been face to face, I'd have been freer to talk to him. But I just never could get him in his office at that particular time. When I walked there I couldn't get him. He wasn't in or something that day." (#8, p.11)

Clarity was also a problem, though rarely in terms of complex medical jargon. CPs were comfortable about making physicians explain unfamiliar terms, and the physicians were typically successful in making themselves understood. Problems arose, though, with imprecise terms that possessed a variety of meanings. CP#8 was uncertain whether a doctor's statement about the need for her partner to stay away from drugs referred only to the patient's IV drug habit or included prohibition of alcoholic beverages as well. CP#7 was told his patient had "unstable blood" but expressed confusion about what that meant. It became clear after he got the patient home that it meant the patient was near death.

Vagueness of information could also be seen in the nature of updates given the CP by physicians. Often times, these consisted of no more than general statements about the patient remaining stable, or experiencing an upturn in health. Such was the case for CP#8 who nonetheless accepted the information as helpful and valuable:

> "[The doctor] would tell me he just needs more vegetable foods and he need to keep his immune system up and let go of his drinking. That's not good for him and drugs are not good for him...,Or they would say he was doing much better today than he was yesterday and the treatments are coming on really good. All we got to do was just lay with him and hang in there. He was pretty sick at the time, but they did make him better," (CP#8, p.4,7).

Empathy was not typically associated with physicians in the present sample of CPs. However, CPs did not seem to expect it of them:

> "The physicians were, well, they're a different breed. I think they weren't very empathic...But that's not what I wanted from them. I didn't want them to be empathic...I mean it's not appropriate to start talking about your feelings. I mean, [the doctor's] there for medical reasons. Not empathy. If you want empathy, you need a social worker or a nurse or something," (CP#12, p.20).

CPs expressed a similar tendency to excuse physicians for their other communication-impairing behaviors as well. One CP specifically noted that infectious disease specialists had typically selected that specialty because they did not want to engage in a lot of direct patient care, and as such were not comfortable and skilled at consistent communication with patients, let alone CPs. Others noted that physicians had other patients to attend to and subsequently could not be expected to spend much time with the CP detailing information about the patient's developments.

Nurse Communication

For the most part, nurses were viewed positively by CPs. Nurses' strengths lay more in the provision of emotional support than as sources of information, particularly in terms of helping the CP prepare for the patient's death and allowing the CP to be active in patient care requirements. Nurses were the most likely source of information that the patient was approaching death.

> "The nursing staff was very honest...The last week, two nurses were good. They would just inform me that he was really bad and it had traveled to the base of the skull and he probably wouldn't make it. Am I prepared [for that]? They were real good. Just the nurses though...One nurse [in particular] informed me that week that he was very, very sick and in a lot of pain. Was I ready to deal with it cause I had to get ready to deal with it. I had known it in the back of my mind, but I just had to have someone say it to me. She was that person and I think she knew that," (#3, pp.17,19).

Such activity was contrasted with physician behavior in these instances. Not one CP reported being informed of the patient's approaching death by the attending physician. This did not appear overly problematic to CPs, however. What seemed important was simply that <u>someone</u> inform them of the poor state of health to which the patient had advanced.

The empathic interaction practiced by nurses was marred only by the occasional practitioner who exhibited excessive fear of interacting with the patient. CPs expressed an understanding of such behavior, but it was nonetheless frustrating for them. Persistence of such behavior typically led to requests that the individual in question be reassigned away from the patient.

The greater empathic nature of interaction with nurses, however, was offset by their greater inability to provide complete information about the patient's status and medical developments. CPs generally reported that information available through nurses was less complete and certain than that possessed by physicians. CP#8 expressed this difficulty in precise manner: "<u>It's kind of hard; I talked to the nurses. Well, they just have so much to say, you know before you talk to the doctors.</u>" CPs who desired information from the medical staff and were willing to actively seek it out often thus arranged to speak with the physician in charge. At times, the nursing staff served to link the CP with the physician:

> "The primary physician was so hard to get a hold of. Sometimes he would come in the morning, sometimes he would pop in at 11:00 at night. Weekends you couldn't reach him. I dealt mostly with the nurses, the head nurse. I would tell her what I wanted to know and she wouldn't know, but she would get the information from Dr. Krishna and if he didn't want her to know, he'd call with the answers to my questions the next day." (#3, p.12).

However, the most informed and active CPs in terms of information search were more likely to be critical of the level of nursing knowledge about HIV and their associated treatment. CP#1's partner had a very advanced, complex case of AIDS and both patient and CP experienced frustration at the hands of the nursing staff, though again, understanding was expressed:

> "...the nurses don't know [what different treatments are incompatible]. I mean the nurses have let his IVs run out, they put the blood back up all the way up the lines, they've, they haven't administered in the appropriate doses, or the appropriate drip rates. You know it's up to Al to really, you know, watchdog after himself...The nurses don't know a thing about--well they are under strict orders they'll lose their job if they do anything that deviates whatsoever from what the doctor orders...I guess they interface with so many patients with so many different problems they don't really understand the specifics or the protocols of the medicines. I think [the reasons for this are] number one, as you indicated the advanced nature of [the patient's case], number two, HIV being a complex thing to treat, and number three it's just a systemic problem in a large health care organization when you're dealing with a thousand bed hospital and you got probably 800 different problems you're treating in that thousand bed hospital. You know you can't possibly really become an expert on all that otherwise you'd be a doctor." (#1, pp.14-15).

The above quote also denotes frustration with nurses being handcuffed by hospital rules about altering medical care for the patient, a problem reported by other CPs as well. Nurses did violate "rules of silence" imposed on them by physicians. Several instructed the CP about their patient's approaching death but warned against telling the the doctor about the exchange for fear of negative repercussions. They were also capable of altering treatment in indirect ways. For instance, a nurse informed one CP that he could ask the doctor to prescribe morphine which would help the patient stop his vigorous resistance against an imminent death:

> Bless their hearts, it was the nurses who pulled me aside and said, 'You know the doctors wouldn't like it, but he can put him on a drug. And if you do that and increase that dose, it doesn't kill him, but it will make him relax, and frankly it will make it go faster". Why couldn't the doctor tell me that when he was talking to me? Why does a nurse have to come and say, 'The doctors wouldn't like it, but if you go and ask them...?' Why does it have to be like that? Because the doctor was perfectly willing, when I said, 'What about a drug? He's not relaxing, he's still fighting it, what about a drug?' Then I told her, 'You go back and call the doctor and say that I wanted to know.' Well, than that was fine. The nurses knew what to do. Why did it have to be like that?" (#7, p.29).

Nurses did on occasion make changes in non-medical aspects of patient care and these were appreciated by CPs. Typically these had to do with increasing patient comfort, as in the case of CP#3 whose partner was moved to a larger, more private room in the last weeks of his life in order to allow more visitors to congregate around him. This was reportedly done without the prior consent of the physicians. Such activities appeared to be interpreted by CPs as an extension of the compassionate care provided by the nursing staff in general.

Thus, a rough picture of CP interactions with physicians and nurses caring for their partner can be constructed from the present data. Physicians are less likely to be empathic, but are seen as being the most desired source for information. This desire is often frustrated or at least hampered by the inaccessibility of physicians relative to nurses. Establishing a cooperative relationship with the primary physician was important for the CP. Non-recognition or discouragement of the CP's role in the patient's illness leads to frustration and reduced overall involvement for the CP. Physicians did appear to be rather clear in their communication, with problems occurring more with vague statements than with complex medical jargon. Completeness of information was hampered by lack of access and CPs reported having to be fairly precise with the questions and concerns in order to fit everything into the truncated interactions they typically had with physicians.

Nurses were generally viewed as more understanding and supportive than physicians, albeit less well-informed with relation to HIV infection. Further, the majority of problems CPs discover in patient care were the result of nursing actions. Thus, nurses, or at least specific nurses, were generally seen as more incompetent. This was at various times attributed to being overly burdened with patients, having a poor attitude, and simply lacking the requisite skills.

Important insights on the value of the communication variables explored above are also provided through results of the survey data. All of the primary communication variables had significant positive correlations with the exception of the relationship between the primary medical contact's full disclosure of information and empathy (see Table 5). Most important, however, is the strong positive relationships between the specific communication behaviors of the primary medical contact and overall CP satisfaction with that individual's communication.

Furthermore, the data in Table 6 reveal that the communication practices had a significant impact on CP perceptions of illness-related knowledge. CPs' perceptions of their personal knowledge of general HIV issues were positively related to the primary medical contact's clarity of communication, full disclosure of information, and overall communication satisfaction. CPs' perceptions of knowledge regarding home care requirements were positively related to complete information and full disclosure. Of note, there were <u>no</u> significant relationships between the communication variables and CP perceived knowledge about patient-specific issues. This is troubling in that the medical staff is seen to be the only real source for such information. However, given the strong reliance of the present sample on the patient as an information source, CPs

Table 5. Correlations between Communication Variables

	AVAIL	CLARITY	COMPL	DISC	EMPATHY	COMMSAT
AVAIL	--					
CLARITY	.86**	--				
COMPL	78**	.50*	--			
DISC	.48*	.56*	.44*	--		
EMPATHY	.84**	.55*	.74**	.16	--	
COMMSAT	.87**	.71**	.64**	.67**	.67**	--

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

AVAIL = Availability
CLARITY = Clarity of Communication
COMPL = Completeness of Communication
DISC = Full Disclosure
EMPATHY = Empathic Concern
COMMSAT = General Communication Satisfaction

Table 6. Correlations between Communication Variables and CP Outcomes

	AVAIL	CLARITY	COMPL	DISC	EMPATHY	COMMSAT
GENHIV	.17	.44**	.02	.62***	.16	.36**
SPCHIV	-.14	-.09	-.21	.20	-.23	.02
HOMEKNOW	.19	.03	.29*	.33*	.24	.16
CAREBURD	.05	.25	.01	-.13	.03	.14
PHYSYMP	-.07	-.18	-.19	-.37*	.01	-.19
DEPRESS	-.01	-.18	-.08	-.22	-.03	-.09

* $P < .15$
** $p < .10$
*** $p < .05$

AVAIL = Availability
CLARITY = Clarity of Communication
COMPL = Completeness of Communication
DISC = Full Disclosure
EMPATHY = Empathic Concern
COMMSAT = General Communication Satisfaction
GENHIV = Perceived General HIV Knowledge
SPCHIV = Perceived Patient-Specific HIV Knowledge
HOMEKNOW = Perceived Home Care Knowledge
CPBURD = Perceived Care Burden
PHYSYMP = CP Physical Symptoms Index
DEPRESS = CP Depression

may have been able to derive satisfactory information directly from the patient.

The value of influencing CP perceptions of knowledge is underscored in Table 7, where a number of significant reductions in mental and physical stress are reported by CPs. That is, CPs with higher reported knowledge of general HIV issues revealed lower levels of physical symptoms and depression. CPs with higher reported knowledge of patient-specific HIV issues, revealed lower levels of burden and physical symptoms. Finally, CPs with higher reported knowledge of patient home care requirements, revealed lower levels of all three outcome variables: burden, physical symptoms, and depression.

However, it should be noted that perceptions of knowledge are not the same as objective knowledge. The fact that CPs may overestimate their knowledge is substantiated in Table 8. The only significant relationship was between perceived knowledge of general HIV issues and knowledge of current drug therapies used in treating HIV infection. With the exception of epidemiological knowledge about HIV, perceived knowledge of home care appeared to <u>restrict</u> CP knowledge of treatment issues and overall knowledge about HIV. Such perceptions may actually be detrimental to CP actual knowledge through promoting a conception of HIV infection as an undifferentiated illness that does not require specialized knowledge.

Table 7. Correlations Between Perceived Knowledge and CP Outcomes

	GENHIV	SPCHIV	HOMEKNOW	CPBURD	PHYSYMP	DEPRESS
GENHIV	--					
SPCHIV	.49**	--				
HOMEKNOW	.33	.70***	--			
CPBURD	-.04	-.37*	-.47**	--		
PHYSYMP	-.34*	-.41*	-.60***	.19	--	
DEPRESS	-.47**	-.03	-.38*	.19	.74***	--

* $p < .10$
** $p < .05$
*** $p < .01$

GENHIV = Perceived General HIV Knowledge
SPCHIC = Perceived Patient-Specific HIV Knowledge
HOMEKNOW = Perceived Home Care Knowledge
CPBURD = Perceived CP Care Burden
PHYSYMP = CP Physical Symptoms Index
DEPRESS = CP Depression

Table 8. Correlations between Expanded Objective HIV Knowledge Test and CP Outcome Variables.

	TRANS	TREAT	EPID	HIVSYMPT	HIVTEST	DRUGKNOW
GENHIV	.17	-.01	-.02	.10	-.22	.44***
SPCHIV	.23	.02	-.21	.17	-.18	.23
HOMEKNOW	-.13	-.39**	.60***	-.15	-.44***	.03
CPBURD	-.04	.35**	.52***	.07	.27*	-.04
PHYSYMP	-.23	.45***	.27*	.09	.27*	-.08
DEPRESS	-.10	.49***	.27*	.13	.37**	.04

* p < .15
** p < .10
*** p < .05

TRANS = HIV Transmission Knowledge
TREAT = HIV Treatment Knowledge
EPID = HIV Epidemiology Knowledge
HIVSYMPT = HIV Symptomology
HIVTEST = Composite HIV Knowledge Test
DRUGKNOW = Knowledge of Drug Therapies in Use or Under Investigation for HIV
GENHIV = Perceived General HIV Knowledge
SPCHIV = Perceived Patient-Specific HIV Knowledge
HOMEKNOW = Perceived Home Care Knowledge
CPBURD = Perceived Care Burden
PHYSYMP = CP Physical Symptoms Index
DEPRESS = CP Depression

Table 8 also reveals some important findings between CPs' actual HIV knowledge and CP outcome variables. In particular, the findings suggest that knowledge may not always be comforting in light of the inability to effect the course of illness. Thus, knowledge of treatment issues with HIV was associated with higher levels of CP burden, physical symptoms and depression. CP knowledge of epidemiology and overall performance on the test revealed the same pattern of relationships, though of lesser significance. Such findings are consistent with the observation made by CP#10 about her preparations to visit her partner in California during a downturn in his health:

> "Information always reduces fears. But it didn't just happen like that [snaps her fingers]. I cried so much, to where I wished somebody would go with me [to California] because I kept having the feeling like it was going to be bad, which it was," (p.25).

Taken as a whole, the statistical results of this study presents a complex picture of the value of communication with the primary medical contact. Communication does appear to increase CP perceptions of knowledge with subsequent reductions in the physical and mental stress outcomes. However, objective knowledge is associated with increases in these same outcomes. So far as addressing issues of CP stress and burnout, the value of perceptions is both encouraging and unproblematic. However, the impact of such overestimations in knowledge on the quality of patient care may be important, and will need to be examined in future research.

A final finding of relevance to CP interactions with medical staff relates to the tendency of CPs to excuse problems they encountered with medical staff behaviors. Inherent in such discounting was the assumption or worry by CPs that their desires for interaction (both quantity and quality) were out of line. This tendency revealed itself in a variety of contexts and behaviors: staff who expressed fears over patient interaction were exasperating, but the behavior was typically explained away by CPs as understandable given low levels of experience with and knowledge of HIV+ persons; doctors and nurses who were not available for regular interaction were excused for being too busy trying to cope with an unmanageable case load; nurses who were seen as lacking HIV knowledge were excused because of the rapidly changing nature of the illness, especially in relation to experimental treatments; the inability of some physicians to communicate clearly and comfortably was explained away as a lack of training and personality characteristics which led them to specialize in infectious disease to begin with; the unwillingness of physicians to leave talk of the patient's death to nursing staff was seen as a necessary extension of emotional detachment required for their job; and, perhaps most important, the tendency to suppress or downplay CP involvement was justified through acknowledgement of the strong physician-patient dyad interaction norms in the traditional medical model. In short, while each of the above characteristics of medical staff behavior were seen as frustrating, CPs were willing to provide justification for the behaviors rather than resort to unconditional criticism.

Several CPs went so far as to acknowledge that medical care was interactive and that patients and CPs were as much to blame in some instances as the medical professionals:

> "<u>I think hospitals and hospital staff need some real training on how to handle patients, but I think patients could do well with an orientation early on, especially if you're going to be involved in a terminal illness, and you know there's going to be--probably--a long-term hospitalization</u>. [There should be] a patient orientation where the patient has an opportunity, and the family who are going to be primary caregivers, have an opportunity to talk about, 'Look if you ask the nurse this way, what do you think her reaction is going to be? Or if you ask this way...' I think people, you know, because I work with a lot of them and I see the way a lot of the patients, how things end up when they get [to the hospital]. I think patients buy a lot of they're own problems because they tend to think that it's a hotel stay, and that they're paying and the [medical staff] owes them," (CP#7, p.32).

The tendency to forgive frustrating behavioral aspects of medical staff interaction <u>can</u> serve a positive function by reducing CPs' perceived frustration and stress. However, such willingness can also stifle attempts to reconfigure the medical interaction toward greater effectiveness. Thus, CPs may experience less stress by justifying current interaction, but not receive the information and guidance which would help them in their care partnering work. This potential is discussed at greater length in the discussion section.

CPs also practiced mental adjustments in relation to assessments of the quality of care provided to their partner. In general, CPs desired indicators and/or assurances that the patient was receiving quality care and was satisfied with the treatment. While cooperative relations were desired between themselves and the medical staff, CPs were willing to take the back seat unless problems in patient care warranted increased monitoring and advocacy. Many CPs, however, objectively knew that the patient was not receiving the absolute best care available, and made adjustments in their criteria for assessing care quality. Generally, adjustments took one of two forms: (1) acknowledging that the staff working with the patient might not be the most qualified in the area, or even in the country, but expecting that they perform as best they could under the circumstances and within their level of expertise, and (2) including patient desires and satisfaction with care in the calculus of care quality determinations.

As noted, adjustments based on medical staff expertise were made at both the national and local level. CP#1, for instance, was aware that greater expertise and a wider array of experimental treatments were available in California and

New York, but noted that a good level of care was still available in the less expert Midwest region. Another CP (#3), who was himself HIV+, was strongly motivated to find better care for his ailing lover and repeatedly attempted to persuade his partner to shift his care location from the local, public hospital to more expert care available at a private institution downtown or the more qualified help at a nearby university hospital. Despite growing realization that the public hospital was unable to provide sound basic HIV care, the patient's desires to remain there led the CP to downscale his criticisms of the care provided. While critical of the value of care at an objective level, he noted that given their level of training, the staff did their best.

Structural constraints in the form of hospital funding and patient case load were also used to adjust care quality perceptions. This was particularly relevant for low-income CPs and patients who were dependent on publicly-financed medical care and thus relegated to less expert, local public hospitals where staff attempted to juggle demanding case loads on small budgets. CP#8 expressed empathy for the staff in such situations:

> "I feel like the staff the doctors and everybody else has done the best they can but <u>I feel like the money they are getting they can't do no more than they are doing with no more then they are getting because I have seen that hospital in blooming condition and it doesn't look like that now. That's the</u>

> <u>way I feel. 'Oh Westland Medical, you're going there to die.' That's what everybody says in the neighborhood but still it's a hospital</u>. It has to come up to certain requirements to be a hospital." (#8, p.16)

As with the willingness to justify current patterns of medical interaction, this tendency to readjust care quality perceptions appeared helpful in reducing CP stress and worry over issues of care. It also underscores the importance of positive relationships with the medical staff that make-up at least emotionally, for the less expert physical care available. Such adjustments may simply be a way of coping with a situation in which choice either does not exist (e.g., the patient without medical insurance cannot afford the best medical care) or is severely limited (e.g., the only way to access better care is to move out of the state or accept a two-hour drive time to access more expert local care).

CHAPTER FOUR: DISCUSSION

In attempting to develop a theory of the role of care partners in illness management systems for AIDS patients, this study has identified the core construct of CP involvement, conceptualized as the nature and degree of CP participation in the various tasks required for management of the patient's illness. Specifically, these tasks consisted of: hospital care, home care, medical appointments, medical regimen, information search, and emotional support and sustenance of patient mental well-being. Variations in CP involvement were then linked to differences in a number of exogenous variables: patient health status, CP life philosophy/personality, CP motivation to care, prior CP experience, CP-patient relational history, and structural limitations. As a causal force, CP involvement was used to explain differences in CP interaction with medical staff as well as underlying perceptions of uncertainty and stress. CPs whose level of involvement was self-perceived as appropriate were less likely to be upset or frustrated with medical interaction patterns.

The current study also illustrates the necessity of CP negotiations with both patient and medical staff in order to establish CP legitimacy. That is, patient and physician had to both acknowledge and accept the CPs' level of involvement in the patient's illness management in order to legitimate the CPs' status and activity. Legitimized status was more likely to result in greater interaction with medical staff, greater flow of communication between CP and medical staff, and greater CP satisfaction with medical staff interaction.

The importance of legitimacy is heightened in the case of AIDS where non-traditional relationships are common, particularly in the case of homosexual relationships. In several instances, possession of power of attorney by the CP was necessary or helpful in establishing legitimacy claims for greater involvement. Ability to spend large amounts of time with the patient during hospitalizations also sanctioned CP involvement.

Thus, a theory of CP participation in AIDS patient management contains a number of constructs, applied in two domains. The first pertains to the private world of the CP in determining desired level of involvement, constructed from the interplay of the exogenous variables defined in this study. The second theoretical domain stands in the realm of interaction, where CP desires must be made real through incorporation in the social world of the illness management system. These two domains are bridged by the CPs' desired level of involvement; constructed at the individual level, this desire is carried into interaction where the CP negotiates (explicitly or implicitly) with patient and medical staff to arrive at an enacted level of involvement accepted as legitimate.

The findings of this study may be embedded in several bodies of theoretical thought and research: work on <u>illness management</u>, the nature and functions of <u>social support</u>, and the nature and functions of <u>empathy</u>.

ILLNESS MANAGEMENT

Research on illness management has been predominately performed by Strauss and his colleagues (Strauss, 1975; Corbin & Strauss, 1988; Strauss, Fagerhaugh, Suczek & Wiener, 1985). The approach undertaken in this research is focused on the nature of <u>work</u> in relation to the management of illness, based on the concept of an illness trajectory's (see Chapter 1). These researchers argue that as a patient moves through the trajectory, different types and qualities of work will be required. They go on to identify these types of work as: safety work, machine work, comfort work, sentimental work, and articulation work. Movement along the illness trajectory must coincide with recalibration of the illness management system whereby different tasks must be accomplished and members assigned to carry them out. Research on the role of illness trajectories in defining requisite work across stages has focused on the role of medical professionals and patients in the construction and maintenance of illness management practices (though Corbin &

Strauss, 1988, extend their focus to include spouses). The current study builds on the body of work done by Strauss and his colleagues through greater focus on the role of CPs in the illness management systems for the terminal illness of AIDS.

In particular, the ideas of Strauss and his colleagues allow for a greater appreciation of the CP's need to establish legitimacy for involvement. This is derived from Strauss et al.'s (1985) emphasis on the division of labor which defines any illness management system. Glaser, et al. (1986) further argue that division of labor may be examined both in terms of degree (i.e., how great is this division) and basis (i.e., what rationale is used in justifying the role of each party). These distinctions play into what Strauss, et al. (1986) label "articulation work." Such work consists of the communication necessary for achieving the promise of labor division through coordination of the individual efforts of members. The necessity of communication in determining, assigning, and accomplishing tasks, however, takes place on an uneven playing field:

> Of course, different actors in the drama possess quite different degrees of skill, sagacity, influence, and situational or positional power for affecting the evolution ot the trajectory work. Yet that work could scarcely get done if one or more of the less institutionalized modes of articulation were not resorted to by the personnel, by the patient, or by the kin. (Strauss, et al., 1986, p.190).

The concept of articulation provides a concise mechanism by which to critique the current role of CPs in such systems. In general, their efforts are without a strong basis of legitimacy with which to anchor their involvement. This is clearly illustrated through discussion of the negotiation strategies practiced by CPs in establishing involvement levels.

In general, the negotiation practices of CPs in the current study may be most accurately defined as "silent bargaining" (Strauss, 1978). Drawing from earlier research on patient death in hospital settings (Glaser & Strauss, 1965), Strauss defines this as a situation wherein the parties involved (e.g., medical staff and patients) use subtle, predominantly nonverbal, cues for establishing a coordinated, common reality. In the research on dying, this took the form of a "ritual drama of pretense" in which all parties appeared to establish a silent agreement against open discussion of the patient's approaching or likely death. Silent bargains are typified by the imposition of limits by at least one party in the relationship, within which activity is constrained and assessed for legitimacy (Strauss, 1978). The lack of open negotiation may be dysfunctional as circumstances change (e.g., the patient desires to discuss death issues as the moment of death appears more immediate).

This line of theoretical reasoning has two major implications for the findings of the present study. First, the "drama of pretense" clearly extends beyond the medical setting and interactions between medical staff and patients. Patients and CPs in the current study generally avoided forthright discussion about the probable terminal nature of HIV infection. There were few attempts to prepare for a potential decline in patient health and function, as evidenced in the absence of filing legal papers or planning for the structural or strategic changes that would be required at home if patient physical function became impaired.

Perhaps more important, though, CPs in the current study lacked explicit articulation about the exact role they should play in the illness; discussions of this nature were rarely accomplished with either patient or physician. This is in large part due to the limits set by the patient and physician, who silently constrain the actions of the CP. Attempting to act in a context where the traditional medical model downplays--often excludes--direct third party involvement, CPs are beseiged by problems of legitimacy from the outset of the patient's infection. As illustrated in Chapter 1, the patient and physician are accorded primacy, and thus the power to establish limits on the role of CPs. While the patient is typically viewed as the most central, powerful actor at the level of making decisions regarding the general nature of treatment, formal medical settings constrain this power. Thus, while a patient may make the decision to receive chemotherapy for AIDS-related cancer, the physician and allied medical staff wield a great deal of control in how and when such therapy will actually be pursued. In relation to CPs, such institutional and professional control is most clearly evidenced in the form of restrictions on visiting hours which restrict CP access to the patient and thus participation in the various aspects of patient care during hospitalization. While such policies were often relaxed for CPs in this study, it is still clear that permission for such policy departures must be granted by the medical staff.

Over the course of the illness, then, CPs are faced with limits imposed by both patient and medical staff (most typically the physician). Patient normalization desires and adult status provide initial barriers that frustrate fulfillment of CP desires for greater interaction. Even when patients opt for allowing greater CP participation at later illness stages, the physician may enact limitations by insisting on policy and/or refusing to recognize the legitimacy of the CP.

It is important to note, however, that despite the limitations imposed upon CPs by the patient and physician, many CPs were able to overcome them at different points in the illness trajectory. Specifically, when the patient suffered a serious acute episode, was impacted by medical staff error or oversight, or was perceived by the CP as moving permanently toward a greater disability, CPs were likely to insist on greater involvement. At times this resulted in a more explicit discussion of the CP's role in illness management, but more often it consisted simply of increasing CPs' motivation to challenge the limits imposed by the traditional medical model. Oftentimes, the limitations gave way in light of the patient's physical exigence and CPs were often successful in integrating with the staff and assisting with patient feeding, bathing, waste removal, and transportation. For the most part, such arrangements were established with nurses rather than physicians, and CPs generally expressed strong satisfaction with the nursing staff.

The main limitation still faced by CPs in the hospital setting was information exchange with the physician. CPs were often required to actively seek out the physician and acquire desired information, activity which only increased in difficulty when the patient returned home. While information acquisition is only one aspect of illness management involvement, it has immediate implications for all other facets of involvement: skill and knowledge, perceptions of competence and confidence, effectiveness of treatment involvement, and general information uncertainty. Thus, consistent problems in establishing open channels of communication with physicians--especially for those CPs dealing with public health services where doctors were more transient and case management continuity more fragmented--can be seen as a limitation imposed by physicians, presumably on the assumption that the patient will inform the CP about all necessary case developments.

While CPs wishing greater personal involvement in institutional settings were typically successful, it is more important to address the question of why the majority did not engage in such active involvement. And further, why were CPs so willing to accept a passive role during times of stable patient health? Clearly, the answers to these questions are complex, and lie partly in such factors as the structural constraints of work demands, the level of patient health, perceptions of the patient as an accurate source of information, and CP motivation to involve themselves in an arena where others were available to provide patient care. However, much of the passivity in CPs appeared to derive from their acceptance of the limiting conditions established in the traditional medical model. The CPs without active insitutional involvement belonged to one of two groups: those who desired greater involvement but perceived such desires as unreasonable, or unacceptable to either or both patient and physician, and those who so accepted the traditional model that they did not even experience frustration with the limitations. The majority of CPs engaged in the justifying behavior illustrated in Chapter 3, wherein perceived communication failures were interpreted as acceptable given the patient's adult status and the busy schedules of medical staff.

In general then, this study reveals a marked lack of explicit discussion of the CP's role in illness management. The articulation work of coordinating the division of labor in caring for the patient--of establshing a strong "negotiated order" (Strauss, 1978)--took place apart from the CP. This investigation of the overall role of CPs in illness management then extends the ideas of Strauss et al., (1986) concerning "patient work," wherein they identify the various activities patients engage in during the course of illness. The dimensions of patient work drawn in this research--explicit vs. implicit work, legitimate vs. illegitimate--are readily transferable to the work of CPs as revealed in the current study.

SOCIAL SUPPORT

The findings in this study also hold implications for continuing research in the area of social support. One key finding in this regard is the lack of participation by the CPs in support groups developed to assist persons caring for the HIV-infected. CPs devalued such groups, viewing them as either simple "gripe sessions" or irrelevant to the task demands faced by the CPs. Underlying such complaints was the fact that such groups were rarely able to provide the instrumental assistance most needed by CPs. This is consistent with the formulation of most support groups which focus primarily on the provision of emotional and informational support to like others suffering in situations of distress (Yalom, 1985). The majority of CPs studied did not perceive needs on either of these levels, and so opted not to participate. The three CPs who were involved in support groups saw themselves as needing the support offered and were grateful for the opportunity to interact with others in similar situations.

This lack of reliance on support groups has two implications for research on social support. First, it reveals limitations to the positive regard which has been accorded support groups in our modern era of consumer-oriented health. The criticism lodged by CPs in this study suggest the need for an instrumental component to support groups. Beyond this, however, there is a need to temper the enthusiastic expectations that support groups are ideally constructed to deal with the psychosocial stressors and demands which impinge on CPs (Adelman, 1989).

The second implication, more methodological in scope, is that care should be taken to guard against over-reliance on support groups as sample sources for research on caregiving. It appears highly likely, given the findings of this study, that the types of people who participate in such groups are unique, and that theories and empirical findings based on such CPs will yield only partial answers to the complex phenomenon of care partnering. In short, while the current study oversamples care partners with no support group membership, others oversample care partners from within support groups. There is a strong need to perform comparative studies that allow us to understand the specific circumstances under which support groups will be valuable to care partners.

The criticism that support groups lack an instrumental component also speaks to the continuing debate among researchers about whether social support is a unidimensional vs. multidimensional construct. The lack, whether real or perceived, of this instrumental dimension undermined the perceived supportiveness of membership in "support" groups and kept CPs in this study from using them. CPs spoke of their greatest concerns focusing on the ability to juggle all their specific daily tasks, or locating someone to help balance multiple, competing demands. CPs did realize the emotional component of such groups, but devalued the worth of this component either because their emotional needs were fulfilled by friends and family, or because of a negative evaluation of support group meetings as "gripe sessions." Information needs which might also be serviced by support group membership (e.g., advice on securing government services and assistance, information on HIV/AIDS, physical management) were typically fulfilled by AIDS case management agencies, viewed as a centralized storehouse for such direction and advice. Given this option, a support group would be redundant.

It would seem, then, that CPs are cognizant of the various forms social support may take, and actively seek the particular form of support likely to ameliorate their specific stressors. Thus, unidimensional definitions of social support may significantly undermine the fundamental importance of pragmatic assistance to CPs. This can be illustrated through the definition set forth by Sarason, Shearin, Pierce, & Sarason (1987), wherein social support is seen as "the extent to which an individual is accepted, loved and involved in relationships where communication is open," (p. 813). Within such a definition, it is assumed that individuals who are thus supported will be able to access the specific assistance (whether informational, emotional or instrumental) required for meeting situational demands. CPs in the current study, however, did not so much report overall perceptions of being undersupported; rather, they had specific needs which were unfulfilled.

Finally, this study's exploration of a "justification mechanism" among CPs in evaluating the actions of medical staff as well as others in the CPs' support system, provides an interesting angle on the role of negative social support. Negative support has recently been introduced to social support research as a way of countering its overly-positive connotations (Rook, 1985). The basic argument is that the contacts through which support is garnered may generate negative as well as positive support. A number of events which might be termed negative support occurred with CPs in the current study: non-acceptance of CP by physicians and specialists, verbal rebuffs by individual staff members, antagonistic and non-cooperative behavior of staff, staff member avoidance of patient, and staff errors in patient care. What appears unique is the willingness of CPs to justify these actions. These justifications protected the CPs' perceptions of overall staff support and quality; the negative potential of such comments and actions was neutralized and did not necessarily result in lowering overall perceptions of supportiveness. Thus, future research could explore the role of such justifications in the interaction of positive and negative support which underlie the perception of general support.

EMPATHY

The individual decisions of CPs to involve themselves in the patient's illness management constitutes what is termed as prosocial behavior (Stiff, Dillard, Somera, Kim, & Sleight, 1988; Hoffman, 1976). Research on the motivations to engage in such prosocial activity has emphasized the role of empathy. While this was not a direct focus of the current research, several findings can extend our understanding of this construct.

Hoffman's (1976) theory of empathy seeks to explain how emotional and physical distress in an other creates a bias toward prosocial behavior in an observer through the development of "empathic distress." The latter is defined as an internalization of the other's distress which creates discomfort in the observer. A major debate over the resulting prosocial act is whether it results from egoistic (i.e., goal is to reduce one's own internalized distress) or altruistic (i.e., goal is to reduce the other's distress). In arguing for the altruistic option, Hoffman (1976) presents three distinctions between empathic distress and egoism: (1) the distress is aroused by another person's misfortune, (2) the major goal of action is helping the other, and (3) gratification in the observer is dependent on behavior which successfully reduces the the other's distress. Each of these characteristics were apparent in the current study of CPs who responded to the infection of a loved one, sought to help the patient in any number of ways, and drew satisfaction when their actions were successful in helping to ameliorate at least some of the patient's distress. These results are thus consistent with Hoffman's (1976) position, as well as more recent research by Stiff, et al. (1988) which provided stronger empirical support for the altruistic model in a laboratory setting.

Of more importance, however, is the portion of Hoffman's (1976) theory which identifies mechanisms by which the empathic response is impaired or neutralized. These include observers' perceptions that the distressed other is personally responsible for creating the distressing conditions, empathic overexposure of observers, and dissimilarity between distressed individuals and observers.

If individuals are deemed responsible for their distress, they may be <u>judged</u> guilty, and therefore, undeserving of empathy. Such persons are seen to have engaged in behaviors which directly caused their current suffering and therefore, to have abdicated their right to place claims on societal goodwill and assistance.

Hoffman (1976) also argues for the existence of self-defense mechanisms which keep individuals from becoming overexposed to empathic distress. Hoffman argues here that:

> "...empathic overarousal may be assumed to have occurred when the distress cues from the victim were extremely intense. In the natural state this must have occurred when the victim's situation was hopeless. For the observer to try to help under these conditions would have served no useful purpose and might at times have been suicidal. Empathic overarousal, then, might be a self-preserving mechanism that...contributed to the survival of the species."

Hoffman's proposition receives support in the research of Stiff, et al. (1988) in which emotional contagion (equivalent to empathic overexposure) interfered with subjects' perceptions of their ability to appropriately respond to a distressed other.

Hoffman presents further evidence that individuals in such a state of overarousal may employ perceptual and cognitive strategies aimed at inhibiting the empathic response. For example, a nurse wishing to maintain some emotional distance from a dying patient may seek not only to spend less time with the patient (i.e., avoid the distress), but may also focus specifically on the medical tasks at hand in an officious manner (e.g., taking a pulse, checking machinery readouts) as a cognitive diversion to the distress of the patient.

Finally, a number of studies reveal that perceptions of dissimilarity significantly reduce the likelihood that people will respond to empathic distress with prosocial behavior designed to ameliorate that stress (Klein, 1971; Krebs, 1975). Whether such differences are perceived at the concrete physical level (e.g., race, attractiveness) or a more abstract, cognitive level (e.g., values, attitudes), they serve to again neutralize empathic response.

Taken as a whole, these empathy-blocking mechanisms are consistent with the national history of AIDS in the United States. The societal hysteria generated by fear of widespread infection during the early years of the epidemic only furthered the identification of the primary categories of AIDS patients as substantially distinct from the "normal" population; so long as only homosexuals and IV drug uses acquired the illness, the rest of the country could ignore the problem. Further, the illicit practices of these groups were seen to be the direct cause of their illness, and thus, individuals were fully responsible for their admittedly severe distress. Finally, the high fatality associated with the illness and its resistance to all known medical treatments has generated a feeling of hopelessness even among those who overcome other empathy barriers, exposing them to high levels of personal stress which causes them to burnout.

On the surface, then, it would appear that AIDS patients represent one of the greatest challenges to empathic response, and as such, provides a strong test of Hoffman's (1976) theory. According to the theory, the hopeless, excessively distressing situation of AIDS patients who are substantially different from other members of the population and who brought the illness upon themselves, should result in an empathic collapse. And yet everyday, people provide care for AIDS patients, volunteer for community AIDS agencies and groups, and, as in the current study, care for loved ones who are infected.

A number of factors can explain this "failure" of the theory. At one level, all of the characteristics of AIDS patients described above which should inhibit empathy have been challenged, paving the way for effective empathic response: massive research programs are underway to develop a cure, AIDS advocates exchange quantity for quality of life, stress the threat of AIDS to the entire population, and dispute the claim that AIDS patients are individually responsible for their illness. To the extent that such counter-positions are held, the empathic response should function normally and the theory maintains its validity.

However, it appears that the theory remains unable to fully explain CP involvement as revealed in the current study. Particularly, it fails to take into account the strength of social bonding which may sustain the empathic response even in the most "hopeless" situations. Of special importance in the present study was the prior relationship between CP and patient. While this might be argued to be an issue of similarity, such a position diminishes the value of relational history and commitment to the other in establishing a secure base that maintains the empathic response. Even though many of the CPs in this study viewed the patient as responsible for his illness, this did not impair the empathic response to provide care and assistance. True, CPs did hold onto the hope that a cure would be found, or avoided facing the probable terminal nature of the illness (both of which would serve to justify current caring efforts). But it appears that a strong emotional bond can do much to sustain empathy under circumstances where Hoffman (1976) would predict it to fail.

What would seem more important in the case of person's working with AIDS patients, whether professionals or family members, is limiting the negative effects of empathic overarousal. And to this effect, the cognitive strategies for interfering with empathic response can be seen as a <u>positive</u> rather than a negative factor. Many of the CPs in this study referred to the ability to lose themselves in the pragmatic effort of accomplishing daily tasks, whether the procedural steps involved with the patient's medical regimen, or unrelated tasks like preparing meals or cleaning the home. As one CP stated, it was just a "step thing," continually doing what needed to be done without thinking about the larger picture which indeed might undermine the validity of patient assistance. CPs also focused on their ability to assist in reducing patient distress through the maintenance of social bonds and engaging in positive relational exchanges and recreational activity. Thus, while they could not remove the underlying cause of distress, they could still have a significant impact on the patient's experience of his or her illness.

Such approaches are consistent with research by Miller, Stiff and Ellis (1988) in which the ability to differentiate empathic concern and emotional contagion contributed to health care workers' ability to avoid the negative outcome of burnout. This is made more significant by Stiff, et al.'s (1988) finding of a significant positive relationship between empathic concern and emotional contagion. What is needed then, is greater understanding of the process by which these two dimensions of the empathic response can be separated. It appears that selective perception of the full impact of a patient's distress, whether conscious or unconscious, is one important mechanism for accomplishing this helpful division.

One final limitation in Hoffman's (1976) model is its focus on guilt as an empathy-inhibiting factor. Though stated by only a few CPs in the current study, guilt (both real and anticipated) was actually able to <u>promote</u> or <u>sustain</u> CP involvement with the patient. The perception that the patient would have nowhere else to turn if care was either withdrawn or not offered, served to bind CPs to the care situation. Again, such guilt can be tied to the existing personal relationship between CP and patient.

It would appear then, that Hoffman's (1976) model is aimed more at an overall societal understanding of empathy, rather than a direct model of the individual empathic response, at least in application to AIDS, and perhaps to other situations of terminal illness. What is needed is an extension of Hoffman's (1976) to include the importance of strong social bonds to explain the function of empathy in eliciting prosocial behavior.

IMPLICATIONS FOR PRACTICE

CP Involvement

One of the greatest potential threats to CP health is overinvolvement with the patient's case, or, to use Hoffman's (1976) phrase, empathic overarousal. In its extreme form, such involvement may be appropriately labeled "ownership" wherein the CP feels that he or she is solely responsible for all aspects of patient care. While such ownership took place for only two CPs in the present study, several predictive factors which appear useful for determining CPs likely to become overextended to the detriment of their own mental and physical health. Medical staff and social workers should pay close attention to the following warning signs: strong prior relationship between patient and CP, valiant life-saving efforts by the CP during an acute patient health crisis, willingness to do <u>everything</u> asked by the patient, and, especially in the case of AIDS, abandonment by other family and friends.

The identification of varying levels of involvement also has significant practical implications. Clearly, those CPs more fully enmeshed in all aspect of patient care are exposing themselves to greater levels of stress. More directly, however, an understanding of the type and nature of involvement desired by the CP can aid in defining the interaction he or she has with various service personnel involved in patient care. If a CP is particularly eager to aid in the information search, assistance can be provided toward making the search maximally productive. If a CP wishes to focus more centrally on instrumental support of the patient, care can be taken to insure opportunities for him or her to do so, particularly within the hospital context.

Beyond shaping the nature of assistance offered to the CP by service personnel, identification of involvement expectations can provide social workers and/or medical staff with a gauge for assessing the CP's readiness for patient home care. If a CP is centered on emotional support of the patient, extra attention may need to be placed on educating him or her on factual information about HIV and caring for the HIV+ patient. Thus, specification of a CP's involvement expectations/desires is useful for both identifying possible overextension of the CP and potential shortcomings which leave him or her unprepared for the requirements of care partnering.

Inquiring about the metaphor(s) used by the CP to define his or her participation may be a useful method for assessing involvement. While more research is needed to explore the relationship between the metaphor and actual involvement, the links in the present study appeared important.

Negotiating CP Involvement

A second implication for practice arising from the current research is the need to formalize CP role negotiation. While patient desires to maintain normalcy will necessarily limit the CP's involvement during the asymptomatic stage of HIV infection, the trajectory for HIV is such that the CP will eventually become an important, vital partner in care. Discussion about the role a CP might play should be presented along with an HIV+ diagnosis, preferably with the likely CP present. While the CP is typically a family member or relational partner, the patient should be provided with a list of issues to consider when selecting a CP. The selected CP should also receive an orientation in which he or she is helped to assess his or her ability to care: demands on time from work and other family, physical ability, knowledge, and emotional stability and strength. Warnings about "ownership" of patient illness should be explicitly presented to potential CPs, and assistance provided with constructing a support system of appropriate community agencies, support groups, family and friends which can be relied on for assistance by the CP.

Such formalized discussion of the CP role in patient illness would serve a number of functions. First, it would provide an early impetus for patients and CPs to discuss appropriate CP involvement. It was clear in the present study that patients and CPs had different expectations about what was appropriate and such a discussion would allow clearer examination of differences. The majority of CPs studied felt that discussion of such issues as increased involvement with medical staff produced the same effects as talking about living wills and power of attorney; it sapped hope from the patient by signifying an acceptance of his eventual death. Ideally, however, discussing the involvement of a CP early on can be cast as an important survival mechanism for the patient. One might even use the metaphor of the patient entering a marathon-- he's going to want a coach to make him work hard and effectively. Thus, CPs can gain access without having the patient pay the high cost of lost hope.

A second benefit of formal involvement discussion is that both the patient and CP can grasp the situation more realistically. Both can explore the meaning of an illness partnership and identify how the sharing of illness responsibilities will proceed. It might even prove useful to construct a formal contract which clearly establishes how responsibilities will be initially distributed and how they should shift given specific illness developments.

Finally, such a discussion can provide a more sound footing for the CP in negotiating interaction space with the medical staff. Ideally, the discussion between the CP and patient should be facilitated by someone with case management experience in order to insure a realistic examination of responsibility sharing. This might be a social worker, nurse, or the attending physician. The advantages of the latter are obvious, in that he or she is the third member of the care triad. The outcome of such a facilitated discussion would be clear acknowledgement of the nature and scope of the CPs involvement over the course of the illness. However, even if an agreement is arrived at by the CP and patient through the assistance of some third party, formal recognition of the CP can be translated into more full and open communication with the physician and allied medical staff.

Formal recognition of the CP would provide him or her with specific rights to information, especially in the context of inquiring about specific questions he or she has regarding the patient's health status and/or treatment regimen. Of course, such information sharing might impinge on the patient's freedom, and thus care is required. Unfortunately, discussion of this issue can be complicated by the existence of denial mechanisms which may be advantageous for the patient during early infection. The ethics of a physician sharing information with the CP which is not acknowledged by the patient, or the discovery of denial through realizing areas where the patient is actively filtering information, needs to be addressed.

CP Medical Staff Interaction

CPs appeared to have rather simple desires regarding medical staff interaction. CPs wanted to be assured that their partner was receiving quality care, both in terms of medical regimens and personal treatment. CPs especially desired the absence of behaviors which produce a stigmatized status for the patient (i.e., excessive gowning, fears of contact, refusal to enter the patient's room). CPs also wanted their involvement to be acknowledged by medical staff and treated with respect in an attitude of cooperation. CPs wanted to be informed about developments in the patient's case and the probable effectiveness of various treatments provided the patient. CPs willingly accepted that medical staff are busy and may not always be able to speak with them. What they desired, however, is that the staff exhibit a willingness to contact CPs within a reasonable time frame. While empathy was valued on the part of the attending physician, CPs appeared willing to rely on others (nurses in particular but also family and friends) for this so long as the physician was capable of providing competent care. Throughout the illness situation, the major concerns and focus of the CP were on the patient and his or her treatment by the medical staff. Given this rather straightforward list of desires, it would appear fairly easy for the medical staff to adequately incorporate the CP without excessive additional demands on their time.

The existence of an ever-changing care team for lower-income patients is of potential concern. Relying as they do on public assistance for financing medical care, such patients are not afforded the stability of a single physician who engineers his or her care for the duration of HIV infection. Low-income patients typically see interns or residents who are assigned to a specific ward for a limited amount of time before moving on to other assignments. While HIV infection may best be treated by younger physicians with more recent training and expertise, regular changes of attending physicians interrupts the relational development of the care triad, and requires new role negotiations. While such transitions were reportedly smooth in the current study, this practice should be more carefully examined in terms of possible outcomes for patient care. In a follow-up conversation six months following the initial interview, One CP (#21) spoke about the lack of a consistent medical provider as her major frustration in communicating with medical staff about her son's illness. She reported having been told by a physician that he wasn't up on all the aspects of her son's case and that she should call the records department. This would appear to raise questions directly about the quality of patient care as well as causing information difficulties for the CP.

The disruption in continuity of care also means that the new physician is reliant on the patient's medical records for information about his or her case. Unfortunately, such records do not translate into a full knowledge of the patient's experience with HIV. In this regard, the presence of a knowledgeable, informed CP who can assist in filling the physician in about major events, experiences and emotions encountered by the patient to date may be especially helpful. While stable care teams with full knowledge of the patient's case are most desirable, achieving this would appear unlikely given the current state of public health care financing.

CP Use of Support Groups

A last major implication relates to the limited use of support groups by CPs. Such groups were generally perceived as being simply a place where people go to gripe and complain, or as being too passive in assistance. In the latter regard, one lower-income CP reported a willingness to participate only if the group met in the homes of different members to help with maintenance issues faced by the CP. While clearly contingent on geographic limitations, adding this activity component might be a valuable addition to traditional support group activity for all CPs as well as those in lower income brackets.

LIMITATIONS AND DIRECTIONS FOR FUTURE RESEARCH

The study's results are subject to a number of important limitations. The two most substantial are limited sample size and the one-sided nature of the interviews.

In total, 23 complete interviews served as the basis for the results. While grounded theory makes no requisite statement regarding adequate sample size, it will be necessary to test the current findings on a wider sample. Such efforts will again be subject to the laborious data collection process necessary for the investigation of the care partnering phenomenon. Although triangulation of methods has gained some ascendency in scholarly research, any study aimed at testing or expanding the present findings will have to rely substantially on qualitative methodology. The complex phenomenon of the illness situation cannot easily be reduced to standardized quantification. Thus, gathering rich interview data is necessary to uncover the complex interaction components which drive the triad of patient, physician and CP.

Probably of greater value than simply repeating the present study with a larger sample would be the application of the findings in a wider theoretical frame (Strauss & Corbin, 1990; Strauss, 1986). This again refers to testing the findings in contexts which may falsify them and thus improve the present base of knowledge by specifying the exact realm of application. Thus, future research will need to explore more specifically how the care partnering process develops and proceeds in different populations (e.g., children) and different illnesses (e.g., Alzheimer's, cancer). Care partners for an ill child typically have automatic inclusion in the care process given their clear responsibilities for the child's welfare. Other illnesses such as Alzheimer's are less centered in societal fringe groups and less subject to transmission fears and patient stigma. Thus, it might be predicted that negotiation strategies are obviated in the care of a child and acceptance more easily accomplished for the Alzheimer's CP due to reduced stigma and attributions of patient responsibility for his or her illness.

The second major limitation of the current study is the sole reliance on CPs for data regarding their own involvement. To fully understand the process through which CPs come to operate in the illness situation, it will be necessary to interview the other members of the triad. Since acceptance of the CPs' level of involvement is seen as a negotiated arrangement, the expectations and perceptions of physicians and patients must be examined. With such data, it would be possible to more completely define and demonstrate the negotiation and involvement processes.

In particular, it is important to investigate medical staff perceptions of the self-presentation skills CPs spoke of using to facilitate harmonious, cooperative interaction. Additionally, specific attention needs to be paid to physicians' willingness to include CPs in the care process.

Patient perceptions about the inclusion of a CP would also prove invaluable. The expectations of the patient with regard to appropriate CP involvement is expected to be the primary determinant of the nature and degree of involvement actually achieved by the CP. Additionally, the extent to which the patient relies on the CP for reconstructing discussions with the medical staff could be examined.

The third limitation is connected with the first, in that limited sample size did not afford an adequate test of the scales created to test medical staff empathy, availability, and clarity and completeness of information exchange, as well as CP perceptions of illness-related knowledge, adequacy of care skills, and perceptions of control in the illness situation. Given the promising utility of these scales in future research, a wider sample allowing full statistical analysis of scale quality is necessary.

Finally, the current sample contained very few cases with significant and burdensome home care of the patient. Thus, while one of the main aims of the study was to investigate CP interactions with medical staff during times of home-based care, it was not adequately tested here. To some extent, this lack of demanding patient care outside the hospital context can be linked to the low levels of perceived stress and depression found here. However, the potential for such negative outcomes remains much greater in the context of high-demand home care where CP support systems necessarily requires greater coordination of a looser network of services from community agencies, family and friends. Given the greater risk of system collapse at home and the significant impact of such collapse on CP physical and mental health, the investigation of home care is mandated. While care partnering need not necessarily be burdensome (indeed, those interviewed here spoke of the values gained through the illness struggle with the patient), it is likely that some negative outcomes will accrue. Whether the situation is primarily positive or negative for the CP will be largely dependent on the ability of researchers and practitioners in the variety of health-related fields to fully understand the illness situation and provide instruction to all the key players (medical staff, patient and CP) about healthy styles of interaction and cooperation.

It has been argued in this study that inclusion of the CP in a care triad could serve to counteract patient information filtering. This filtering may take place as a result of conscious choice by the patient, as well as simple loss as the information is processed and interpreted by the patient. It would be important to examine the full extent of information loss which accrues when the patient is the sole information link between the medical staff and the CP. This could be accomplished by gaining permission to record a patient's office visit and then follow up with the CP two days later to inquire about what information he or she knows regarding the patient's recent office visit. Comparisons of the recall might be susceptible to forgetting by the CP, but would be an indicator of the degree of information which the patient relays to the CP.

The impact of constantly changing care providers to low-income patients on Medicaid is another area requiring further research. In such a situation, it is the physician role in the care triad that becomes more problematic than the CP role. Patients may see a different physician every time he or she goes to the hospital or clinic which clearly hampers the development of even the traditional dyadic relationship between physician and patient, let alone expanding to incorporate the CP. While several CPs in the current study report having stable care for six months to one year prior to a change, others reported a higher turnover rate. The lesser frequency of medical appointments during asymptomatic HIV infection should serve only to exacerbate the instability of care providers assigned the patient.

CONCLUSION

The current research provides a strong foundation for the construction a complete theory of formal CP involvement in illness. As the suggested research above is completed, the theory can be refined and examined for validity across the spectrum of chronic/terminal illnesses to which the majority of Americans now succumb. What is required from researchers and practitioners alike is continued effort on mapping out the practical value for patient, physician and CP alike of widening our focus from its current narrow concern with the patient-physician dyad. We can continue to exclude the CPs--leaving them to toil in uncertainty and making do the best they can, while physicians also fall under the strain of patient care--or we can reach out in a more humane fashion, to make the death of patients less harrowing and more gentle.

BIBLIOGRAPHY

BIBLIOGRAPHY

Adelman, M (1989). Social support and AIDS. AIDS Public & Policy Journal, 4(1), 31-40.

Albrecht, T.L. & Adelman, M.B. (1987). Communicating social support. Beverly Hills, CA: Sage.

Altman, L.K. (1990). Advances in treatment change face of AIDS. The New York Times, National Ed., June 12, C1.

Arntson P. & Droge, D. (1987). Social support in self-help groups: The role of communication in enabling perceptions of controls. In T. Albrecht & M. Adelman's (Eds.) Communicating social support. Beverly Hills, CA: Sage.

Aronson, M.K., Levin, G. & Lipkowitz, R. (1984). A community-based family/patient group program for Alzheimer's disease. The Gerontologist, 24(4), 339-342.

Barbarin, O.A. & Chesler, M.A. (1984). Relationships with the medical staff and aspects of satisfaction with care expressed by parents of children with cancer. Journal of Community Health, 9(4), 1984.

Beck, A.T., Ward, C.H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. Archives of General Psychiatry, 4, pp. 53-63.

Black, L., Hersher, L., & Steinschneider, A. (1978). Impact of the Apnea Monitor on family life. Pediatrics, 62(5), 681-685.

Blumenfield, M., Smith, P.J., Milazzo, P.J., Seropian, S., & Wormser, G.P. (1987). Survey of attitudes of nurses working with AIDS patients. General Hospital Psychiatry, 9(1), 58-63.

Bogdan, R., Brown, M.A., & Foster, S.B. (1982). Be honest but not cruel: Staff/parent communication on a neonatal unit. Human Organization, 41(1), 6-16.

Brandt, A. (1986). AIDS: From social history to social policy. Law, Medicine and Health Care, 14(5-6), 231-242.

Breu, C. & Dracup, K. (1978). Families of critically ill patients. American Journal of Nursing, 51-53.

Brody, E.M. (1985). Parent care as normative family stress. The Gerontologist, 25(1), 19-29.

Brody, S.J., Poulschock, S.W., & Masciocchi, C.F. (1978). The family caring unit: A major consideration in the long-term support system. The Gerontologist, 18(6), 556-561.

Bunn, T.A. & Clarke, A.M. (1979). Crisis intervention: An experimental study of the effects of a brief period of counselling on the anxiety of relatives of seriously injured or ill hospital patients. British Journal of Medical Psychology, 52, 191-195.

Callahan, D. (1990). What kind of life? New York: Simon & Schuster Inc.

Cassell, E. & Siegler, M. (Eds.) Changing values in medicine. New York: University Publications of America, Inc.

Charmaz, K. (1990). "Discovering" chronic illness: Using grounded theory. Social Science & Medicine, 30(11), 1161-1172

Cluff, L. (1981). Chronic disease, function and quality of care. Journal of Chronic Disease, 34, 299-304.

Corbin, J. M. & Strauss, A. (1988). Unending work and care. San Francisco: Jossey-Bass Publishers.

Crossman, L., London, C. & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. The Gerontologist, 21(5), 464-470.

Culhane, M (1990). Why are health care costs so high? Michigan Programmers Insurance Agency: Spring Newsletter, 1-2.

Davies, M. (1988). The role of general practitioners in supporting carers of the elderly in the community. Journal of the Royal College of General Practitioners, 38(310), 194-195.

Dzau, R.E., & Boehme, A.R. (1978). Stroke rehabilitation: A family-team education program. Archives of Physiological and Medical Rehabilitation, 59, 236-239.

Eckholm, E. (1989). AIDS virus carriers facing dim future. The New York Times, National Ed., March 13, 23.

Ellis, B.H., Miller, K.I., & Given, C.W. (1989). Caregivers in home health care situations: Measurement and relations among critical concepts. Health Communication, 1(4), 207-226.

Egan, T. (1990). Oregon lists illnesses by priority to see who gets Medicaid care. New York Times, National Edition, May 3, A1.

Evashwick, C.J. (1987). Definition of the continuum of care. In C.J. Evashwick & L.J. Weiss's (Eds.) Managing the continuum of care. Rockville, MD: Aspen Publishers, Inc., 295-310.

Field, D. & Howells, K. (1986). Medical students' self-reported worries about aspects of death and dying. Death studies, 10, 147-154.

Finlayson, A. (1976). Social networks as coping resources: Lay help and consultation patterns used by women in husbands' post-infarction career. Social Science and Medicine, 10, 97-103.

Fiore, J., Becker, J., & Coppel, D.B. (1983). Social network interactions: A buffer or a stress? American Journal of Community Psychology, 11, 423-439.

Fisher, L.R. & Eustis, N.N. (1988). DRGS and family care for the elderly: A case study. The Gerontologist, 28(3), 383-389.

Friedland, G.H. (1990). Early treatment for HIV: The time has come. The New England Journal of Medicine, 322(14), 1000-1002.

Gerbert, B., Maguire, B., Badner, V., Altman, D., & Stone, G. (1989). Fear of AIDS: Issues for Health Professional Education. AIDS Education and Prevention, 1(1), 39-52.

Gelman, D., Hager, M., & Quade, V. (1989). The brain killer. Newsweek, December 18, 54-56.

Getzel, G.S (1981). Social work with family caregivers. Social Casework, 61, 201-209.

Given, C.W, Stommel, M., Collins, C., & King, S. (1988). Development of scales to assess the reactions of caregivers of patients with physical impairments and Alzheimer's disease. Unpublished manuscript, Michigan State University, Department of Family Practice, East Lansing.

Glaser, B.G. & Strauss, A.L. (1967). _The discovery of grounded theory_. Chicago, IL: Aldine Publishing Company.

Glaser, B.G. (1978). _Advances in the methodology of grounded theory: Theoretical sensitivity_. Mill Valley, CA: The Sociology Press.

Glenn, M.L. (1987). _Collaborative health care: A family-oriented model_. New York: Praeger Publishers.

Goffman, E. (1963). _Stigma: Notes on the management of spoiled identity_. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Goldstein, V. Regnery, G., & Wellin, E. (1981). Caretaker role fatigue. _Nursing Outlook_, _29_(1), 24-30.

Gottlieb, B.H. (1981). _Social networks and social support_. Beverly Hills, CA: Sage Publications.

Govoni, L.A. (1988). Psychosocial issues of AIDS in nursing care of homosexual men and their significant others. _Nursing Clinics of North America_, _23_(4), 749-765.

Grad, J. & Sainsbury, P. (1968). The effects that patients have on their families in a community care and a control psychiatric service--A two year follow-up. British Journal of Psychiatry, 114, 265-278.

Granovetter, M. (1973). The strength of weak ties. American Journal of Sociology, 78, 1360-1380.

Greif, G.L. & Porembski, E. (1988). AIDS and significant others: Findings from a preliminary study. Health and Social Work, 13(4), 259-265.

Grieco, A.J., & Kowalski, W. (1987). The "care partner". In L. Bernstein, A. Grieco, & M. Dete's (Eds). Primary care in the home. Philadelphia: J.B. Lippincott Company.

Gulick, P. (1990), Internal Medicine Specialist, Michigan State University, East Lansing, Michigan. Personal communication.

Hampe, S.K. (1973). Needs and concerns of the grieving spouse in a hospital setting. Iowa City, University of Iowa. (Unpublished masters thesis).

Hampe, S.K. (1975). Needs of the grieving spouse in a hospital setting. Nursing Research, 24(2), 113-120.

Hawker, R. (1983). Interaction between nurses and patient's relatives. Unpublished PhD thesis, Exeter University, Devon, U.K.

Haley, W.E., Levine, E.G., Brown, S.L., Berry, J.W., & Hughes, G.H. (1987). Psychological, social and health consequences of caring for a relative with senile dementia. Journal of American Geriatrics Society, 35, 405-411.

Hilts, P.J. (1990). New study says AIDS bias grows faster than disease. The New York Times, National Ed., June 17, 20.

Hobfoll, S. (1985). Limitations of social support in the stress process. In I.G. Sarason & B.R. Sarason's (Eds.) Social support: Theory, research and applications. Dordrecht, the Netherlands: Martinus Nijhoff, 51-72.

Hoffman, M.L. (1978). Empathy, its development and prosocial implications. In H.E. Howe, Jr. & C.B. Keasey's (Eds.) 1977 Nebraska Symposium on Motivation, Vol. 25, 169-217.

Hofling, C.K, & Lewis, J.M. (1980). _The family: Evaluation and treatment_. New York: Brunner/Mazel.

Hunter, J.E., & Gerbing, D.W. (1982). Unidimensional measurement, second order factor analysis, and causal models. _Research in Organizational Behavior_, _4_, 267-320.

Hurd, H. (1913). The hospital as a factor in modern society. _The Modern Hospital_, _1_, 33.

Katoff, L. (1989). _Living with AIDS: A guide to resources in New York City_. New York: Gay Men's Health Crisis, Inc.

Kazak, A.E., & Marvin, R.S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with handicapped children. _Family Relations_, _33_, 67-77.

Kazak, A.E., & Wilcox, B.L (1984). The structure and function of social support networks in families with handicapped children. _American Journal of Community Psychology_, _12_(6), 645-661.

Kelly, J.A., St. Lawrence, J.S., Smith, S., Hood, H.V., & Cook, D.J. (1987). Stigmatization of AIDS patients by physicians. American Journal of Public Health, 77(7), 789-791.

Klein, R.F., Dean, A., & Bogdonoff, M.D. (1967). The impact of illness upon the spouse. Journal of Chronic Disorder, 20, 241-248.

Kleinman, A. (1988). The illness narratives: Suffering, healing, & the human condition. New York: Basic Books, Inc.

Knaffl, K.A., & Deatrick, J.A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. Research in Nursing & Health, 9, 215-222.

Kosecoff, J., Kahn, K.L., Rogers, W.H., Reinisch, E.J., Sherwood, M.J., Rubenstein, L.V., Draper, D., Roth, C.P., Chew, C., & Brook, R.H. (1990). Prospective payment system and impairment at discharge: The 'quicker and sicker' story revisited. The Journal of the American Medical Association, 264(15), 1980-1983.

Krant, M.J., & Johnston, L. (1978). Family members' perceptions of communications in late stage cancer. International Journal of Psychiatry in Medicine, 8(2), 203-216.

Lazarus, R.S. (1974). Cognitive and coping processes in emotion. In B. Weiner (Ed.) Cognitive views of human motivation. New York: Academic Press.

LeShan, L., Bowers, M. & Jackson, E. (1969). Counseling the dying. New York: Nelson & Sons.

Leventhal, H., Nerenz, D.R., & Steele, D.J. (1987). Illness representations and coping with health threats. In A. Baum, S. Taylor, & J. Singer's (Eds.) Handbook of psychology and health: Social psychological aspects of health, Volume IV.

Ley, P. (1982). Satisfaction, compliance and communication. British Journal of Clinical Psychology, 21, 241-54.

Lief, H.I, & Fox, R.C. (1963). Training for "detached concern" in medical students. In H.I. Lief, V.F. Lief, and N.R. Lief (Eds.) The psychological basis of medical practice. New York: Harper & Row.

Linsk, N.L., Osterbusch, S.E., Simon-Rusinowitz, L. & Keigher, S.M. (1988). Community agency support of family caregiving. Health and social work, (Summer), 209-218.

Litman, T.J. (1974). The family as a basic unit in health and medical care: A social-behavioral overview. Social Science and Medicine, 8, 495-519.

Longo, D.C., & Bond, L. (1984). Families of the handicapped child: Research and practice. Family Relations, 33, 57-65.

Mayo, L. (1975). Problem and challenge. Guides to action on chronic illness, New York, National Health Council, 9-13, 35, 55.

Mechanic, J.D. (1977). Illness behavior, social adaptation, and medical models. Journal of Nervous and Mental Disease, 165, 79-89.

Miller, K.I., Ellis, B.H., Zook, E.G., & Lyles, J.S. (1990). An integrated model of communication, stress and burnout in the workplace. Communication Research, 17(3), 300-326.

Miller, K.I., Stiff, J.B., & Hartman-Ellis, B. (1988). Communication and empathy as precursors to burnout among human service workers. Communication Monographs, 55(3), 250-265.

Mishel, M.H. (1984). Perceived uncertainty and stress in illness. Research in Nursing & Health, 7, 1632-171.

Monette, P. (1988). Borrowed time. New York: Harcourt Brace Jovanovich, Publishers.

Monsen, R. (1986). Phases in the caring relationship: From adversary to ally to coordinator. American Journal of Maternal Child Nursing, 11, 316-318.

National Center for Health Statistics (1972). Home care for persons 55 and over, U.S., July 1966-June 1968. Vital and health statistics, Series No. 10, No.73, DHEW Publication HSM72-1062.

Nerenz, D.R. & Howard, L. (1983). Self-regulation theory in chronic illness. In T.G. Burish & L.A. Bradley's (Eds.) Coping with chronic disease: Research and applications. New York: Academic Press, 13-38.

New York Times, National Edition, (1991). U.S. reports AIDS deaths exceed 100,000, January 25, A18.

Nichols, K.A. (1987). Chronic physical disorder in adults. In J. Orford (Ed.) Treating the disorder, treating the family. Baltimore, MD: The Johns Hopkins University Press.

Nichols, K.A. (1985). Psychological care by nurses, paramedical and medical staff: Essential developments for the general hospitals. British Journal of Medical Psychology, 58, 231-240.

Nichols, K.A. (1984). Psychological care in physical illness. Philadelphia: The Charles Press, Publishers.

Orford, J., O'Reilly, P., Goonatil, A. (1987). Expressed emotion and perceived family interaction in the key relatives of elderly patients with dementia. Psychological Medicine, 17(4), 963-970.

Parsons, T. & Fox, R. (1952). Illness, therapy and the modern urban family. Journal of Social Issues, 8, 31-44.

Peabody, B. (1986). The screaming room. Stanford, CT: Oak Tree Publishing.

Peck, R.L. (1983). Home caregivers: Toward a new partnership with doctors. Geriatrics, Sept., 38(9), 124-125,128.

Pomerance, L.M. & Shields, J.J. (1989). Factors associated with hospital workers' reactions to the treatment of persons with AIDS. AIDS Education and Prevention, 1(3), 184-193.

Quist, J.C. (1989). Helping a caregiver keep up the good work. RN, 52(4), 87-91.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurements, 1, 385-401.

Redding, R. (1980). Doctors, dyscommunications, and death. Death Education, 8, 371-385.

Rew, L., Fields, S., LeVee, L.C., Russell, M.C., Leake, P.Y. (1987). AFFIRM: A nursing model to promote role mastery in family caregivers. Family Community Health, 9(4), 52-64.

Rice, D.P., & Hodgson, T.A. (1978). Scope and impact of chronic disease in the United States. National Arthritis Advisory Board Forum on Public Policy and Chronic Disease.

Rook, K. (1985). The functions of social bonds: Perspectives from research on social support, loneliness and social isolation. In I.G. Sarason & B.R. Sarason's (Eds.) Social support: Theory, research and applications. Dordrecht, the Netherlands: Martinus Nijhoff, 51-72.

Rosenthal, C.J., Marshall, V.W., MacPherson, A.S., & French, S.E. (1980). Nurses, patients and families. New York: Springer Publishing Company.

Sawa, R.J. (1985). Family dynamics for physicians: Guidelines to assessment and treatment. Lewiston, NY: The Edwin Mellen Press.

Schilling, R.F., Gilchrist, L.D., & Schinke, S.P. (1984). Coping and social support in families of developmentally disabled children. _Family Relations_, _33_, 47-54.

Siegel, K. (1986). AIDS: The social dimension. _Psychiatric Annals_, _16_(3), 168-172.

Siegler, M. (1979). The nature and limits of clinical medicine. In E. Cassell & M. Siegler's (Eds.) _Changing values in medicine_. New York: University Publications of America, Inc.

Silliman, R.A., & Sternberg, J. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. _The Gerontologist_, _28_(3), 377-382.

Silverman, A.G. & Brahce, C.I. (1979). "As parents grow older": An intervention model. _Journal of Gerontological Social Work_, _2_, 77-83.

Somers, A.M. (1971). Health Care in transition; directions for the future. _Chicago Hospital and Education Trust_.

Sontag, S. (1988). AIDS and its metaphor. New York Review, 35, 89-99.

Sontag, S. (1978). Illness as metaphor. New York: Vintage Books.

Speedling, E.J. (1982). Heart attack: The family response at home and in the hospital. New York: Methuen, Inc.

Steinmetz, S.K. (1981). Elder abuse. Aging, (Jan.-Feb.), 6-10.

Stiff, J.B. Dillard, J.P, Somera, L., Kim, H., & Sleight, C. (1988). Empathy, communication, and prosocial behavior. Communication Monographs, 55(2), 198-212.

Stone, R. (1987). Exploding the myths: Caregiving in America. Congressional Research Service.

Strauss, A.L (1975). Chronic illness and the quality of life. St. Louis: The C.V. Mosby Company.

Strauss, A.L. (1978). Negotiations. San Fransisco: Jossey-Bass Publishers.

Strauss, A. & Corbin, J.M. (1988). <u>Shaping a new health care system</u>. San Francisco: Jossey-Bass Publishers.

Strauss, A. & Corbin, J. (1990). <u>Basics of qualitative research: Ground theory procedures and techniques</u>. Newbury Park, CA: SAGE Publications.

Strauss, A.L., Corbin, J., Fagerhaugh, S., Glaser, B., Maines, D., Suczek, B. & Wiener, C.L. (1975). <u>Chronic illness and the quality of life</u>. St. Louis: The C.V. Mosby Company.

Strauss, A., Fagerhaugh, S., Suczek, B. & Wiener, C. (1986). <u>Social organization of medical work</u>. Chicago: The University of Chicago Press.

Teusink, J.P. & Mahler, S. (1984). Helping families cope with Alzheimer's disease. <u>Hospital and Community Psychiatry</u>, <u>35</u>(2), 152-156.

Thoits, P. (1986). Social support and psychological well-being: Theoretical possibilities. In I.G. Sarason & B.R. Sarason's (Eds.) <u>Social support: Theory, research and applications</u>. Dordrecht, the Netherlands: Martinus Nijhoff, 51-72.

Thompson, T.L. (1990). Patient health care: Issues in interpersonal communication. In E. Ray & L. Donohew (Eds.) _Communication and health_. Hillsdale, New Jersey: Lawrence Erlbaum Associates.

Thompson, E.H. & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. _Family Relations_ (July), 379-387.

Thompson, D.M & Haran, D. (1985). Living with an amputation -- the helper. _Social Science and Medicine_, _20_, 319-328.

Tiblier, K.B., Walker, G., & Rolland, J.S. (1988). Therapeutic issues when working with families of persons with AIDS. In E.B. Macklin's (Ed.) _AIDS and families_. New York: Haworth Press, 81-128.

Torrens, P. (1987). The continuum of care: The patient and family's view. In C. J. Evashwick & L.J. Weiss's (Eds.) _Managing the continuum of care_. Rockville, MD: Aspen Publishers, Inc., 295-310.

Trice, A.D. (1988). Post-traumatic stress syndrome-like symptoms among AIDS caregivers. _Psychological Reports_, _63_, 656-658.

Turk, D.C. (1979). Factors influencing the adaptive process with chronic illness. In A. Sarason & C.D. Spielberger (Eds.) Stress and anxiety, Vol. 6, Washington, D.C.: Halsted Press, 291-311.

Tyler, A., Harper, P.S., Davies, K., & Newcomb, R.G. (1983). Family break-down and stress in Huntington's Chorea. Journal of Biosociological Science, 15, 127-138.

Volberding, P.A., Lagakos, S.W., Koch, M.A., Pettinelli, C., Myers, M.W., Booth, D.K., Balfour, H.H., Reichman, R.C., Bartlett, J.A., Hirsch, M.S., Murphy, R.L., Hardy, W.D., Soeiro, R., Fischl, M.A., Bartlett, J.G., Merigan, T.C., Hyslop, N.E., Richman, D.D., Valentine, F.T., Corey, L., & AIDS Clinical Trials Group of the National Institute of Allergy and Infectious Diseases (1990). Zidovudine in asymptomatic human immunodeficiency virus infection. The New England Journal of Medicine, 322(14),

Walwork, E., & Ellison, P.H. (1984). Follow-up of families of neonates in whom life support was withdrawn. Clinical Pediatrics, 24(1), 14-20.

Watkins, J.D. (1988). Responding to the HIV epidemic: A national strategy. _American Psychologist_, _43_(11), 849-851.

Watson, W.H. (1976/77). The aging sick and the near dead: A study of some distinguishing characteristics and social effects. _Omega: Journal of Death and Dying_, _7_, 115-123.

Wright, K. & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. _Cancer Nursing_, 371-374.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. _The Gerontologist_, _20_(6), 649-655.