HIV INFORMAL CAREGIVING: ROLE RESPONSIBILITIES AND THE EFFECTS OF CASE MANAGEMENT

By

Nancy R. Reynolds

Submitted in Partial Fulfillment of the
Requirements for the Degree
Doctor of Philosophy in the
Graduate School of
The Ohio State University

The Ohio State University
1993

Dissertation Committee

Carole A. Anderson
Jennie Nickel
Pamela Salsberry
Angelo A. Alonzo

To the participants of this study
who allowed me the privilege
of entering their world

ACKNOWLEDGMENTS

I am deeply indebted to a number of individuals who have enabled this project to take form. There can be no words to adequately express the depth of my appreciation.

First, I wish to thank my dissertation committee members. Dean Carol Anderson, my advisor and chairperson, for her intelligent guidance and compassionate humanism that first inspired my interest in the social psychological problems surrounding AIDS. I would also like to thank my other dissertation committee members, Jennie Nickel and Pamela Salsberry for their high standards in the research process and for enabling me, by working with their project, to greatly expand my understanding of AIDS in the community. I would especially like to thank Angelo Alonzo, for generously sharing his expertise, for lending invaluable affirmative support, for nourishing my aspirations, and for gently urging me toward greater depths of critical thinking and understanding in work and self.

I would additionally like to thank the Agency for Health Care Policy and Research for funding the study and my professors and others at The Ohio State University College of Nursing who have created an environment that fosters scholarship and research efforts. I am also grateful to my peers, particularly Gayle Timmerman, whom I admire greatly, whose interest and support sustained me throughout my doctoral program.

I would also like to express my appreciation to my family, Steve, for encouraging me to pursue doctoral study, and Cory and Elizabeth for constantly demonstrating enthusiasm and pride in my academic pursuits. I know I will never fully know the measure of their sacrifice which facilitated this endeavor.

Finally, I would like to thank the participants of this study who so graciously shared of their time and of themselves. My world view has been indelibly transformed by their experiences and it is my great hope that I have represented their experiences in a way that can bring meaningful understanding to persons concerned with HIV/AIDS health care delivery.

VITA

March 3, [redacted]	Born - Cleveland, Ohio
1977	B.S.N., The University of Michigan, Ann Arbor, Michigan
1987	M.S., Community Nursing, Wright State University, Dayton, OH

PUBLICATIONS

Reynolds, N.R., Timmerman, G.M., Anderson, J., & Stevenson, J.S. (1992). Meta-analysis with descriptive research. Research in Nursing and Health, 15, 467-475.

Salsberry, P.J., Nickel, J.T., O'Connell, M., Reynolds, N.R., Brady, D.L., & Bentz, P.R. (1993). Home health care services for AIDS patients: One community's response. Journal of Public Health Nursing, 10, 39-53.

Kirchhoff, K.T., Pugh, E., Calame, R.M., & Reynolds, N. (1993). Nurses' beliefs and attitudes toward visiting in adult critical care settings. American Journal of Critical Care, 2, 238-246.

FIELDS OF STUDY

Major Fields:	Nursing AIDS Caregivers, Stress, Community, Social Psychology

TABLE OF CONTENTS

LIST OF TABLES

FIGURES

CHAPTER I

INTRODUCTION TO STUDY

Over the last decade, the care strategies for persons infected with the Human Immunodeficiency Virus (HIV) have changed. As the treatments for HIV infection and the opportunistic illnesses characteristic of AIDS have improved, HIV has essentially come to be regarded as a chronic illness and the focus of care has turned to long-term care in nonhospital, community settings. Although there is now general agreement that HIV/AIDS care should be community based, there are a variety of difficulties particular to HIV community health care. These difficulties stem in part from: (1) the complex clinical demands of AIDS-related opportunistic infections and diseases; (2) the lack of essential or poorly organized community services; and (3) the stigma associated with AIDS (Layzell & McCarthy, 1992).

Case management has been suggested as a possible solution to the problem of coordinating care in the community. Informal caregivers have also been identified as a central component of effective community care. Although informal caregivers play a crucial role in the delivery of a variety of services/care that enable the patient to remain at home, research has demonstrated that when an illness is long and extended, informal care is typically not given without considerable stress and cost to the caregiver's health and well-being (Baumgarten, 1989; Maes, Vingerhoets, & Van Heck, 1987). Thus, providing informal care has implications for the health and well-being of the informal caregiver. It has additional implications for the well-being of the patient because HIV patients may find that when their needs are the greatest, they have exhausted their informal resources for assistance. This may place them at high risk for unmet needs or necessitate placement in an extended care facility.

To date there is relatively little known about HIV informal caregiver role stress. Most of the informal caregiver research has focused upon the informal caregivers of the elderly or persons with Alzheimer's disease. While much of the theoretical orientation that has guided prior informal caregiver research can be applied to HIV caregivers, what has been learned elsewhere does not fully apply to this group (Pearlin, Semple, and Turner, 1988). Certain features of the stress process impinge similarly on caregivers of different populations, yet given the extraordinary demands and stigma associated with HIV/AIDS, it is inferred that HIV informal caregiver role-related stress has unique dimensions.

Although there is little information available regarding the HIV informal caregiver role, there is even less information available regarding how informal caregiving intersects with formal care strategies. While case management is a service delivery intervention that has been recommended for home-based HIV patients and ongoing research is assessing the effectiveness of case management for HIV patients, data concerning its effects on the informal caregivers of HIV patients are not available.

PROBLEM STATEMENT

Informal caregivers play a vital role in providing home care to persons with HIV infection and are at risk for stress-related outcomes (altered health/well-being), yet little research is available regarding the HIV informal caregiver role over time or how the informal caregivers are affected by case management strategies.

PURPOSE

The purpose of this study is to enlarge upon an understanding of HIV informal caregivers. The specific aims of this study are:

1) To explore the role responsibilities of HIV informal caregivers over the course of HIV illness.
2) To assess the impact of case management on HIV informal caregiver's health/well-being and satisfaction with formal home care/community services.

BACKGROUND AND SIGNIFICANCE

The Human Immunodeficiency Virus

Since 1981, the HIV/AIDS epidemic has assumed major proportions. The human immunodeficiency virus is transmitted through sexual contact and parenteral routes. While significant progress has been made in the treatment of the disease, there is no known cure and predictions indicate that a vaccine will not be developed for HIV in the near future (Cohen, 1993). The most that can be expected of the current treatments, directed at associated opportunistic infections, is that they will extend life. This increases long-term care requirements. In the meantime, the number of cases of HIV/AIDS has grown to the point where in some cities it has taxed health care resources and posed an economic threat (Institute of Medicine, 1988).

Infection with the human immunodeficiency virus, HIV, results in a spectrum of subclinical and clinical manifestations ranging from asymptomatic infection to severe immunodeficiency (Smiley, 1988). HIV causes a progressive derangement of immune function of which AIDS is a late manifestation of that process. Presence of opportunistic infection, cancers, and a CD4+ T-lymphocyte count less than 200 are the primary criterion of the CDC diagnosis of AIDS (CDC, 1993). The emergence of opportunistic infections is a reflection of extreme deterioration in immune function. It is during this end-stage that persons infected with HIV experience severe declines in physical, intellectual, and self-care behavior (Martin, 1988; Redfield & Burke, 1988; Rothenberg, Woelfel, Stoneburner, Milberg, Parker, & Truman, 1987; Schietinger, 1986; Smiley, 1988). While the disease progresses slowly, typically over many years, following a diagnosis of AIDS, death usually occurs within 2-4 years.

A vast array of opportunistic diseases can develop in the individual with AIDS and cause profound physiologic impairment (Redfield & Burke, 1988; Smiley, 1988). Bacteria, fungal or viral infections (e.g., toxoplasmosis, cryptococcus neoformans) often infect the central nervous system and can lead to a variety of neurologic problems including hemiparesis, aphasia, lethargy, behavior and personality changes, seizures, and obtundation that can progress to coma. In the terminal stages of HIV infection, many individuals suffer from the AIDS dementia complex, a syndrome characterized by gradual loss of precision in both thought and motion (Redfield & Burke, 1988). Dysphagia, diarrhea, weight loss and abdominal pain are typical gastrointestinal disturbances that may be caused by intestinal infections such as MAI, candida albicans, herpes simplex virus, and cryptosporidium. Other common opportunistic diseases include such fungal infections as cryptococcosis (which frequently causes meningitis but can also damage other tissues, including the liver, bone, and skin) and histoplasmosis, which causes disseminated infection of the liver, bone marrow, and other tissues and is a frequent cause of chronic fevers. A common viral infection is cytomegalovirus, which is a cause of pneumonia, encephalitis, and blindness. A variety of other symptoms can be experienced as well. The pain that occurs in approximately 53% of patients with AIDS (Schofferman, 1988), is most often caused by headache due to lymphoma or direct infection of the brain with HIV or parasites; localized or diffuse lymphadenopathy; peripheral neuropathy or esophagitis. Other common signs and symptoms, related to Pneumocystis carinii pneumonia, Kaposi's sarcoma and other opportunistic infections or medications used to treat the infections are dyspnea, tachypnea, persistent cough, and pruritic dermatitis (Schofferman, 1988; Smiley, 1988).

In addition to the overwhelming physical debilitation, HIV/AIDS generally has profound psychosocial impact (Christ, Wiener, & Moynihan, 1986; Donlou, Wolcott, Gottlieb, & Landsverk, 1985; Flaskerud, 1987; Forstein, 1984; Schofferman, 1988). Schofferman (1988) observes that psychosocial issues are so complex that they often dominate the clinical picture of the person dying of AIDS. Awareness that the disease is terminal and knowledge concerning the potential for extreme debilitation are noted to be primary sources of emotional distress (Flaskerud, 1987; Schofferman, 1988; Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986). However, the psychological impact of HIV/AIDS on the individual appears to also be affected by feelings about the implied association of the illness with activities considered deviant by society and public fears of contagion (Donlou et al., 1985; Forstein, 1984). A number of scholars (e.g., Frierson, Lippman, & Johnson, 1987; Wolcott et al., 1986) have observed that stigmatization and avoidance are common public responses to persons with

HIV/AIDS and thus, the social networks of HIV/AIDS patients typically become more constricted.

HIV infected persons may also suffer psychological conflicts over continuing personal relationships especially if these have a sexual component (Flaskerud, 1987). Many persons with HIV/AIDS are already estranged from their families as result of conflicts and disapproval over their lifestyle. In other cases, patients have been abandoned by their families once they learn of the HIV/AIDS diagnosis. Persons with HIV/AIDS may also face a variety of problems in the area of employment, housing, and insurance. For example, some individuals have been fired from their jobs because of their employer's and co-worker's fears of contracting HIV/AIDS. Others have had to leave jobs because of permanent physical disability. In many cases health insurance is lost when the job is lost. In addition, some insurance companies have tried to avoid covering HIV/AIDS patients because of the high cost of care. As a result, many patients with AIDS are without financial security, personal and social resources, and health insurance.

Typically, the AIDS patient experiences multiple hospitalizations for treatment of acute opportunistic infections. Between acute episodes, the patient may be able to resume some normal activities and assume responsibility for self-care. However, persons with AIDS generally require more care over time. Repeated episodes of infection and other evidence of disease progression leads to physical disability and greater dependence on others for care. As the patient begins to deteriorate, complicated physical and neurologic changes often make it difficult for the person with AIDS to carry out even simple daily routine tasks (Martin, 1988; Schietinger, 1986).

Informal Caregivers

The Institute of Medicine (IOM) report, Confronting AIDS: Update 1988 outlines a model for HIV/AIDS care that is based on the principle that, to the greatest extent, care should be provided in community settings, rather than in hospitals, to make it more humane and cost-effective. The patient's partner, family, or friends may provide a significant amount of the care in the home, whether it is by helping persons providing formal home care services or taking sole responsibility for the person. Even when much of the physical caregiving is provided by professionals, the informal caregiver remains as a major source of emotional support (Grief & Porembski, 1988). However, such care may not be given without physical and emotional cost to the caregiver. The complex physical, psychological, and social needs of an HIV infected person present tremendous challenges to these caregivers.

A considerable amount of research concerning family caregivers has been completed during the past decade which suggests that the cost of providing emotional and physical support is far-reaching and diverse, causing a negative impact in numerous aspects of caregivers' lives. While a large amount of research has identified the factors that contribute to the altered health outcomes experienced by those who care for the elderly (Young & Kahana, 1987; Zarit, Reeves, & Bach-Peterson, 1980; Poulshock & Deimling, 1984) or individuals with chronic diseases such as Alzheimer's (Fiore, Becker, & Coppel, 1983; Pagel, Becker, & Coppel, 1985; Zarit & Zarit, 1982), there has been virtually no systematic investigation of the significant others who care for individuals with HIV/AIDS. In addition to the unusually heavy physical caregiving demands, family members may face a variety of issues which are particular to AIDS which may impact their role as caregivers such as complex treatment regimes that change over the course of the illness, expensive medications, and stigma.

Informal and Formal Caregiving

The formal and informal networks of care exist hand-in-hand in the dynamics of caring for patients. Thus, problems encountered by informal caregivers and their efforts to manage and cope with these problems cannot be viewed as being separate from the systems of formal supports that are available to them. The nature and range of informal caregiving activities and the psychological and physical toll they exact are, to a substantial measure, impacted by the availability of formal supports. The ways in which informal caregivers contend with patient care -- what they must attend to and what they can obtain assistance with is largely governed by the formal resources and services that are available (Pearlin, Semple, & Turner, 1988).

Case management is a service delivery strategy that has been recommended for home-based HIV patients (Presidential Commission, 1988). Previous research has demonstrated that it is a comprehensive, cost-effective means of providing care to other chronically ill populations (Carcagno & Kemper, 1988; Goerning, Wasylenki, Farkas, Lancee, & Ballantyne, 1988; Rapp & Chamberlin, 1985) and caregiver satisfaction is improved (Christianson, 1988; Greene, 1983). While ongoing research is testing the effectiveness of case management for HIV patients (Nickel & Salsberry, 1988), data concerning its impact on the informal caregivers of HIV patients is lacking.

Case management is an intervention strategy designed to ensure that the services provided in the home are appropriate for the client's needs. In concept, through constant contact with the patient, the patient's family/caregivers, and the service care providers, the case manager ensures that the client's needs - whether they are health care, psychologic, social, financial, or legal - are met appropriately. The case manager's functions include client identification and outreach, individual and family assessment and diagnosis, service planning and resource identification, linking clients to needed services, service implementation and coordination, monitoring service delivery, and client advocacy (Ryndes, 1989).

It can be reasoned that case management activities may likely decrease the likelihood of negative caregiver physical/emotional outcomes. By facilitating appropriate formal services offered to the patient, caregiver burden may be reduced and satisfaction with formal services improved. Furthermore, case managers may directly address informal caregiver concerns by providing instrumental, informational, and emotional support, thus buffering stress and reducing negative physical and emotional health outcomes (House, 1974; Maes, Vingerhoets, & Van Heck, 1987).

Summary

As the treatments for HIV infection and the opportunistic illnesses characteristic of AIDS have improved, AIDS has essentially become a chronic illness. Persons with HIV-related illnesses are living longer and it is increasingly recognized that many of the needs of HIV/AIDS patients are now better met in the care systems of the community than within the acute care orientation of the hospital care system. Informal caregivers are able to provide many of the needed services/care that enable the HIV/AIDS patient to remain at home, and as such, represent an important resource. Yet, providing such care may involve considerable stress and cost to the HIV/AIDS informal caregiver's health and well-being. This important source of support may thus become jeopardized when most critical to the HIV/AIDS patient.

Although it has been suggested that HIV/AIDS caregiver stress has unique dimensions, to date, there has been little systematic study of the stressful problems experienced by the informal caregivers of persons with HIV/AIDS. It is beneficial to understand what these stresses are and how caregivers manage to constrain their magnitude and intensity. Such information may be used by health care providers to plan and maximize care to persons with HIV/AIDS. There is additionally little information available regarding the interplay between formal and informal care. Given the extraordinary demands of the HIV/AIDS caregiving situation, it can be reasoned that the informal caregivers may experience especially high levels of depression, anxiety, and stress-related physical complaints. It is thus important to know how health care strategies such as case management impact the informal caregiver health/well-being outcomes. Case management is likely to improve caregiver health outcomes, but research is needed to support this proposition. Such information may be used by health care planners/policy makers in decision-making concerning home care for HIV infected persons. From a public policy standpoint, the overriding issue concerns options available for providing comprehensive, cost-effective care to persons, as well as minimizing or making more manageable the impact imposed by caring for someone with HIV-related illnesses in the home.

RESEARCH QUESTIONS/HYPOTHESES

One research question and two hypotheses are examined in this study.

Research Question

1. What are the role responsibilities of HIV/AIDS informal caregivers?

Hypotheses

1. The informal caregivers of HIV infected patients who receive the case managed home care will have better health/well-being than informal caregivers of HIV infected patients who receive the routine home care.

2. The informal caregivers of the case managed HIV infected patients will be more satisfied with formal health care services than informal caregivers of the routine home care HIV infected patients.

CHAPTER II

LITERATURE REVIEW

A growing body of research supports the contention that home care should figure prominently in plans to provide health care services to individuals with HIV/AIDS (McCormick, 1989). Initial studies suggest that patient satisfaction and quality of life are improved and the total cost of care is reduced when home care is emphasized in lieu of hospitalization (McCormick, 1989). In the home care setting, informal caregivers play a substantial role in providing care that enables the patient to remain at home, yet rendering such care is not without cost to the caregiver. Research has demonstrated that the demands of caregiving are often stressful, adversely affecting the physical and emotional health status of the caregiver (Biegel, Sales, & Schulz, 1991). This indicates that the welfare of the informal caregiver should be considered when formal home care strategies are initiated for HIV patients.

Case management is a home care intervention that is often recommended for HIV/AIDS patients, yet the existing literature does not demonstrate how HIV/AIDS informal caregivers are substantially effected by case management strategies. Furthermore, the factors that may contribute to HIV/AIDS caregiver distress have not yet been adequately delineated in a way to lend understanding to how formal services interact with informal caregiving stress (Pearlin & Turner, 1990; Raveis & Siegel, 1989).

This chapter provides an overview of the extant literature relevant to three content areas: Part I, the epidemiology and biopsychosocial dimensions of HIV/AIDS; Part II, informal caregiving; and Part III, case management.

Part I begins with a review of the epidemiology and biopsychosocial dimensions of HIV/AIDS to establish the nature and scope of the problem. A relatively extensive review is provided of both the biophysical and socioemotional dimensions of HIV/AIDS in order to establish a foundation for understanding how the caregiver role may interact with the patient's illness trajectory.

Part II provides background concerning informal caregiving including a broad overview of research, theory, and methods as well as a review of the existing research concerning HIV informal caregiving.

Part III reviews the case management literature including the origins of the strategy and research examining its effectiveness with different populations.

EPIDEMIOLOGY/ILLNESS COURSE

Etiology

The Acquired Immunodeficiency Syndrome (AIDS) is a syndrome of diseases resulting from deterioration of an individual's immune system that is believed to be caused by infection with the human immunodeficiency virus (HIV). HIV primarily infects a subset of human T lymphocytes which express the virus receptor, the CD4 antigen, on their surface. While the majority of human cells that express CD4 antigens are T4 lymphocytes, the cells of the monocytemacrophage family, EBV-transformed B cells, dendritic cells, and microglial cells also express a CD4 protein and are sometimes infected (Grady, 1992).

Replication within the CD4+ T lymphocyte eventually leads to its death (Grady, 1992; Merz, 1991). Replenishment of the CD4+ T lymphocytes does not occur, and consequently, the number of circulating CD4+ lymphocytes gradually declines. CD4+ T lymphocytes are the helper cells for various immunologic processes, and depletion leads to an immunologic imbalance that is reflected in the CD4+/CD8+ ratio, and clinical signs of immunocompromise. When the CD4+ T lymphocyte count falls to 400/uL, delayed-type hypersensitivity begins to wane, and partial anergy develops. Further depletion of the CD4+ T lymphocytes leads to complete anergy. Concomitantly, the risk of acquiring an opportunistic infection or AIDS-defining neoplasia increases markedly (Merz,1991).

Incidence and Prevalence

It is estimated that there are currently one million persons in the United States who are infected with the HIV virus (CDC, 1992a). From 1981 through December 1987, the first 50,000 AIDS cases were reported to the Centers for Disease Control (CDC, 1992a). By August 1989, 100,000 cases had been reported (CDC, 1992a). As of December 31, 1991, a total of 206,392 cases of acquired immunodeficiency syndrome as indicated per the revised (CDC, 1987a) uniform cases definition of AIDS, were reported to the CDC (CDC, 1992b). Of the total number of cases reported, there have been 133,232 deaths (CDC, 1992a). The CDC projects that by the end of 1993 the number of AIDS cases will be between 390,000 and 480,000 with 285,00 to 340,000 total AIDS-related deaths since 1981.

Population Groups at Risk for HIV Infection

The first cases of AIDS were identified in the middle of 1981 when several outbreaks of Pneumocystis carinii pneumonia and Kaposi's sarcoma in previously healthy young homosexual male men were reported to the CDC (CDC, 1981a, 1981b). Prior to these reports, these diseases usually were diagnosed only in persons with recognized causes of immune system compromise, such as rare genetic diseases, immunosuppressive treatments for organ transplants, and cancer chemotherapy (Needle, Leach, Graham-Tomasi, 1989). By the end of 1982, 738 cases of AIDS were reported and additional groups were represented among these cases including IV drug users, hemophiliacs, transfusion recipients, female sexual partners of men at risk for AIDS, and infants born to infected mothers (CDC, 1983). The numbers of AIDS cases as of October 1991, by sex, exposure category, and race/ethnicity are reported in Table 1.

Geographic Distribution

The distribution of reported AIDS cases by geographic region has also altered. Initially, AIDs was reported in major urban centers, particularly New York City and San Francisco. Today, although the majority of cases are still from those cities, the proportion of cases from the rest of the United States has increased substantially.

In 1991, (CDC, 1991) 19% of the total number of AIDS cases were reported in the New York City standard metropolitan statistical area (SMSA). Other SMSAs of varying sizes with 2% or more of the total number of AIDS cases were, Los Angeles (7%), San Francisco (6%), Houston (3%), Washington, D.C. (2.8%), Newark (2.7%), Chicago (2.4%), Miami (2.4%), Philadelphia (2.0%), and Atlanta (2.0%) (CDC, 1988b). Among the 10 metropolitan areas with the largest number of AIDS cases diagnosed in 1991, the area with the greatest percentage increase since 1990 was Miami

Table 1

AIDS cases by sex, exposure category, and race/ethnicity reported to the Centers for Disease Control through October 1991 (AIDS, 1992).

Category	White	Black	Hispanic	Other	Total
Male Homosexual/ Bisexual Contact	80,820 (76%)	19,783 (35%)	12,801 (40%)	1,082 (71%)	114,749 (59%)
History of IVDU: Women and Heterosexual Men	8,943 (8%)	22,076 (40%)	12,740 (40%)	110 (7%)	43,964 (22%)
History of IVDU: Male Homosexual/Bisexual	7,355 (7%)	3,478 (6%)	1,846 (6%)	66 (4%)	12,761 (7%)
Persons with Hemophilia	1,363 (1%)	126 (0%)	134 (0%)	26 (2%)	11,330 (6%)
Heterosexual Contacts	2,391 (2%)	6,743 (12%)	2,109 (7%)	56 (4%)	11,330 (6%)
Transfusion Recipients	2,946 (3%)	750 (1%)	459 (1%)	88 (6%)	4,253 (2%)
Other/Undetermined	2,590 (2%)	2,930 (5%)	1,657 (5%)	95 (6%)	7,322 (4%)
Adults, total	106,408 (100%)	55,886 (100%)	32,746 (100%)	1,523 (100%)	196,034 (100%)
Adult Men	101,156	45,224	27,545	1,382	175,725
Adult Women	5,252	10,662	4,201	141	20,309

(22.9%). Other metropolitan areas with large increases since 1990 were Philadelphia (19.2%), Chicago (11.3%), Newark (10.4%), Atlanta (7.9%), and San Francisco (7.3%).

The distribution of AIDS cases by selected risk factors varies geographically. For example, whereas by mid-1988, 63% of the total AIDS cases in the United States were related to gay/bisexual contact, only 58% of all AIDS cases in New York State had been classified as homosexual/ bisexual, compared to 92% of all cases in California. New York and, to a greater extent, New Jersey, report higher percentages of AIDS cases among IV drug users. In 1988, 48% of all AIDS cases in New Jersey were IV drug users; in New York, 33%; and in California, 2.5% (Needle, Leach, Graham-Tomasi, 1989).

During 1988-1991, the largest number of cases and the most rapid increase in cases among homosexual/bisexual men occurred in the South (CDC, 1992b). In contrast, in the Northeast, the annual number of diagnosed cases among homosexual/bisexual men remained relatively stable or decreased. While the number of AIDS cases among heterosexual men who are IDUs remained highest in the Northeast, the most rapid rate of increase occurred in the South. Cases among persons exposed to HIV through heterosexual contact increased in all regions, yet again, the largest number of such cases in 1991 and the most rapid increase in cases during 1988-1991 occurred among persons from the South (CDC, 1992b).

Racial and Ethnic Characteristics

While the numbers of AIDS related deaths are greatest for white males, in the United States, the AIDS epidemic has disproportionately affected black and Hispanic populations. Blacks represent 11.6% of the U.S. population and Hispanics represent 6.5% of the U.S. population (Curran, Jaffe, Hardy, Morgan, Selik, & Dondero, 1988), yet, among the first 100,000 reported cases, 27% of the adult cases occurred among blacks and 15% among Hispanics. Among the second 100,000 AIDS cases, these proportions increased to 31% and 17% among blacks and Hispanics, respectively (CDC, 1992a).

The high representation of AIDS among blacks and Hispanics is thought to be a result of the high prevalence of intravenous (IV) drug use among these populations in certain areas of the United States (Curran et al., 1988). In the adult population, as of October 1991, 40% of IV drug-use AIDS cases were black, 40% were Hispanic, and 19% were white (AIDS, 1992).

Age Distribution

Although cases have been reported for infants, adolescents, and older individuals, the AIDS epidemic has chiefly affected mostly young and middle-aged males and females. Of the reported cases of AIDS in 1991, 19% occurred in the 20-29 year old age group, 46% occurred in the 30-39 year old age group, and 23% occurred in the 40-49 year old age group (see Table 1).

Modes and Rates of Transmission of HIV Infection

Sexual Transmission. The most common mode of HIV transmission is sexual contact with an HIV-infected person. It can be spread from male to female, female to male, and male to male. Female-to-female transmission, although extremely rare, has been also been reported (Curran et al., 1988). Risk for HIV infection is thought to depend on a number of factors, including the number of sexual partners, the probability that a sexual partner is HIV-infected, the type of sexual activity, clinical status of the partner, and the presence of genital lesions in either partner (Fineberg, 1988; Moss, Osmond, Bacchetti, Cherman, Barre-Sinoussi, & Carlson, 1987). Infection can occur from a single sexual contact (Mann, 1988), however, the risk of acquiring HIV infection from a single sexual encounter with an infected person has not been established (Friedland & Klein, 1987).

While the high-risk groups have not changed over the course of the epidemic, the proportion of cases in these categories is changing over time. Overall, the proportion of reported AIDS cases occurring among homosexual/bisexual men has decreased, yet the number and proportion of AIDS cases associated with heterosexual transmission has been increasing steadily.

The percentage of homosexual/bisexual cases of AIDS decreased from 61% of the first 100,000 cases to 55% of the second 100,000 cases (CDC, 1992a). Sexual contact is the primary mode of transmission of HIV among gay or bisexual men. Anal intercourse, specifically receptive anal intercourse without use of condoms, has been demonstrated to be a major risk factor for HIV infection (Kingsley et al., 1987; Office of Technical Assistance [OTA], 1988). Seroprevalence among this group has ranged from 10% to 70% depending on geographical area (CDC, 1987b).

Since 1983, when the first evidence for heterosexual transmission was reported (CDC, 1983), there has been a steady increase in the number of persons with AIDS for whom the only risk factor was heterosexual contact with a person known to be HIV-infected or at risk for such infection. The number of cases of AIDS associated with heterosexual transmission increased from 5% of the first 100,000 cases to 7% of the second 100,000 cases (a 44% increase) (CDC, 1992a). Heterosexual transmission has occurred in heterosexual partners of HIV-seropositive IV drug users, female sex partners of HIV-infected bisexual men, sexual partners of infected hemophiliacs or persons infected through transfusion, clients of infected prostitutes, and the heterosexual partners of other infected individuals. The rates of heterosexual spread are highest among partners of IV drug users having unprotected sexual intercourse over extended periods (Curran et al., 1988). As of October, 1991, 11,330 cases of heterosexual AIDS with no other known risk factor had been reported (see Table 1).

Transmission Through Exposure to Blood or Blood Products. As of October, 1991, intravenous drug users accounted for 22% (N=43,964) of adult/adolescent AIDS cases (see Table 1). In addition, there were 12,761 cases of AIDS where 2 risk factors were present: male homosexual contact and IV drug use. It is estimated that there are 1.1 to 1.3 million IV drug users in the U.S. (Schuster, 1988). Overall, between 70% to 90% of IV drug users are thought to share injection equipment resulting in high risk for contracting and transmitting AIDS. Needle-sharing practices and seroprevalence rates vary by city. In the New York City area, the seroprevalence rate has ranged from 50% to 65%; in other areas other than the East Coast, the seroprevalence rate among IV drug users has been mainly below 5% (CDC, 1987b).

Infected intravenous drug users are the major bridge for heterosexual and perinatal transmission of HIV. About 75% of IV drug users are males (OTA, 1988). Most male IV drug users are heterosexual (Drucker, 1986) and most have their primary sexual relationship with women who are not IV drug users (Des Jarlais et al., 1984). Moreover, 51% of all women diagnosed with AIDS are IV drug users and 30% to 50% of female drug users have engaged in prostitution at some time in their drug-using histories (Drucker, 1986). The risk of contracting and transmitting AIDS among drug users depends on the number of people sharing needles, syringes, and other paraphernalia and the number of times equipment is shared with persons who are HIV-infected. There is also recent concern that crack users are engaging in sexual activity for money, thus increasing the possibility of contracting HIV infection and other STDs.

Early in the epidemic, it was demonstrated that HIV could be transmitted through infected blood or blood products from donors to transfusion recipients. Certain blood products, notably Factor VIII taken by hemophiliacs to prevent coagulation problems, could also be contaminated. To date, 3% of the adult/adolescent cases and 13% of the pediatric cases have occurred through blood transfusions and blood products (see Table 1).

For hemophiliac men in the U.S., seroprevalence rates ranging from 33% to 92% and 14% to 52% have been reported among those diagnosed with Hemophilia A and Hemophilia B respectively (CDC, 1987a). As of October, 1991, it was estimated that approximately 1,655 hemophiliacs were HIV-infected and that 5% to 20% of their spouses were also infected (see Table 1).

Laboratory workers and health care personnel who provide care to persons with HIV infection are considered to be at some risk because of their occupational exposure to infected blood, but the risk is low. Health-care workers who become HIV-infected, like persons in other occupations, do so through the primary modes of transmission: IV needle-sharing and sexual contact with infected persons. Three prospective studies (Gerberding, Bryant-LeBlanc, & Nelson, 1987; Henderson et al., 1986; Weiss et al., 1988) to assess the risk for U.S. health-care workers of acquiring HIV infection have reported a very low risk of developing HIV antibodies, even following needlestick injuries or through exposures to laboratory specimens or other body fluids from patients with HIV infection.

Perinatal Transmission. Perinatal transmission accounts nationwide for 84% of cases of HIV infection in prepubertal children less than 13 years old (N=2,839) (see Table 1). Infants born to mothers with HIV infection may become HIV-infected in 3 ways: (a) passage of the virus to the unborn baby through the placenta, (b) exposure to infected maternal blood and vagina fluids during labor and delivery, and (c) ingestion of breast milk containing the virus (Rogers, 1987). In 1988, it was estimated that in New York City, about 3% of women of reproductive age were infected with HIV (U.S. House of Representatives, 1988). An HIV-infected mother will transmit the virus to her infant in 20% to 60% of pregnancies (Watkins et al., 1988).

Unsubstantiated Transmission Sources. Other suspected modes of transmission, such as casual contact, insect bites, kissing, saliva, sweat, and toilet seats have not been shown to transmit HIV infection. There is additionally no evidence of household transmission. Studies involving over 400 family members of HIV-infected individuals have found no evidence of transmission to members of the household who were not sexually involved with the infected individual (Rogers, 1987). People living with persons with AIDS, sharing their bathrooms and eating utensils, and hugging and kissing them at frequent intervals have not developed AIDS as a result of this type of contact (Friedland et al., 1986).

Disease Progression/Manifestations

As destruction of CD4+ T lymphocytes by HIV progresses, HIV-infected persons usually proceed along a disease course ranging from acute infection to asymptomatic infection to constitutional symptoms to life-threatening opportunistic infections or cancers. Generally, the risk of developing CDC-defined AIDS (CDC, 1993) after infection increases over time. Among adults, progression to AIDS is usually very low in the first few years. It is estimated that it will usually take 12 years or more for an individual to progress from infection through AIDS (Institute of Medicine, 1988; Siegel & Krauss, 1991).

Although HIV disease can generally be expressed as a continuum that begins with acute infection and ends with AIDS-defining illnesses, not all persons progress clinically along a defined disease course. For example, some persons with acute HIV infection progress directly to an AIDS-defining opportunistic infection or malignancy without experiencing a latent or extended asymptomatic period. In other cases, HIV-infected persons may have CD4+ cell counts in the normal range, yet have subtle signs of HIV infection, such as oral hairy leukoplakia. Conversely, patients with low CD4+ cell counts (<200/mm3) might not present with clinical signs of HIV infection. In fact, in 1992, approximately 125,000 persons who did not have an AIDS-defining illness were estimated to have a CD4+ lymphocyte count <200 cells/uL (CDC, 1992a). The CDC thus expanded the AIDS surveillance case definition to include these persons and thus facilitate a more complete reporting of all persons with severe HIV-related immunosuppression and who are at the highest risk for developing serious illnesses or death (CDC, 1993). The definition of AIDS was previously revised in 1987 when the CDC changed the case definition for AIDS to include two AIDS-indicator diseases that were neither opportunistic infections or malignancies; HIV wasting and HIV encephalopathy (CDC, 1987a).

HIV infection begins when the virus enters the bloodstream and stimulates the immune system to develop antibodies. Antibodies to HIV usually develop within 3 months of infection, and by 6 months approximately 95% of infected persons can be expected to seroconvert. HIV antibodies are usually detectable by the enzyme-linked immunosorbent assay (ELISA) or the Western blot test. The initial acute infection with HIV is generally characterized by a mononucleosis-like syndrome, usually appearing 2 to 6 weeks after seroconversion. This syndrome, that presents with symptoms such as maculopapular rash, fever, myalgia, arthralgia, headache, diarrhea, and sore throat, may accompany seroconversion in as many as 50% to 90% of adults. A number of HIV-infected persons, may however, undergo asymptomatic seroconversion.

Months to years after HIV infection, generally following a latent period of asymptomatic disease of four years or more, many persons develop manifest clinical expressions linked to the virus, such as oral candidiasis (thrush), oral hairy leukoplakia, and constitutional symptoms such as sustained weight loss, fatigue, night sweats, and persistent diarrhea. These early manifestations do not meet the original or revised CDC definition of AIDS (CDC, 1993), but are regarded as clinical predictors of the likely progression to AIDS. AIDS usually develops within five years. As a syndrome, AIDS is characterized by a number of opportunistic infections, HIV wasting syndrome, HIV dementia, CD4+ lymphocyte count <200 cells/uL and neoplasms whose development represents the more severe end of the spectrum of HIV disease. The specific opportunistic infections are a function of the patient's degree of immunosuppression and history of exposures. Some of the more common organ/system manifestations are summarized below.

Respiratory Tract Manifestations. Approximately 49% of HIV infected persons present with Pneumocystis carinii pneumonia (CDC, 1991). Other less common causes of pneumonitis in HIV infected persons include cytomegalovirus, fungi including cryptococci, MAI and Kaposi's sarcoma. Individuals with respiratory involvement typically manifest a nonproductive cough and dyspnea and often require hospitalization for treatment.

Neurologic Manifestations. A variety of central nervous system complications are common in persons with AIDS and include: (1) opportunistic infections, such as toxoplasmosis encephalitis, cytomegalovirus encephalitis, and cryptococcal meningitis; (2) central nervous system tumors, such primary brain lymphoma, and; (3) HIV encephalopathy or AIDS dementia complex (ADC) (Grady, 1992). Findings suggest that the third group, found in up to two thirds of people with AIDS, is a direct result of HIV infection (McArthur, Palenicek, & Bowersox, 1988).

Neurologic manifestations may include headache, nausea, vomiting, photophobia, seizures, hemiparesis, aphasia, lethargy, blindness, ataxia, behavior and personality changes and changes in cognitive ability or cognitive impairment including, memory impairment, inability to concentrate, generalized confusion and obtundation that can progress to coma.

In addition to ADC, HIV may be responsible for other common neurologic complications in patients with AIDS, including peripheral neuropathy (with painful dysthesias and paresthesias) and vacuolar myelopathy (vacuolar degeneration of the spinal cord) (Price et al., 1988).

Ocular Manifestations. Studies have shown that between 40% and 90% of persons with AIDS have some ocular involvement. Ophthalmologic complications include: (1) primary retinal microvascular disease; (2) opportunistic infection (OI) of the eye and adnexa (especially CMV, HSV, and varicella-zoster virus); (3) neoplasms of the eye (Kaposi's sarcoma), and; (4) neurophthalmic abnormalities (such as those seen with ADC or OI of the central nervous system). Ocular changes may be accompanied by severe morbidity and in some cases blindness. Severe morbidity is most often associated with OIs of the eye, especially CMV retinitis. Cytomegalovirus retinitis usually presents as a reduction in visual acuity or visual fields. The commonest ocular abnormality is primary retinal microvascular disease, which is usually characterized by transitory cotton wool spots (Grady, 1992).

Gastrointestinal Manifestations. Gastrointestinal manifestations are common among HIV infected persons and can be severely disabling and debilitating. The entire GI tract is a major target for HIV disease. Clinical and pathologic changes have been found in the oral cavity, esophagus, stomach, liver, small and large intestines, and rectum. The scope of GI pathology is broad. In a given individual with HIV-related GI dysfunction, the etiology is likely to be multifactorial (Cuff, 1990) and may be caused by: (1) opportunistic pathogens, especially Candida, Cryptosporidium, CMV, Mycobacterium avium, M. isospora, and Microsporidium; (2) neoplasms (e.g., Kaposi's sarcoma and lymphomas); (3) adverse effects of medications; and (4) unknown causes (Grady, 1992). GI involvement may cause dysphagia, postprandial emesis, hematemesis, diarrhea (ranging from moderate to severe), weight loss, abdominal pain, malabsorption, and malnutrition.

Cardiac manifestations. A wide variety of cardiac abnormalities, with or without associated signs or symptoms, have been reported in people with AIDS. These abnormalities include ventricular dysfunction, neoplastic involvement, nonbacterial endocarditis, myocarditis, dilated cardiomyopathy, and pericardial effusion (Grady, 1992). Although the incidence of cardiac abnormalities may be as high as 73% (Nyamathi, 1989), cardiac disease has not played a major role in the clinical course of most HIV-infected patients. In fact, many of the abnormalities have only been found at autopsy or by invasive exploration (Acierno, 1989). AIDS-related heart disease is generally regarded as an end-stage manifestation of chronic disease in a dying patient. However, it has been suggested that cardiovascular problems may become more prominent in AIDS if the therapeutic efficacy for noncardiac disease continues to improve and prolong survival (Acierno, 1989; Coplan & Bruno, 1989).

Treatment of HIV Infection

A tremendous amount of scientific information about HIV, its structure, characteristics, life cycle, and pathogenesis has accumulated over the last decade. A variety of strategies for preventing, controlling or halting the damage done by HIV are being studied.

Development of a vaccine that elicits sufficient immunity to prevent infection on exposure is one line of research being completed that has high priority because of the global prevalence of HIV. There are, however, a number of obstacles to the development of an HIV vaccination including: the way HIV integrates into the cellular genome, hides inside the cell, and remains somewhat dormant; the diversity of various isolates of HIV; the lack of an adequate animal model for HIV disease; the lack of understanding of what constitutes protective immunity against HIV; the possibility that HIV transmission can occur via infected cells; and the numerous ethical difficulties in conducting phase II and III vaccine trials (Grady, 1992).

Another major strategy being studied is the use of anti-retroviral drugs or agents to eliminate or suppress HIV infection. Zidovudine is the primary antiretroviral drug that is approved and widely available for HIV-infected people. Zidovudine is a dideoxynucleoside analogue of thymidine (one of the building blocks of DNA). In the cell, zidovudine triphosphate competes with thymidine triphosphate as a substrate for DNA polymerase. In this way zidovudine inhibits viral reverse transcriptase and/or terminates DNA chain elongation (Grady, 1992). Research has indicated that Zidovudine prolongs survival and reduces morbidity. Originally zidovudine was approved only for people with advanced HIV infection. However, its use is now approved for all HIV-infected persons with fewer than 500 T4 cells/mm3. This change in indications approved by the Food and Drug administration occurred in March 1990 as a result of two studies showing that zidovudine delayed progression to AIDS or symptomatic disease in infected individuals who were either without symptoms (Volberding et al., 1990) or mildly symptomatic (Fischl et al., 1990). Although zidovudine can prolong lives and prevent adverse events in infected persons, it is also toxic and expensive. Major toxic effects are anemia and leukopenia, which are often severe enough to necessitate dose adjustment or cessation of the drug.

A third strategy under investigation is reconstitution or repair of the immune system damaged by HIV. Repair of the immune system can theoretically be accomplished by reconstitution of the system or by enhancement of existing immune components and responses (e.g., through transfusion of mature, competent, histocompatible lymphocytes or transplantation of bone marrow) (Lane, 1989). So far none of the agents evaluated for their ability to enhance the function of an infected person has demonstrated significant enhancement (Lane, 1989).

In addition to strategies for controlling or eliminating the virus and the immune damage it inflicts, considerable research has been aimed at developing treatment and prophylactic agents for opportunistic infections and other diseases that occur in patients with AIDS as a consequence of the severe immunosuppression. A number of successful therapies have been developed. For example, CMV retinitis has been effectively treated with intravenous ganciclovir. The drug has been reported to cause clinical improvement, disease stabilization, or slowing of disease progression (Holland et al., 1989; Jabs, Enger, & Bartlett, 1989).

Psychosocial Impact

While HIV infection has extreme physiological impact, it has profound psychosocial impact as well (Christ, Wiener, & Moynihan, 1986; Donlou, Wolcott, Gottlieb, & Landsverk, 1985; Flaskerud, 1987; Forstein, 1984;

Schofferman, 1988). Certain crisis points in the course of the disease typically precipitate intense anxiety, fear and depression (Flaskerund, 1992). Awareness that the disease is terminal and knowledge concerning the potential for extreme debilitation are noted to be primary sources of emotional distress (Flaskerud, 1987; Schofferman, 1988; Wolcott, Namir, Fawzy, Gottlieb, & Mitsuyasu, 1986). However, research and clinical literature (eg., Bennett, 1990; Brown & Powell-Cope, 1991; Flaskerud, 1992; Forstein, 1984; Fullilove, 1989; Siegel & Krauss, 1991; Stulberg & Buckingham, 1988; Weitz, 1989) suggest that the psychological impact of HIV/AIDS on the individual is compounded by several unique aspects associated with the disease. Persons diagnosed with HIV disease are generally young and the entire continuum of HIV disease, from exposure through infection, is characterized by extreme uncertainty (Brown & Powell-Cope, 1991; Weitz, 1989) and feelings related to the implied association of the illness with activities considered illicit by society, particularly homosexual activity or intravenous drug use (Forstein, 1984). In addition to the commonly recognized feelings of fear, anxiety, depression, and anger that accompany other life-threatening illnesses, persons with HIV disease are also vulnerable to feelings of guilt, self-hatred, rejection, and ostracism (Forstein, 1984; Stulberg & Buckingham, 1988). HIV disease requires lifelong changes in behavior that can threaten a person's most intimate relationships (Flaskerud, 1992; Forstein, 1984). Furthermore, the diagnosis of HIV infection may force the person's identification as a likely member of a stigmatized minority. Because of moral disapproval and negative societal attitudes, there is also a general tendency to blame the infected person for the disease, particularly if he or she is homosexual or an IV drug user (Weiner, Perry, & Magnusson, 1988). The social stigma and fear associated with the contagious aspect of the disease can cause others, even family members, to avoid social and physical contact with the infected person (Forstein, 1984; Flaskerud; 1992).

AIDS has had a highly visible social and political impact. The disease has attracted a barrage of media attention that is not always accurate, is often stressful to persons with AIDS, and aggravates public fears (Flaskerud, 1992). Persons with HIV/AIDS may face a variety of problems in the area of employment, housing, and insurance. Further, health care professionals and the current patient treatment system for persons with AIDS are severely taxed and often overwhelmed by the complexity and multiplicity of problems associated with AIDS (Institute of Medicine, 1988). Moreover, fear, lack of knowledge, and insensitivity among health care workers can negatively effect patient care (Kelly, St. Lawerence, Smith, Hood & Cook, 1987). Thus, in the face of extreme physiological and psychological demands, many persons with AIDS also have little financial security, inadequate insurance, and circumscribed personal and social resources.

Health Care Needs

A person with AIDS may require several hospitalizations for treatment of acute opportunistic infections. Between acute episodes, the individual may be able to resume many normal activities and assume responsibility for self-care. However, repeated episodes of infection and other evidence of disease progression leads to greater dependence on others for care. As the person begins to deteriorate, complicated physical and neurologic changes often make it difficult for the person with AIDS to carry out even simple daily routine tasks (Martin, 1988; Schietinger, 1986).

The Institute of Medicine (IOM, 1988), has outlined a model for HIV/AIDS care that recommends care be provided in community settings, rather than in hospitals, to make it more humane and cost-effective. However, despite the availability of a variety of formal (professional) home care services, these services can rarely provide for all the needs of the home-based HIV patient and there are few long-term care facilities (Nichols, 1989). Typically the person with AIDS will rely upon his/her partner, family, or friends to provide a significant amount of the care in the home. The informal caregivers will assist by helping persons providing formal home care services or by taking sole responsibility for the HIV-infected person's home care. Although informal caregivers play a crucial role in delivery of a variety of services/care that enable the patient to remain at home, when an illness is long and extended, informal care is often not given without considerable stress and emotional and physical cost to the caregiver (Biegel, Sales, & Schulz, 1991).

INFORMAL CAREGIVING

In recent years, informal caregivers have been increasingly recognized as a vital component in long-term, home care for impaired persons (Gwyther & George, 1986; Rose, 1990). Consensus about the importance of informal caregivers has led to numerous research efforts to better understand the distribution, correlates, and consequences of caregiving (Gwyther & George, 1986). Caregivers have become a prominent research focus because societal trends have made clear the expanded and complex demands being placed on the informal caregivers by illnesses such as Alzheimer's, AIDS, and other long term disabling diseases.

Concern about the strains of caregiving emerged first in the areas where it was recognized by health care professions that heavy demands were being placed on the informal caregivers. Specifically, initial attention focused on patients with diagnoses of mental illness, retardation, and more recently Alzheimer's disease. Investigations of informal caregiving with other chronic illnesses have been slower to emerge. However, there is now a growing body of literature pertaining to informal caregiving of a variety of population groups, including HIV/AIDS.

Background

The earliest research on informal caregiving was completed during the 1960s (Daniels & Irwin, 1989). This research accompanied the trend toward deinstitutionalization of chronic psychiatric patients from long term hospitalization to community based care. Grad and Sainsbury (1963, 1968) studied the caregivers of psychiatric patients who were diagnosed with either functional psychiatric disorders or organic brain syndromes. They (Grad & Sainsbury, 1963, 1968) reported adverse effects on mental health (63%) and deterioration in physical health (58%) in these caregivers. Social and leisure activities were disrupted in half of these caregivers, and about 19 percent of them reported a decline in income. In addition, it was reported that the relationship between the family caregiver and other family members became strained, and domestic routines altered. The most severe burdens were reported among caregivers who experienced competing demands (e.g., work and caregiving responsibilities). The problems reported by family caregivers were found to be associated with the patient's age and duration of illness. Family caregivers of elderly psychiatric patients were twice as likely to report "severe burdens" as compared to caregivers of younger psychiatric patients. Further, the chronicity of the illness experienced by the patient was also related to caregiver burden. While the gender of the infirm individual was not associated with caregiver burden, higher initial socioeconomic status appeared to buffer negative mental and physical health outcomes. Finally, caregiving adult children reported more burden than caregiving spouses.

Hoeing and Hamilton (1966) also studied elderly psychiatric patients and their family caregivers in the 1960s and found a high percentage of distressed caregivers. In their study, 80 percent of the family caregivers reported "significant burdens." These researchers conceptually differentiated "objective caregiver burden" and "subjective caregiver burden." Objective burden included adverse effects on the household of the caregiver, such as a decline in caregiver health and income. Subjective burden involved the caregiver's perception of the extent to which the patient's illness burdened the caregiver. Both objective and subjective burdens were highest among the family caregivers of persons who were demented or terminally ill.

Caregivers were later called "the hidden patients" in a seminal conceptual paper by Fengler and Goodrich (1979). Focusing on the mental health factors of caregiving, the authors found that morale scores of disabled husbands and their wives were associated. Low morale was linked to social isolation, loneliness, economic hardship, and role overload.

Brody (1981) responded to what she referred to as a prevalent "myth" that the elderly were being cared for in diminishing degrees by family members. Brody's work helped to establish that large amounts of care were in fact being provided by family members, particularly by female offspring of the elderly. She coined the phrase "women in the middle" and described the role overload middle aged women were experiencing meeting role demands as mother, wife, and worker, as well as caregiver to aging parent.

Cantor (1983), in a landmark study of four types of caregivers of the frail elderly, including spouses, children, other relatives, and friends/neighbors, documented how the strain and burden of caregiving was significantly different depending on the blood/role relationship between the frail elderly and the caregiver. Of the four types of caregivers, spouses were found to be most troubled by financial issues and by the morale of their husband or wife. Spouses also reported the most significant physical and financial distress. Adult children, on the other hand, expressed relatively more distress over obtaining adequate help for the frail dependent than the other caregiver groups. While caregivers who were friends/neighbors expressed the least amount of burden, all caregivers expressed worry over the health of the frail elderly.

Cantor (1983) also examined the impact of caregiving on the everyday lifestyle of the caregiver. Caregivers were more likely to restrict their personal activities, such as socializing with friends or taking vacations, but were able to maintain job and familial responsibilities. Again, of the four groups of caregivers, spousal caregivers were most severely impaired in their personal activity sphere. Two factors, spousal caregiving and the degree of emotional closeness between the frail elderly and the caregiver, appeared to predict the distress of caregiving. Cantor's work underscored the importance of clearly defining the caregiver type and quality of relationship in any study of caregiver stress.

The early caregiver studies helped to establish that some form of burden/stress is experienced by family members who take on the caregiving role and that there are a variety of contributing factors. Studies conducted in the later 1980's and 1990's have become increasingly sophisticated and understanding about informal caregiving has grown in many respects.

Theoretical Perspectives

Although there are different theoretical perspectives that may be useful in understanding caregiving, to date, the vast majority of caregiver studies have focused on the individual caregiver using, implicitly or explicitly, a stress model.

Stress is a complex concept that has been defined variously. Three theoretically distinct conceptualizations of stress can be identified in the broad literature: (1) stress as stimulus; (2) stress as response, and; (3) stress as process or transaction. An examination of each of these approaches suggests that the transaction model is the most compelling for the study of informal caregiving stress.

Stress as Stimulus. Stress is sometimes conceptualized as an environmental event or stimulus that causes or contributes to a disrupted response. Historically, the stimulus orientation had its roots in the works of Holmes and Rahe (1967, 1974) who focused on the development of the tool known as the Social Readjustment Rating Scale (SRRS) or Schedule of Recent Experiences

(SRE). The tools were developed to measure the effects of significant life changes on health. In the early 1970s, Holmes and Rahe made a semantic shift from the concept of change to the concept of stress, consequently, they assumed that the SRRS or SRE measured stress in the form of life changes or life events.

The primary theoretical relationship proposed by the stimulus model is between adjustment demands posed by stressful events and adaptational consequences. The magnitude of individual events and number of life events/changes are thought to increase vulnerability to illness, that is, the impact of events is additive. Critical assumptions underlying the stimulus model of stress include: (a) events lead to stress because the organism is fundamentally intolerant of change; (b) life change events are normative and result in the same expenditure of "adaptation units" across time and across people; (c) a person's perception of the event as positively toned or negatively toned is irrelevant, and; (d) there is a common threshold beyond which disruption occurs.

The assumptions form a framework for a model that essentially depicts the person as a passive recipient of stress. Stress is viewed as a stable, additive phenomenon that is measurable by researcher-selected life

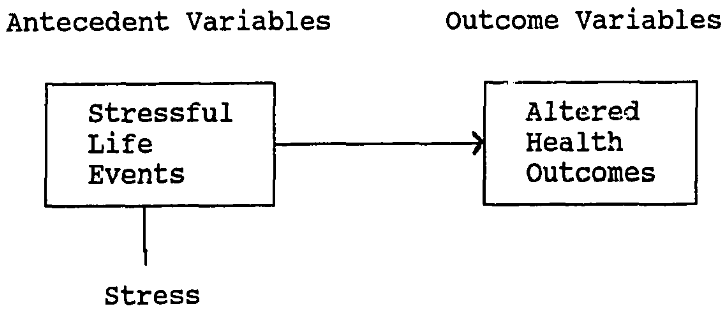


Figure 1. Stress as stimulus.

events that have preassigned normative weights derived from mean scores. The stress score is obtained by summing the weighted responses or by simply counting the events that have occurred.

Stress as a response. When stress is defined as a response, it represents the disruption caused by a noxious stimulus or stressor. Therefore, in the response model, stress is essentially the dependent variable rather than the independent variable as in the stimulus model. The notion of stress as response draws heavily from the work of Selye (1956, 1976). Stress is regarded in the response model as a nonspecific response of the body to demands placed on it (Selye, 1956, 1976). The essential theoretical assumption underlying this view is that regardless of the cause, situational context, or psychological interpretation of a demanding situation, the stress response is characterized by the same chain of events and the same pattern of physiological correlates. Although Selye acknowledged the critical role of perception in psychological stress experiences in the late 1970s, he did not modify his theoretical explanations and maintained that stress was a nonspecific syndrome represented as the General Adaptation Syndrome.

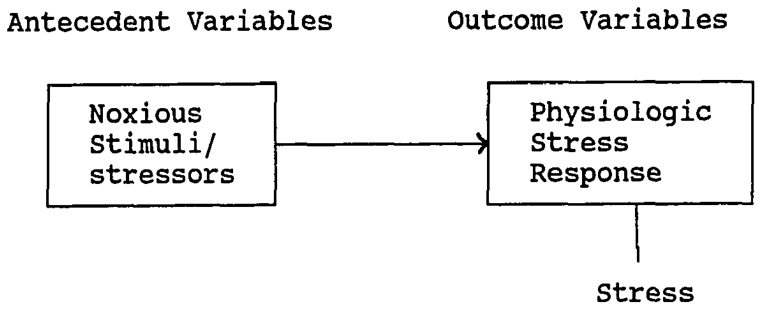


Figure 2. Stress as response.

Stress as transaction. In a process or transactional model, stress is conceptualized relationally by reference to both the person and the environment. A transactional model places emphasis on the person's evaluation of the potential harm imposed by a stimulus. The perception of threat arises when the demands imposed upon an individual are perceived to exceed his or her felt ability to cope with those demands. This imbalance gives rise to the perception of stress and to a stress response that may be physiological and/or behavioral in nature. Stress then is not defined solely in terms of the stimulus condition or solely in terms of the response variables, but rather in terms of the transaction between the person and the environment.

The model does not suggest that there is a linear, unidirectional relationship between objective conditions and outcome variables, rather it is suggested that whether or not an objective condition is experienced as stressful depends upon the appraisals of the individual subjected to it. Furthermore, the perceived meaning of objective conditions will depend on both the nature of person and nature of the conditions or context.

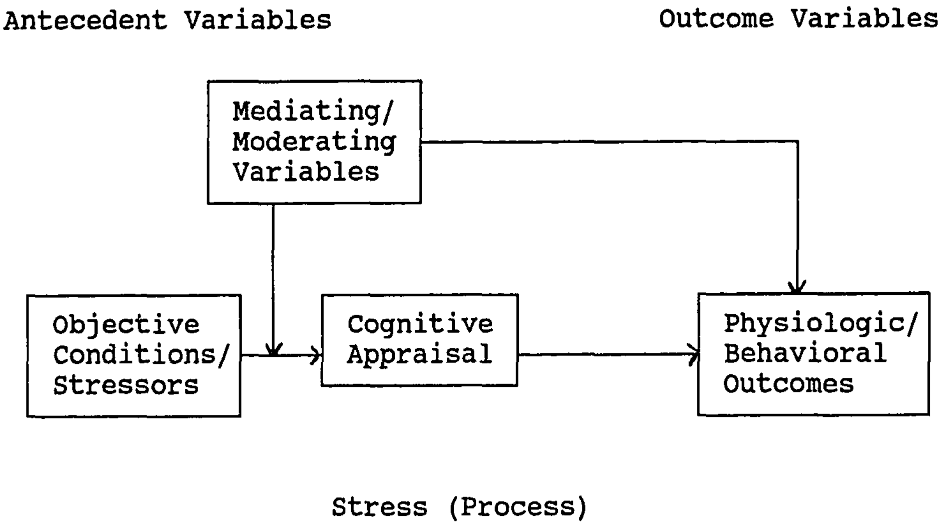


Figure 3. Stress as transaction/process.

Thus stress is conceptualized as a complex system made up of interdependent antecedent, process, and outcome variables. The assumptions central to the transactional approach include: (a) stress is not measurable as a singular concept, and; (b) cognitive appraisal mediates stress experiences. It can be seen that the transactional stress framework is a suitable model for the study of informal caregivers. A number of studies have reported that the high levels of stress experienced by informal caregivers may lead to a number of negative outcomes (e.g., emotional health problems). However, existing literature on caregiving demonstrates that there is considerable variability in individual response to the demands of caregiving and that there is only a moderate relationship between objective measures, such as the amount of time per day spent taking care of a disabled person, and the psychological and physical health of the caregiver. Unlike the stimulus and response models, the transactional model allows for explanation of this variability. Variability can be explained in terms of differences in individual appraisals of the caregiving situation. A number of possible mediating variables (e.g., coping, social support) are considered in relation to the stressors in an effort to account for differences in caregiver appraisal and outcomes. This analysis ultimately lends to a more comprehensive, dynamic, process oriented view of caregiving, which focusses on individual differences in stress experiences.

For the most part, a transactional or stress-coping theoretical framework such as that proposed by House (1974) or Lazarus (1986) has been used in the study of informal caregivers in an attempt to link some antecedent variables to outcomes assessing the well-being of individuals who have been identified as providing primary support to impaired individuals. A typical antecedent variable in this conceptualization is the functional or behavioral status of the patient or content of caregiving provided (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Sheehan & Nuttall, 1988; Zarit, Todd, & Zarit, 1986). The focus is often on the nature and number of specific tasks involved in providing care such as bathing, transporting, grooming, preparing meals, or giving financial assistance. In a comprehensive review of the caregiving literature, Clark and Rakowski (1984) identified 45 separate caregiving tasks.

Some of the mediating variables that have been examined are social support received by the caregiver (Baillie, Norbeck, & Barnes, 1988; Crotty & Kulys, 1986; Haley, Levine, Brown, & Bartolucci, 1987; Zarit, Todd, & Zarit, 1986); coping strategies used by the caregiver (Haley, et al., 1987; Rabins, 1981; Zarit & Zarit, 1982); age (Haley, et al., 1987), type and quality of the relationship between caregiver and patient (Cantor, 1983; Sheehan & Nuttall, 1988; Soldo & Myllyluoma, 1983; Zarit, Todd, & Zarit, 1986), or personality characteristics of the caregiver, such degree of self-esteem (Lazarus, et al., 1981), and locus of control (Levine, Dastoor, & Gendron, 1983).

Studies have also documented a variety of emotional, social and physical outcomes associated with providing care. In a review of the caregiving research, Horowitz (1985) concluded that the emotional burdens associated with caregiving, which stem from a constant concern for the ill person's health and safety and a need to come to terms with the changing nature of the relationship, are the most pervasive and difficult with which to deal. Chronic fatigue, physical exhaustion, and a deterioration in their own health are among the physical burdens experienced by caregivers (Archbold, 1980; Chenoweth and Spencer, 1986). Recent studies suggest that the chronic stress of caregiving may actually have a negative impact on immune functioning (Kennedy, Kiecolt-Glaser, & Glaser, 1988; Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Speicher, 1987), placing the caregiver at risk for a variety of altered health outcomes.

Methodology considerations

Despite the growing body of literature about the plight of informal caregivers, reports of correlates of caregiver stress are often conflicting or inconsistent. Variables such as the mental condition of the patient, the level of impairment, or the amount of care required have been supported as predictors of negative caregiver outcomes in some studies and not in others (Deimling & Bass, 1986; Zarit, Todd, & Zarit, 1986). Although these inconsistencies may be explained to some degree in terms of differences in caregiver cognitive appraisal, some of these conflicting findings are a function of various methodological problems.

First, divergent findings may be related to differences in outcome measures. It has become increasingly recognized (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Kosberg, Cairl, & Keller, 1990) that for conceptual clarity, it is important to independently assess stressors, mediating variables, and diverse caregiver outcomes, rather than to use summary measures (e.g., "burden") which can confound these aspects of caregiving. Studies which use measures of burden have been problematic because burden has been defined in diverse ways that make measurement and cross-study comparisons difficult. Some definitions range from burden as emotional costs (e.g., feelings of embarrassment and overload) to specific changes in caregivers' day-to-day lives such as disruption of daily routine (Poulshock & Deimling, 1984). Other definitions include financial difficulties, role strain, and physical health deterioration (e.g., Robinson, 1983; Zarit, Reeves, & Bach-Peterson, 1980). Because of the breadth of issues that have been subsumed under the general term, its use as a unified concept has been questioned (e.g., George & Gwyther, 1986; Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Poulshock & Deimling, 1984). A few investigators have attempted to deal with this problem by dividing the concept into two components labeled "subjective" and "objective" burden (e.g., Thompson & Doll, 1982; Poulskock & Deimling, 1984), yet this approach has not proved to be a satisfactory solution as a potpourri of items are still subsumed within each category. As George and Gwyther (1986) observe, "Reliance upon summary measures masks dimension-specific patterns of caregiving impact and precludes identification of the different antecedents or correlates of specific dimensions of caregiving burden" (p. 254).

Second, conflicting findings in the informal caregiver research may be a function of differences in samples. Many of the studies are based on small, nonrepresentative samples of caregivers selected from a particular geographical region, income level, or living arrangement. Another explanation is related to the fact that much of the caregiver research to date has been descriptive, examining simple bivariate relations. Any constellation of simple stressor-dependent variable correlations is not likely to explain or predict caregiver stress outcomes (Frese & Zapf, 1988). It is apparent from much of the research already completed that stress outcomes and their antecedents are multidimensional and relations among them are complex. More recently, different researchers have begun testing more sophisticated, multivariate models of caregiving (e.g., Baille, Norbeck, & Barnes, 1988; Haley, et al., 1987; Schulz, et al., 1987; Sheehan, & Nuttall, 1988).

Third, few caregiver studies have, to date, incorporated a control group. The use of control groups could also make a positive contribution to caregiver stress concept development. Work completed by George and Gwyther (1986) demonstrates the advantages of such an approach. George and Gwyther (1986), compared caregiver data with normative information available from several survey's of older adults' well-being, using essentially the same measures. This comparison showed that, in terms of physical health, caregivers did not use more medical services or rate their health worse than random community samples. However, wide discrepancies appeared on the mental health indicators. Caregivers averaged nearly three times as many stress symptoms as the other samples, along with low levels of affect balance and life satisfaction.

Another problem noted in the informal caregiver research is that most of it is cross-sectional and fails to control for duration of caregiving. Incorporation of more longitudinal designs could be beneficial in this regard (Frese & Zapf, 1988). However, certain difficulties may persist unless the study is carefully designed. For example, Zarit (1989), notes that a longitudinal study can help to identify effects of changes in coping patterns, but the researcher may still not be able to fully evaluate patterns of behavior begun earlier in the course of caregiving. In the study of stress and coping it is usually presumed that coping mediates the effects of stressors, but coping may also change the stressor. The caregiver who is coping in effective ways (e.g., able to calm down a disruptive patient) will report fewer behavior problems, while the less effective coper will report more. The findings, then, will show a relation of disruptive behavior and caregiver outcomes, with the full impact of coping underestimated, since the effects preceded the study. However, unless duration of caregiving is controlled, it will continue to be difficult to identify certain antecedent-consequent relations.

While multivariate approaches are likely to increase an understanding of the concept of informal caregiving stress as a complex system made up of interdependent antecedent, intermediate, and outcome variables, investigators (e.g., Bowers, 1987; Philips & Rempusheski, 1986; Wilson, 1989) have also found qualitative methods, particularly grounded theory, useful in examining the processes involved in informal caregiving. Grounded theory, as described by Glaser and Strauss (1967), is a systematic way to induce theory from data. The goal of this approach is to develop theory that accounts for human behavior rather than to develop descriptions of behavior with the goal of verifying theory (Glaser & Strauss, 1967). While grounded theory is a useful strategy for exploring areas where little is known, it is also an effective means for addressing gaps and clarifying, developing, or redirecting research in a content area about which much is already known. This approach can lend a fresh perspective which has the potential to contribute toward a deeper understanding of informal caregiving. For example, Bowers (1987), using grounded theory, made a provocative contribution to the caregiving research by identifying several dimensions of intergenerational caregiving that had not previously been distinguished. Her (Bowers, 1987) analysis revealed five categories of caregiving, only one of which included what is generally regarded as caregiving --hands-on caregiving behaviors or tasks. The other four types (anticipatory, preventive, supervisory, and protective) were identified as processes considered crucial to intergenerational caregiving.

HIV/AIDS INFORMAL CAREGIVERS

In contrast to the burgeoning data concerning informal caregivers of the elderly or persons with Alzheimer's disease, comparatively little is known about informal caregivers who provide care to HIV infected persons. Initial empirical data suggest that HIV informal caregivers may serve functions similar to other caregiving populations in assisting the ill person to remain at home longer, avoid hospitalizations, and maintain well-being (Hepburn, 1990). However, like caregivers of other populations, HIV/AIDS informal caregivers also suffer from role-related stress.

Pearlin, Semple, and Turner (1988) interviewed San Francisco men who provided care in their homes to AIDS patients. They identified three types of stressors: (1) the demands within the caregiver role itself; (2) the uncertainties the caregivers experienced concerning their own future related to the fact that homosexual caregivers are often exposed to the same set of health risk factors as the patients, and; (3) stressful problems created in other roles as a result of being a caregiver.

Another study was based on interviews with nine lovers of persons who had died from AIDS (Geis, Fuller, & Rush, 1986). Major sources of stress identified in this sample were societal stigma and isolation from their usual support networks including family, friends and religious organizations. Similarly, Grief and Porembski (1988) found that significant others (friends, lovers, parents, and siblings) of persons with AIDS experienced difficulties in coping due to rejection by and conflicts between the person with AIDS and his family of origin.

In a grounded theory study (Brown & Powell-Cope, 1991), with 53 individuals (lovers, spouses, parents, siblings and friends) who cared for a person with AIDS at home, managing "uncertainty" was identified as the critical challenge. Five subcategories of uncertainty were identified including: (1) managing and being managed by the illness; (2) living with loss and dying; (3) renegotiating the relationship;(4) going public, and; (5) containing the spread of HIV.

An ongoing longitudinal study at Memorial Sloan-Kettering Cancer Centers is designed to identify the burdens and consequences of being a primary caregiver of an AIDS patient (Raveis & Siegel, 1990). Caregivers are initially interviewed within 18 months of the patient's AIDS diagnosis and reinterviewed every 4 months until the patient dies. Data drawn from the baseline interviews with 47 caregivers suggest that 30% of the caregivers have made financial changes in their life-styles due to the patient's illness, and 33% have passed up financial opportunities. Although none of the caregivers report having very serious financial problems due to the patient's illness, 13 percent of the lovers and family members report somewhat serious financial problems. The caregivers report that providing care to an AIDS patient affects the extent to which the caregiver socializes with his or her family members. Seventeen percent of the lovers and 25 percent of caregiving friends or volunteers report less frequent visits or phone calls with their family since the patient's diagnosis. Similar changes have occurred with their contact with friends. In contrast, 25% of the familial caregivers report an increase in contacts with other family members, but no changes in their contact with friends. A large majority (87%) of the caregivers do not feel that their own health has changed perceptibly since the patient's diagnosis and their assumption of the caregiving role, although 60% are at least somewhat worried that they might develop AIDS.

Compatible with the large informal caregiver literature, initial empirical findings on HIV caregivers suggest that they encounter a significant number of stressors (Brown & Powell-Cope, 1991; Geis, Fuller, & Rush, 1986; Giacquinta, 1989; Grief & Porembski, 1988; Pearlin, Semple, & Turner, 1988; Raveis & Siegel, 1990). While some of these challenges are common to most informal caregivers, HIV caregivers face a number of psychosocial issues that are unique to HIV infection. In addition to the unusually heavy physical caregiving demands and a vast range of clinical activities, the HIV informal caregiver must also confront the terminal condition of a (usually young) loved one, manage uncertainty, and possibly face one's own HIV seropositivity. Of particular note, the informal caregiver, like the patient, must also address a number of concerns related to the stigma of AIDS. Although the literature has begun to identify how HIV stigma impacts the HIV-infected patient, there has, to date, been little systematic exploration of how it impacts the informal caregiver role, and how this may change over the course of HIV caregiving.

While a number of stressors have begun to be identified, an additional deficiency noted in this body of literature concerns the dearth of information regarding the stress outcomes of HIV informal caregiving or mediating variables that may modify responses to stress. Further, although the greatest number of HIV-infected individuals in the U.S. are bi-coastal, increasing numbers in other regions suggest more understanding of caregiving is needed for these (e.g., mid-western) populations. It is uncertain how the demands of HIV caregiving or support services may vary, if at all, among patients in different regions.

CASE MANAGEMENT

Increasing emphasis on the development of an integrated system of community/home-based services for HIV patients has been accompanied by attention to mechanisms, such as case management, for facilitating service coordination (Benjamin, 1988; Knickman, Harnett, & Kohn, 1989; Presidential Commission, 1988). The formal and the informal are interdependent in the dynamics of caring for patients. The problems encountered by informal caregivers and their efforts to manage and cope with these problems cannot be regarded as separate from the systems of formal supports that are available to them (Pearlin, Semple, & Turner, 1988). Thus, case management as a service delivery strategy for HIV patients has implications for HIV informal caregivers.

Case management defined

Numerous definitions of case management have appeared in the literature in recent years (Bailey, 1989; Intagliata, 1982). For example, Schwartz, Goldman, and Churgin (1982) described case management as "providing a client with an individual who is responsible for helping coordinate the clients' care and treatment within a complex human services system" (p. 1006). Although the definitions vary, case management generally refers to a process designed to ensure that the services provided to a patient are coordinated, effective, and efficient. In concept, through constant contact with the patient, the patient's family/caregivers, and the service care providers, the case manager ensures that the patient's needs -- whether they are health care, psychologic, social, financial, or legal -- are met appropriately. The case manager's functions are multiple and include client identification and outreach, individual and family assessment and diagnosis, service planning and resource identification, linking clients to needed services, service implementation and coordination, monitoring service delivery, and client advocacy (Ryndes, 1989). It has been observed (Bailey, 1989) that the role of the case manager may vary considerably according to client needs, the availability of community services, the philosophical orientation of the agency responsible for providing case management services, administrative location of case management within the overall service delivery system, personal beliefs of the case manager, and administrative authority delegated to case managers.

Background

Although case management is not a new idea, it has gained popularity in recent years as a mechanism for improving service delivery to chronically ill/impaired persons, particularly the mentally disabled and the elderly. The need for case management emerged in response to two movements (Bailey, 1989; Intagliata, 1982). First, there was the rapid expansion of human service programs that took place throughout the 1960s and continued into the 1970s. As a result of this expansion, the overall availability of services increased significantly. However, because public funding for these programs was provided primarily through narrow categorical channels, the network of services that resulted was highly complex, fragmented, duplicative, and uncoordinated. Numerous individual programs were developed to provide very specialized services or to serve narrowly defined target groups. While these factors potentially interfere with service accessibility for all potential users, the barriers were recognized as being particularly burdensome for those persons whose complex problems required them to engage in multiple, disconnected programs in order to get the assistance they need (Intagliata, 1982).

In response to these problems increasing attention was given to the concept of services integration, especially by federal, state and local levels of government. In the early 1970s, the Department of Health, Education, and Welfare recognized the need for improved coordination of its own programs at state and local levels, and proposed a legislative initiative, the Allied Services Act, to facilitate integration of services. The Department also began a series of demonstration projects, the Services Integration Targets of Opportunity (SITO) grants, to test various services integration techniques at the state and local levels (Intagliata, 1982).

Under the SITO grants numerous service integration techniques were developed and demonstrated, including client-tracking systems, information and referral mechanisms, one-stop service centers, specialized management information systems, interagency planning and service delivery agreements, computerized resource inventories, and management reorganization projects (Mittenthal, 1976; Morrill, 1976). An additional feature that was common to most of the SITO projects was creation of the role of "systems agent," operationally a case manager, who was expected to coordinate systems resources for individual clients and to be accountable for successful client transit of the system. Thus, the widespread use of case managers as part of SITO efforts directed increased attention to the case management concept (Intagliata, 1982).

A second force that contributed to the popularity of case management was deinstitutionalization. As an outgrowth of advocacy efforts and the normalization principle (Wolfensberger, 1972), hundreds of hospitals and residential facilities began returning mentally disabled or ill clients to their local communities. When mentally disabled persons were released from institutions, responsibility for their care and support generally became diffused among several agencies and levels of government. Many of the clients often did not receive the services they needed, either because the services did not exist or because they were unable to obtain them on their own (Test, 1979). In response, a number of initiatives were developed to ensure that the ultimate aims of deinstitutionalization were not thwarted by the failure of local community support systems. The historical rationale and goals of case management are summarized in a 1978 statement from the Task Panel on Deinstitutionalization, Rehabilitation, and Long-Term Care of the President's Commission on Mental Health. As reported by Bailey (1989, p. 120-121), the panel noted that:

> The chronically mentally disabled are made more visible and are singularly disadvantaged by a complex and fragmented service system. They not uncommonly need a range of health, mental health, and social services provided by many different agencies, but the agencies may have conflicting and incompatible goals that make coordinated care difficult. Frequently, too, these agencies prefer to serve the least disabled and may neglect the development of individualized treatment plans for the most disabled. As a consequence, there has too often of services for some chronically mentally disabled persons and a lack in continuity of care for others. Recognizing this serious problem, the Task Panel recommends that (6) (a) States receiving federal funds for the care of the chronically mentally disabled must, in conjunction with local authorities, designate an agency in each geographic area to assume

> responsibility for ensuring that every chronically mentally disabled person's needs are adequately met, and (6) (b), those agencies designed to assume responsibility must provide, or assure the provision of, case management services to ensure that every chronically mentally disabled individual receives quality mental health care and supportive services, irrespective of where the individuals reside.

Thus, the rapid expansion of human service programs created a large, fragmented network of services and the subsequent attention given to the difficulties experienced by consumers in general, and the deinstitutionalized mentally disabled in particular, led to the current widespread interest in services integration techniques, particularly case management.

Effectiveness of case management

While there is growing interest in case management as a means for providing comprehensive and cost-effective care to patients, there is, to date, little research that adequately demonstrates its effectiveness. Findings from initial case management studies suggest that clients who receive case management services are generally pleased with them (Baker & Weiss, 1984; Zimmerman, 1987) and a range of client outcomes are enhanced (Cohn & DeGraaf, 1982; Morrow-Howell, 1984; Simmons, Ivry, & Seltzer, 1985). However, conclusions from these studies are questioned because of their failure to use rigorous experimental designs (Bailey, 1989). Rapp and Chamberlain (1985), for example, criticized the existing case management studies for: inadequately described case management interventions (the independent variable); faulty outcome measures, and; nonrandomized comparison groups.

More recently, stronger studies have become available. The National Long-term Care Demonstration, known otherwise as the "Channeling Demonstration," was initiated in 1980 to assess the impact of comprehensive case management in allocating community services appropriately and cost effectively to the elderly in need of long-term care. Results of an evaluation of these demonstration programs indicate that case-management services reduce the unmet needs reported by clients, enhance client and caregiver confidence and satisfaction, and increase the use of community-based, noninstitutional services. Case management had little impact on client health and functioning, and little or no effect on the use of institutional services (Kemper et al., 1986). Other research also suggests that targeting case-management resources to specific subsets of those at-risk may produce some positive outcomes for patients, although the costs of care will not be reduced (Benjamin, 1988).

Although case management is increasingly recommended for community based persons infected with HIV, there is, to date, little research that adequately demonstrates its effectiveness, scant research that demonstrates its impact on caregivers, and no research that demonstrates its impact on caregivers of persons with HIV infection. Health care professionals need to know how to advise and support families to maximize and sustain their role as caregivers in the community. Before planners can knowledgeably design and implement intervention strategies, it must be understood how, for whom, in what context, and for what type of problems the interventions are appropriate. At this time it is difficult to know whether case management will impact HIV/AIDS caregiver stress since there have been few controlled case management studies. Despite the anecdotal evidence suggesting its value (e.g, Rose & Catanzaro, 1989), it is by no means certain that case management is an effective strategy for HIV patients or caregivers. There is a need for more systematic study. Ongoing research is examining the effectiveness of case management for HIV patients (Nickel & Salsberry, 1988), yet additional data concerning its impact on the informal caregivers of HIV patients is also needed.

CONCLUSION

The spread of the AIDS epidemic continues and efforts to curtail its spread have had limited success. The cumulative total of more than 200,000 reported AIDS cases emphasizes the rapidly increasing magnitude of the HIV epidemic in the United States. The first 100,000 cases were reported during an 8-year period, whereas the second 100,000 cases were reported during a 2 year period. Although most reported cases of AIDS have occurred among white homosexual/bisexual men, the number and proportion of AIDS cases in both heterosexual and minority populations has been increasing steadily.

Infection with the human immunodeficiency virus results in a spectrum of subclinical and clinical manifestations ranging from asymptomatic infection to severe immunodeficiency. HIV causes a progressive suppression of immune function of which AIDS is a late manifestation. The emergence of opportunistic infections is a reflection of extreme deterioration in immune function. It is during this end-stage that persons infected with HIV experience severe declines in physical, social, intellectual, and self-care behavior. Although progress has been made in the treatment of the disease, there is no known cure and predictions indicate that a vaccine will not be developed for HIV in the near future. The most that can be expected of the current treatments, directed at associated opportunistic infections and neoplasms, is that they will extend life. This increases long-term care requirements.

Although from an epidemiological perspective the impact of this epidemic is counted in terms of the numbers of infected persons, the actual number of persons whose lives are impacted is much greater. HIV has the potential to affect not only the individuals who are infected, but friends and families as well, particularly those who provide long-term informal care. The complex physical, psychological, and social needs of an HIV infected person present tremendous challenges to the persons responsible for their care and may impact these informal caregiver's health/well-being outcomes.

The large body of research concerning informal caregivers completed during the past decade has established that informal caregiving can be a source of profound stress. Researchers have generally examined the relationship between various role-related antecedent variables (stressors) and outcome variables, and have determined that caregivers are at risk for altered health/well-being outcomes. Despite the growing body of literature about the plight of informal caregivers, reports of correlates of caregiver stress are sometimes inconsistent. Variables such as the mental conditional of the patient, the level of impairment, or the amount of care required have been supported as predictors of negative caregiver outcomes in some studies and not in others. Some of these conflicting findings may be a function of theoretical configurations or study/design methods. A review of the literature suggests that the study of informal caregivers is best approached with the use of a sound theoretical framework and longitudinal, multivariate designs or when indicated, qualitative approaches. While a transactional stress paradigm provides a useful theoretical umbrella that can be used to guide caregiver research, there has, to date, been little infusion of other social or psychological theory. An integration of other theoretical insights could lend greater specificity to understanding informal caregiving and direct intervention strategies more precisely.

Like other informal caregiver populations, a transactional stress framework can be used in the study of HIV informal caregivers to guide the investigation and place findings into a broad theoretical perspective. Early empirical findings suggest that HIV informal caregivers are exposed to a number of stressors which may give rise to altered health/well-being outcomes.

A transactional model places emphasis on the person's evaluation of the potential harm imposed by a stimulus. The perception of threat arises when the demands imposed upon an individual are perceived to exceed his or her felt ability to cope with those demands. This imbalance gives rise to the perception of stress and to a stress response that may be physiological and/or behavioral in nature. Within the transactional stress framework, case management can be conceptualized as a mediating variable. It can be suggested that case management activities may decrease the likelihood of altered health outcomes. By facilitating formal services offered to the patient, the number of informal tasks/responsibilities may be reduced and satisfaction with formal services improved. Furthermore, case managers may directly address informal caregiver concerns by providing instrumental, informational, and emotional support to the caregiver thus buffering stress and reducing negative health/well-being outcomes.

While the extant caregiving literature renders some insight concerning stressful factors that may transcend any caregiving situation, it generally fails to provide an adequate understanding of factors unique to informal caregivers of persons with AIDS. Of particular note is HIV/AIDS-related stigma. Although stigma is often cited as an important component effecting the patient and family experience of HIV infection, to date, it is unclear precisely how stigma impacts the informal caregiver experience. It is also unclear how informal caregiver role responsibilities will change over time. Drawing from Strauss' (1975) notion of illness trajectory or illness course, the assumption can be made that the role responsibilities and care strategies of HIV informal caregivers are not only multidimensional, but will change over the course of HIV illness.

CHAPTER III

METHODS

The purpose of this study was to enlarge upon an understanding of HIV/AIDS informal caregivers. The specific aims were to: (1) explore the role responsibilities of HIV/AIDS informal caregivers over the course of HIV illness, and; (2) assess the impact of an intervention strategy, case management, on HIV/AIDS informal caregiver's health/well-being and satisfaction with formal home care services.

DESIGN

Indepth interview data were collected to provide a qualitative analysis of the informal caregiver role(s) HIV informal caregivers over time. Subjects were asked a series of closed and open-ended questions regarding: caregiving activities, patient illness factors, amount/nature of assistance caregiver received with caregiving activities, competing demands/role overload, economic concerns, quality of caregiver-patient relationship, stigma, social support, and competence/qualifications for caregiving role. A prospective design was used to facilitate the exploration of the developmental and emergent nature of the caregiving role.

In addition to the qualitative data collection, standardized measures were collected to assess if case management had an effect on the caregiver's health/well-being and satisfaction with formal home care. A group of caregivers who cared for HIV positive patients who received case managed home care were compared with caregivers of HIV positive patients who did not receive case managed home care. Evaluation was based upon a standardized measures of health/well-being and a standardized measure of satisfaction with formal home care patient services.

SAMPLE

Sample criteria

The sample used in this study were primary informal caregivers of HIV positive patients residing in Columbus, Ohio. The "primary" informal caregiver was specified as the person who was identified by the patient or case manager as the nonprofessional assuming the major responsibility for assisting the HIV positive patient with the management of his or her illness.

Sample recruitment

The sample was obtained in two ways. First, participants were recruited from The Collaborative Home Care Project (Nickel & Salsberry, 1988), an existing experimental study that was examining the effects of case management on HIV infected persons eighteen years and older. The patients who were participating in The Collaborative Home Care Project were receiving home care services from one of six different home care agencies (public and proprietary). Permission was obtained from the research team of the Collaborative Home Care Project (Nickel & Salsberry, 1988), the Human Subjects Review Board, and participating agencies to contact the informal caregivers of patients participating in this study.

Additional subjects were recruited from the Columbus AIDS Task Force. Because of issues of confidentiality, the Columbus AIDS Task Force would not provide access to names of HIV informal caregivers affiliated with their agency. However, they were willing to place a monthly advertisement in the Columbus AIDS Task Force Bulletin for four consecutive months. The advertisement explained the purpose of this study and requested that potential subjects contact the researcher if interested in participating in the study per the telephone number provided.

Sample size

A total of twenty subjects participated in the study. The sample was comprised of 12 informal caregivers of patients who were participating in the Collaborative Home Care Project (Nickel & Salsberry, 1988) and 8 informal caregivers who responded to the advertisements placed in the Columbus AIDS Task Force (CATF) Bulletin.

MEASURES

Measurement of study variables consisted of a combination of: (a) one orally administered two-part questionnaire that had a combination of short answer and open ended questions (Informal Caregiver Interview); (b) one orally administered standardized measurement instrument of health/well-being (The Quality of Well-Being Scale); (c) one self-administered standardized measurement instrument of emotional health/well-being (Profile of Mood States); and (d) one self-administered standardized measurement instrument of satisfaction with patient services (Client Satisfaction Questionnaire).

Informal Caregiver Questionnaire

<u>Part I - Demographics</u>. Part I of the informal caregiver questionnaire was comprised of short answer questions developed to collect information concerning caregiver demographics, caregiver relationship to patient, length of

time the caregiver had been living with the patient, length of time the caregiver had been caring for the patient, number of persons in the patient household, and the HIV status of the caregiver (See Informal Caregiver Questionnaire, Part I, Appendix A).

Part II - Components of Informal Caregiving. Part II of the Informal Caregiver Questionnaire was developed to collect information concerning the HIV caregiver role and care strategies (See Informal Caregiver Questionnaire, Part II, Appendix A). Questions were developed based upon relevant information derived from a review of the informal caregiver literature, clinical experiences with HIV/AIDS informal caregivers, and analysis of an indepth interview with an informal caregiver of an AIDS patient. This instrument was piloted with five informal caregivers of HIV/AIDS patients and subsequently revised. In the completed instrument, data were collected on the following dimensions:

Caregiving activities. The type of caregiving activities in which HIV informal caregivers were involved was considered to be any behavior that the informal caregiver initiated which was perceived as helpful to the care recipient (patient). Caregiving activities were regarded as including specific physical care tasks (e.g., assistance with bath) as well as psychosocial emotional support (e.g., protection of patient self-concept). Subjects were first asked an open ended question regarding the ways in which they assisted or supported the patient. This question was followed by more specific questions designed to elicit specific information concerning caregiving behaviors.

Amount of time spent in caregiving activities. Caregivers were asked how much time was spent, on average, each day with the patient to determine the approximate amount of time the caregiver spends engaged in caregiving activities. This question was designed to elicit information concerning the amount of time spent in physical as well as psychosocial caregiving activities.

Amount of assistance with caregiving activities. Questions were asked to determine to what degree caregiving activities were shared. Questions were designed to elicit information concerning the amount and nature of additional sources of informal and formal assistance, whether these were perceived by the caregiver as adequate, and if the caregiver perceived that caregiving responsibilities changed in relation to the amount of formal services provided.

Patient illness factors. Information concerning the nature of the patient's illness was elicited by asking the caregiver to describe the patient's course of illness and present condition.

Competing demands/role overload. Information concerning competing demands were derived by asking if the patient's illness had been disruptive to the caregiver's lifestyle; if it was difficult for the caregiver to fulfill other responsibilities because of caregiver responsibilities; if recreational, social or work activities were restricted because of the patient's illness, and; how did this make the caregiver feel and how was it managed.

Economic stressors. Subjects were asked a series of questions to determine if the care recipient's illness was a source of financial strain to the caregiver and what measures were taken to avoid financial hardship.

Quality of relationship. A series of questions were asked to determine caregiver's perceptions regarding the quality of his/her relationship with the patient and whether the relationship had changed since the patient became HIV positive.

Competence/qualifications for caregiving. Caregivers were asked a series of questions designed to ascertain if the caregiver felt competent in his or her role as caregiver; whether s/he had received adequate information about HIV/AIDS; what his/her sources of information were, and if s/he felt capable of meeting the emotional and physical demands of caregiving.

Stigma. Questions were asked to explore how stigma impacted the caregiver. Caregivers were asked: if they felt that they or the patient had the potential to be stigmatized; if they or patient had experienced stigmatic episodes (enacted stigma); whom had been informed of the patient's HIV status; how this decision was made, and; what were responses of people who had been told.

Social support. Information was obtained with a series of questions concerning the caregivers' perceived adequacy and nature of their social support network and whether the nature of the caregivers' relationship with others had changed since the patient's illness.

Additional questions. Several open-ended questions were asked to identify additional stressors and/or positive aspects of the informal caregiving. These included:

What are your major concerns at this time?

What are your hopes for the future?

What is most rewarding for you about assisting someone with HIV/AIDS?

Has caring for someone with HIV/AIDS changed the way you view the world?

Is there anything that we have not already discussed that you would tell other people about what it is like to care for someone with HIV/AIDS?

An abbreviated version of the Informal Caregiver Questionnaire, Part II, was used at Time 2 and Time 3 (See Appendix B) and a modified version of the Informal Caregiver Questionnaire was used with caregivers of patients who were already deceased (See Appendix C).

Standardized Measures of Health/Well-being

Quality of Well-being Scale. The Quality of Well-Being Scale (QWB) (Fanshel & Bush, 1970) is a general health status index that offers advantages of assessment of the range from health through death on a single scale. The instrument measures functioning in mobility, physical activity, social activity, and self-care through retrospective report for the six day period prior to the date of the interview. The functional outcomes are additionally weighted by social preferences as to the desirability or undesirability of the functional state (Patrick, Bush, & Chen, 1973) and by concurrent symptoms. Validity assessments of functional status based on data from 1,324 (ill) individuals have estimated sensitivity of the scale as 0.90 and specificity as 0.99 (Kaplan, Bush, & Berry, 1976). Convergent validity assessments yielded correlations of -0.75 between the QWB score and related symptoms and -0.96 between the score and number of health problems (Kaplan, Bush, & Berry, 1976). Reliability tests yielded correlations of 0.93 on test-retest (Kaplan, Bush, & Berry, 1978). The scale takes approximately 10 to 15 minutes of respondent time.

<u>Profile of Mood States</u>. The <u>Profile of Mood States</u> (POMS) (McNair, Lorr, and Droppleman, 1971), was used to supplement the psychological dimensions of the QWB. This instrument is a 65-item adjective rating scale that measures six identifiable mood states: anxiety, depression, anger, vigor, fatigue, and confusion. Factor analytic studies have established the independence of the six states. Test-retest reliability ranged from .65 to .74. Internal consistency was .90 or above for all the items within each factor. Predictive and construct validity have been established through various studies, including short-term psychotherapy studies, outpatient drug trials, and studies of emotion-inducing conditions. Concurrent validity was established through significant correlations with three clinically derived scores from the Hopkins Symptoms Distress Scales (Derogatis, 1977). This instrument has been used with caregivers of the elderly (Baillie, Norbeck, & Barnes, 1988) and with persons with HIV infection (Zich &

Temoshok, 1987). If the caregiver was HIV positive, it was recognized that the disease process (e.g., HIV-induced dementia) could impact the individual's affective response independent of the caregiving situation.

Standardized Measure of Satisfaction with Services

Client Satisfaction Questionnaire. The Client Satisfaction Questionnaire (CSQ-8) (Larsen, Attkisson, Hargreaves, & Nyguyen, 1979) is an eight-item scale that measures directly respondent satisfaction with services actually received as opposed to general health attitudes toward health services (Pascoe, Attkisson, & Roberts, 1983). The scale has been administered to over 3,000 persons in 76 mental health and public health clinics across the United States (Nyuyen, Attkisson, & Stegner, 1983). Psychometric tests based on these studies show high indices of internal consistency, with coefficients alpha of 0.86 to 0.87 across varying gender and racial groups. Although there are no reports of use of the scale to assess satisfaction with home services, the questions are appropriate for this use. The Client Satisfaction scores of national clinic populations were used for comparison with the scores of the informal caregivers.

DATA COLLECTION PROCEDURES

Pilot Study

Before official data collection began, the instruments and interview were piloted with five informal caregivers, including the parents of a deceased patient, the partners of two deceased patients, and a friend of a patient living with AIDS. The pilot procedure provided: (a) suggestions for revisions of the interview questions and organization of the study questions; (b) more exact data on time required for completion of the data collection procedures; and (c) caregiver's perceptions regarding the acceptability of the interview format.

Interview Procedure

The names of potential participants from the Collaborative Home Care Project were obtained from the case manager of the project on a weekly basis and contact was initiated by the investigator. Potential subjects who responded to the advertisement initiated contact. The number of an office telephone with an answering machine for voice messages was provided in the advertisement.

All potential participants were first contacted by telephone. The telephone contact served to provide information about the study, answer questions about the study, and to establish an initial agreement and interview appointment with interested participants. Appointments were arranged with persons interested in participating at the time of their convenience. Interviews were conducted in the subject's home or preferred site specified by the caregiver. Only one caregiver elected to be interviewed in a non-home setting. This caregiver was interviewed in an interaction laboratory at The Ohio State University.

Upon the beginning of the interview session, the study was explained in greater depth and signed consent was obtained as stipulated by the Ohio State University Human Subject Review Committee (see Appendix D). Effort was made to assure the subject's comfort and privacy during data collection. With subject consent, subject responses to the informal caregiver questionnaire were tape recorded. The length of the interviews ranged from 90 minutes to 4 hours with a mean of 2 hours.

Data were collected for a period of one year. The data collection interviews were conducted with subjects at study entry (Time 1), 3 months (Time 2), and 6 months (Time 3). Caregivers in Group 1 and Group 2 were followed as long as they provided care to the HIV patients or for a total of six months. If the patient died during the course of the interviews, the caregiver was interviewed one time following the patient's death. Caregivers in Group 3 were interviewed at Time 1 only.

It was uncertain if the order of the instrument administration would impact subject responses. Therefore, the measures were randomly ordered. An additional uncertainty concerned use of the POMS over time. Repeated administration may sensitize subjects to their moods and impact their response. The study design controls for testing as main effect and interaction, but does not enable measurement of this possible threat to validity (Campbell & Stanley, 1963).

The standardized health/well-being and satisfaction measures were completed at each interview. The informal caregiver questionnaire, Part I, was completed at Time 1 only. The Informal Caregiver Questionnaire, Part II, was collected at Time 1. The abbreviated version of the Informal Caregiver Questionnaire, Part II, was used at Time 2 and Time 3. The modified version of the Informal Caregiver Questionnaire was used with caregivers of patients who were already deceased.

At the completion of the interview, each caregiver was provided with the opportunity to talk further about his or her situation and offered the opportunity to ask about the study. Subjects were offered a summary of findings upon conclusion of the study.

In a few cases it was apparent that the caregiver could benefit from an intervention strategy such as counseling. Because the study was ongoing, the researcher preferred not to suggest intervention strategies. However, if there was evidence of significant emotional disturbance or if the caregiver requested resource information, the case manager was notified.

Table 2

Summary of variable measures and collection protocols.

Measures		Frequency
Standardized Measures		
Quality Well-Being Scale	(QWB)	Time 1, Time 2, Time 3
Profile of Mood States	(POMS)	Time 1, Time 2, Time 3
Satisfaction with Client Services	(CSQ-8)	Time 1, Time 2, Time 3
Informal CG Role		
Caregiver Demographics	(Part I)	Time 1
Informal Caregiver Questionnaire	(Part II)	Time 1
Modified Informal Caregiver Questionnaire	(Part III)	Time 2, Time 3

*Note: Time 1 = Baseline; Time 2 = 3 months; Time 3 = 6 months

DATA ANALYSIS PROCEDURES

Research question

Content analysis of the informal caregiver interview (Part II) provided a descriptive account to answer the research question, "What are the role responsibilities of HIV/AIDS informal caregivers?" Codes were derived from respondents' answers and data were thematically analyzed.

Text was transcribed verbatim from the tape recordings of the informal caregiver interview (Part II) by a professional transcriber. The data was initially coded by hand and then entered on Ethnograph (computer program for qualitative data analysis) (Seidel, Kjolseth, & Seymour, 1988) in order to facilitate delineation of themes and categories. Consistent with a grounded theory approach, data were analyzed using a "constant comparative method" (Strauss, 1987), that is, the comparing of new data to concepts generated by the inquiry. The following procedure (as explicated by Chenitz & Swanson, 1986, p. 8) was used:

1. The first data collected (Informal Caregiver Questionnaire, Part II, Time 1) were compared for similarities and differences and coded with substantive codes that reflect the substance of what people said. Codes were either: (1) in vivo codes, terms used by the participants in the study, or; (2) researcher-constructed codes, codes formulated by the researcher using nursing/social science knowledge.

2. Codes were compared and similar codes were clustered and given an initial label, thus forming a category (groups of concepts, linked and distinct by their relationship with each other). Further data collection (Time 2 and Time 3) and analysis produced other categories; some was later recoded and some categories were combined with others. The data was then analyzed for patterns of relationships between two or more categories.

3. Relationships between categories was continued to be developed until a pattern among relationships was conceptualized. Analysis then focused on the interrelationships and a general conceptualization about these relationships produced.

It was anticipated that partners and members of the family would identify different caregiving roles. It was additionally anticipated that individual perceptions would vary depending upon the stage or severity of the HIV/AIDS patient's illness. Such categories were developed as deemed appropriate to the data analysis.

Hypotheses

The two hypotheses in this study were:

1. The informal caregivers of HIV infected patients who receive the case managed home care will have better health/well-being than informal caregivers of HIV infected patients who receive the routine home care.

2. The informal caregivers of the case managed HIV-infected patients will be more satisfied with formal health care services than informal caregivers of the routine home care HIV infected patients.

Two plans for analyses of Hypotheses #1 and #2 were initially proposed: (a) descriptive statistical analyses, and; (b) inferential analyses involving the development of statistical models to assess the effects of the case manager on the designated outcome variables. Because the sample size did not satisfy the power requirements or provide a ratio of at least 10 subjects for each variable as needed for multivariate analysis, the analysis was confined to descriptive techniques. The sample was compared in terms of three groups: Group 1 (case managed caregivers); Group 2 (non-case managed caregivers; and Group 3 (non-case managed CATF caregivers). Group 3 was included as an additional control group.

Group 1. Group 1 was comprised of seven caregivers who provided care to patients who were receiving home care that was planned, coordinated and monitored per a case management protocol that was established in the Collaborative Home Care Project (Nickel & Salsberry, 1988) (See Appendix E). Case management was conceived as an administrative and management strategy that included ongoing assessment and the development of a comprehensive care plan. The plan of care was initially developed by the nurse case manager and revised with an interdisciplinary team every month. The case manager arranged for the delivery of appropriate services through referral, brokering, advocacy, and coordinating services. Case managers were responsible for the evaluation of services and for guaranteeing that services were available and appropriate.

The case managers were also responsible for both the establishment of formal linkages (contracts) with community agencies and management of individual patient care. Formal contracts, which detail the payment mechanism and quality control, were negotiated when services were not available through participating agencies (e.g., dental services). The case managers negotiation varied by the resources available to them as well as the specific patient needs.

Group 2. Group 2 was comprised of five caregivers who provided care to patients who were receiving usual home care through the existing (non-case managed) home care routines. The services available through this existing system generally included the following services: physical therapy; occupational therapy; speech therapy; home health aides, and; hospice care. Care for this group was provided by home health nurses who could suggest these or additional services, but had no authorization to ensure that services were available nor any formal quality monitoring function of these other services. General home health nurse functions were to: (a) assess patients; (b) develop a plan of care; (c) implement the plan, including direct caregiving; (d) supervise less qualified caregivers, and; (e) evaluate services.

Because hospice care includes additional support services (e.g., respite care), patients were stratified by home or hospice referral prior to randomization into the case managed and non-case managed groups.

A comparison of case managed and non-case managed care is provided in Table 3, with commonalities between groups listed first, then differences.

PROBLEMS

The foremost problem encountered in this study was obtaining a desired sample size. The final sample of 20 participants fell well below the projected need.

The sampling recruitment plan used in this study was chosen for two reasons. First, the Collaborative Home Care Project provided the investigator of this study with the names of HIV informal caregivers who could then be contacted by telephone. Second, it enabled the investigator of this study to have access to informal caregivers of patients who were currently receiving either case managed or routine home care services per protocols of the Collaborative Home Care Project (Nickel & Salsberry, 1988). However, a drawback to this sampling approach was that it failed to generate the desired sample size as potential participants fell below projections. The parent study

Table 3

A comparison of the case managed and non-case managed services.

	Case Managed	Non-Case Managed
Knowledge/Experience in Care of the HIV Patient	Specialized	Generalized
Knowledge of the Community	Extensive	Varies with Years of Experience
Comprehensive Initial Assessment of Patient/Family Needs	Yes	Yes
Development of Care Plan that Includes a Focus on Patient Self-Care Strengths	Yes	Yes
Evaluation of Care Plan	Yes	Yes
Revisions of Care Plan	Yes	Yes
24 Hour Oncall Coverage	Yes	Yes
Patient Contact	Initial Case Manager; Weekly Phone Calls; Monthly Visits; Home Health Nurse Visits as Required.	Home Health Nurse Visits as Needed. As Needed
Communication with Primary Physician	Monthly (Minimum)	As Needed
Interdisciplinary Team Involvement	Monthly (Minimum)	By Nurse Request
Thorough Assessment of Current Services to Determine Gaps and Overlap	Yes	
Work with Provider Networks to Facilitate the Development of Needed Services	Yes	
Contract with Other Agencies for Provision of Services	Yes	
Authorization for Needed Services	Yes	
Quality Monitoring of Others' Services	Yes	
Facilitate Inpatient Admissions and Discharge Planning	Yes	

terminated before an adequate sample size was obtained to assess the effects of case management on the caregiver. An alternative plan was thus instigated (CATF advertisement).

Prior to the initiation of subject recruitment, calculations were completed to determine a suitable sample size. Calculations were based on a standard deviation of 0.0791 documented from California-based AIDS research using the Quality of Well-Being Index (J.F. Anderson, communication, November 30, 1988). It was determined that in order to detect a mean difference of 0.06 between the case managed and non case managed groups, with a significance level of 0.05 and a power of 0.80, 32 subjects per group were required (Hulley & Cummings, 1988).

In July 1990, the incidence of AIDS and HIV-infection was projected for Columbus-Franklin County through 1992 (see Appendix F). These projections indicated that between 1991-1992, there would be approximately 3,056 new cases of HIV-infection and 382 new cases of AIDS in this community. Based upon these projections, it was anticipated that an adequate sample size would be obtained to satisfy the power requirements. However, (1) actual case numbers fell below projections, (2) only modest numbers of HIV-infected patients used home care services over the course of this study, (3) only a portion of these home care patients had informal caregivers, and (4) the parent study terminated. The alternative sampling recruitment method was thus utilized wherein an advertisement for participants was placed. This approach introduced the bias of self-selection and an addition problem was encountered. Several of the caregivers who responded to the advertisement had cared for patients who were deceased at the time of contact. The decision was made to include these persons in the study for purposes of providing a descriptive, retrospective account of the caregiving experience and to provide qualitative information about termination of the caregiver role.

Given the limitations imposed by the sample size, the qualitative portion of the data analysis was emphasized. The qualitative analysis thus provides the key focus of the analysis.

While a longitudinal/prospective design has several advantages over a cross-sectional approach in that it may capture changes in phenomena over time, there was an insufficient research base to suggest when it was best to collect data to capture any changes. Data were collected every three months, although it is acknowledged that these data points were somewhat arbitrary. However, the data derived from questions in the caregiver questionnaire were beneficial in that it provided an opportunity for a retrospective descriptive account of changes. These retrospective accounts were important because caregivers proved to be less available or willing to be interviewed during times of extreme demand.

PROCEDURES TO PROTECT HUMAN SUBJECTS

This study received initial approval from the Ohio State University (Biomedical Sciences) Human Subject Review Committee (See Appendix D). Part 1 was later revised and approved to include caregivers recruited from the Columbus AIDS Task Force Bulletin (See Appendix D).

CHAPTER FOUR

FINDINGS

The study findings are presented as follows. First, a description of the sample is provided. This is followed by qualitative data analysis that provides a description of the HIV caregiver role responsibilities and care strategies over the course of caregiving. Lastly, the results of the data analysis assessing the effects of case management on HIV informal caregivers are presented using descriptive statistics to compare case managed and non-case managed caregivers' health/well-being and satisfaction with services.

SAMPLE DESCRIPTION

Sample generation

A total of twenty subjects participated in the study. Twelve of the participants were informal caregivers to patients who received care from one of six home health care agencies. Seven of these caregivers were in the case managed home care group (Group 1) and five of these caregivers were in the routine home care group (Group 2). The rest of the sample (Group 3) was comprised of 8 informal caregivers who responded to an advertisement placed in the Columbus AIDS Task Force (CATF) Bulletin. Six of the CATF caregivers had cared for patients who were already deceased. These caregivers provided a retrospective account of the HIV caregiving experience and information regarding termination of the caregiving role.

Two caregivers who were eligible for participation, elected not to participate in the study. One was a mother who stated that she was too busy to take time for an interview. The other was a partner who stated he did not wish to participate in the study (no reason provided).

An initial interview (Time 1) was completed with each of the twenty study participants. Two follow up interviews (Time 2 and Time 3) were completed with a subgroup of caregivers. The follow up interviews were completed at three month intervals with caregivers from Group 1 and Group 2. A total of 7 caregivers participated in the follow up interviews. Two of the caregivers in Group 1 and three of the caregivers in Group 2 did not participate in follow-up interviews. Two of the caregivers in Group 2 (a sister and a partner) declined a follow up interview indicated that they were too busy. A follow up interview was not completed with a third subject in Group 2, with 1 subject in Group 1, or with any of the subjects in Group 3 because the first interview with these caregivers was not completed until the end of the specified data collection period.

The other participant in Group 1 who did not participate in follow-up interviews was interviewed at Time 1 over the phone. This interview was conducted over the telephone because when the subject was contacted by telephone to arrange an interview, the subject stated that he desired to be interviewed immediately and indicated that he preferred the anonymity offered by a telephone interview. Interestingly, as the interview proceeded, the subject became agitated, and expressed suicidal and homicidal thoughts. With the subject's consent, the study case manager was notified. Follow-up interviews were not completed because it was deemed that the caregiver's emotional status was too unstable. Written questionnaires were not completed by this subject.

Sample Description

Participants resided in a midwestern, urban community with the exception of one caregiver in Group 3 who resided in a rural community 90 miles southeast of the city.

Table 4 summarizes the demographics of the sample. Eleven of the caregivers were the patient's partner (55%). Five members of the sample were the mothers of the patient (25%). Three of the caregivers were sisters of the patient (15%) and one caregiver was a friend of the patient (5%). Groups 1, 2, and 3 had comparable relationship distributions with the exception of Group 3 which had a higher representation of mother's (3) compared with group 1 (1)

Table 4

Frequency distributions of selected demographic variables.

	Group 1		Group 2		Group 3		Total	
	F	%	F	%	F	%	F	%
Relationship								
Partner	4	57.1	3	60.0	4	50.0	11	55.0
Mother	1	14.3	1	20.0	3	37.5	5	25.0
Sister	1	14.3	1	20.0	1	12.5	3	15.0
Friend	1	14.3					1	5.0
Gender								
Male	5	71.4	3	60.0	4	50.0	12	60.0
Female	2	28.6	2	40.0	4	50.0	8	40.0
Total	7	100.0	5	100.0	8	100.0	20	100.0
Race/Nationality								
Euro-American	4	57.1	4	80.0	8	100.0	16	80.0
African-American	3	42.9	1	20.0			4	20.0
Education								
Some H.S.	1	14.5					1	5.0
High School	1	14.5	2	40.0	2	25.0	4	20.0
Some College	4	57.1	3	60.0	4	50.0	11	55.0
College	1	14.3			2	25.0	2	10.0
College Plus			1		1		2	10.0
Employment								
Full-time	4	57.1	4	80.0	5	62.5	13	65.0
Part-time	1	14.3					1	5.0
Not Employed	1	14.3	1	20.0	2	25.0	4	20.0
Retired					1	12.5	1	5.0
Disability	1	14.3					1	5.0
Annual Income								
10-14,999	2	28.6	1	20.0			3	15.0
15-19,999	2	40.0	2	25.0			4	20.0
20-29,999	3	42.9	1	20.0	4	50.0	8	40.0
30-39,999	2	28.6			1	12.5	3	15.0
40,000 +			1	20.0	1	12.5	2	10.0
Total	7	100.0	5	100.0	8	100.0	20	100.0

and Group 2 (1). Group 1 was the only group in which a friend provided care. Of the caregivers with a known HIV status, two partner caregivers in Group 1 and one partner caregiver in Group 3 were HIV positive.

Gender. Twelve of the caregivers in the total sample were men (60%) and 8 were women (40%) (See Table 4). The higher percentage of males is explained by the greater proportion of male partners and friends providing care in this sample. Group 1 had the highest percentage of males (71%), followed by Group 2 (60%) and Group 3 (50%). Consistent with these figures, Group 3 had the greatest percentage of female caregivers (mothers and sisters).

Race/Nationality. Sixteen participants were Euro-American (80%), while 4 of the participants were African-American (20%) (see Table 4). In Group 1, 3 of the participants were African-American. One of these subjects was a mother, one was a sister, and one was a heterosexual male partner. Only one of the subjects in Group 2 was African-American. This caregiver was a sister of the patient.

Education. Most (15) of the caregivers in this sample had at least some college education (75%) (see Table 4). In the total sample, 11 participants had some college education (55%), 2 were college educated (10%), and 2 had more than a college education (10%). 5 participants had some high school or had completed high school (25%). Groups 1, 2, and 3 possessed similar levels of education.

Employment. Most (14) of the caregivers in this sample were employed full-time (13) or part-time (1). Four participants were not employed either because they were housewives, were retired, or were on disability. Groups 1, 2, and 3 had a similar distribution of employment, with Group 2 having the highest number of full-time employed caregivers (4).

In the total sample, the majority (40%) of the subject's incomes ranged between $20,000-29,000 (see Table 4). Twenty-five percent had annual incomes of $30,000 or more and 35% had incomes at or below $19,000. Groups 1 and 3 had similar income levels, whereas Group 2 had a lower income level with 60% of the sample with incomes at or below $19,999. This is curious given the greater percentage of full-time employment reported by subject's in Group 2. Obtaining an accurate level of income was complicated by the fact that many of the households were supported by dual incomes, and income was in flux because of the patient's illness and reduced employment or the caregiver's cutting back on hours of employment to accommodate the patient's illness.

Age. In the total sample, the age of the caregivers ranged from 26 to 62 years of age, with a mean age of 40.4 years (see Table 5). Group 1 and 2 had similar mean ages, 38.4 and 38.8 respectively. Group 3 had a slightly higher mean age (43.4) which is indicative of the higher number of mothers represented in this group.

Table 5

Mean age (N=20).

Group	N	Mean	SD	Range
1	7	38.4	8.30	26-47
2	5	38.8	11.19	28-57
3	8	43.4	15.11	27-62
Total	20	40.4	11.52	26-62

Table 6

Mean years caring for patient.

Group	N	Mean	SD	Range
1	7	3.0	1.90	<1-5
2	5	2.5	2.30	<1-6
3	8	1.8	0.90	<1-3
Total	20	2.4	1.60	<1-6

Table 7

Mean number in patient household.

Group	N	Mean	SD	Range
1	7	2.1	1.33	1-4
2	5	3.2	1.50	2-5
3	8	2.8	1.33	2-5
Total	20	2.6	1.35	1-5

Length time caring. The length of time in which the subject cared for the patient ranged from less than one year to six years (see Table 6). Caregivers reported a mean of 2.4 years caring for the patient. Group 3 reported a slightly lower mean of 1.8 years, compared to Group 1 and Group 2 which reported mean years of 3.0 and 2.5 respectively. The lower mean number of years spent caring for the patient in Group 3 is consistent with the larger number of mothers in this group. Mothers and sisters tended to provide care for a shorter period of time. However, this figure is variable depending upon the caregiver's notion of what constitutes "caregiving." When questioned, it was clear that many of the caregivers had begun administering more subtle forms of caregiving prior to the year cited. Further discussion follows in following section "Beginning the Caregiver Role."

Number in household. The number of people residing in the patient's household ranged from 1 (patient living alone) to 5 (see Table 7). The mean was 2.6. Group 1, 2, and 3 reported similar household size with Group 1 somewhat lower with a mean of 2.1 compared with a mean of 3.2 in group 2.

Description of Patients. Two of the patients were women. The other 18 were men. The 18 men were gay or bisexual and 3 also had a history of intravenous drug use. The patients were in different stages of HIV illness. As indicated previously (Chp. 2), although disease progression varies widely among individuals, the HIV disease course can generally be regarded as having four discrete biophysical stages: Stage 1 -- Initial infection to time of diagnosis: a transient flulike syndrome associated with seroconversion, developing within weeks or months of infection; Stage 2 -- Latent: an asymptomatic period of more than four years average duration; Stage 3 -- Early manifest: symptomatic HIV infection of more than five years average duration; and Stage 4 -- Late manifest: Full blown AIDS characterized by opportunistic illnesses, HIV wasting syndrome, HIV dementia, lymphomas, and other neoplasms, averaging 9 to 13 months for treated and untreated individuals combined, and 21.3 months for those receiving antiviral medical treatments.

Subjects in Groups 1 and 2 cared for patients who were in stages 3 and 4 of the HIV disease course. Over the period of time in which the interviews were conducted, some of the patients remained stable in a given stage, and others experienced a downward decline. In Groups 1, three patients remained in Stage 3, two patients moved from Stage 3 to Stage 4, and two of the patients died. In Group 2, two patients remained stable in Stage 3, one patient was in Stage 4, and two patients died. Two of the subjects in Group 3 cared for patients in Stage 4. The other six caregivers in Group 3 had provided care to patients who were deceased at the time of the interview. The interval between time of death and the interview ranged from 2 months to 2 years. These six caregivers provided a retrospective account of the caregiving experiences for HIV patients across the illness trajectory. A brief description of each participant is provided in Appendices G (Group 1), H (Group 2), and I (Group 3).

CAREGIVER ROLE RESPONSIBILITIES

Qualitative analysis procedures were used to answer Research Question #1: What are the role responsibilities of HIV caregivers over the course of the HIV illness trajectory? This analysis was based upon data collected in interviews that were guided by a semi-structured interview format designed to elicit information concerning the caregivers' experiences and caregiving strategies (see Appendices A, B, and C). The interviews were audiotaped and transcribed. Data were coded and analyzed using grounded theory techniques. Extant literature and theoretical perspectives were incorporated in the data analysis to lend to the form and interpretation of the data when relevant. This approach is consistent with grounded theory methodology as explicated by Chenitz (1986). Chenitz (1986, p. 45) stresses that in the grounded theory study, the literature review is an ongoing process that is conducted to "fulfill the needs of the analysis." The review may be used to: (1) use literature as a source of data to verify and elaborate categories; (2) elaborate on the structural conditions; (3) learn more about the area's structural conditions; and (4) discover and learn about related subjects as they arise.

Analytic Framework

Content analysis of the caregiver interviews distinguished several dimensions of the HIV informal caregiver role including: (1) Deciding to Care

(2) Modifying the patient-caregiver role relationship; (3) Performing patient-centered activities; (4) Managing courtesy stigma; (5) Living with loss and sorrow; (6) Minimizing fear of exposure; (7) Handling role conflict/overload; and (8) Mourning patient death.

These dimensions are considered in this analysis in the context of three phases: (1) beginning the HIV caregiver role; (2) sustaining the HIV caregiver role; and (3) ending the HIV caregiver role. These phases provide structure for detailing the dimensions of HIV caregiving and various subcategories, which specify caregivers' responses to the stressors or challenges characteristic of each phase. A summary of this analytic framework is seen in Table 11.

Table 11

Dimensions of HIV caregiving role.

Phase of Caregiving	Dimension of Caregiving
Beginning	Decide to Care Modify Patient-Caregiver Relationship
Sustaining	Perform Patient-Centered Activities Manage Courtesy Stigma Live with Loss and Sorrow Minimize Fear of Exposure
Ending	Handle Role Conflict/Overload Mourn Patient Death

The first phase of HIV informal caregiving identified in this analysis, *beginning the informal caregiving role*, focuses on the challenges and strategies used to reduce stress when assuming the role. The second phase, *sustaining informal caregiving*, centers on four areas of caregivers' lives that are most problematic and describes the primary strategies used by caregivers to sustain their role over time. The last phase of the role, *ending informal caregiving*, involves two different processes that are involved in ending the caregiver role. One is the process by which caregivers relinquish their role prematurely; and second, the grief and bereavement processes that occur following patient death.

The essential process of HIV informal caregiving identified in this analysis that cuts across the different dimensions of role responsibility was finding "balance." In the broadest sense, balancing was identified as a self-regulatory process by which caregivers seek to secure coherence and equilibrium between several interacting and often opposing processes in which they are engaged. This analysis suggests that an individual establishes balance by weighing options and acting to offset undesirable circumstances or tension states. In sociopsychological terms, balancing involves interpretation and choice (Pinder, 1988). While managing illness, caregivers are actively engaged in making decisions about what, when, and how to accomplish certain goals and tasks, and defining the dimensions that have to be taken into account in order to achieve these. In making such determinations, various alternatives are negotiated in search of the most viable and desirable outcome at any one point in time in terms of self and others. Balancing is thus both a personal and a sociopsychological process and involves transactions with others as well as oneself.

The possibility of being off-balance or in a state of disequilibrium is present for individuals at all times. For example, conflict or imbalance can arise when individuals fail to balance different dimensions of their life in a satisfactory manner (e.g., work and child care responsibilities), when there is disagreement with others or uncertainty over priorities, when the social environment changes, or when the appearance of new manifestations (e.g., illness symptoms) require new calculations to be made and a new equilibrium negotiated. With balancing strategies, most people are able to achieve or maintain an overall sense of stability or coherence (Pinder, 1988). While individuals must continuously adapt to disruption, coherence (Antonovsky, 1987) is achieved to the extent that people usually predicate their lives on the notion that the world is fairly manageable, comprehensible, and predictable. Plans are generally made in the reasonably confident expectation that they will materialize. This perception essentially protects individuals from experiencing the world as intolerably chaotic. Highly disruptive life events, such as HIV, can interrupt this perspective and render an individual's world chaotic and uncertain. However, a sense of chaos and uncertainty will not necessarily persist over the course of illness. Individuals may utilize balancing strategies to restore a sense of coherence. These strategies are fluid and involve revising, reconsidering, negotiating and drawing upon available resources and previously underutilized personal capacities. At the most positive end of the spectrum, an individual's sense of coherence and self-regard will be enhanced as a result of this balancing process. Conversely, an individual may be unable to find balance and their sense of coherence may dissipate.

The following analysis elaborates upon this initial conceptual formulation. It must be noted that the different dimensions of HIV caregiving flow into one another and sharp boundaries cannot be delineated. While qualitative differences can be distinguished, it must be recognized that these dimensions are interactive and one dimension cannot be discussed with complete exclusion of the other. This is especially true of stigma which is highly influential, particularly in terms of effecting the balancing strategies selected by caregivers.

BEGINNING THE ROLE

Caregiving is a process intended to assist a patient to restore, maintain or optimize health and well-being following HIV illness onset. Caregiving develops in response to the patient's emerging emotional or physical needs following illness onset. In a process of mutual patient-caregiver consent, the patient engages and the caregiver becomes engaged in caregiving activities.

The key psychosocial processes involved in beginning the HIV informal caregiver role are: (1) deciding to care, and (2) modifying the patient-caregiver role relationship.

Deciding to Care

Partners/Friends

For partners or close friends participating in this study, the caregiving role often began early in the HIV illness trajectory. In other health care populations (e.g., elderly), women customarily assume the caregiving role. The literature (e.g., Brody, 1981) suggests that this reflects the moral imperative of women in our culture. In this sample, as noted in the following excerpts, men expressed similar notions of moral obligation or personal desire, perceiving the caregiver role to be apart of the responsibility of a committed relationship as partner or friend.

> S: I haven't really thought about not being there for Terry. I feel strongly for Terry and I love him ... there's those vows for better or for worse and I think that I knew going in seven years ago that this was always a possibility ... I wouldn't run away from him ... I don't take the chicken way out of something ... life's tough, I'm not just here for all the fun.
>
> T: I will be here through the end. At times I will wonder what the hell I am doing here, you know, why, why, why, do I put myself through this, but that's part of the commitment that I made when we first got together, so through thick and thin, better or worse, sicker or poorer - that type of thing. This is sicker and sometimes poorer, but, I'm going to stay here. He doesn't have to worry about me leaving.

> M: I've heard stories about people abandoned. I couldn't even conceive that. It never occurred to me as an option. It was not brave. It was not undertaking something difficult. This was about love and he would have done the same thing for me.
>
> B: There were periods where it was rough, but there's never been any doubt in my mind that I would be there until the end.
>
> R: I did it because morally I couldn't see anything else to do. I looked at my relationship as anyone would their marriage...In my heart I couldn't do anything else but what I did.

For one HIV positive caregiver, care was assumed because the caregiver feared that he was responsible for his partner's HIV illness and he thus felt an obligation to care for his partner. For the friend in this sample, the caregiver role was assumed because the friend regarded himself as the patient's only alternative or alternative to being admitted to a nursing home. The friend deemed this as an unacceptable option.

> D: Nobody else wanted to do it so I decided to. I was there, there's nobody else there for him ...I can't send him to a nursing home. He wouldn't like a nursing home and he can't live by himself and his family, they can't do anything, so then, that's it.

For partners and friends, the transition to caregiver role is usually very subtle and it is difficult to establish precisely when caregiving begins. There is a grey area where it is difficult to distinguish when everyday (and accepted) support becomes 'caregiving.' For example, one caregiver had been involved in a number of physical and emotional care activities for some time, but he did not regard himself as a "caregiver" until very late in patient's illness trajectory when patient could no longer reciprocate emotionally.

A resistance to regarding oneself as the patient's caregiver may represent a desire to protect the patient's identity as an autonomous being. That is, one who is functioning well enough that he or she does not need supplemental care. Failure to regard oneself as "caregiver" may thus reflect an act of "mutual pretense" (Strauss, 1962) wherein the caregiver is in collusion with the patient to minimize acknowledging his or her declining participation as a partner or friend. Failure to regard oneself as a caregiver may also reflect the nature of caregiver role development which is extremely gradual in these situations. The caregiver, like patient, seemingly "drifts" (Matza, 1964) into his or her role and the change may not be recognized until it is signaled by some event that is meaningful to the caregiver (Strauss, 1962) (e.g., total loss of emotional reciprocity).

Mothers/Sisters

For members of the patient's biologic family in this sample, caregiving typically did not begin until late in the illness trajectory, usually following an AIDS diagnosis. Unlike the partner caregiving situations, the AIDS patient and the family member were usually not living together at the time when the family member learned of the patient's diagnosis. Care typically developed following an evaluation by the family member that the patient's current circumstances were not adequate. The decision to care was made because the family member perceived that the patient needed help and there were either no other options for care or the family member desired to be involved in this manner. In these circumstances, the transition to the caregiving role tended to be abrupt and usually began when the family member recognized the patient's need for assistance and acknowledged this to the patient. The caregiver would suggest that the patient return home for care or this option was made known.

> L: I just said, "I think you need to come home." It was because she was so frightened. I think she needed her parents to be with her.
>
> N: It got so he and his roommate couldn't take care of each other, so it was his decision to come home, we let him know that he could.
>
> M.L.: He was alone. I said, "I think you should come home." It took a while before he did.

For mothers, providing care to one's child was an unexpectedly painful and difficult task, but within the scope of one's responsibility as "mother." For example, one mother, assumed the role when the patient's partner, who was also HIV positive, became too ill to provide care.

> N: This is not what I wanted to take on, but he needs somebody to take care of him and I'm his mother.

Although assuming the caregiver role appears, in part, to be a function of the role expectation or sense of moral obligation felt as partner or family, it is also related to the degree of familiarity established and socially sanctioned in these relationships. In this sample, care was most often provided by those with whom the patient had the closest relationship. For partners, providing care was usually a natural outgrowth of the intimacy of a paired relationship.

When a partner was not available for care, the patient usually preferred someone with whom he or she had a history of a very familiar relationship which had been sustained to some degree during patient's adult life, particularly at the time of illness. All of the mothers in this sample described having maintained very close relationships with their HIV-infected son or daughter.

> M.L.: Caring for him came naturally. It was just like caring for him when he was sick when he was little.

Although the sisters in this sample did become the primary caregiver to a sibling, their role was constructed in less familiar ways, that is, with fewer intimate, personal care tasks provided.

Sources of Conflict

When beginning the caregiver role, caregivers consider feelings of obligation to provide care in relation to other responsibilities and the availability of other appropriate care options for the patient. This was particularly evident among the three sisters in this sample where the caregiving role was experienced as being in direct conflict with their other family responsibilities. However, they began to provide care to the patient because no one else in the family would and, at the time, the patients did not have partners available.

> A: To be honest with you, if I had to do it all over again, I would have had him do it with my parents ... I feel like he's not my child, he's my parents. They put the guilt on me and I said, hey, I have no guilt. I've done more than my share. I said, you're the one

> that ought to be feeling guilty, not me. They don't have any kids at home and it should be their responsibility not mine...It's really been rough, I'll tell you ... My mother won't change her mind and I can't turn my back on him, I'm not that kind of person, I can't do what she's doing. That's not me.

In this case, the parents were unwilling to assume care for their son because of their fears of HIV contagion and a desire not to reveal to their friends that their son was homosexual.

> A: They're old fashioned. They don't want anybody to know anything about it, although the whole family knows. They're embarrassed because they've always thought he was homosexual but they never knew it for sure. They've got two things wrong now so they're very indifferent. I mean they're there if he needs money or if he calls and that kind of thing ... they're there for those things, but it's all on me and it's becoming a strain to my family.

In another situation, a sister stated that she assumed care for her brother because she was not satisfied with the care her brother was receiving from other sources.

> W: Bobby was living with a friend of a friend and I didn't like the way they were treating him so I told him to come home with me ... Where he was living, it was just no place for anyone to live ... Everyone asked why I was doing it. He's my brother and I love him. That's all there is to it.

This sister assumed the role despite pressure from her family. She was told she was a "bad mother" for having an HIV-positive person in her household and jeopardizing the well-being of her own children.

> W: My sister called me one day after she heard that Bobby was staying with me and said, "I thought you really cared about your babies, but you're letting Bobby live with you with AIDS." Apparently my whole family felt that way. I said that's not how it goes. I care about my babies, but Bobbies not a threat.

This conviction meant grappling with her own fears about exposing her children to the HIV virus.

> W: I don't think God is going to take one of my babies just because I'm taking care of Bobby. I don't think God punishes. I don't think God would give one of my babies to AIDS just because I was trying to help my brother out. That's what I told everybody who was against Bobby living here. I don't think God would do that, I really don't.

Similarly, partners would assume the caregiver role despite overt suggestions by others that they should not.

> C: ...I never really figured it out, I just, you know, I don't even talk to them anymore. I thought that was kind of overstepping their bounds. Right away they started it, they weren't really concerned about me, they were more like saying that I shouldn't do it, but I just really can't do that.

When there is more than one person available who also desires to provide care to the patient, conflict can ensue regarding who will assume the role as primary caregiver. One caregiver described the struggles he encountered with his partner's parents who did not accept him as their son's partner. In this case, the parents invoked their legal prerogatives as parents. For example, during one hospitalization, they had their son placed in a nursing home despite the partner's desire to continue providing care at home. The partner described how he eventually convinced the nursing home staff to allow him to take the patient home each evening without the parents' knowledge.

Modifying the Patient-Caregiver Relationship

Altered Role Relationship. Informal caregiving involves a relationship between two people who have usually known each other well before the HIV diagnosis. Caregiving can begin at any number of points along the HIV disease trajectory, but it will involve introducing changes to the structure of the former relationship as the needs for caregiving become manifest.

HIV generally strikes during a time of life when individuals are autonomous and at a very low risk for life-threatening illnesses. Whereas the evolving HIV patient "sick role" (Parsons, 1951) entails relinquishing autonomy and coming to terms with a stigmatized illness and probable premature death, the evolving HIV caregiver role involves coming to terms with premature loss and assuming increased responsibility in order to lend support to the patient and off-set or compensate for the patient's diminishing psychological, social, and biophysical capacities. Restructuring the former patient-caregiver relationship can create strain for the caregiver because the new role expectations may be ambiguous or in discord with the patient's or others expectations for the caregiver's role.

In this sample, caregivers eased the tension of their role alteration by negotiating with the patient to clarify role expectations or terms of the new relationship. This involved an extremely subtle interactional process and the changes that were negotiated were not necessarily acknowledged overtly between the patient and the caregiver. As Strauss (1978) suggests, such negotiations may be so subtle that the respective individuals may not be thoroughly aware that they have engaged in or completed a negotiated transaction.

Negotiate/Clarify Role Expectations. A symbolic interactionist interpretation of roles and role behavior focuses on the meaning of acts and symbols among interactants. This view can be used to explain how roles begin and evolve over time, and the means by which present role patterns can be altered (Conway, 1978). The term role-making describes the process taking place when role modification and negotiation occurs. Role-making involves taking the attitudes of others who are involved in an interaction; that is, both an individual and another endeavor to understand the meaning of each other's symbolic gestures. In role making, the interaction is structured in such a way as to modify it and, in doing so, certain aspects of the role are made explicit (Turner, 1962). Thus, when the behavior of a role partner departs from expectation, and the other accepts that departure, role making occurs.

Considered within the interactionists context, the HIV caregiving role is negotiated from a sequential pattern of successive action/response patient-caregiver transactions. It begins with a departure from the previously held patient-other role expectations and it is dependent upon new patient-other role expectations that develop based upon the patient's evolving "sick role" (Parsons, 1951) following an illness diagnosis. The informal caregiver role may include a variety of emotional and physical or task oriented behaviors such as assuming increased responsibility for the ill person's household chores, taking the ill person to health care appointments, or administering medicines. These actions will be negotiated with the patient and will alter over the course of illness depending upon the patient's, as well as the caregiver's, capacities and commitment to the situations in which he or she is a participant (Alonzo, 1979).

Summary

Over the course of their illness, HIV patients assess their capacities and parlay their environment to balance or compensate for areas of deficiency. Generally, the patients must balance a desire for autonomy with a need for assistance if they are to have their care optimized or wish to remain in a home environment. Patients consider available resources and negotiate a combination of situational support that is most comfortable to them. This support is contingent upon what resources and services are actually available to the them, what the patients perceive as being available, perceived and actual affordability of available services, as well as the patients' personal comfort with a given service or source of care. For some, making a sacrifice in terms of physical well-being may be preferable to suffering what they regard as the indignity of relying upon others for personal care. In other words, the degree and type of care or support accessed by the patient will depend upon the patient's interpersonal style and priorities, as well as, the availability of resources in relation to the patient's capacities. Informal care is usually the most desirable form of support available to HIV patients, and it is often the only way the patient can remain at home, or in a home environment. Without informal caregiver assistance there would often be significant gaps in the ill person's care, a need for long-term institutional care, or a demand for additional home care professional services.

For informal caregivers, the willingness to provide care is established when the potential caregiver perceives that care is needed and when he or she feel a moral obligation to do so. In making the decision to provide care, HIV caregivers weigh their desire or willingness to care against their ability to fulfill the role responsibility. Like patients, caregivers assess their own capacities, the patient's capacities, other responsibilities or priorities, and available resources. Caregivers decide to commit to the role based upon their assessment of the meaning of this activity, their perception of what will be involved and their perceived capacity to succeed. Whether the caregiver role is begun gradually or in a more precipitous manner, it begins with a subtle patient-caregiver interaction where caregivers negotiate with the patient regarding what aspects of his or her care to assume and how this will be accomplished. Caregiving is thus begun with patient and caregiver striving to balance needs and possible options for care against one's capacities and sometimes opposing desires and responsibilities.

SUSTAINING THE ROLE

Once the role is begun, caregivers contend with a variety of sociopsychological challenges related to HIV patient care and an emerging caregiver identity. Caregivers who sustained the role over time utilized a combination of strategies to achieve a measure of balance and coherence. The role of the patient with HIV disease changes over the course of the illness and the caregiver role alters correspondingly. The development of the caregiver role is gradual with the caregiver imperceptibly assuming an increased number of responsibilities as the patient's condition declines and he or she drifts into the sick role. For partners, the transition to the caregiver role typically involved a subtle, but eventually dramatic shift in the nature of the patient-partner/caregiver relationship. Although providing care was generally regarded as an integral component of a loving relationship, the mutuality upon which the relationship is premised declines as the patient becomes unable to fulfill normal role expectations. The caregiver must thus continue to alter relational expectations as she or he adapts to assist the patient with an unpredictable and physically and emotionally devastating disease, assume an increased number of instrumental tasks, and fulfill external responsibilities, such as work.

The major sociopsychological and instrumental challenges identified in this phase of HIV caregiving include: (1) performing patient-centered activities; (2) managing courtesy stigma; (3) living with loss and sorrow; and (4) minimizing fear of exposure.

Performing Patient-Centered Activities

In this sample, HIV informal caregivers performed a wide range of activities to lend emotional and practical support to the patient. HIV informal care represents a continuum that changes depending upon individual circumstances and variations in the HIV disease trajectory. Emotional support was likely to be the prevalent form of care provided by informal caregivers in the earlier stages of the HIV trajectory. Progressively large amounts of both emotional and practical support were likely to be rendered by caregivers in the latter part of the illness trajectory when the illness becomes manifest and the patient's physical capacities diminish. However, this is not absolute this analysis suggests it will vary considerably depending upon the patient's overall well-being at any given point in time in the illness trajectory and what has been negotiated between the patient and the caregiver.

Providing Patient Care

HIV caregiving may demand considerable time and energy as the caregiver endeavor's to manage a combination of caregiving activities to meet the needs of the patient. Major categories of caregiving activities identified in this analysis include: (1) Being available; (2) Assessing and anticipating; (3) Fostering emotional well-being; (4) Lending practical support; and (5) Coordinating formal care.

Being available. "Being available" refers to being accessible to the patient to meet his or her needs as necessary. Caregivers indicated that much of the time spent with patients did not involve actually doing anything for the patient, but just being available to the patient in the event a need arose. The desire to be available to the patient tended to increase as the patient's illness progressed. Toward the end of the patient's illness trajectory, caregivers typically find it difficult not to be available to the patient for even short periods of time. Caregivers indicated that they were particularly anxious to be with the patient at the time of his or her death.

Assessing and anticipating. Caregivers spend a considerable amount of time observing the patient to determine his or her health status and to evaluate the significance of any changes. Caregivers look for early changes in the patient's condition because they are anxious to intervene to prevent major problems or medical crises.

> L: I want to keep her well as long as I can ... If I can keep her from the infections by fighting them when they're small and getting rid of them when they're small, then it won't zap her out real quick. I think that the larger infections do zap them out and that's when they get into trouble and it escalates into bigger things.

Caregivers consider the patient's strengths and resources and evaluate possible options for treatment or services as needed.

Lend practical support. Caregivers also engage in a number of activities to lend practical support to the patient. These activities may include: supervising or carrying out prescribed treatment and general recommendations; managing illness-related finances/paperwork; assisting with mobility; doing extra home maintenance work; providing transportation; performing personal care for patient; doing extra housework; making adjustments in housing arrangements; managing medical crises; supervising or directly managing patient's resources; doing things to protect the patient from injury or accidents, and; encouraging nourishment.

Over the course of the patient's illness, most caregivers provide a combination of these types of practical support as well as engage in a number of activities with the intent of fostering the patient's emotional well-being.

Fostering emotional well-being. It is clear that alleviating the emotional suffering that accompanies the patient's illness is a central concern of most HIV informal caregivers and a substantial amount of emotional support is rendered.

> R: There's a lot of thought that went into his care; the physical part of it and the emotional part of it. I think the most difficult thing is the psychological health caregiving.

Caregivers are cognizant of, and distressed by the patient's anguish when his or her physical capacities decline.

> K: It was very difficult watching the effects of the disease on him, to watch him lose control of bodily functions. Not so much necessarily that, but the way that effected him psychologically. He was losing his

> self-respect because he had to have someone clean him up, change his diaper. That psychological effect was much more difficult than the physical.

Caregivers work to avoid imposing further assaults on patient's sense of self and work to promote the patient's sense of emotional well-being by completing activities such as: trying to keep patient's life as normal as possible within bounds of his/her impairments; "running interference" for the patient in social and community; touching (e.g., hold hands, hug); doing things to bolster the patient's self-image; encouraging patient to engage in social and recreational activities; enabling patient to have desired religious/spiritual support; and using humor to ease tension.

> M: I fixed the meals and had to coax him to eat. He called me "the food monster." He would say, "Oh no, here comes the food monster."

Caregivers continuously attempt to strike a balance between what is best for the patient both practically and emotionally.

> M: He didn't like to be dependent on anyone. He didn't want to be a burden. I went out of my way to avoid treating him like an invalid and I avoided making concessions that would make it seem like I was feeling sorry for him. Sometimes it involved letting him do things that I thought he probably shouldn't be doing, but better that he should do it so he would feel independent and useful rather than my taking over and doing them. I had frequently to fight an inclination to make compensations and do things for him. There was plenty to do and he wanted to do as much as he could do.

> K: Initially you want to baby a person. I had to make myself not do that, let him do as much for himself as he could...he wanted to be very independent.

> R: I literally got on my hands and knees in front of him when he was sitting at the kitchen table one day and I said, please, don't drive the care, please. I never took the car away from him, because, you take away the car and you take away their... you can't do that.

While caregivers generally encourage the patient to remain independent and manage their own illness as much as possible, they keep a watchful eye to assure that the patient is completing self-care as caregiver thinks he or she should. One caregiver expressed her uneasiness about the relationship between normalization and denial. This mother realized that denial helped her daughter emotionally in terms of minimizing perceived stigma, but she was concerned that denial could limit preventive actions that could enhance her daughter's longevity.

> L: Kris is a denier and I don't want her to deny. I want her to look at it the way it really is, but I don't want her to look at it in the present stigma way. I don't want her to look at it like, that's it, there's nothing else. I guess I want her to be optimistic, but not deny things. We are in a situation where it is very, very, vital that you take very good care of yourself as long as you can.

It has been suggested that when individuals are symptomatic they tend to "drift" into an illness relationship with their situations (Alonzo, 1979). In so doing, the patient begins by relinquishing participation in less important and less valued situations and activities, while attempting to cope with or contain signs and symptoms in highly committed situations where he or she and others feel participation is necessary. Similarly, when the individual perceives a congruence between capacity and situational demands, the individual will drift back into situations on the basis of priority (Alonzo, 1979). The caregiver typically encourages the patient's situational participation and will act to facilitate it. While HIV caregivers do not expect the patient to "get well," as suggested by the Parsonian (1951) conception of "sick role," caregivers repeatedly express their expectation that the patient "fight" the disease process.

> B: It is really not any different than when he was first diagnosed. He's very aggressive with the disease; does not allow the disease to get the best of him. He's there fighting the whole time; he's not letting it get to him most of the time. There were a couple of periods during the last two and a half years where he was ready to hang it up and just pack it all in, but he's got a lot of support and a lot of friends and they're not going to let him do that. His biggest thing for going is not only for himself, but he's stated several times, he's not going to let his friends down and just let it get the best of him. So that keeps him going.

Urging the patient to "fight" the disease and maximizing situational participation through caregiving activities may represent a desire to enhance the patient's sense of self and well-being. It may also represent the caregiver's desire to avoid loss associated with the patient's "social death." Caregivers are very concerned that the patient's emotional health status be maximized and believe that health care providers could be beneficial in this regard. For example, one caregiver described how she regarded the emotional support provided by a home health aide to be important to her son's well-being.

> N: He has a home health aide come in twice a week. It's not necessary right now but Mike likes to talk to her and she's real nice so she kind of lifts his spirits.

Caregivers are aware of the patient's emotional suffering and are concerned when health care providers seem to focus exclusively upon the patient's physical being. Caregivers repeatedly expressed a desire for health care professionals to be cognizant of the patient (and significant others) as socioemotional beings and ventilated their concern that this was often not the case.

> L: I don't think anybody could understand this unless they went through it ... It affects her entire life style. She doesn't go out like other kids; she doesn't have any sexual life. She's very, very, reserved, frightened almost, of men. It just totally affects the person. It doesn't just affect the person, it affects her whole surroundings and it affects everybody that's in her life. Maybe they [health care professionals] can empathize about the medical side of it, but not the personal side, not the personal side of it or the environmental side of it ...

> R: These two doctors are marvelous people, don't get me wrong, they know exactly what they're doing, and they did everything that they could, but Dr. Guy does not speak; he stands ten feet away from the bed as if he's afraid to touch you; says two or three words and walks out the door. I mean that's all you get out of him. He does not involve himself with family matters and those are very important things because that's what gives the family of the person who's taking care of the patient the strength to go on ... you know how most people feel about physicians, they're God ...so if a physician says to me or touches me, puts their hand on me or puts their hand on my shoulder and says, I've got alot of faith in you, you can do it, I will do it dammit, but no one ever said that to me.

> K: [During patient's hospitalization] the basics were taken care of but many things were lacking. [Nurses] did the minimal, but the quality of care suffered. Nurses needed a course in AIDS to understand every aspect of care that needed to be addressed. Nurses are very busy, but there's alot more to care then just the physical part. [They] must try to address the psychological component.

> M. His [patient] first doctor was not helpful, not competent; so he changed to a really terrific doctor. It made a great difference to his attitude about sickness to have a doctor he could trust, who was clearly concerned and understood and was responsive and aware of the illness -- had worked with patients with HIV. It made a huge difference in his view and in mine. I could sense how unhappy he was with the doctor before. You know how the medical profession so often encourages a feeling of dependence and I'm afraid his previous doctor did this sort of

> thing and when he had this new doctor she was quite different and she encouraged him to learn about what was going on and ask questions to clarify. I'm not sure he was any better medically but he was certainly better from a human point of view. I'm sure [L] responded much better and made improvements and died more comfortably then if he had the other doctor he was dealing with or someone else who was less caring.

Some caregivers felt health care providers did not recognize their role as "partner" and were disturbed that their relationship was not recognized as having depth and affectional qualities as heterosexual couples.

> R: To the day Jimmy died, Dr. Guy was not sure who I was. He knew he recognized me but he didn't know who I was. I resent that because it really hurts.

Caregivers may also be upset by manner in which care is provided which may not be perceived as being in best interests of patient.

> R: Every doctor's visit was at least five hours; every single doctor's visit, no matter whether it was just to take blood, get weight and go home. Everyone comes in at the same time; everyone gets chemo; everybody gets what they need and there's one doctor. These are the things that we have to stop in the health care system because these people can't take it. They can't take it. They are scared to death to go to the doctors in the first place and when they find out by the third time that every time they go it's going to take them all day ... it takes you as the person at home, as the significant other, three days to get them back on their feet from one office visit. It's not fair. It's not right.

Several caregivers stated that they preferred the infectious disease unit in one hospital because health care professionals on the unit understand the needs of HIV patients.

Coordinating Formal Care. Caregivers generally want to do a great deal for the patient. Over the course of the illness, the caregiver will assess and reassess the patient's, as well his or her own capacities and limitations. The caregiver evaluates the patient's needs in relation to available resources and sometimes seeks additional resources to compensate for perceived deficiencies or lend support to the caregiving situation.

Initially, the patient assumes responsibility for arranging necessary health care services with formal care providers. The patient will often consult with the caregiver, and decisions may be made jointly.

> L: We usually agree about what she needs. We sit down and talk it through and then she makes the decision. Now I tell her how I feel about it, you know, I say well, I think that this should be done or this is the way or this sounds like a good idea. She determines what she wants to do about it.

Caregivers vary regarding their desire for participation in decision making.

> R: I always told Jimmy, you're in charge. When I was a volunteer at the AIDS Task Force, it always bothered me to see families who got together and decided what was going to happen to the person who was ill and they just went ahead with it. The person who was ill had no say. So when Jimmy got sick, the first thing I said to him was, this is your gig, you make the decisions; you decide what's going to happen.

As the disease progresses, the patient may become increasingly unable to manage his or her own care and the caregiver will often assume greater responsibility for providing care and coordinating formal patient care services. Even in instances when a case manager takes on some portion of these functions, the informal caregiver often have the ultimate decision-making responsibility.

The extent to which caregivers use formal home care services is influenced by several factors including a perceived need for formal services, desire for additional services, availability of and comfort with informal resources, and availability of formal services.

Some caregivers expressed regret that more formal home care services had not been utilized over the course of the patient's illness. Typically, the patient and caregiver would negotiate what, if any, additional home services were needed. Many patients preferred to have the caregiver do everything, and caregivers often chose to honor this request if possible. Although some recognized that additional help would have been beneficial, they desired privacy.

> R: I never had any help until the very end and that was probably my fault and it also was Jimmy's fault. Whenever I did suggest it, he would say I don't want anyone in the house; I don't need anyone.
>
> R.J.: There were always people in the house all the time so we didn't need hospice. I mean we didn't need strangers around, he had all of his friends.
>
> M: Initially he was resistent to hospice because he didn't want someone from outside. He finally did out of concern for me.

Caregivers sometimes demonstrated a measure of pride in not utilizing services. For them "doing it all" was a measure of their competence and devotion to the patient.

When caregivers needed assistance they would often draw upon a network of friends and/or family to supplement care. This depended upon the caregiver's comfort with available assistance. One caregiver described his uneasiness with relying upon an informal network.

> B: I needed somebody to watch him all the time but even though people would volunteer, I wouldn't, I was not comfortable with calling his friends and saying would you come babysit? Because a lot of his friends are younger couples from his church that have children and they're watching their kids and it's like I can't stick an adult kid in with all these young kids and expect them to be able to take care of him because there's no way of knowing what he was going to do and it was not something we wanted to subject the kids to either because a lot of the kids knew him before he was sick and, trying to explain what was going on is not something we wanted to get into so it was rough. It was real difficult.

Some caregivers were very practical about utilizing additional assistance and desired and sought as much additional help as available. However, there were different barriers to care including inadequate income or insurance coverage. Furthermore, at the systems level, needed services had to be available in the community.

> M: If there were more services available I would have used them. You bet I would. There were some days I was so tired I couldn't eat, I couldn't think straight. Yes, I would have used them.

HIV caregivers tend to develop one of three types of relationships with formal providers including: (1) the informal caregiver(s) provides all the assistance without any formal home care services; (2) one or more specific tasks are provided by formal home care service providers and informal caregivers provide the rest of the care; (3) informal caregiver and formal service providers assist with different tasks, and there is overlap in some of the responsibilities.

Caregivers sometimes demonstrated confusion about which home services the patient was receiving and what was available in the community. This was, in part, because the patient (or case manager) was assuming responsibility for coordinating care and was thus more aware of which services had been arranged. It was also apparent that some caregivers understood health care provision better than others and were more savvy in managing and understanding nature of formal care provided. It often takes time for caregivers to become acquainted with community resources.

Role Incompetence/Uncertainty

Caregivers may experience considerable uncertainty in their role as care provider. Uncertainty has often been recognized as a critical concern of chronically and terminally ill persons and their caregivers (Conrad, 1987; Glaser and Strauss, 1968; Mishel, 1984; Weitz, 1989). Uncertainty is thought to exist when individuals lack a cognitive framework for understanding their situations and thus feel they cannot predict the outcomes of their behaviors (Weitz, 1989).

HIV caregivers face multiple sources of uncertainty that are particularly problematic at the time of the patient's diagnosis and when the patient develops a new HIV-related illness. The uncertainty is enhanced if the HIV-related illness diagnosis is indefinite.

Following an HIV diagnosis, there may initially be much anxiety and uncertainty regarding what to expect in terms of the HIV trajectory. How long will the patient live? When will the patient become seriously ill? This sense of uncertainty is compounded by the fact that the disease is not fully understood, its course cannot be predicted, and treatment regimes are variable and are changing rapidly. If the source of infection is unknown, caregivers and patients often seek to find the probable source. Finding the source and time of exposure appears to be an attempt to determine what to expect in terms of the length of time left in the patient's HIV trajectory. One caregiver described how he and his partner incorrectly anticipated that the illness would progress rapidly.

> J: ... we thought then he was going to die, you know, just like that ... We thought it was probably going to be a quick progression.

Later, when the patient's illness becomes manifest, caregivers face renewed uncertainty surrounding the disease process.

> B: During the period of time when he was experiencing severe dementia, he had no idea what was going on. It was scary because I didn't know what to do.

> B: There were things that were going on that people weren't able to control ... you get through it but it's difficult those first couple of times because you don't know what to expect; everything's new. It's like you walk in the room one day and he's fine and you walk in the room the next day and he's rambling and its like 'why?' And nobody could tell you and then the next day you walk in and he's fine and then the next day you walk in and there's something else until you've gone through all of the, until you *think* you've gone through all of the different things.

> L: So far we've kept her out of big infections. I'm not saying what's going to happen tomorrow. When she gets something new it is an anxiety. It creates a scary feeling. See, the little things can be big things.

> R: You need to know before you enter into this how not to allow that to happen, how to avoid those horrifying feelings and all those sleepless nights and all those days of worry. Am I doing enough? Am I doing the right thing? There's got to be something I can do to save him. There has to be. There has to be something I'm doing wrong. Why does he have a fever today? Why is he losing weight? Why is he still losing weight? Why is he eating more? Sure he's having six bowel movements a day because he's eating so much, but he's not gaining a pound. Why is this happening? Hello doctor, can you help me? Well, no we're not interested; we're not interested in talking to you; we're not interested in explaining things to you; we don't have time.

Although caregivers regard the patient's emotional well-being as very important, they are also often very uncertain about what the patient is experiencing emotionally and about their ability to "say the right thing."

> M: Sometimes I was uncertain about the right thing to say. I would say that to him and he would say, "Don't worry about it. That's o.k. There's nothing you can say..."

Saying "the right thing" can clearly present a challenge.

> R: I remember one day him saying to me, "I want pancakes." I said, "Fine." I gave him pancakes and he looked at them and he said, "You know, if you were my mother you would have these cut up for me." I said, "Well, I'm not your mother," but I didn't say, you can cut them up... I never called him and said, how are you feeling today; I always called him and said hi; I never reminded him of his illness because I was constantly afraid that he might not be thinking about it at that moment. Why should I bring it to his mind; he's got to be thinking about it constantly anyway.

Caregivers relationships with health care providers do not necessarily promote a sense of competence or reduce uncertainty.

> R: I had to learn how to give him injections which no one at all cared to teach me. No one ever said, this is how you give an injection.

Caregivers may also disagree with the health care providers assessment and management of the patient's situation or become distressed if their role is perceived differently. One mother was concerned because physician did not want to include her in the decision making concerning her daughter.

> L: I don't know how well I can communicate with health care professionals. Her first doctor was very open with me, but with this new doctor I can't. He's kind of locked me out and I don't like that because we're working on this together ... He's got the idea in his head that he never has to deal with anybody but her. I guess that might be true with most people, but not in this case. We're working this thing out the best we can together. I think that's a good way because there are alot of times that he can't see the issues as clearly as someone else on the outside does ... I want to know where she is at all times, so we're going back to her first doctor.

Another caregiver was upset because she felt health care professionals closed her out by not taking time to adequately explain the patient's situation and used vocabulary that was inaccessible.

> L.B.: I don't think they [health care professionals] take the time to explain things. They'll use those big words and you won't know what they're talking about. I find that I don't see people take the time to sit you down and really explain to you. I don't know if it's something that they learn in school to be a nurse or doctor, but I just get that feeling when I'm around them.

Another caregiver was distressed that a doctor intimated that the patient was losing weight because he was not pushing nourishment more.

It has been suggested that when developing a role, behavioral norms facilitate the process. In talking with caregivers, it was not clear where they developed expectations for the HIV caregiving role. Caregivers were asked how they learned to care for the patient. While a few indicated that they had assumed the role as caregiver in other circumstances, this was typically their first caregiving experience. Caregivers indicated that information about HIV/AIDS and HIV/AIDS care was obtained in a nonsystematic manner from a variety of sources including television, radio, magazines, health care providers, pamphlets, and AIDS service organizations.

Balancing Uncertainty

Although caregivers face multiple sources of uncertainty over the course of the patient's illness, in this sample, they often adapted to uncertainty over time. In contrast to Brown and Powell-Cope's (1991) study where caregivers often spontaneously used the term "roller coaster" to describe the relentless lack of control they experienced in caregiving, caregivers in this study never used that metaphor. When asked specifically if they would use the term "roller coaster" to describe the constant changes inherent in caregiving, several caregivers reflected a moment and responded to the effect, " I guess you could say that."

More often, caregivers' responses demonstrated a sense of control and an increased confidence in their ability to manage unpredictable aspects of the disease process over time.

> _R_: It was very difficult in the very beginning because I didn't know how to organize everything right away.

While caregivers acknowledged that there were aspects of the HIV disease process that they could not control, they were generally able to accept this.

> _S_: Sometimes I resort back to my old ways of worrying about things, but we've learned to adjust. We plan things and he may not feel well. We may find something to do a month from now and the night comes to do it and he may not feel good. I can't control it, I can't change it, so I accept it.

> _M_: I was grateful for any day he was feeling good, or somewhat better than before, and when he wasn't, we just accomodated to that.

This finding is consistent with Weitz's (1989) who found that AIDS patient's learn to cope with uncertainty over time. Although HIV clearly challenges the caregiver's perception of the world as stable and predictable, many caregivers are able to reestablish balance and a sense of coherence. Establishing a sense of control may in fact be central to successful caregiving.

While uncertainty is reintroduced with each change in the illness, the caregiver learns to expect and accommodate this. For example, caregivers may learn what community resources are available and know they can access these if necessary.

> B: The first time that you go through different things is usually a little bit rougher. If we have the dementia again, it's still probably going to be impossible to handle but at least I know what to expect. I'm more aware of what's going to happen and I'm more aware of what I need to do in preparation for it instead of waiting to the last minute ...

While caregivers indicated that health care professionals had not provided information about HIV care to them deliberately, they generally expressed confidence about their ability to learn how to meet patient needs independently. This confidence tended to increase over time.

> B: ... I just do what I think is necessary ... there really not been any special training or anything like that. I've learned about it from reading and knowing other people who have had the disease. Really just living with it, living with it has been the best teacher.

> N: I read about it, just about everything that's in the papers about AIDS or listen when they have programs on T.V. But caring for him, that just comes natural, I guess because he's my son.

The caregiver is thus able to reduce uncertainty by seeking knowledge and acting on that knowledge. The caregiver may also balance uncertainty by avoiding unpleasant information. For example, caregivers may avoid or ignore persons who propose pessimistic definitions of their situations or if not pleased with medical explanations, will devise own. Many have thus turned to alternative treatment modes.

By incorporating such strategies, caregivers are using a form of sequencing whereby a normative framework is constructed that enables them to explain their situation to themselves. In this manner, they are able achieve sense of control and coherence because these frameworks give the caregiver the sense that they understand what has happened and can anticipate what will happen (Weitz, 1989).

Summary

Providing patient care is both a means of restoring balance as well as a source of stress for the caregiver. The patient's illness process and accompanying suffering create tension for the caregiver. Providing care and bringing comfort to the patient is a means of restoring equilibrium by alleviating this source of distress. However, providing care also creates its own measure of demand and strain for the caregiver because the caregiver encounters many sources of uncertainty. Moreover, as the disease progresses, the situation becomes more complex and can exacerbate already existing strains in the caregiver's life.

Caregivers generally want to do great deal for the patient. Over the course of the illness, the caregiver will assess and reassess the patient's, as well his or her own capacities and limitations. The caregiver evaluates the patient's needs in relation to available resources and sometimes seeks additional resources to compensate for perceived deficiencies or lend support to the caregiving situation.

Managing Courtesy Stigma

Since its identification in the early 1980's, HIV infection has been viewed as a highly stigmatized illness. One caregiver lamented:

> R: There is still a horrifying stigma attached to this virus and it need not be. The horror should come at the moment that the virus is passed from one person to the other. That's where a person should feel utter and complete horror, not later on. It's senseless, it's a waste of time.

Stigma is a complex, ambiguous, social construction that is difficult to examine in a large part because of the illusive nature of the cultural and social norms that are central to its creation. It is generally agreed that stigma refers to a undesired differentness that discredits or disqualifies an individual from full social acceptance. The literature suggests that social disqualification rests upon an interactional process whereby differentness is given social meaning (Ainlay, Coleman, & Becker, 1986; Goffman, 1963; Katz, 1978; Stafford & Scott, 1986). Stigma represents the discrepancy between societal normative expectations and actual social identity. Individuals are discredited or stigmatized if their attributes make them less than what is expected for the social categories into which they are placed or aspire. The discrediting attribute is deemed undesirable based on societal norms and is powerful in that it overshadows other positive characteristics and becomes the focus of personal evaluations (Goffman, 1963).

As Goffman (1963) notes, stigma is not merely an attribute, but represents a language of relationships. The possessor of a stigma, confirms the usualness of another. Stigma creates outsiders and social boundaries between normals and the stigmatized. In so doing, the life chances of the stigmatized are reduced (Goffman, 1963).

HIV/AIDS is thought to be an unusually stigmatizing illness because it is associated with deviant behavior; tainted by a religious belief as to its immorality and/or thought to be contracted via a morally sanctionable behavior and therefore thought to represent a character blemish; perceived as contagious and threatening to the community; associated with an undesirable and unaesthetic form of death; not well understood by the lay community; and viewed negatively by the medical community (Alonzo & Reynolds, 1993, p. 10).

Felt and Enacted Courtesy Stigma

HIV caregivers are effected by a variety of stigma-related experiences. Stigma may be experienced by caregivers covertly with fear and anxiety about potential HIV stigma-related social consequences or it may be experienced in response to episodes of "enacted stigma" (Scambler, 1984), wherein the individual feels discredited by actual social interactions.

Avoidance or rejection, by individuals who were once regarded as good friends, is a disturbing and common form of enacted stigma experienced in HIV caregiving. Caregivers are particularly distressed when the friends from whom they anticipate support, withdraw and not available for the patient when needed.

> M: I didn't let him [patient] know, but I got upset with so called friends that decided they didn't want to be involved. They didn't call or come to see him or anything like that. Prior to the beginning [of patient illness] they would call two or three times a week. They couldn't deal with this illness. This made me extremely angry. I didn't want to make a big deal about it to him. I know it hurt him. That bothered me a lot. I still have nothing to do with these people. I've cut them out of my life.

> K: The really hard part that last year was how many people you thought were friends that suddenly you don't hear from again. It ticked me off in a way, but it hurt the most because I could see the hurt in his eyes.

Caregivers also describe negative social behavior that is directed toward them. With stigmatizing illnesses "disreputability and even evil" may adhere to the afflicted person (Freund & McGuire, 1991, p. 137) and, as Goffman (1963) notes, to his or her family and friends in the form of "courtesy stigma." This phenomenon, wherein someone close to the stigmatized individual becomes a bearer of the stigma, is demonstrated in the following examples where caregivers were rejected by individuals with whom they were very close.

> R.J.: Paul thought it would be best if he didn't see me anymore because my son had it. My son died of AIDS and he was afraid of me. And I was like, I took care of him, I didn't sleep with him.

> M.L.: I had one friend who cut me off cold. She was my best friend. After I told her I never heard from her again.

Caregivers may suspect that certain episodes of apparent discrimination are AIDS-related, but it is not always clear. One caregiver thought that he was denied housing as a result of revealing the patient's diagnosis.

> J: We went to look at new place and everthing was just fine until I told the landlord that Jack had AIDS. All of a sudden he couldn't rent the place to us.

While caregivers may encounter such incidences of enacted courtesy stigma, they also *fear stigma*. This is a result of internalized broad social norms and comments made in everyday situations where others are not aware of their HIV caregiving status.

> B: I don't have any first hand experiences with it [stigma] but I pick it up in conversations. I see people's reactions when the word [AIDS] is mentioned. I see people's reactions and misconceptions in conversations when they start talking about something they suspect. I see it in the newspapers and all this other kind of stuff. It's there.

Caregivers are aware that they can suffer unwanted social consequences by merely being regarded as "at risk" for HIV infection. HIV caregivers also fear and wish to avoid the potential for a falsely ascribed stigma. Several caregivers expressed the concern that if others knew of the patient's diagnosis, they would assume the caregiver was HIV positive as well.

> J: The only people that I don't talk about it with real openly are some of the people I work with. When they find out they're probably going to be somewhat saying why didn't you tell us? But I just don't want to deal with that everyday because I know they're the types that also think that because Jack has it, that I also have it and they would think I was lying when I told them I was negative. So, I just don't like dealing with them.

Among gay caregivers, concern also focuses on the fact that the revelation of a patient's HIV/AIDS diagnosis can expose the patient's as well as their own previously concealed homosexuality. Although some caregivers suggest that they avoided telling parents of the HIV diagnosis as long as possible in order to protect them from the worry, this reluctance often represents a desire to delay forcing parents to confront that their that son is gay.

> K: I am gay was not said explicitly to his parents until the AIDS diagnosis.
>
> R.J.: Mitch didn't even tell his parents he was gay until he was diagnosed with AIDS.
>
> J: I didn't tell my parents that Jack had the virus or AIDS until he went into the hospital ... My Mom was saying, you can't tell your Dad. If you tell your Dad, he's going to die. He's going to have a heart attack. And yesterday was the first day that I talked with my Dad openly about it. Well, he didn't die ... He handled it as far as I could see.

The fear of stigma can also create other barriers. A mother described how an HIV positive friend's options for home care were limited by his fears of enacted stigma and consequent desire to maintain "anonymity."

> R.J.: He has a lot of family, but he don't want to go live with them because it's a small town atmosphere and their houses will be stoned. God knows what will happen to the family. He wants anonymity and in order to have that he has to stay up here, therefore, he's alone. Guess if you live in a small town, it's the talk of the town obviously ... There are a lot of mothers in the position to be able to take care of them [gay sons], but they're, I think they're afraid...

Managing Stigma

Caregivers utilize a variety of strategies to manage stigma. Caregivers weigh various options for stigma management and select a course of action to balance the discomfort created by felt or enacted stigma. As discussed in the following section, these strategies involve avoiding potentially discrediting social interactions, participating in social encounters while "passing" as "normal" (Goffman, 1963), or offsetting the effects of enacted stigma with strategies that modify the meaning of stigmatic behavior (e.g., discounting its importance).

Passing. Many patients and caregivers choose to "pass" in as many situations as possible, for as long as possible, by concealing the HIV diagnosis in social situations.

> L.B.: I don't tell anybody. It is not because I'm ashamed or anything, it's because of the reaction. I know people's ignorance of it so I don't even bother to say anything. I might say I have a sister that's ill or whatever, but Idon't go into what's the matter with her really to nobody.

For caregivers, concealing the diagnosis is a way to meet social expectation by preserving a "normal" identity. However, while strategies used to conceal stigma may maintain balance in social encounters and reduce the risk of social rejection, this strategy can also become a source of stress. Passing can be isolating because even in social situations where the concealer is regarded as "normal," the concealer is aware that he or she is secretly different from others (Goffman, 1963). Further, attempting to pass can create tension in maintaining a lie. Caregivers worry about inadvertently "giving off" (Goffman, 1963) information that will expose their secret. This was particularly problematic for one caregiver in the military who feared that revelation that he was gay would force him to be discharged.

> S: I can't go into work and talk about things at home. Some of the people hear me talk about Terry. They know he's my "room mate." I do a real good job of always saying he's my room mate...I worry I'll say something to someone by mistake and everyone will know.

Caregivers may also feel uncomfortable or conflicted about lying.

> S: I don't have a job where I can be open about it...I'm not really proud of not talking about it. I wish I could be open. I just wish I could be more open about it.

Several caregivers managed the conflict created with passing by not deliberately attempting to conceal, but not volunteering the information either. In other words they concealed by "omission" rather than by "commission."

> M: I told people who were close and who I thought would care. I didn't volunteer the information, like one doesn't volunteer that you're gay, but I'm sure a lot of people were well aware. I didn't hide it, but I didn't advertise.

On the other hand, caregivers may choose to deliberately disclose the diagnosis to selected, potentially sympathetic, individuals.

Disclosure. Following an HIV diagnosis, the HIV positive individual struggles with managing the potential discovery and orchestrating its disclosure to companions, family, friends and relevant others. As Goffman (1963) suggests, the primary question becomes, "To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where" (p. 42). A partner who assumes the HIV caregiver role is often the only one, or one of few, who is initially informed about the patient's HIV-positive status. The caregiver and patient carefully negotiate whom to tell. In the early stages of the illness trajectory, disclosure is usually confined to few close friends or family members.

> M: At first I just told a few people.

> J: Years ago, when he first came down with the virus, we just told our very closest friends. We didn't even tell his Mom until a year ago because we just didn't want her to worry unnecessarily for years...I mean our reasons for not telling our other friends earlier wasn't so much that we feared that there would be any sort of negative response from them. It's just that it wasn't their problem. I mean I didn't really want to deal with them not knowing how to react. It's just to avoid that whole kind of awkward thing.

Initially, when the illness is asymptomatic, concealment is possible and disclosure can be carefully controlled. However, as the disease progresses to its manifest stage, caregivers tend to disclose the patient's diagnosis to more people.

> M: As time went on I didn't conceal it.

> B: ... as the disease gets progressively worse or it becomes more noticeable that he's not doing as well as he was, the people that understand and know the situation have become much more supportive of the situation and those that aren't tend to stare a lot more.

Disclosing to more people may be related to the impracticality of concealment as well as becoming resigned to the reality that a "spoiled" identity can no longer be avoided.

> J: But when his T cell count dropped real significantly and he had to go on medicine, that's when we told his Mom. And pretty much since he went into the hospital in the last few months we told all our other friends ... for practical reasons. It's kind of obvious. There's no reason that they shouldn't know. We never try to hide his medicine or anything like that ... As he was getting sicker we just wanted them to know what's going on...

Once the patient's illness becomes manifest, physical changes can become a source of strain in social encounters. Physical changes alone (that is, independent of an HIV/AIDS diagnosis), can become a source of self consciousness and an obvious object of concern to others. Management strategies may then need to be renegotiated. Disclosing the diagnosis may now become a desirable option as a means of restoring balance in social interactions by relieving the ambiguity created by the patient's altered physical appearance.

Caregivers are the most unlikely to disclose the fact that they are caring for someone who is HIV positive in their work settings. Caregivers generally perceive that they will not receive a sympathetic response or are uncomfortable about receiving support from people with whom they are not close.

> J: The only people that I don't talk about it with real openly are some of the people I work with. Actually a lot of people I work with are my good friends and a lot of them know. But just like some people I just don't want to deal with. I don't need their sympathy or pity. And plus, they're not people I'm really close to and that's just kind of an awkward situation because Jack used to work there years ago so a lot of them know Jack and like ask how's he doing and stuff.

Limiting disclosure at work, or perhaps in some other selected setting, may also represent a desire on the part of caregivers to preserve a sense of normalcy in one portion of their life. However, as the patient's disease progresses, caregivers must usually confide to at least one person at their place of work in order to explain a need for absences.

> S: He went into the hospital and I thought how am I going to tell my boss I can't go out and do what I'm supposed to do..

Caregivers weigh the benefits of not disclosing against benefits of disclosure. As the disease progresses, priorities change. Many caregivers decide that a potential benefit of disclosure is the opportunity to access additional social support, either formal and/or informal.

Social Support. Once the diagnosis is disclosed, caregivers are sometimes surprised by the degree of sympathy and support offered from sources they did not anticipate.

> M: What was surprising was how supportive many people [at work] were. Surprisingly more so than many of our so called friends...they were more caring and concerned, more compassionate.

> J: Even my own family, which doesn't accept my relationship with Jack at all, has been more supportive. They never like to approve of the relationship. They're just really religious people. They like to pray. They think if they put their stamp of approval on our relationship, condoning it, will help us, be responsible for us, going to hell. But even they've become a lot more supportive recently. They came and saw me and Jack when he was in the hospital and they never come to see me, so I think they're going to be more supportive.

As discussed previously, caregivers may also be rejected by persons from whom they anticipated support. This may make them wary about additional revelation.

> M: Many of my preconceived notions were completely unfounded. People I expected to exhibit concern were often the ones who failed to give it.

In a philosophical moment, one caregiver commented:

> K: AIDS brings out the best and the worst. You see the strength that it takes for a person to fight the illness and all the things that come along with it. It gives you a certain amount of faith. When you see some of the prejudice that exists, people you thought were friends disappearing, it also destroys some of your faith. It some ways it destroyed my faith in humanity, in other ways it's restored it.

When suitable social support is not forthcoming, caregivers may seek additional support by turning to a social support group. This may be a particularly important outlet for caregivers who do not have anyone to confide to within their social network. For example, one caregiver said he went to a support group because he had no one else he could talk to and he "had to talk to someone."

It has been suggested that support groups can help to balance the effects of stigma (Lubkin, 1986). By separating or isolating into small, similar groups, stigmatized individuals may effectively defend against stigma. The closed interaction from within a small, like group, is thought to enhance one's feeling of normality and validate one's worth because one is surrounded by others who are similarly stigmatized. For many caregivers in this sample, such possible benefits apparently did not outweigh its disadvantages. While nearly every caregiver suggested that he or she had considered attending a social support group, or had attended a few times, most provided reasons why they did not find them satisfactory. First, caregivers may be more likely to desire social support when the patient's condition has deteriorated and the patient is less able to reciprocate emotionally. However, caregivers are more likely to be very busy with the patient at this time and are thus less able to get away to attend a support group. As the illness progresses, caregivers may become reluctant to leave home for even short periods of time.

A second problem concerns the support group member "mix". Partner caregivers who do not have an open gay identity may fear "guilt by association." Heterosexual caregivers may also feel ill at ease in a support group with gay members. Several of the non-gay caregivers expressed that they felt uncomfortable with gay members. In the community where this study was completed, the group responsible for running the majority of support groups were activists for gay rights and it was assumed that having separate groups for gay and non-gay members would only perpetuate negative homosexual stereotypes.

A third problem concerned the times during which the groups met which sometimes interfered with the caregivers' work schedule. Caregivers also suggested that they simply could not make attending a support group a priority while balancing many other responsibilities.

Finally, some caregivers declined participation in social support groups because that felt that no one else could understand the nature of their problem.

> M: I thought about counseling or social support groups. But how could people who don't know me be of any use to me? I'm sure they couldn't possibly understand, which is probably more egotistical than real...I presumed no one could address my problems at the level they needed to be addressed.

A few who were caring for someone in the earlier phases of the illness trajectory, also indicated that were alarmed by the severity of problems experienced by persons in later stages. One caregiver commented, "I felt worse coming out then before I went in and I don't think that's the way it is supposed to be."

Disavowal and Disregard. When episodes of enacted stigma do occur (e.g., rejection by friends), caregivers will often "disregard" (Dudley, 1983) the stigmatic behavior by choosing not to reflect on or focus on the painful, discrediting incidents.

> B: There have been a few [friends] that have turned their backs on him. A couple that did surprised me. We just blow it off. It's like fine, if that's the way they want to be, we don't need them either.
>
> M.L.: I don't have time to worry about people who turned their back on me.
>
> K: A lot of people I just don't bother talking to anymore.

Some caregivers may choose to manage stigma by disavowing it's existence and operating as if stigma does not exist. This strategy seems particularly popular among politicized groups. With strategies such as these, the individual is able to minimize the effects of stigma by altering one's perception of it or its consequences.

Summary

The phenomenon of stigmatization permeates the experiences of HIV caregivers. Caregivers, as recipients of "courtesy stigma," utilize strategies to balance the discomfort created by potential or enacted episodes of stigma. Management strategies may vary over the course of illness. The caregiver and patient will renegotiate strategies as demanded by their circumstances, priorities, and options afforded by the illness. Caregivers will weigh the benefits of a particular strategy at a given time against its disadvantages. The strategies used to balance stigma create a particularly intricate dynamic because those utilized to offset the opportunity for enacted stigma may create their own measure of sociopsychological stress which must then be balanced if coherence is to be optimized.

Living With Loss and Sorrow

HIV caregivers live with loss and a measure of sorrow pervades their everyday existence. Their lives are interrupted by the difficulties posed by an illness that is suffused with complex social meanings and desolating physical consequences. Caregivers do not merely face the threat of untimely loss of someone for whom they care, but loss related to other aspects of their life or personhood as well. Ultimately, caregivers suffer from what is "lost of self in relation to the world of objects, events, and relationships." (Cassell, 1991, p. 40). As Cassell (1991) observes, such suffering occurs because "...our intactness as persons, our coherence and integrity, come not only from intactness of the body but from the wholeness of the web of relationships with self and others" (p. 40).

Loss may be experienced by HIV caregivers across a number of dimensions. Prominent facets of loss endured by HIV caregivers include (1) loss of former ways of life, and (2) loss of a future.

Loss of former ways of life

An HIV diagnosis brings a change in the identity of the HIV infected individual. The patient's status changes from that of a well or worried well individual to that of an HIV-positive person who has a chronic, contagious, and stigmatized, terminal illness. As the patient grapples with his or her altered identity and limitations, the caregiver also faces changes and the loss the illness brings and the impact these have on social relations and daily existence.

HIV caregivers describe a variety of ways in which their former ways of living are lost. Changes may be gradual or abrupt, striking or subtle, and often depend upon what is occurring in the patient's illness trajectory. At every change in the trajectory, the ill person must reassess where he or she is and come to terms psychologically with what is lost. In this manner, the HIV-infected person is continually becoming a new person unto themselves and to those around them (Strauss et al., 1984). The caregiver goes through a parallel process. They must face limitations imposed upon them because of the sick person's altered identity, physical status, and impending death. As the merly enjoyed by caregivers. Loss of spontaneity, or a reduction of it, is a form of disadvantage that is experienced by caregivers in terms of diminished internal control in relation to increased external constraint. It has been noted previously (Strauss, 1975; Kelleher, 1988), that loss of spontaneity is a central part of withdrawal from social relationships in chronic illness. As Davis (1973) suggests, spontaneity is one of the key aspects of everyday interactional situations because "sociability is furthered by the free and spontaneous initiation of joint activities." (p. 147).

In caregivers' efforts to conceal the patient's diagnosis, and later by adhering to care regimes that attempt to prevent or manage illness manifestations, caregivers lose spontaneity while they become increasingly "managed by" (Brown & Powell-Cope, 1991) the patient's illness situation. The caregiver consequently loses opportunities for spontaneous social encounters and may become increasingly socially withdrawn and isolated.

HIV informal caregivers not only suffer loss in terms of changes in their former ways of life and sense of being, but they also lose their expectations for the future.

Loss of Future Expectations

Caregivers come to realize that many of their aspirations for the future will not be realized. Initially, as caregivers confront the probability of an extended caregiving period and the patient's eventual death, they begin to restructure how they think about future, long-term plans. Later, even plans for the immediate future will be contingent upon the severity of the patient's illness at a given moment. Intense unhappiness can result from a loss of one's expectations for the future for, as Cassell (1991) suggests, it is in this dimension of existence that hope dwells.

One mother described the sadness she and her ill son shared regarding the fact that he would not be available to assist or care for her as she aged.

> M: He cried when I changed him. I said, "What's the big deal? I changed you when you were a baby and I can do it now." He said, "But I wanted to be here for you." That's not what God had planned.

Caregivers may try to anticipate what life will be like without their partner or family member.

> J: His surgery was one of the first major things I had to deal with. It's been lots and lots of little minor things but the operation was very dangerous for him. I tried to mentally prepare myself for his just dying and I thought I was more mentally prepared for it than I was. When I thought over the years I thought I'd be somewhat adjusted to the idea that he's going to die. But I realized I wasn't emotionally prepared for losing him ... I don't know what's going to happen when he dies.

> M: I can't see life as ever being the way it was. I expected to grow old with someone who was growing old with me.

Recognizing that their life with the patient will not extend as far into the future as they expected, caregivers struggle with the extent and nature of plans that they should make with the patient. Caregivers worry that if they proceed with previously made plans for the future, this may demonstrate an insensitivity to the patient or to the patient's illness process. For example, one caregiver described how he continued with plans to buy a new house, but later worried if this was the right thing to do because he wondered if the patient wouldn't have been happier in former, more familiar surroundings. Conversely, caregivers are uncomfortable by not proceeding with plans made jointly for the future. By not continuing with such plans, they are in essence openly acknowledging to the patient that a future together is not anticipated. However, plans that are made and must then be abandoned may also serve as a cruel reminder of the patient's diminishing capacities.

Emotional Response

The sense of loss experienced by caregivers can engender a host of emotional responses that have been observed in other terminal illnesses. Anger is not unusual.

> R.J.: We had one or two major fights and that was it. It was not too long before he died. I was mad at him for dying and he was mad at me because I was still going to be here.

Caregivers' may focus anger on the person who was the source of infection. One mother discussed the rage she felt toward the man who was an intravenous drug user who had infected her daughter.

Caregiver's may also struggle with issues of the patient's responsibility in acquiring the virus. It is difficult to accept that the illness and accompanying loss could have been prevented. One mother sought explanation regarding how her son was infected. She considered different explanations, but found the most comfort in the explanation that lessened her son's, and really her, culpability.

> R.J.: We have various ideas as to where Jeff got it. He never cared. He said he knew he'd been promiscuous and he had no idea where he got it. He could have gotten it anywhere. But he had been raped at one time. He was mugged and raped in the parking lot of a garage and the timing was about right ... His best friend Vance and I are assuming that's where he got it because the timing is just about perfect for it.

In another situation, the caregiver had to confront the hurt and anger he felt knowing that his partner's HIV-positive status was a consequence of infidelity. Caregivers may also suffer "survivor guilt." One partner caregiver with a negative diagnosis felt guilty, suggesting he was one who rightfully should have become HIV-positive given his sexual behavior during his relationship with the patient.

> M: Sometimes I felt guilty because I didn't have it and he did. I had probably been far more likely to get it given my lifestyle. I was probably more active than he was. But then on the other hand I realize that's stupid too because you start developing attitudes like that and you fall into a trap that you think it's punishment for what you've done.

For families, an HIV diagnosis may be their first knowledge or confirmation that their family member is a homosexual or drug user. In these cases, families experience grief for the loss of their relative's former identity, as well as sadness for his or her new terminal identity.

HIV caregivers live with the constant threat of loss through untimely death and as the disease progresses they describe the distress of watching the person they care for suffer. Caregivers often feel helpless when they are unable to alleviate the patient's anguish or prevent physical deterioration.

> R: The frustration that you experience watching someone that you love dying in front of you. Every day they die a little more.
>
> M: There were times when I felt really desolated and alone. I had to go to the next room and almost break down at times when he wouldn't eat or was really weak or something like that. Seeing him suffering and thinking there is nothing I can do.

For some, the patient's inevitable decline may be experienced as their own failure.

> R: I thought if I could just care well enough I could keep him from dying.

For this caregiver, keeping the patient engaged in normal activities was a measure of his success as caregiver. Ultimately, this caregiver hoped that if he could care well enough, he could prevent his partner from dying.

> R: ... that year was absolute hell, constant. I fought every day to try to find the right way to make him interested in something to eat; to get him interested in what I was feeding him. Nothing tasted right to him. He had cravings at odd hours, things of course that I didn't have in the house. I spent a hundred dollars or more a week on food for two people and most of it went in thegarbage, but I had to have a lot of things on hand, because if he had a craving for something, you better have it on hand because if he eats that's wonderful. In the back of your mind you go through, you're going to save him, you're going to save him. Something's going to happen; somethings going to give; you've got to save him; they've got to find a cure; you're going to be able to do something; he's going to start putting weight on all of a sudden. It never happens, at least in my case it didn't.

Caregivers suggest that the times when the patient is hospitalized may be particularly difficult because their feelings of helplessness are accentuated.

> J: The hardest part is when he's in the hospital. He's just like laying there in so much pain and I just couldn't do anything. I guess it's a hopeless feeling you have when you're watching somebody you love in pain and you can't help him.
>
> L: When she first came home she was really sick. I think that the hospital atmosphere pulled her down. It might be that hospitals have alot of germs ...when she's in the hospital it seems to me that she goes down rather fast ... I don't think that's particularly the right atmosphere or something.
>
> M: I felt the most helpless during hospitalizations. There was nothing I could do to make things better. It was better when he was home because I couldn't think about myself.

Balancing Loss

As the caregiver experiences loss over the course of caregiving their sense of coherence may slowly erode. Interestingly, however, in this sample, there was little evidence of sustained feelings of depression or hopelessness among caregivers in response to their losses. Caregivers described episodes of deep despair that did not seem to dominate their daily lives. As the caregivers work to cope with the many changes, they seem to learn, along with the patients, ways of living with the burdens of loss over an extended period. This is accomplished by incorporating different strategies that balance their sense of loss by accentuating what remains, or rather, has not been lost and what may even have been gained in their caregiving experience. Two key strategies that are used are: (1) normalization, and (2) finding meaning.

Normalization. One strategy that is commonly employed by caregivers involves living life as normally as possible. Both patient and caregiver strive to maximize the present by maintaining usual activities and involvements.

> L: She doesn't like to talk about it too much ... She's trying to live normal, without it. You know, keep going even though its there and it's a problem. I've never seen her cry over it ... Uh, I do try to keep her life pretty normal, she goes out, she does what she wants to do. She does not sit in the bed.

Normalization may represent a form of denial or desire to avoid the reality of loss or eventual loss and continue life "as is."

> R.J.: In the very beginning Vance was so traumatized there was no way that his mind could handle that his best friend was not going to be there and so he really just ignored it.

However, for HIV informal caregivers, normalization is not necessarily a means of avoiding the reality of what is lost, but rather a means of accentuating what has not been lost. In other words, normalizing does not indicate that the patient and caregiver necessarily deny the reality of their situation, but rather seek to preserve or maximize what is still "normal" or has not been lost. Normalization may involve minimizing the meaning of what has been lost or emphasizing the importance of that which has not been lost. In this manner, loss is restricted to more discrete aspects of one's life.

> B: ...Basically we live our lives like there was no diagnosis. We don't let it stand in the way of anything. So, we keep trudging. We've got, he's got a wheel chair because he tires easily if he has to walk distances. We take it along just in case, but we don't use it that often.

Of course normalization is only possible to a certain extent. As the illness progresses, patient and caregiver must face the significance of each change in the patient's illness trajectory.

> J: This last year has been the hardest, emotionally probably the worst, because now his T cell count has disappeared to like nothing and he's starting to get sick again and it's just much more real now.
>
> S: I'd say it was three years probably before he had any sign or symptom, other than maybe we talked about it some, a little bit, not a whole lot. But I think when he went on the medication for the first time was a, How long are you going to be on this? Forever. ...I guess until you see some of those outward signs you kind of think of him as normal.
>
> B: The first couple of times he was in the hospital was emotionally difficult to handle because its facing reality ... He ended up in the hospital in June and that was the first sign, the reality that it's more than just an HIV positive diagnosis.

Over time it becomes increasingly difficult for the patient to remain involved in as many "normal" or usual activities. Yet, caregivers stress that patient and caregiver continue to try to normalize as much as possible, adapting to the patient's capacities on any given day.

> M: He would get better for periods of time, but there was a slow overall decline, gradual downhill...he did not go gently by any means. He was not inclined to stay in bed. The only time he would stay absolutely in bed was when he had no other choice...I was grateful for anytime he was feeling good or somewhat better than before and when he wasn't, we just accommodated to that.

Strauss (1978) suggests that many patient-caregiver type transactions are established in a process of "mutual pretense" whereby one individual sets limits and the other individual willingly or reluctantly agrees to abide by the limits. For example, a dying patient and his caregiver who both know the patient is dying may pretend otherwise, both agreeing to act as if the patient were going to live. If it is the caregiver who wishes not to talk about dying, and the patient introduces the subject, the caregiver will set limits by ignoring, reprimanding, or chiding (e.g., "don't think about such things"), thus continuing the mutual pretense. The patient may agree to this, not necessarily because he fears reproof, but because there is sensitivity to the caregiver's embarrassment or distress. Conversely, if it is the patient who wishes to sustain the pretense, he will reject the caregiver's offers to talk about impending death or act as if were not imminent.

Both sides will work at maintaining mutual pretense by adhering to implicit rules: in this case, by staying away from topics likely to lead either to the forbidden ground of the patient's death or to events touching on the far future; or, if something happens or is said tending to expose the fiction that both parties are attempting to sustain, then each pretends nothing has gone awry. Thus, each shares responsibility for maintaining the pretense. The major responsibility may be transferred back and forth, but each person supports the other's efforts. Such negotiations are essentially trade-offs between caregiver and patient, each respecting the other's stake in the game of mutual pretense, but only up to the limits set by whomever is able.

Ultimately, the caregiver has to face the patient's impending death and may struggle with his or her personal desire to avoid loss and keep the patient alive. One mother expressed the fear that her desire to keep her son alive was more in her own interests than in his.

> M: There were times when I thought I was being selfish trying to hold on to him and keep him alive. He said I'm not going to do it much longer Mom. I can't take this.

Similarly, another caregiver indicated that he thought the patient was prepared for death before the caregiver was ready to lose him.

> M: I didn't think about the finality until really very late. I think he was more or less ready, or resigned, at a much earlier stage than I was.

While caregivers utilize strategies to "normalize" and in so doing achieve balance by maximizing the present, they also balance loss by focusing upon what may have been gained by their caregiving experience.

Finding Meaning. Although caregivers sustain profound losses, they also often describe positive aspects of their experiences as well. For example, one caregiver described how living with sense of loss improved the quality of his relationship with his partner.

> J: I wonder sometimes if our relationship would have been as good as it is, as it's always been if it was limited to a certain extent. When you really don't know how much time you have, you really just take advantage of, make the best of every day. You don't get bogged down in some stupid fight or something, you don't waste your time. So in a sense I think it made our relationship just a bit better and I think we're much more likely to communicate honestly with each other than maybe some other couples. At least we value what we have more, make sure we don't take things for granted.

It has been suggested that stressing positive aspects of their circumstances is form of rationalization or "making lemonade out of lemons" phenomenon. Certainly, caregivers may adapt by finding the most comfortable way of viewing a painful reality. For example, one caregiver described how he adjusted to the demands of caregiving by coming to view his situation as less unnerving.

> R: You're working every day; you're taking care of the home; you're taking care of the cars; you're feeding somebody; you're cooking for them; you're doing their laundry; you're shopping for them ... If you don't look at it as such a horrifying situation at every moment, at every turn, you can deal with it. That was what really snapped in my mind.

However, caregivers portrayals of their experiences often had a remarkable poignancy and a certain ethereal quality which suggested that aspects of the caregiving experience actually transcended its more difficult features. For example, several of the caregivers described a growing sense of competence and pride in being able to fulfill the responsibilities of caregiving.

Another caregiver described how the caregiving experience resulted in a rich and deepened friendship with his partner.

> K: We became very close friends. Most couples are good acquaintances that sleep together, but we became really good friends. The hardest part was knowing that I was going to lose that friend.

> M: We were just as close or closer after this occurred...In some ways the illness actually relieved some of the tension that had been between us.

Although caregivers must adapt to the loss of their former identity, they sometimes do appear to discover new aspects of themselves that enrich their existence. While caregivers may depict experiences punctuated by stunning grief, their sense of loss also seems, at times, to be transcended by the immediacy, vitality, and power of their caregiving activities. The closeness often engendered in caregiving may break old boundaries in a relationship with new forms of intimacy created. HIV caregivers may also find intense purpose in having the privilege of caring for someone they love in their final and most vulnerable hours.

In interactionist social psychological terms, an individual emerges out of a interactional process and is constantly developing or becoming. Changes or turning points in development occur when an individual has to take stock, re-evaluate, revise, resee, and rejudge (Strauss, 1962). HIV caregiving is an experience that can precipitate the revision or transformation of identity in a meaningful way. Becoming an HIV caregiver may involve taking a role that was previously unknown or viewed with suspicion and in so doing, the caregiver comes to discover new aspects of self that have positive meanings.

Minimizing Fear of Exposure

In discussing their experiences, HIV caregivers repeatedly described feelings of fear and anxiety.

> L: She was really frightened and God, I didn't know this but I was terribly frightened too.
>
> N: I think he hides a lot, but I know he's scared ... I lay awake at night and worry. I worry about everything.

Often viewed as the modern-day leprosy, HIV is unquestionably regarded as a highly dreaded disease. The fact that it is so lethal, contracted from other people, and much of the science is evolving accounts for most of this perspective. Over the course of HIV care, caregivers must struggle with a number of their own fears and anxieties about the risk of exposure to the HIV virus.

Exposure

Some caregivers fear risk based upon their past sexual behaviors. Watching the patient's illness can become frightening reminder of their own vulnerability and possible fate.

Partners described how they were often tested for HIV seropositivity at the same time or near the time that the patient was tested. If the partner caregiver had been tested and was also HIV positive, the couple had to face the realization that one may have been responsible for the other's seropositivity. If the partner caregiver had been tested and was negative, he or she worried whether he or she had been exposed to the virus by the patient or felt guilty for survival.

For some caregivers, the fear of being HIV positive is great, and they may chose not to be tested, preferring ambiguity, over the possibility of a definitive positive diagnosis.

> M: It took me quite a while to decide to get the test because I thought if I have to care for Leroy it wouldn't do me any good to worry about myself. Finally, I became convinced that it could be useful if I could begin an earlier treatment if I were positive. It was a personal relief when I wasn't.

One caregiver described how his fear of exposure through the sexual relationship with his partner intensified as his partner's illness became symptomatic. Caregivers fear infection through non-sexual routes as well. For example, a sister caregiver discussed her deep apprehension that her son had been exposed to the virus because he had taken a sip from her HIV-positive brother's glass.

The degree of fear experienced by HIV caregivers with regard to exposure varies greatly and is dependent upon past behaviors as well as their level of knowledge regarding modes of transmission. Even when caregivers can comprehend on a cognitive level that they are at very low risk for the HIV infection, for many there there continues to be nagging doubt that they may be exposed through their caregiving activities.

Avoiding Exposure

Caregivers assess their risk and weigh options for avoiding or minimizing exposure utilizing a variety of strategies, ranging from minimal to rigorous.

Certain caregivers, particularly those active in the gay community, may be quite knowledgeable about HIV transmission and how to reduce exposure when they assume the caregiving role. Others lack information about exposure and seek it at the onset of caregiving. Increased information helps to allay the anxiety of many caregivers when they learn that they can virtually eliminate their exposure to HIV using simple preventive techniques. However, several caregivers suggested that their fears were heightened by inconsistencies in recommendations by health care professionals.

> A: I know they say you can't get it off dishes or just by touching someone, but like my husband says, do they really know?

Most of the caregivers slip into a comfortable daily routine to avoid exposure. All of the caregivers stated that they had surgical gloves available in case of contact with the patient's body fluids and most indicated they used these, or planned to, as necessary. Several caregivers mentioned that they used bleach to wash dishes and one caregiver indicated that she always served food to the patient on paper plates.

For partner caregivers, there is variation in whether or not they elect to continue a sexual relationship with the patient.

> K: We always practiced safe sex and just continued to after he was diagnosed...

For others, the sexual relationship ended immediately. One partner described how he and his partner discussed regarding whether or not the relationship should continue following the patient's HIV positive diagnosis.

> J: When we found out that he was positive, we had been seeing each other less than a year. He wanted to break up because of that, but I didn't really think we should. He was thinking that maybe he should break up with me or something for my sake.

Caregiver's often feel ambivalent about utilizing strategies to reduce exposure stemming from a desire to shield the patient from feeling that he or she is stigmatized or being regarded as a "leper." To balance this, caregivers rationalize the strategies as being used for the "good of the patient."

> R: There are things when you are negative and you're taking care of a positive person that you need to watch out for. You know, you need to be very careful. I always washed, I always put bleach in the dishwasher, just for him, not for me. I know I can't receive the virus in my system any other way but passing body fluids so I was never worried about drinking out of the same glass or eating off the same plate or eating the food he just ate. I'm proof that does not happen.

> J: I discovered he had been using my soap. I had to tell him that this was an unsafe practice because he was increasing his risk for opportunistic infections.

Many caregivers express discomfort if others use preventive strategies that they do not think are necessary.

> R.J.: I found my Mom bleaching the dishes. That upset me highly. I stormed out of the house because I just couldn't handle it.

Several caregivers were dismayed when hospital personnel seemed excessive in their use of preventive strategies.

Ultimately, for many, the fear of exposure is balanced by feelings of affection that override their concerns about exposure.

> M: People asked me aren't you afraid? I would be if he weren't related to me. How can I be afraid of my own son?

> M: There was never any question. I refused to wear gloves or not touch him. We slept in the same bed even when he was having problems with physical processes and things like that. When I thought about it in past track, I thought I don't think I would do that. But when it was happening it never occurred to me that I was doing anything unusual. People said to me it must be hard for you. It wasn't hard. It just never occurred to me that anyone would do anything else.

> K: I used gloves if my hand was cut or changing diapers. With time I was less careful. Maybe I should have been more careful. Whatever the risk was I wasn't going to let it get in the way of making sure that things got done.

ENDING THE ROLE

In making the decision to assume the HIV caregiver role, the caregiver assesses his or her willingness as well as ability to fulfill the obligation. Caregivers decide to commit to the role based upon their perception of what will be involved and their perceived capacity to succeed. However, as the caregiving role responsibilities intensify, caregivers may reassess their commitment to the role.

> D: There are sacrifices, things I give up ... It's not easy ... but once you do it, I don't think you should quit. ... It's hard. Sometimes I wonder how I do it myself. But I made a commitment to take care of Dale so I'm going to do it. I can't send him to a nursing home. He wouldn't like a nursing home and he can't live by himself and his family, they can't do anything, so then, that's it.

> E: Well, sometime, you know, you get to a point that you just want to say, uh, I want to leave, leave me alone, but I can't do that ... at least it feels good to be wanted ... to do something when they need it ... I

> wouldn't feel bad about nothing, if something happen to her I said, well, at least I was there for her, you know, when she needed me.
>
> C: I don't think I would choose to be in this position, but once you're involved in it, you know you can't give it up. I can't walk away from it.
>
> T: There have been a couple times when I thought that I won't be able to make it through this, I just won't be able to do it ... but I made a commitment to him. I told him I would stay with him through the whole thing and that's what I'm going to do.

Some caregivers ultimately decide they are not able to meet caregiving role responsibilities and end the role prematurely. Others commit to the role and sustain it until the patient's death. Either way, ending the informal caregiving role is often fraught with a number of difficulties.

Role Conflict/Overload

In the beginning of caregiving, caregivers are likely to form tentative images of themselves as caregivers and what they expect of the experience. They ask themselves, "How will I do this? How involved will I be?" These questions will continue over the course of caregiving and caregivers will continue to consider their resources, and how much they are prepared to give of themselves. While caregivers decide to commit to caregiving based upon their notions of what will be involved in the role, very few caregivers really understand the realities of caregiving. They take on the role, but later may face unforeseeable duties and hardships as they simultaneously strive to meet the needs of the patient, self, and others. The caregiver may experience considerable conflict over how to prioritize competing demands, or accommodate unwelcomed changes in expectations for relationships, lifestyle, work, and finances.

Sources of Conflict/Role Overload

Conflict in patient-caregiver relationship. As discussed previously, an HIV diagnosis disrupts the equilibrium in a relationship between patient and caregiver. When a person becomes ill with HIV, established patterns of interaction and role responsibilities are disrupted. Numerous sources of conflict can ensue as the caregiver confronts changes imposed by the illness and assumes more responsibility for routine tasks of daily living, assists the patient with his or her illness in terms of physical and emotional dimensions, and adapts to changes in the relationship, such as diminishing reciprocity.

For some partners, assuming more household responsibility is problematic. This is related to feelings of self-doubt about being able to competently manage new tasks. As the patient relinquishes former responsibilities, he or she may also be critical of the ways in which the caregiver is now managing the tasks and this creates additional tension.

Some caregivers also describe that having to limit social and leisure activities with the patient can create conflict. Partners who did not understand the limitations imposed by the patient's disease process tended to feel resentful toward the patient.

> S: The first couple of times I couldn't understand why he was tired and wanted to go home and sleep. I have gotten a little better, not as good as I'd like to be, in understanding why he's tired.

For mothers, caregiving often involves the difficulties of integrating a previously independent adult child back into their home.

> N: When you take kids back home that you're not used to having, you don't have any room for them, even though they were raised here. It's not good. I mean he feels like he should be on his own too. I know it's hard on him too because he hasn't been home to live for so long.

A variety of other conflicts can ensue when an adult "child" returns home often revolving around the patient's lifestyle choices. Living with a gay child for an extended period of time is particularly problematic for many parents because it means a forced confrontation with the son's gay identity and life style choices. One mother discussed how parents may handle this by not allowing the patient to have gay friends visit. She described how problematic this was for the patient because ultimately it was socially isolating.

> R.J.: I think they're afraid of contagion. I think when they take them in they want them to completely be cut off from that lifestyle like it never happened. So, their friends aren't welcome in the home. Therefore, the person who has the AIDS is totally cut off from any network they ever had and they virtually die alone.

Conflict can also ensue over a number of lesser issues, such as whether or not the patient is allowed to smoke.

Competing demands. In addition to conflict that may result from changes in patient-caregiver relationship, caregivers may also have difficulties managing opposing demands. In this sample, the two primary sources of competing demand involved work and children.

As patient's disease progresses, work and finances can become a source of strain in one of several ways. First, in households that are dependent upon the patient's income, its loss, once he or she is no longer able to work, creates financial strain. This problem is often compounded by problems or worries about insurance coverage.

> M: I worried about what would happen if insurance stoppped.

> K: There was much additional stress when [we] found out there was no insurance. We were very worried about the money.

One caregiver described running up large VISA bills buying medication when awaiting the start of Medicaid coverage. As the patient's illness progresses, another source of strain occurs when the caregiver needs to miss work to accommodate the patient's illness because sick day benefits are typically restricted to a worker's illness. Also, even if eligible, many caregivers were not comfortable disclosing the nature of patient's illness at work.

While the caregiver often prefers and needs to continue working, they sometimes had difficulty arranging necessary coverage for the patient when at work. One caregiver described at length his difficulties arranging appropriate care.

> B: I was very close to having him committed but nobody would take him. I was at my wits end trying to get help from everybody and find out what to. There was nobody that could help. There was alot of stress and frustration in that nobody in the system would deal with it. Nobody in the system could handle it; nobody in the system would take him. He's not mentally deranged enough, or doesn't have the potential

> to harm himself, so he's not able to be committed. I can't commit him because he is of sound mind according to the evaluations ... he would have to commit himself. There is no mental health care facility that will take an AIDS patient. There's no mental health facility other than like state hospitals that would even consider it and at that point he becomes a ward of the state and, it's like, okay, what do I do? I mean I contacted Ohio State; I contacted his doctor; I contacted social workers; I contacted the AIDS task force; I took him to the Short North Mental Health facilities and there was nothing anybody could do ... He was at a point where if I turned my back, he would take off and go somewhere and I would have no idea where he went; I would have no idea what he was doing and he wasn't aware of it at all ... I couldn't stay home and watch him. I couldn't tie him down. I had to rely on some physical sense of his own, some mental stability that would at least not let him do anything really outrageous. I would go off to work and I wouldn't know what I would find when I would come home. I didn't know if I would find him home; I didn't know if I'd find him dead on the street; I didn't know if I'd find him, you know, in a car somewhere. Once he took off and went home for a class reunion and he was lost for a whole night and nobody knew where he was. He had basically run out of gas and pulled over on the side of the highway and just stopped and slept in the car all night. But its like I had no way of knowing what was going on and I had no way of knowing where he was. I mean it's hard to deal with that because his family was not really supportive and there really wasn't anything that anybody could do other than say, if you need anything let me know and it's like, yeah, hey, fine.

When a patient is being cared for in a home with young children a number of difficulties can ensue. In cases where the mother of young children is HIV positive, it can be particularly difficult for the caregiver to assume increased responsibility for child care as well as patient care. Caregivers are particularly likely to suffer "role overload" wherein they are unable to demands of both roles adequately.

Realign Responsibilities

Drawing from role theory (Hardy & Conway, 1978, Turner, 1962), it can be seen that HIV caregivers experience different types of role problems that can result in role strain, or a felt difficulty in fulfilling role obligations (Goode, 1960). The norms that are relevant for the HIV caregiving role are, to some degree, vague and unclear. To the extent that ambiguous conditions prevail, the role performance of the caregiver may be idiosyncratic, while sanctions may be inconsistent and haphazardly applied. Thus, caregivers may experience role ambiguity. Second, role conflict occurs when existing role expectations are contradictory or mutually exclusive. That is, while certain aspects of role expectations are clear, they compete with one another. A third source of difficulty in fulfilling role obligations may arise when the caregiver finds that expectations for role performance run counter to self-perception, disposition, attitudes and values (role incongruity). Fourth, the caregiver may experience role incompetence, where the caregiver's resources are inadequate relative to the demands of his or her position. A final source of difficulty in fulfilling role demands, role overload, can occur when the caregiver is confronted with excessive demands. Although caregivers are able to perform each role demand competently, they may be unable to carry out all of the role obligations in the time available.

It may also be difficult for caregivers to balance the sources of role struggle because the caregiver may have difficulty acknowledging his or her anger and resentment over the situation. However, the caregiver who experiences role-related strain will attempt to utilize personal resources and problem-solving processes to realign role responsibilities and minimize the discomfort.

Caregivers will generally decide to what degree to allocate their personal resources in their different role relationships. The caregiver may covertly or overtly negotiate with the patient and other role partners concerning the allocation of their resources. The caregiver may modify the caregiving role through the processes of role-taking and role-making. In addition, the caregiver may influence his or her performance in the role relationships by controlling his or her availability, accessibility, and visibility.

Caregivers must find a comfortable balance or they will decide to abandon the role. In this sample, four of the twenty caregivers ended the caregiving role prematurely. This included each of the three sisters and one heterosexual male. In each of these situations, demands of the caregiving situation exceeded the caregivers ability to manage the situation adequately with the primary conflict responsible for terminating the role being children.

One sister had three very young children in the home and said she told her brother that if he ever threatened the well-being of her children in anyway she would no longer provide his care in her home.

> W: I told Bobby [patient] that if ever there was a time that you threaten my kids, you're going to have to go.

This brother was eventually placed in a community shelter after an episode in which he became angry at his nephew and shook a broom at him.

For the male caregiver of a female patient with two children, the role ended when the patient was no longer able to manage child care or any household responsibilities and the caregiver was unable to meet all of the demands of work, child care, and, the necessary total patient care. The caregiver indicated that the breaking point came when he was never able to sleep given his swing shift work and daytime care responsibilities. The available home care services were not adequate to meet needs. The caregiver was initially reluctant to tell his family about the patient's diagnosis, but eventually did when he needed additional assistance. The caregiver's family helped, but they could not provide assistance as regularly as needed in this situation. Eventually, the patient was placed in a nursing home. The caregiver continued to care for the youngest child, and the older child went to live with his father. The patient lived for a number of months after nursing home placement, but rarely saw her children.

Another sister was in constant conflict with the patient about the degree of care she provided. The patient had been placed in a nursing home, but eventually returned to his own apartment where his sister was the primary source of care. She was married with one school age and two teenagers. She worked full-time during the day. Her husband was not supportive of her caregiving and he particularly fearful of HIV exposure and only wanted minimal contact. The caregiver was afraid that her marriage was threatened by her caregiving activities and she was also conflicted about her role responsibilities to her children and her brother. She was called one day at work to come to the emergency room where she waited to determine if her brother was going to be admitted. That evening her daughter was to be honored at school and thus causing role conflict.

Toward the end of the patient's life, the caregiver struggled with the decision of whether to go to California on a trip her family had been planning for several years, or to stay and care for her brother. She eventually decided to go on her trip and the patient was hospitalized while she was away and died few days after her return from trip.

In another situation, it was unclear what led to termination of caregiving role. Each had teenage children and the sister had been caring for her sister in her home the sister declined to be interviewed after her caregiver role was terminated, stating the patient's daughter had a baby and they just decided to get their own place.

In each of these situations, the caregiver became unable to meet demands of the situation or was unable to resolve the conflicts that were created from dual roles. In households with children, it was particularly difficult to meet the needs of both the patient and the children. Interestingly, while caregivers abdicated their caregiving role and arranged to have the patient cared for elsewhere, they continued to perceive of themselves as functioning in the caregiver role.

Patient Death

For caregivers, death brings an ending to their caregiving role.

> M: I prayed he would get well or stop suffering. One of those prayers was answered.
>
> R: I sat down on the edge of the bed and I pulled him up to my chest and I told him how much I cared about him, how much I loved him, how important he was to me, how important all the years were and I told him I would be okay and to stop fighting, to let go. Then I put the music on his ears and I laid him back down and I left the hospital. He was dead 20 minutes later.

Although most caregivers engage in some sort of anticipatory grief, not all feel ready when patient dies.

> M: I wasn't ready for Bobby to die when he did. I thought I had more time.

Caregivers often describe that their initial response to patient's death is one of relief.

> M: My initial reaction after he died was relief because he had been suffering so much. I was upset with myself that I was so relieved. After a while self-pity started to set in when I realized how lonely I was. What's the rest of life going to be like?

Although the grief process is very individualized, for HIV caregivers, feelings of relief are typically followed by profound grief.

> M: I could never have predicted how I responded. I would never have predicted that I would have felt as much loss as I did...the loss, sadness, and sorrow was like nothing I had ever felt in my whole life.

> M. ...No one has ever meant as much. I knew he meant so much to me, but it is only now that the loss makes it clear how much he meant to me. There's no loss that I've ever had that's even remotely like this. I can't imagine anything or anyone who's absence makes me feel so empty. I think about it every hour of the day and night regardless of where I am -- sometimes happily, sometimes sadly. I had always wondered if I would ever care for anyone enough to feel that kind of loss. I always questioned my own capacity, but it's pretty clear the capacity is there. I find out now. It's a greater loss than I ever expected.

Mourning loss

Grief is a process that must be experienced in order to overcome the sense of loss. However, for HIV caregivers the grief process is often complicated by several factors: (1) closeness which often develops with caregiving activities and reduced social network, (2) guilt, (3) a partner relationship not sanctioned by society.

Closeness and reduced social network. First, the caregivers sense of loss is accentuated by the caregiving process which brings the caregiver closer to patient. Further, many caregivers experienced a loss in not being actively engaged in caring for the patient any longer, which had rendered their existence very meaningful.

> R: I'm really, really, trying to be as strong as I possibly can and I'm succeeding. It's emotionally hard. It's going to take a little time. I mean my life is very different. Everything's changed. I still have this feeling inside of me that I have to rush into the house and I have to rush home, that I, you know, and when I open the door nobody's here...

> M: I don't remember the physical fatigue [of caregiving]. It was pretty much routine. Actually, when it stopped it left my life very empty. For weeks afterward I would wake up thinking I'm going to get him some water.

The void that is left by the patient's death may be harder to fill initially because many caregivers have become socially isolated.

Guilt. The grief process may also be complicated by the caregiver's sense of guilt. For parents, they may feel that the death was somehow their responsibility. They reason that if homosexuality put the patient at risk, did they somehow cause the death by establishing an environment in their child's upbringing that ultimately contributed to death?

> R.J.: My oldest son remarked to me, you could have prevented this. I'm like, how do you think I could have prevented this Mike? What was I supposed to do, lock him up? Oh, you could have prevented this gay thing a long time ago. I said, uh, right.

For partners, guilt may be experienced if the patient was infected by the caregiver, or the caregiver may experience "survivor guilt."

Role not Acknowledged. Finally, the partner's grief process may be complicated by the fact that AIDS is related to cultural taboos concerning homosexuality, sex, and drugs that stigmatize individuals in their adaptation and response to the grieving process.

Certain rituals and customs such as funerals are undertaken to help survivors process the loss of loved ones. Planning and participating in these facilitates the grieving process (Doka, 1987). In nontraditional relationships, survivors lose a significant role when the partner dies, and there is no defined role (as in grieving widow) for them to assume. In cases in which the relationship is secret, grief must also be secret. Furthermore, the relatives of the deceased person, may be embarrassed if the gay survivor attends a memorial service as a final act of love and request that the surviving partner not attend the funeral service. Partners are often excluded from the planning process and from participation in or recognition at funerals, wakes, or memorial services (Doka, 1987; Murphy & Perry, 1988), as if the relationship never existed. Even if gay survivors attend the services, they must carefully guard their outward expression of grief and their very presence may lead to resentment and hostile comments from family members.

> R: I think the most difficult thing too is that society doesn't recognize me.
>
> K: Death ends life but not a relationship. The final resolution you may never find. You don't stop loving a person. You don't stop missing a person.

DISCUSSION/CONCEPTUAL DEVELOPMENT

In this analysis, HIV informal caregiving was viewed as a developmental process insofar as the role develops over time as the caregiver makes the decision to provide care, manages the demands of the caregiving, and seeks to explain the significance of this event in his or her life. The data revealed that, in contrast to other informal caregiver populations (e.g., alzheimers), the construction of the HIV informal caregiver role is particularly intricate because the role expectations are complicated by the unusual social meanings surrounding AIDS and gay relationships.

Eight dimensions of HIV informal caregiving were identified in the context of three phases: (1) beginning the HIV caregiver role; (2) sustaining the HIV caregiver role; and (3) ending the HIV caregiver role. The essential caregiver role responsibility that cut across these different dimensions was finding "balance."

The concept of balancing, as developed from the data, draws upon Antonovsky's notion of coherence (1987), Mead's (1938) conception of the social act, General Systems Theory (Bertalanffy, 1967), and Strauss'(1962, 1975, 1978) ideas regarding implicit negotiation, chronic illness and identity formation.

Balancing and the Stress of Caregiving

In the caregiving literature, caregiving is typically conceptualized within a stress framework wherein a variety of situational factors related to patient care are regarded as stressors that may result in pathological outcomes for the caregiver. This study was initially conceived within this theoretical formulation. However, contrary to expectation, what was often striking about the experience of caregivers, was that although they discussed a variety of stressful and distressing features of their experiences, this perspective was often contrasted by the caregiver's marked demeanor of calm, confidence, and depth of compassion or emotional expressiveness. Further, a number of the caregivers described that while they initially worried that the progression of the patient's illness would result in high levels of stress, in reality this was often not the case. Interestingly, caregivers repeatedly described their impression that the actual situation was not as stressful as they had anticipated, that they experienced a sense of loss when caregiving activities were discontinued, and a number discussed a sense of pride in their own capacities to deal successfully with the challenge of caregiving. This phenomenon is illustrated in the following caregiver comments:

> M: At the beginning I worried about having the emotional stamina to get through it. Then I didn't worry about it at all when one would think it would have been necessary. It just never occurred to me to worry about it. I had too much else to do. But before it became necessary I worried all the time. How can I possibly get through it? I knew what my mother had been through. My father had cared for her. She was ill most of her late life. How can I ever manage to do that? All the things I had been worrying about just didn't occur to me at the time they should have. Obviously it was hard and stressful, but I didn't feel it. I was much more concerned about him. I never thought about the strain.
>
> N: My doctor says I'm under stress, but I don't feel under stress.
>
> J: You know its strange, I thought this would be so difficult, but its not, everything seems pretty under control.

Thus, while HIV caregivers clearly encounter uncertainty and a variety of acute and chronic stressors, they apparently are often capable of adapting and their sense of coherence may actually be strengthened over the course of the caregiving experience. As a consequence of this assessment, the concept of balancing was incorporated into a stress paradigm.

Within the balance/stress process framework, stressors are conditions that generate an imbalance or create a tension that is perceived as stressful by an individual thereby creating the potential for altered health/well-being outcomes. However, an individual may make decisions or take actions that can restore balance or prevent imbalance thereby reducing perceived tension/stress and the potential for altered health/well-being outcomes. Within a stress paradigm, balancing may be regarded as either a mediator or outcome variable. For example, if a caregiver makes the decision to secure additional formal home care services, this can be regarded as an outcome of the tension created for a caregiver following increased patient physical care demands and the imbalance or stress created by this circumstance. Increased formal home care services may also serve to mediate the caregiver's perception of increased patient physical care demands as stressful. In either case, individuals who are able to successfully offset or balance undesirable or tension producing circumstances will reduce stress.

When balance is achieved, tension is reduced despite the possible continuing presence of "stressors." This suggests that the stressors associated with caregiving, while omnipresent, do not necessarily have a negative impact on the caregiver's health/well-being. In fact, they may promote growth and development. This view is consistent with Antonovsky's (1987) supposition that the consequences of stressors are not necessarily pathological, but quite possibly salutary, contingent on the character of the stressor and the successful resolution of tension.

Antonovsky (1987) defines "stressor" as a characteristic that introduces entropy into the system, or rather, a life experience characterized by inconsistency, under- or overload, and exclusion from participation in decision making. Chronic stressors are seen as "the phenomenon of persisting or increasing scarcity, perjuring conditions of loss or deprivation, and continuing experiences of inadequate resources or role opportunities" (Antonovsky, 1987, p. 29). While it can be seen that caregiving may involve many such characteristics, these features have the potential to be successfully offset in the caregiving situation with balancing strategies. Balancing is thus conceptualized as a process by which an individual responds to psychological, social, or biophysical challenges/stressors.

Balancing is comprised of three qualitatively different dimensions which are intertwined, and interdependent. These dimensions include: (a) weighing; (b) offsetting, and; (c) sequencing. Balancing is essentially, in Mead's (1938) terms a "social act" that requires perception or a consciousness of alternatives and choice. Balancing is thus preceded by a stimulus that arouses selective attention and the perception that there is a lack of accommodation between the individual and his/her internal or external environment. This is to say that an individual will perceive or become aware of stimuli as a consequence of an immediate sensory stimulus which is perceived as problematic because it indicates disequilibrium, discomfort, or disruption, whether biological, social, or psychological. Prior to the existence of the stimulus indicating an imbalance, the environment may be taken for granted because it is operating in a manner the individual accepts as satisfactory/comfortable or coherent. Once the stimulus is assessed as problematic, the individual begins to covertly evaluate the situation as to its qualities and characteristics in terms of how to restore equilibrium or reduce discomfort and distress. It is at this point that the individual begins to weigh various solutions and covertly construct a solution.

Weighing refers to a type of cognitive assessment whereby an individual considers a problem, "weighs" various options, and establishes priorities including consideration of personal capacities, resources and possible outcomes.

Offsetting refers to ways by which an individual will act to overtly manipulate one's environment to compensate for or restore a sense of balance or coherence. Covertly constructed strategies are actively carried out to restructure a given situation. Offsetting involves manifest action where an individual accesses available resources or support (informational, instrumental, or emotional) to obviate stressors or at least make them more manageable or predictable. Offsetting may also involve a number of sociopsychological processes whereby an individual will co-create a more comfortable reality or utilize strategies to avoid problems that cannot be modified. For example, an individual and another may engage in a process of "mutual pretense" (Strauss,

1978) wherein each interactant pretends an indicator of impending death is not an indicator when in fact it is.

Sequencing refers to an evaluative process by which an individual establishes a meaningful framework for life circumstances, decisions, and courses of action. It is in this manner that an individual will be able to fully establish coherence following experiences that are not consistent with expectations. As Strauss (1962) suggests, the subjective feeling of coherence and continuity turns not merely upon the number or degree of changes, but upon the framework of terms within which otherwise discordant events can be reconciled and related. For example, past purposes and commitments may be challenged and abandoned, but when viewed as part of a larger temporal design, they will not produce feelings of self-betrayal. Strauss (1962) suggests that it is the lack of design that is reflected subjectively in feelings of "personal discontinuity, of wrecked or abandoned selves, or more mildly experienced in the lack of meaningful purposes, in conceptions of certain periods of one's life that were wasted, or senseless, or did not lead anywhere" (p. 84). Thus, unexpected, disruptive circumstances can be reconciled or made to appear uniform despite their apparent diversity if they, and one's response to them, can be encompassed in a unified interpretation. Consider the following statement made by one mother who was starting an AIDS Task Force in a rural community six months following her sons death from AIDS:

> M: I'm going to work with AIDS patients and families. That's what I got. I think that's why I'm here. I've always wondered. I've done so many different things and had so many careers, but I haven't hit what it is I'm supposed to do. I always thought when I find it I'll know. I think I've found it. Now I'm doing God's work the way he wanted me to do it. I've got a guardian angel on my shoulder. I may have lost my son, but I think I have gained a lot through my love for him and what he suffered which made me a lot more compassionate than I was.

Balancing thus explains how stressors can be adapted to, but it also suggests how an individual's identity and sense of coherence can be altered in this process. In the most successful caregiving situations, the caregiver may realize a role and identity which they find extremely meaningful.

A variety of balancing strategies were used by caregivers over the course of HIV caregiving in response to the different sociopsychological and instrumental challenges that are inherent to the different phases of HIV informal caregiving. A summary of this analytic framework is seen in Table 12. Subcategories, which identity specific balancing strategies, specify caregivers' responses to the stressors or challenges characteristic of each phase.

Table 12

HIV caregiver stress/balance analytic framework.

Phase	Stressors/Challenges	Balancing Strategies
Beginning Role	Altered Role Relationship	Negotiate/Clarify Role Expectations
Sustaining Role	Provide Patient Care	Access Resources Alleviate Uncertainty
	Courtesy Stigma	Passing Disclosure Social Support Disavowal and Disregard
	Loss and Sorrow	Normalization Finding Meaning
	Fear Exposure	Reduce Risk
Ending Role	Role Conflict/ Overload	Realign Responsibilities
	Patient Death	Mourning Loss

EFFECTS OF CASE MANAGEMENT

Quantitative analysis procedures were used to examine the two study hypotheses:

(1) The informal caregivers of HIV infected patients who receive the case managed home care will have better health/well-being than informal caregivers of HIV infected patients who receive the routine home care.

(2) The informal caregivers of the case managed HIV infected patients will be more satisfied with health care services than informal caregivers of the routine home care HIV infected patients.

This analysis was based upon data collected in Time 1, Time 2, and Time 3 interviews using three standardized instruments. The patients of caregivers in Group 1 (case managed) and Group 2 (non-case managed) had been receiving home care services per protocols of The Collaborative Home Care Project (Nickel & Salsberry, 1988) at Time 1 for a mean of 7.2 months and 7.3 months respectively. Time 2 and Time 3 data were collected at subsequent 3 month intervals with a subset of seven participants. Given the small sample size, the study hypotheses were not tested. Alternatively, data were analyzed with descriptive statistics. Scores of the subset of participants were then examined individually across data collection points. Group data were compared and interpreted drawing from qualitative data collected in Part I of this study.

Analytic framework

In this study, case management was conceptualized within the stress process framework as a mediating variable. It was reasoned that case management would decrease the likelihood of altered caregiver health outcomes by providing either direct and/or indirect support to the caregiver and thus alleviating stress. The caregiver could be supported directly by the case manager making appropriate recommendations for informal or formal service interventions for the caregiver (e.g., social support group, counseling, respite care). The caregiver could be supported indirectly by the case manager arranging appropriate services for the patient that would subsequently alleviate caregiver responsibilities/burden and perceived stress.

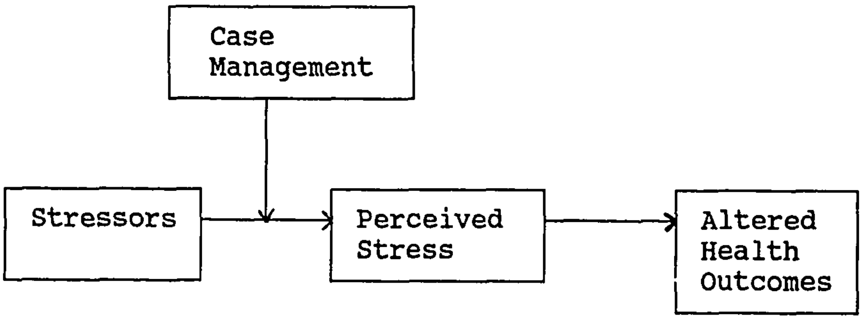


Figure 4. Case management as mediator of stress.

PRELIMINARY ANALYSES

Health and Well-being

Hypothesis 1 was examined by comparing measures of the case managed caregivers' health/well-being with measures of the non-case managed caregivers' health/well-being at Time 1, Time 2, and Time 3. Health/well-being was measured with two instruments: Profiles of Mood States (POMS) and the Quality of Well-being Scale (QWB).

Profile of Mood States. The Profile of Mood States is an instrument comprised of 65 items measuring mood states. Respondents selected one of five possible responses (0= Not at all; 1 = a little; 2 = moderately; 3 = quite a bit; 4 = extremely) for each mood item. Participant's responses were scored were summed. Mean scores for the Total POMS and six subscales for Total Group and Group 1 (case-managed), Group 2 (non-case managed), and Group 3 (other) at Time 1 are presented in Table 10. Mean scores for the subgroup of participants in Group 1 and Group 2 who completed the POMS at Time 2 and Time 3 are presented in Table 11 and Table 12. Table 13 provides a summary of all group scores across data collection points. Higher scores indicate negative mood state with exception of the subscale "vigor" where a higher score indicates a more positive mood state. "Vigor" is weighted negatively in Total POMS score.

It can be seen that the case managed and the non-case managed caregivers had similar POMS measures. Group 1 tended to have slightly above Total Group mean measures, while Group 2 had slightly below Total Group mean measures. Group 3, which was comprised primarily of caregivers of deceased patients, had the most negative scores, but these were still below college student norms and considerably below psychiatric patient norms as reported by McNair, Lorr, and Droppleman (1971).

Table 10

Profile of Mood States - Time 1.

		Group 1 N=6	Group 2 N=5	Group 3 N=7	Total N=18
Tension/	M	7.00	4.80	7.14	6.44
Anxiety	s	4.60	7.69	3.71	5.11
Depression/	M	8.40	8.40	14.67	10.75
Dejection	s	7.53	14.72	6.71	9.89
Anger/	M	8.50	7.00	10.57	8.89
Hostility	s	6.50	6.59	5.25	5.89
Fatigue	M	7.33	5.50	9.80	7.81
	s	3.20	2.89	4.71	3.95
Confusion/	M	2.00	-1.00	4.50	2.20
Bewilder.	s	3.24	4.69	3.88	4.28
Vigor	M	14.17	20.60	17.85	17.38
	s	3.87	6.95	7.56	6.54
Total Score	M	10.25	3.83	28.60	16.17
	s	7.68	46.54	20.11	26.17

Table 11

Profile of Mood States - Time 2.

		Group 1 N=5	Group 2 N=2	Total N=7
Tension/	M	2.80	1.00	2.28
Anxiety	s	3.56	5.66	3.82
Depression/	M	8.60	8.50	8.57
Dejection	s	9.61	12.02	9.25
Anger/	M	6.00	8.00	6.57
Hostility	s	8.24	8.48	7.63
Fatigue	M	8.00	8.50	8.14
	s	4.80	4.95	4.41
Confusion/	M	1.20	-0.50	0.71
Bewilder.	s	4.09	3.53	3.73
Vigor	M	13.00	18.00	14.43
	s	4.69	7.07	5.38
Total Score	M	13.60	7.50	11.86
	s	29.65	41.71	29.75

Table 12

Profile of Mood States - Time 3.

		Group 1 N=4	Group 2 N=1	Total N=5
Tension/	M	4.25	-3.00	2.80
Anxiety	s	7.50		7.25
Depression/	M	11.00	1.00	9.00
Dejection	s	12.23		11.51
Anger/	M	7.50	5.00	7.00
Hostility	s	11.73		10.22
Fatigue	M	8.50	5.00	7.80
	s	6.19		5.59
Confusion/	M	2.50	-4.00	1.20
Bewilder.	s	6.03		5.97
Vigor	M	13.25	22.00	15.0
	s	5.12		5.92
Total Score	M	20.50	-18.00	12.80
	s	41.20		39.62

Table 13

Profile of Mood States - Time 1, 2, and 3.

		T	D	A	F	C	V	Tot
Time 1								
Group 1	M	7.00	8.40	8.50	7.33	2.00	14.17	10.25
N=6	s	4.60	7.53	6.50	3.20	3.24	3.87	7.68
Group 2	M	4.80	8.40	7.00	5.50	-1.00	20.60	3.83
N=5	s	7.69	14.72	6.59	2.89	4.69	6.95	46.54
Group 3	M	7.14	14.67	10.57	9.80	4.50	17.85	28.60
N=7	s	3.71	6.71	5.25	4.71	3.88	7.56	20.11
Total	M	6.44	10.75	8.89	7.81	2.20	17.38	16.17
N=18	s	5.11	9.89	5.89	3.95	4.28	6.54	26.17
Time 2								
Group 1	M	2.80	8.60	6.00	8.00	1.20	13.00	13.60
N=5	s	3.56	9.61	8.24	4.80	4.09	4.69	29.65
Group 2	M	1.00	8.50	8.00	8.50	-0.50	18.00	7.50
N=2	s	5.66	12.02	8.48	4.95	3.53	7.07	41.71
Total	M	2.28	8.57	6.57	8.14	0.71	14.43	11.86
N=7	s	3.82	9.25	7.63	4.41	3.73	5.38	29.75
Time 3								
Group 1	M	4.25	11.00	7.50	8.50	2.50	13.25	20.50
N=4	s	7.50	12.23	11.73	6.19	6.03	5.12	41.20
Group 2	M	-3.00	1.00	5.00	5.00	-4.0	22.00	-18.00
N=1								
Total	M	2.80	9.00	7.00	7.80	1.20	15.0	12.80
N=5	s	7.25	11.51	10.22	5.59	5.97	5.92	39.62

Quality of Well-Being. The Quality of Well-being Scale (Fanshel & Bush, 1970) is a instrument that assesses functioning in mobility, physical activity, social activity, and self-care through retrospective report for a six day period. The functional outcomes are weighted by social preference as to the desirability or undesirability of the functional state and by concurrent symptoms. Participant's responses were scored and summed on a single scale. Mean scores for the composite QWB score for Total Group and Group 1 , Group 2 and Group 3 (other) are at Time 1, Time 2, and Time 3 are presented in Table 14.

It can be seen that the case managed and the non case managed caregivers had similar measures across data collection points. Group 1 tended to have below Total Group mean measures, while Group 2 had above Total Group mean measures which indicated a higher overall quality of well-being. However, given the small sample size, much of the difference can be accounted for by one Group 1 participant who had serious chronic health problems that existed prior to the assumption of the caregiver role.

Table 14

Quality of Well-being Time 1, 2, and 3.

		Group 1	Group 2	Group 3	Total
Time 1	M	731.0	934.6	878.6	846.7
	s	108.0	90.4	137.4	139.6
	N	6	5	8	19
Time 2	M	760.0	825.0	--	778.6
	s	151.8	247.5	--	92.2
	N	5	2	--	7
Time 3	M	820.3	1000	--	856.2
	s	213.0		--	201.5
	N	4	1	--	5

Satisfaction with Services

Hypothesis 2 was examined by comparing measures of the case managed caregivers' satisfaction with services to measures of the non-case managed caregivers' satisfaction with services. The Satisfaction with Services (CSQ-8) instrument was used. This instrument is comprised of evaluative semantic-differential scales. Respondents chose a point along a continuum between two adjectives that expressed their attitude toward the item. Each scale was scored from -3 to +3, a higher score reflecting a more positive attitude. Table 15 provides a summary of mean scores calculated for each group and the Total Group score at Time 1. Table 16 and Table 17 provide a summary of mean scores calculated for the subsample of participants in Group 1 and Group 2 at Time 2 and Time 3 respectively.

Each group showed positive satisfaction with services. Group 1 had the highest overall satisfaction with services followed closely by Group 2, then Group 3 at Time 1. Group 2 has a higher overall satisfaction with services at Time 2 and Time 3, but this was based upon response of only one participant.

Table 15

Satisfaction with Services - Time 1

		Group 1 N=5	Group 2 N=5	Group 3 N=6	Total N=16
Quality of Services	M	1.80	2.20	1.83	1.94
Received	s	1.09	0.84	1.47	1.12
Kind of Service	M	1.80	1.80	1.00	1.50
Wanted?	s	1.09	0.84	2.45	1.63
Extent Program	M	2.20	1.80	1.50	1.81
Met Needs	s	0.45	1.30	1.64	1.22
Recommend to	M	2.80	1.80	1.67	2.06
Friend?	s	0.45	1.64	1.75	1.44
Satisfaction with	M	2.20	2.20	1.16	1.81
Help Received	s	0.45	1.09	2.56	1.68
Services Help	M	2.20	1.80	1.83	1.94
With Problems?	s	0.45	1.30	1.47	1.12
Satisfaction with	M	2.20	2.40	0.17	1.50
Services	s	0.84	0.89	2.48	1.90
Return Program?	M	2.80	2.00	2.17	2.31
	s	0.45	1.41	1.33	1.14
Total Satisfaction	M	2.25	2.00	1.41	1.86
With Services	s	0.51	1.10	1.65	1.20

Table 16

Satisfaction with Services - Time 2.

		Group 1 N=5	Group 2 N=1	Total N=6
Quality of Services	M	2.00	3.00	2.17
Received	s	1.22		1.17
Kind of Service	M	2.00	3.00	2.17
Wanted?	s	1.00		0.98
Extent Program	M	2.00	3.00	2.17
Met Needs	s	1.22		1.17
Recommend to	M	2.60	3.00	2.67
Friend?	s	0.55		0.52
Satisfaction with	M	2.20	3.00	2.33
Help Received	s	1.30		1.21
Services Help	M	2.40	3.00	2.50
With Problems?	s	0.55		0.55
Satisfaction with	M	2.00	3.00	2.17
Services	s	1.22		1.17
Return to	M	2.20	3.00	2.33
Program?	s	1.30		1.21
Total Satisfaction	M	2.17	3.00	2.31
With Services	s	0.97		0.94

Table 17

<u>Satisfaction with Services - Time 3</u>

		Group 1 N=4	Group 2 N=1	Total N=5
Quality of Services	M	1.75	2.00	1.80
Received	s	1.25		1.09
Kind of Service	M	1.75	2.00	1.80
Wanted?	s	1.26		1.09
Extent Program	M	2.50	3.00	2.60
Met Needs	s	0.58		0.55
Recommend to	M	2.50	3.00	2.60
Friend?	s	0.56		0.55
Satisfaction with	M	2.50	3.00	2.60
Help Received	s	0.58		0.55
Services Help	M	1.00	2.00	1.25
With Problems?	s	2.65		2.22
Satisfaction with	M	2.33	3.00	2.50
Services	s	0.58		0.58
Return Program?	M	2.33	3.00	2.50
	s	0.58		0.58
Total Satisfaction	M	2.16	2.63	2.28
With Services	s	0.76		0.66

ADDITIONAL ANALYSES

Given the small sample size, the preliminary findings are difficult to interpret and must be regarded with extreme caution. Results from the preliminary analysis generally do not support the study hypotheses. While the case managed group showed a slightly higher overall satisfaction with services, the non case managed group also showed high overall satisfaction with services. Little difference was demonstrated between the case managed and non case managed groups on health/well-being outcomes although the non case managed group had slightly better health/well-being outcomes.

To lend to the interpretation of the preliminary study analyses, the individual POMS, QWB, and CSQ-8 scores of Group 1 and Group 2 participants were assessed. While the numbers are too small to interpret, it can be seen (see Tables 18 and 19) that the scores appear to vary independent of the case management intervention. Drawing from the qualitative data, Group 1 and Group 2 were considered comparatively in terms of the dimensions of caregiving identified in Part I of this study (qualitative portion) including: (1) Deciding to Care/Modifying the patient-caregiver role relationship; (2) Performing patient-centered activities; (3) Managing courtesy stigma; (4) Living with loss and sorrow; (5) Minimizing fear of exposure; (6) Handling role conflict/overload.

Table 18

Individual POMS Scores at Time 1, 2, and 3.

		T	D	A	F	C	V	Tot
Group 1								
L	Time 1	4	0	2	6	-1	12	-1
	Time 2	-1	0	0	9	-3	-19	-14
	Time 3	-3	0	0	0	-3	-22	-28
D	Time 1	1	4	4	10	0	-8	11
	Time 2	3	4	4	8	0	-14	5
	Time 3	0	3	3	10	0	-10	6
E	Time 1	5	20	13	7	6	-13	38
	Time 2	8	19	20	8	5	-16	44
	Time 3	14	27	25	13	11	-17	73
J	Time 1	9	10	2	8	5	18	16
	Time 2	4	19	6	16	6	5	46
	Time 3	5	14	2	15	2	11	27
A	Time 1	15	13	16	11	8	17	46
	Time 2	0	1	0	4	-2	17	-14
	Time 3	--	--	--	--	--	--	--
Group 2								
N	Time 1	5	8	13	5	-1	-13	17
	Time 2	5	17	14	14	-2	-15	37
	Time 3	--	--	--	--	--	--	--
B	Time 1	-1	0	3	6	-3	-26	-21
	Time 2	-3	0	2	5	-3	-27	-26
	Time 3	-3	1	5	6	-4	-25	-20

Table 19

Individual Group 1 and 2 Composite POMS, QWB, CSQ-8 Scores.

		Time 1	Time 2	Time 3
Group 1				
L	POMS	-1	-14	-28
	QWB	559	577	580
	CSQ			
D	POMS	11	5	6
	QWB	701	741	701
	CSQ			
E	POMS	38	44	73[a]
	QWB	741	741	1000
	CSQ			
J	POMS	16	46	27
	QWB	743	741	1000
	CSQ			
A	POMS	46	-14[b]	--
	QWB	743	1000	
	CSQ			
Group 2				
N	POMS	17	37[b]	--
	QWB	854	650	
	CSQ			
B	POMS	-21	-26	-20
	QWB	1000	1000	1000
	CSQ			

Note: Lower POMS scores indicate more positive mood state.
Higher QWB scores indicate greater quality well-being.
Higher CSQ scores indicate greater satisfaction with services.

[a] Patient in nursing home at time of interview

[b] Patient deceased at time of interview

Deciding to Care/Modifying Patient-Caregiver Role Relationship

No qualitative between differences were noted between Group 1 and Group 2 in factors influencing the decision to provide patient care or in modifying the patient-caregiver relationship. As noted in Part I, the primary factor influencing the caregiver's decision to care was the caregiver's relationship to the patient. Caregiver's who were reluctant to provide care were not differentially impacted by case management strategies.

Performing Patient Centered Activities

Caregivers in Group 1 and Group 2 were compared in relation to the different types of patient-centered activities they indicated they provided including: (1) Being available; (2) Assessing and anticipating; (3) Fostering emotional well-being; (4) Lending practical support; and (5) Coordinating Formal Care. A summary (frequencies) of this comparison is provided in Table 20.

No differences were noted between case managed and non case managed caregivers with regard to being available to patient. One hundred percent of caregivers in Group 1 and Group 2 indicated that "being available" to the patient was one of their caregiving activities. A greater percentage of the case managed caregivers engaged in a greater number of "assessing and anticipating activities" than the non-case managed caregivers (see Table 20). Similarly a greater number of caregivers in

Table 20

Comparison of case managed and non case managed caregiving activities.

Type Activity Case	Case Managed		Non-Managed	
	N	%	N	%
Being Available				
Being available when or if needed.	7	100	5	100
Assessing and Anticipating				
Evaluate options for treatment and/or services.	7	100	2	40
Monitor course of patient's illness and evaluate significance of changes.	7	100	3	60
Evaluate strength/resources of patient.	3	43	2	40
Anticipate needs for future assistance and services.	7	100	3	60
Fostering Emotional Well-Being				
Do things to bolster patient's self-image.	5	71	3	60
Try to keep patient's life as normal as possible.	6	85	2	40
Make sure patient has right amount social/recreational activity.	2	28	1	20

Table 23 (continued)

Type Activity	Case Managed		Non-Case Managed	
	N	%	N	%
"Run interference" for patient in social and community settings.	3	43	1	20
Enable patient to have desired religious/spiritual support.	3	43	0	0
Touch (e.g., hold hands, hug).	7	100	4	80
Lending Practical Support				
Supervise/carry out prescribed treatment and/or services.	4	59	2	40
Structure patient's daily activities.	3	43	0	0
Supervise/manage patient's resources.	3	43	0	0
Perform personal care for patient.	5	71	0	0
Do extra housework.	5	71	4	80
Manage illness-related finances/paperwork.	6	86	1	20
Assist with mobility.	2	28	2	40
Do extra home maintenance work.	4	56	1	20

Table 23 (continued)

Type Activity	Case Managed		Non-Case Managed	
	N	%	N	%
Provide transportation.	5	71	3	60
Make adjustments in housing arrangements.	4	56	1	20
Prevent/manage medical crises.	3	43	2	40
Prepare meals/Encourage patient to eat.	5	71	1	20

Group 1 also indicated that they completed a greater number of activities to foster emotional well-being and lend practical support.

No differences were noted between Group 1 and Group 2 in terms of coordination of formal services. Although the case manager would assume some degree of the responsibility for coordinating care, many of the Group 1 caregivers would continue to be involved in the coordination of home services, often with the encouragement of the case manager. Formal service coordination activities seemed to differ depending upon the nature of the patient-caregiver relationship, the patient's severity of illness, and the caregiver's capacities.

Manage Courtesy Stigma

No differences were noted between Group 1 and Group 2 in terms of how they experienced stigma or selected management strategies. Caregivers in both groups indicated that they were more satisfied with health care providers who demonstrated an understanding of psychosocial aspects of HIV/AIDS. The case manager could seemingly be advantageous in this regard. The case managed caregivers examined a handcard with different possibilities and were asked to indicate the ways in which the case manager was helpful to them (see summary of individual responses Table 21). When asked directly, the case managed caregivers indicated that while case manager provided them with emotional support, they did not perceive that the case manager was helpful to them in terms of managing stigma or discrimination.

Living with Loss and Sorrow

No differences were noted between Group 1 and Group 2 in terms of their experiences with or management of loss and sorrow. Although caregivers in Group 1 did regard the case manager as a source of emotional support, caregivers in both groups expressed a need for additional social support.

Table 21

Case management services received by caregiver.

		L	D	E	J	A
1.	Answers questions about patient care.	x	x	x	x	x
2.	Assists in locating appropriate patient services.	x	x	x	x	
3.	Arranges appropriate care/services for patient.	x	x	x	x	x
4.	Educates about HIV/AIDS so caregiver more knowledgeable about patient care.	x			x	x
5.	Provides caregiver with information about HIV transmission.			x		x
6.	Encourages/provides caregiver with ongoing emotional support.	x	x	x	x	x
7.	Discusses/provides caregiver with information about health care options.	x		x	x	
8.	Helps caregiver manage stigma/discrimination.					
9.	Facilitates reconciliation among family members/significant others.					
10.	Helps caregiver learn how to manage with health care agencies/services.	x	x		x	
11.	Is available if caregiver needs to talk to someone.				x	x
12.	Assists caregiver with financial concerns.				x	
13.	Helps caregiver understand what patient is going through.	x	x	x		x
14.	Helps caregiver understand own needs and what she or he can do to feel better.					
15.	Provides caregiver with information about available social support groups.	x	x		x	

Minimizing Fear of Exposure

No between group differences were noted in terms of fear of exposure. Differences in amount of fear experienced by the caregivers were related to their degree of knowledge about transmission and the affectational qualities of patient-caregiver relationship. Two of the caregivers in Group 1 reported that the case manager had provided them with information about transmission (see Table 21).

Handling Role Conflict/Overload

Both caregivers in both Group 1 and Group 2 had difficulties with role conflict and overload and two caregivers in Group 1 and one caregiver in Group 2 ended their roles before patient death. Each of these caregivers was an African-American, one male partner and two female sisters. The male partner's patient was very ill for an extended period of time and was hospitalized several times. Although the case manager arranged comprehensive home care services, they did not adequately cover needs in this situation and the patient was eventually placed in a nursing home. In the other two cases, no difference was observed in amount/type of services received. Each patient assisted with self-care until close to time of death. Nursing, home health aid, CATF, and AIDS service connection services were used intermittently and both patients were periodically hospitalized. Each died in the hospital.

DISCUSSION

The findings did not support the study hypotheses that case managed caregivers would have better health/well-being and satisfaction with services. While the caregivers with case management showed slightly greater satisfaction with services than the caregivers without case management, both groups demonstrated high satisfaction with services. The case managed caregivers overall health/well-being, while generally good, was lower than the total group mean. Given the small sample size, generalizations cannot be made about these findings.

To lend to the interpretation of the initial study analyses, the individual POMS, QWB, and CSQ-8 scores of Group 1 and Group 2 participants were then assessed. This analysis suggested that the scores appear to vary independent of the case management intervention. Drawing from the qualitative data, Group 1 and Group 2 were finally considered comparatively in terms of the dimensions of caregiving identified in Part I of this study (qualitative portion) including: (1) Deciding to Care/Modifying the patient-caregiver role relationship; (2) Performing patient-centered activities; (3) Managing courtesy stigma; (4) Living with loss and sorrow; (5) Minimizing fear of exposure; (6) Handling role conflict/overload. This analysis also failed to demonstrate substantial differences between the case managed and non case managed caregivers along these dimensions.

CHAPTER V

SUMMARY AND CONCLUSIONS

This study was completed to identify the role responsibilities of HIV informal caregivers over the course of HIV illness and to assess the impact of case management on HIV informal caregiver health/well-being and satisfaction with formal home care/community services.

ROLE RESPONSIBILITIES

Qualitative analysis procedures were used to answer the research question: "What are HIV informal caregiver role responsibilities?" It was found that HIV informal caregiving is a three phase process that involves: (1) beginning the role; (2) sustaining the role; and (3) ending the role. The caregiver role is developed from a sequential pattern of successive action/response patient-caregiver episodes. The role can begin at a number of points along the HIV illness trajectory, but involves a departure from the previously held patient-other role expectations and is dependent upon new expectations that develop based upon the evolving patient "sick role" and the patient's desire or need for assistance or care.

The major role responsibility for HIV informal caregivers that occurred over the three phases was finding "balance." The concept of balancing, as identified in this analysis, refers to a self- regulatory process by which the caregiver sought to secure coherence and equilibrium between several interacting and often opposing processes in which they were engaged. The caregiver was able to establish balance by weighing options and acting to offset undesirable circumstances or tension states.

HIV is a highly disruptive event that can render the caregiver's world chaotic and uncertain. However, it was found that the sense of chaos and uncertainty does not necessarily persist over the course of illness. Caregivers utilized balancing strategies to restore a sense of coherence. These strategies are fluid and involve revising, reconsidering, negotiating and drawing upon available resources and previously underutilized personal capacities. At the most positive end of the spectrum, the caregiver's sense of coherence and self-regard was enhanced as a result of this balancing process. Conversely, if the caregiver was unable to find balance, their sense of coherence would dissipate.

Balancing and Caregiver Stress

Stressors are conditions that generate an imbalance or create tension that is perceived as stressful by an individual thereby creating the potential for altered health/well-being outcomes. An individual may make decisions or take actions that can restore balance or prevent imbalance thereby reducing perceived tension/stress and the potential for altered health/well-being outcomes.

Within a stress process framework, balancing is either a mediator or outcome variable. For example, if a caregiver makes the decision to secure additional formal home care services, this can be regarded as an outcome of the tension created for a caregiver following increased patient physical care demands and the imbalance or stress created by this circumstance. Increased formal home care services may also serve to mediate the caregiver's perception of increased patient physical care demands as stressful. In either case, individuals who are able to successfully offset or balance undesirable or tension producing circumstances will reduce stress. When balance is achieved, tension is reduced despite the possible continuing presence of "stressors." Thus, the stressors associated with HIV caregiving, while omnipresent, do not necessarily have a negative impact on the caregiver's health/well-being. In fact, they may promote growth and development.

Balancing is comprised of three qualitatively different dimensions that are intertwined and interdependent: (a) weighing; (b) offsetting; and (c) sequencing. Weighing refers to a type of cognitive assessment whereby an individual considers a problem, "weighs" various options, and establishes priorities including consideration of personal capacities, resources, and possible outcomes. Offsetting refers to ways by which an individual will act to overtly manipulate one's environment to compensate for or restore a sense of balance or coherence. Sequencing refers to an evaluative process by which the individual will establish a meaningful framework for life circumstances, decisions, and courses of action.

Balancing thus explains how caregiving stressors can be adapted to, but it also suggests how an individual's identity and sense of coherence can be altered in this process. In the most successful caregiving situations, the caregiver realizes a role and identity that they find extremely meaningful.

A variety of balancing strategies were used by caregivers over the course of HIV caregiving in response to the sociopsychological and instrumental challenges inherent to the three phases of HIV informal caregiving. The first phase of HIV informal caregiving, *beginning the role*, involves decisions to assume the role and issues to be negotiated as the caregiver adapts to the altered patient-caregiver relationship. Caregivers find balance by clarifying role expectations. The second phase, *sustaining the role*, centers on matters of identity building and the aspects of managing the role in relation to performing patient centered activities; managing courtesy stigma; living with loss and sorrow; and minimizing exposure to the virus. Balancing strategies used by caregivers in this phase include accessing resources, alleviating uncertainty, passing, disclosing, finding social support, disavowal and disregard, normalization, finding meaning, and reducing the risk of exposure. The last phase of the role, *ending the role*, involves two processes: (1) the process by which caregivers relinquish their role prematurely as a means of minimizing role conflict/role overload; and (2) the grief and bereavement processes that occur following patient death. Balancing strategies used by caregivers as they end their role include realigning responsibilities and mourning loss.

Beginning the Role

The caregiving role is begun and develops in response to the evolving patient role. Over the course of their illness, HIV patients assess their capacities and structure their environment to balance or compensate for areas of deficiency. Generally, the patients must balance a desire for autonomy with a need for assistance if they are to have their care optimized or wish remain in a home environment. Patients consider available resources and negotiate a combination of situational supports that are most comfortable to them. This support matrix is contingent upon what resources and services are actually available to the them, what the patients perceive as being available, the perceived and actual affordability of available services, and the patients' personal comfort with a given service or source of care. Informal care is usually the most desirable form of support available to HIV patients, and it is often the only way the patient can remain at home, or in a home environment. Without informal caregiver assistance there would often be significant gaps in the ill person's care, a need for long-term institutional care, or the necessity for additional formal home care services.

For informal caregivers, the willingness to provide care is established when the potential caregiver perceives that care is needed and when he or she feels a moral obligation to do so. In making the decision to provide care, the potential caregivers weigh their desire or willingness to care against their ability to fulfill the role responsibilities. Like patients, caregivers assess their own capacities, the patient's capacities, other competing responsibilities or priorities, and available resources. Caregivers decide to commit to the role based upon their assessment of the meaning of this activity, their perception of what will be involved and their perceived capacity to succeed. Whether the caregiver role is begun gradually or in a more precipitous manner, it begins with a subtle patient-caregiver interaction where caregivers negotiate with the patient regarding what aspects of his or her care to assume and how this will be accomplished. Caregiving is thus begun with patient and caregiver striving to balance needs and possible options for care against one's capacities and sometimes opposing desires and conflicting responsibilities.

Sustaining the Role

Once there is initial role commitment, caregivers must contend with a variety of sociopsychological challenges related to HIV patient care and an emerging and expanding caregiver identity. Caregivers who sustain the role over time utilize a combination of strategies to achieve a measure of balance and coherence. The major sociopsychological and instrumental challenges involved in sustaining the HIV caregiving role include: (1) performing patient-centered activities; (2) managing courtesy stigma; (3) living with loss and sorrow; and (4) minimizing fear of exposure.

Performing patient-centered activities. HIV informal caregivers engage in a wide range of activities to lend emotional and instrumental support to the patient. HIV informal care represents a continuum that alters depending upon individual circumstances and patient stage in the HIV trajectory. Emotional support is likely to be the prevalent form of care provided by informal caregivers in the earlier stages of the HIV trajectory. Progressively large amounts of both emotional and practical support are likely to be rendered by caregivers in the latter part of the illness trajectory when the illness becomes manifest and the patient's physical capacities diminish. However, this is not absolute and will vary considerably depending upon the patient's overall well-being in terms of the illness trajectory and what has been negotiated between the patient and the caregiver.

HIV caregiving often demands considerable time and energy as the caregiver endeavor's to manage a combination of caregiving activities to meet the needs of the patient. Major categories of caregiving activities include: (1) Being available; (2) Assessing and anticipating; (3) Fostering emotional well-being; (4) Lending practical support; and (5) Coordinating formal care.

Providing patient care is both a means of restoring balance as well as a source of stress for the caregiver. The patient's illness process and accompanying suffering create tension for the caregiver. Providing care and bringing comfort to the patient is a means of restoring balance by alleviating this source of distress. However, providing care also creates its own measure of demand and strain for the caregiver because the caregiver encounters many sources of uncertainty. Moreover, as the disease progresses, the situation becomes more complex and can exacerbate already existing strains in the caregiver's life. Key strategies utilized by caregivers to balance challenges of providing patient care include accessing resources and alleviating uncertainty.

Managing courtesy stigma. The phenomenon of stigmatization permeates the experiences of HIV caregivers. Caregivers, as recipients of "courtesy stigma," utilize strategies to balance the discomfort created by potential or enacted episodes of stigma including: (1) passing; (2) disclosure; (3) social support; and (4) disavowal and disregard. Management strategies may vary over the course of illness. Caregivers will weigh the benefits of a particular strategy at a given time against it's disadvantages. The strategies used to balance stigma create a particularly intricate dynamic because those utilized to offset the opportunity for enacted stigma, may create their own measure of sociopsychological stress which must then be balanced if a sense of coherence is to be achieved.

Living with loss and sorrow. HIV caregivers live with loss and a measure of sorrow pervades their everyday existence. Caregivers lives are interrupted by the difficulties posed by an illness that is suffused with complex social meanings and desolating physical consequences. Caregivers do not merely face the threat of untimely loss of someone for whom they care, but loss related to other aspects of their life or personhood as well, especially loss of their former way of life and loss of an anticipated future.

Caregivers utilize different strategies to manage their daily sense of loss including: (1) "normalizing" and; (2) finding meaning in their caregiving activities. Caregivers normalize in the sense that they focus upon the present and accentuate aspects of their former lives that have not been lost. Many caregivers also find meaning in their caregiving activities in a manner that enriches their lives. For example, caregivers may find that their relationship with the patient grows closer or they take pride in their ability to manage the demands of the caregiving situation.

Reducing exposure. Over the course of HIV care, caregivers struggle with a number of their own fears and anxieties about the illness. The most common source of anxiety in HIV caregiving is fear of exposure to the HIV virus. Some caregivers fear risk based upon their past sexual behaviors. Watching the patient's illness can become a frightening reminder of their own vulnerability and possible fate. Caregivers fear infection through casual contact as well. The degree of fear experienced by HIV caregivers with regard to exposure varies greatly and is dependent upon past behaviors as well as their level of knowledge regarding modes of transmission. Even when caregivers can comprehend on a cognitive level that they are at very low risk for the HIV infection, for many there is a nagging doubt that they may be exposed through their caregiving activities.

Caregivers assess their risk and weigh options for avoiding or minimizing exposure. A variety of strategies, ranging from minimal to rigorous, are utilized by caregivers for protection. Some caregivers, particularly those active in the gay community, may be quite knowledgeable about HIV transmission and how to reduce expose when they assume the caregiving role. Other caregivers lack information about exposure and seek information at the onset of caregiving. Increased information helps to allay the anxiety of many caregivers when they learn that they can virtually eliminate their exposure to HIV using preventive techniques. However, caregivers' fears may be heightened by inconsistencies in recommendations by health care professionals.

Ending the Role

The caregiver assumes a greater number of responsibilities as the patient's condition declines and he or she drifts into the sick role. This typically involves a dramatic shift in the nature of the former patient-caregiver relationship. Although providing care is generally regarded as an integral component of a loving relationship, the mutuality upon which the relationship is premised usually declines as the patient becomes unable to fulfill normal role expectations. The caregiver must thus continue to alter relational expectations as she or he adapts to assist the patient with an unpredictable and physically and emotionally devastating disease, assume an increased number of instrumental tasks, and fulfill external responsibilities, such as work. As the caregiving role responsibilities intensify, caregivers may reassess their commitment to the role.

Some caregivers ultimately decide they are not able to meet conflicting or excessive caregiving role responsibilities and end the role prematurely. Caregivers are particularly prone to role overload if they are young children in the home or if the patient has dementia. Many caregivers remain committed and see the role through to the patient's death. Although the patient's death ultimately ends the caregiver role, the grief process is often fraught with a number of difficulties including: (1) a profound sense of loss which is often heightened by the closeness that developed during caregiving activities; (2) partner "survivor" guilt or parental guilt related son's "aberrant" behavior and subsequent infection with HIV; and (3) lack of socially sanctioned partner bereavement role.

EFFECTS OF CASE MANAGEMENT

Quantitative descriptive analysis procedures were used to examine the effect of case management on HIV/AIDS informal caregiver health/well-being outcomes and satisfaction with services outcomes. To date, most of the caregiver research has focused upon possible causes of caregiver stress and there has been comparatively little examination of the effects of intervention strategies. In this study, little difference was noted between the case managed and the non-case managed caregiver health/well-being and satisfaction with services.

Failure to demonstrate differences between the informal caregiver groups may be related to several factors. First, there are a number of design issues that influence the validity of these observations. One essential problem encountered in this study was the inability to establish that the intervention strategy was independent. Participants were randomly assigned to either the experimental (case managed) or control group. In theory, the groups received differential treatment based upon whether or not they were receiving the case management strategy. However, participants in the control group were able to receive case managed services from other sources, (e.g., the Columbus AIDS Task Force). While the other case management strategies varied in terms of how they were structured, the case managers from the other sources clearly may have either shared a similar expertise with regard to coordinating/

accessing community services, or, in some circumstances, they were aware of the expertise offered by the case manager of this study and would call for information concerning a particular client problem. Unknown to the case manager of this study, the information that was sometimes shared or discussed, concerned participants in the control group. Although it was important for the case manager to be regarded as a resource person in the community in order to establish the necessary authority to fulfill the role, such calls diluted the independence of the intervention strategy.

The selected measures may also have influenced the study findings. While previous caregiver research and stress theory guided the selection of outcome measures used in this study, different measures could possibly have yielded findings that would lend support to greater case managed caregiver effectiveness. It is possible that the study measures were too global to appraise more subtle caregiver responses or the main effects (whatever those might be) of the case management intervention.

An additional problem concerned the time of data collection. It was not clear when it was best to measure the effects of case management in relation to the selected outcome variables. Reliable baseline measures were not obtained because there was often a several week time lag between when the patient started to receive the case managed or non-case managed home care services and the time of caregiver entry into this study. This was primarily related to the fact that caregivers would typically not agree to be interviewed unless the home environment and patient condition were quite stable. When the patient entered the parent study, there was often some instability and confusion until the patient and caregiver became acclimated to the new home services. Further, in order to facilitate sample size, several caregivers of patients who had already been participating in the parent study for several months were interviewed. When the caregivers were finally interviewed, the primary effects of case management may have been missed or the outcome measures tended to be a reflection of caregiver health/well-being and satisfaction with services during periods of relative calm. The generally positive health/well-being and satisfaction with services noted in both the case managed and non case-managed groups is supported by the qualitative portion of this study which suggests that caregivers who continue in the role often respond actively to stressors and adapt successfully or terminate their role. Thus, it must be emphasized that this study essentially represented a sample of caregivers who had adapted successfully to their role. They either had little to benefit from case management services at the times outcomes were measured or they may have already benefitted from case management strategies at the times the outcomes were collected. Thus, it is certainly possible that the actual effects of case management were not appraised at the most appropriate time and actual differences between the case managed and non-case managed outcomes were concealed.

Another significant design problem that was encountered in this study was an inadequate sample size. Twenty caregivers were recruited over the one year period of data collection, and only 12 of these were caring for patients participating in the experimental portion of the study. This precluded the examination of the effects of case management using multivariate statistical analysis techniques, as well as the ability to determine (or control) other sources of variability.

Despite the various design problems encountered in this study, it is certainly possible that failure to demonstrate differences between the case managed and the non-case managed caregiver groups was because the case managed services were actually no more advantageous to informal caregivers than the routine home care services. It was surmised that the case management intervention could benefit the caregiver in one of two ways: (1) indirectly, by improving home care services to the patient and thus relieving caregiver responsibilities; or (2) directly, by accessing or providing the caregiver with social support, counseling, or respite care. Consideration of each of these routes using qualitative data did not suggest any clear advantages of the case managed approach with regard to the caregiver.

Indirect. The case management protocol used in this study emphasized patient-centered services, yet it was not clear from the caregiver interviews whether the patient-centered services provided in the experimental group varied appreciably from the routine home care services. Caregivers in both groups generally tended to perceive use of and satisfaction with formal services similarly. The caregiver's of the case managed patients did not indicate (qualitatively) that they were more satisfied or regarded patient formal home care services to alleviate more burden compared with caregivers of the non case managed group. Similarity between group perceptions may have been, in part, because the non-case managed group could arrange/receive similar patient-centered services via other means. For example, the "non-case managed" group had access to other sources of case management; the routine home care providers (particularly hospice) were adept at providing HIV/AIDS home care; and the caregivers in both the case managed and the non-case managed groups were also often quite capable of accessing/coordinating available community services as needed independently. Initially, caregivers had some difficulties anticipating what services would be needed when different problems developed, however, these skills improved over time. Ultimately, caregivers implied that it was financial constraints that tended to dictate the availability and use of formal services for both groups.

When the case manager was able to arrange additional services which theoretically should alleviate caregiver burden, the caregiver did not necessarily demonstrate any greater satisfaction with the added services. Additional home services also had the potential to introduce more stress into the home situation. Caregivers sometimes complained that excess home service providers invaded their privacy or if the quality of the services was poor, the caregiver would feel the need to supervise the formal care provider and thus not perceive that their sense of stress/burden was alleviated. Home services could also serve as a unwanted reminder of the patient's illness. It was also possible for the case manager or other home service providers to undermine the confidence of the caregiver by challenging the caregiver's explanation and management of the patient care situation. Furthermore, in cases with heavy patient care demands, the case manager was unable to access enough services to adequately meet the patient's home care needs, or the services available/provided were not really suitable to the patient needs.

Direct. The study findings suggested that the case manager focused few intervention strategies directly on the caregiver. While this approach was consistent with the study protocols, as well as with the priorities of the caregiver, it is uncertain if health promotion strategies directed at the caregiver would be effective in sustaining their role or improving health/well-being outcomes. The qualitative portion of this study indicated that caregivers often perceived the need for additional social support or respite services, yet the services available in community designed to address these needs were not necessarily helpful to the caregiver. Social support groups tended to be most problematic in terms of their heterogeneity (e.g., non-gay caregivers were sometimes uncomfortable with gay participants) and available respite services were not perceived as extensive or flexible enough.

IMPLICATIONS FOR HEALTH POLICY

HIV informal caregivers demonstrate a strong commitment and moral obligation to provide patient home care and they generally want to provide as much as care as possible within the confines of their particular situation. In some circumstances, the demands of the caregiving situation may exceed the caregiver's ability to manage. In situations of extreme need, there are not enough patient care resources or enough appropriate patient care resources available to lend adequate support to the informal caregiver. What is particularly problematic for many caregivers is meeting demands of child care and patient care in the home or finding appropriate formal assistance while they are at work, particularly if the patient has dementia or is very physically debilitated. In such circumstances, the informal caregiving role is likely to be more stressful and end prematurely leaving the patient dependent on a different source of long-term care or in need of a long-term care facility.

In general, caregivers demonstrated that they adapted well to the demands of the caregiving role. While they tend to be satisfied with home health care services that address patient needs, in some circumstances, informal caregivers may underutilize available patient care services because they are regarded by the patient and the caregiver to be of poor quality or because the patient and caregiver wish to deemphasize the perception or continual reminder of the patient as "sick" in the home setting.

This raises a related issue concerning how the case manager and/or other health care providers and the informal caregiver should interface in terms of managing patient care. The priorities/goals of care as conceived by the case manager and/or other health care providers, patient, and informal caregiver may not be congruent and this may introduce tension in unanticipated ways. For example, if a patient's nutritional status is compromised, s/he and his or her informal caregiver may wish to bolster the patient's nutritional status with Total Parenteral Nutrition (TPN). While this intravenous therapy is effective nutritionally, it is among health care providers controversial because it is quite costly. In this circumstance, it is unclear if the case manager should operate as a patient advocate (and potentially improve patient satisfaction and longevity if TPN instituted), or being cognizant of the expense and limited resources, discourage the patient from requesting this treatment modality, and thus potentially lower patient care cost, as well as satisfaction and longevity.

It is unclear if caregivers would benefit from intervention strategies aimed at directly promoting the caregiver's well-being. While many caregivers have a need for more social support, the community services available to caregivers in this sample were unsatisfactory in this respect. While it is clear that caregivers may not access these resources because their first priority is to meet the needs of the patient, it is also apparent that available services may not address caregiver needs satisfactorily. For example, while social support groups were available in this community, many caregivers indicated that they did not utilize them because of the mixture of participants (e.g., gay and non-gay) or because of the inconvenient times that they met. Available respite services were also not extensive or flexible enough to be perceived by the caregiver as being particularly helpful.

The findings indicate that social policy regarding HIV/AIDS should facilitate flexible and creative formal home care to adequately respond to the changing needs of the HIV/AIDS patient and caregiver. Social policy ideally should emanate from a strong position regarding who should assume major responsibility for making decisions regarding patient care delivery and what the health care systems relationship should be with the informal caregiver. While informal caregivers play a vital role in providing home care to HIV/AIDS patients, at the present time, formal home care or community services seem to lack the necessary flexibility and expediency to significantly facilitate their role.

IMPLICATIONS FOR PRACTICE

Nurses are responsible for long-term planning in the community to effectively intervene, they need to understand the HIV caregiving situation. Like other caregivers, HIV caregivers need instrumental, informational, and socio-emotional support. Nurses must be sensitive to the patient-caregiver situation and seek to intervene in ways that demonstrate sensitivity to patient's emotional needs and do not undermine the caregiver's sense of role competence.

While caregivers may face a number of sources of psychosocial challenge, nurses may help them to find balance in their situations by enabling them to access appropriate resources. They need to be particularly sensitive to the meanings that patients and caregivers establish in their home situation and intervene in manner that does not disrupt these personal meanings. As result of this analysis, the following recommendations can be made:

1. Nurses need to demonstrate an awareness of and sensitivity to patient and caregiver emotional needs. With HIV/AIDS, emotional needs are accentuated because of the associated stigma that is socially isolating. The nurse can also help the caregiver anticipate what will be experienced in terms of loss. They should encourage the caregiver to maintain a supportive network and anticipate factors that may complicate the grief process. They can also encourage the patient and caregiver to access health care services and providers that are more familiar with or sensitive to the needs of HIV/AIDS patients.

2. Nurses should assess the caregiver's knowledge base and provide information/education as needed. Caregiver's are particularly in need of consistent information regarding the risk of exposure, what the patient is experiencing emotionally, and available community resources that can be accessed as needed. While caregivers learn from a variety of sources how to

provide physical care over time, the home health care nurse could facilitate this process by giving systematic instruction regarding care techniques (e.g., body mechanics).

3. Nurses should be aware that children can strain the caregiving situation and they should anticipate that caregivers with child care responsibilities will have difficulties sustaining their role. When planning for long term home, nurses should be aware that these caregivers, and those caring for patients with dementia may only be able to fulfill the caregiving role on a temporary basis.

RESEARCH IMPLICATIONS

This study provided a broad overview of the HIV informal caregiving role and preliminary findings regarding effect of case management on HIV informal caregivers. The difficulties encountered in this study suggest several areas that should be considered by researchers undertaking a study of this nature.

1. When attempting to assess case management in the community, researchers must be aware that it may be very difficult to keep the case management intervention "independent." It is also essential to delineate the goals of case management strategy, as well as how the case management strategy was actually carried out so that it can be replicated.

2. It is uncertain how the effects of the case management strategy on

caregivers are best measured. Caregivers are unlikely to be able to take time for interviews during the most demanding and presumably, most stressful, times.

3. With this population it is difficult to access an adequate sample size. This may be related to social stigma, the lack of potential respondents perceiving of themselves as "caregiver," or because the demands of the caregiver role are so extensive, that caregivers are reluctant to take time to participate in a study.

4. Researchers should be aware that interviews of this nature are very demanding emotionally. The researcher should plan for debriefing following interviews. The researcher should be aware of the humane response to the interviews. The desire to intervene in adverse home situations must be weighed against an "unbiased, uninvolved" researcher role.

Several areas for additional study were also identified. First, this study provided insight to HIV home care situation from the caregivers' perspective. It would also be valuable to have a greater understanding of patient-caregiver interaction from patient's perspective. Are patient's satisfied with the care they receive from their informal caregivers? Would they prefer more formal home care services to alleviate the informal caregiver's burden? Does quality of care that patient receives from the informal caregiver effect health outcomes? Do patients who have a primary informal caregiver have better health outcomes than those who do not?

Second, it would also be beneficial to study the effects of case management on a larger sample of informal caregivers for a more extended period of time and it would be of interest to comparatively study HIV informal caregiver health/well-being in contrast to the informal caregivers of Alzheimer's informal caregivers. The findings in this study suggest that stress may not be experienced to the same degree by HIV informal caregivers as that experienced by informal caregivers of alzheimers' patients. Further examination of possible contributing factors would lend to the understanding of the informal care stress process. For example, does the length of time one provides care or the age of the patient influence stress outcomes?

Finally, it would be beneficial to systematically assess the effectiveness of social support groups. In this sample, caregivers expressed variety of reservations about social support groups, particularly those with mixed membership of gays and heterosexuals.

CONCLUSION

The basic caregiver role is characterized by physical caregiving tasks and psychosocial demands and stresses. Considered with the trajectory of HIV/AIDS and the nature of stigma associated with it, HIV caregivers require, not unlike other caregivers, direct and indirect, instrumental, informational, and socio-emotional support. However, the needs of the HIV informal caregiver are particularly complex because the HIV informal caregiver role expectations are complicated by unusual social meanings surrounding AIDS and gay relationships.

The problems encountered by informal caregivers and their efforts to manage and cope with these problems cannot be viewed as being separate from the system of formal supports that are available to them. At the points where families and significant others interact with health providers and social agencies, procedures and policies have the potential to support the informal caregivers efforts significantly or, if not sensitively managed, add to another layer of complexity and stress.

REFERENCES

Acierno, L. (1989). Cardiac complications in AIDS. Journal of the American College of Cardiology, 13, 1144-1154.

AIDS (1992). Statistics from the Centers for Disease Control. AIDS, 6, 139-141.

Ainlay, S.T., Coleman, L.M. & Becker, G (1986). Stigma reconsidered. In S.C Ainlay, G Becker, and L.M Coleman, eds. The Dilemma of Difference: A Multidisciplinary View of Stigma, pp. 1-13. NY: Plenum Press.

Alonzo, A.A. (1979). Everyday illness behavior: A situational approach to health status deviations. Social Science and Medicine, 13A, 397-404.

Alonzo, A.A. & Reynolds, N.R. (1993). Stigma, HIV and AIDS: An Exploration and elaboration of the illness trajectory surrounding HIV infection and AIDS. Presented Annual Meetings of the Society for Social Problems, Pittsburgh, PA., August 18, 1992.

Antonovsky, A. (1987). Unraveling the mystery of health: How people manage stress and stay well. San Francisco: Jossey-Bass Publishers.

Archbold, P.G., (1980). Impact of parent caring on middle-aged offspring. Journal of Gerontological Nursing, 6, 78-85.

Bailey, D.B. (1989). Case management in early intervention. Journal of Early Intervention, 13, 120-134.

Baillie, V., Norbeck, J.S., & Barnes, L.E. (1988). Stress, social support, and psychological distress of family caregivers of the elderly. Nursing Research, 37, 217-222.

Baker, F. & Weiss, P.S. (1984). The nature of case management support. Hospital and Community Psychiatry, 35, 925-928.

Baumgarten, M. (1989). The health of persons giving care to the demented elderly: A critical review of the literature. Journal of Epidemiology, 42, 1137-1148.

Benjamin, A.E. (1988). Long-term care and AIDS: Perspectives from experience with the elderly. Milbank Quarterly, 66, 415-443.

Bennett, M.J. (1990). Stigmatization: Experiences of persons with Acquired Immune Deficiency Syndrome. Issues in Mental Health Nursing, 11, 141-154.

Bertalanffy, Ludwig von. (1967). Robots, men, and minds. New York: George Braziller.

Biegel, D.E., Sales, E., & Schulz, R. (1991). Family caregiving in chronic illness. Newbury Park: Sage Publications.

Bowers. B.J. (1987). Intergenerational caregiving: Adult caregivers and their aging parents. Advances in Nursing Science, 9, 20-31.

Brody, E. (1981). Women in the middle and family help to older people. The Gerontologist, 21, 471-480.

Brown, M.A., & Powell-Cope, G.M. (1991). AIDS family caregiving: Transitions through uncertainty. Nursing Research, 40, 338-345.

Campbell, D.T., & Stanley, J.C. (1963). Experimental and quasi-experimental designs for research. Boston: Houghton Mifflin Co.

Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 597-605.

Carcagno, G. & Kemper, P. (1988). An overview of the channeling demonstration and its evaluation. HSR: Health Services Research, 23, 1-22.

Cassell, E.J. (1991). The nature of suffering and the goals of medicine. NY: Oxford University Press.

Chenitz, W.C., & Swanson, J.M. (1986). From practice to grounded theory. Reading, MA: Addison Wesley.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26, 267-272.

Christ, G.H., Wiener, L., & Moynihan, R.T. (1986). Psychosocial issues in AIDS. Psychiatric Annals, 16, 173-179.

Christianson, J. (1988). The effect of channeling on informal caregiving. HSR: Health Services Research, 23, 99-117.

Centers for Disease Control (1981a). Pneumocystis pneumonia-Los Angeles. Morbidity and Mortality Weekly Report, 30, 250-252.

Centers for Disease Control (1981b). Kaposi's sarcoma and Pneumocystis pneumonia among homosexual men - New York City and California. Morbidity and Mortality Weekly Report, 31, 294-301.

Centers for Disease Control (1983). CDC guidelines for isolation precautions in hospitals. In J.S Garner and B.P. Simmons (Eds.), Guidelines for prevention and control of noscomial infections (pp. 47-78). Atlanta: CDC (U.S. Government Printing Office No. 747-459).

Centers for Disease Control (1987a). Revision of the CDC Surveillance case definition for acquired immunodeficiency syndrome. Morbidity and Mortality Weekly Report, 36, 3S-15S.

Centers for Disease Control, (1987b). Tuberculosis and acquired immunodeficiency syndrome - New York City. Morbidity and Mortality Weekly Report, 36, 785-790, 795.

Centers for Disease Control (January, 1991). HIV/AIDS Surveillance Report. Atlanta, GA: Division of HIV/AIDS, Center for Infectious Diseases.

Centers for Disease Control (1992a). The second 100,000 cases of Acquired Immunodeficiency Syndrome - United States, June 1981-December 1991. Morbidity and Mortality Weekly Report, 41, 28-29.

Centers for Disease Control (1992b). Update: Acquired Immunodeficiency Syndrome - United States, 1991. Morbidity and Mortality Weekly Report, 41, 463-467.

Centers for Disease Control (1993). Surveillance and reporting of AIDS. HIV/AIDS Surveillance Report, 5(1), 18-19.

Chenitz, W.C. & Swanson, J.M. (1986). From practice to grounded theory. Menlo Park, CA: Addison-Wesly Publishing Company.

Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26, 267-272.

Christ, G.H., Wiener, L., & Moynihan, R.T. (1986). Psychosocial research is essential to understanding and treating AIDS. American Psychologist, 39, 1309-1314.

Clark, N.M. & Rakowski, W. (1983). Family caregivers of older adults: Improving helping skills. The Gerontologist, 23, 637-642.

Cohen, J. (1993). AIDS research: The mood is uncertain. Science, 260, 1254-1255.

Cohn, A.A. & DeGraaf, B. (1982). Assessing case management in the child abuse field. Journal of Social Science Research, 5, 29-43.

Conrad, P. (1987). The experience of illness: Recent and new directions. Research in the Sociology of Health, 6, 1-31.

Conway, M.E. (1978). Theoretical approaches to the study of roles. In M.E. Hardy and M.E. Conway (eds.), Role theory: Perspectives for health care professionals. Norwalk, CT: Appleton-Century-Crofts.

Coplan, N. & Bruno, M. (1989). AIDS and heart disease: The present and the future. American Heart Journal, 117, 1175-1177.

Crotty, P., & Kulys, R. (1986). Are Schizophrenics a burden to their families? Significant others views. Health and Social Work. 11, 173-187.

Cuff, P. (1990). Acquired immunodeficiency syndrome and malnutrition: The role of GI pathology. Nutrition in Clinical Practice, 5, 43-53.

Curran, J.W., Jaffe, H.W., Hardy, A.M., Morgan, W.M., Selik, R.M., & Dondero, T.J. (1988). Epidemiology of HIV infection and AIDS in the United States. Science, 239, 610-616.

Daniels, M. & Irwin, M. (1989). Caregiver stress and well-being. In E. Light and B.D. Lebowitz (Eds.), Alzheimer's disease treatment and family stress: directions for research (pp. 292-310). Rockville, MA: DHHS Publication No. (ADM) 89-1569.

Davis, F. (1973). Deviance disavowal: The management of strained interaction by the visibly handicapped. In W. Filstead (ed.), An introduction to deviance. Chicago: Rand McNally.

Deimling, G.T., & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 41, 778-784.

Derogatis, L.R. (1977). SCL-90: Administration, scoring, & procedures manual. Baltimore: John Hopkins University.

Des Jarlais, D.C., Chamberland, M.E., Yancovitz, S.R. et al. (1984). Heterosexual partners: A large risk group for AIDS. Lancet, 2, 1346-1347.

Doka, K.J. (1987). Silent sorrow: Grief and the loss of significant others. Death Studies, 11, 455-469.

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

Drucker, E. (1986). AIDS and addiction in New York City. American Journal of Drug and Alcohol Abuse, 12, 165-181.

Dudley, J. (1983). Living with stigma: The plight of people who we label mentally retarded. Springfield, IL: Charles C. Thomas.

Fanshel, S., & Bush, J.W. (1970). A health status index and its applications to health-services outcomes. Operations Research, 18, 1021-1065.

Fengler, A.P., & Goodrich, B.A. (1979). Wives of elderly disabled men: The hidden patients. The Gerontologist, 19, 175-183.

Fineberg, H.V. (1988). Education to prevent AIDS: Prospects and obstacles. Science, 239, 592-596.

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

Fischl, M., Richman, D., Nansen, N. et al. (1990). The safety and efficacy of zidovudine in the treatment of subjects with mildly symptomatic HIV-1 infection: A double blind placebo-controlled trial. Annals of Internal Medicine, 112, 727-737.

Flaskerud, J.H. (1992). Psychosocial aspects. In J.H. Flaskerud and P.J. Ungvarski (Eds.), HIV/AIDS: A guide to nursing care, (pp. 1-30). Philadelphia, PA: W.B. Saunders.

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

Forstein, M. (1984). The psychosocial impact of the acquired immunodeficiency syndrome. Seminars in Oncology, 11, 77-82.

Frese, M. & Zapf, D. (1988). Methodological issues in the study of work stress: Objective vs. subjective measurement of work stress and the question of longitudinal studies. In C.L. Cooper and R. Payne (Eds.), Causes, coping, and consequences of stress at work (pp. 375-411). Chichester: Wiley.

Freund, P.E., & McGuire, M.B. (1991). Health, illness, and the social body. Englewood Cliffs, NJ: Prentice Hall.

Friedland, G.H. & Klein, R.S. (1987). Transmission of the Human Immunodeficiency Virus. The New England Journal of Medicine, 317, 1125-1135.

Friedland, G.H., Saltzman, B.R., Rogers, M.F., Kahl, P.A., Lesser, M.L., Mayers, M.M., & Klein, R.S. (1986). Lack of transmission of HTVL-III/LAV infection to household contacts of patients with AIDS or AIDS-related complex and oral candidiasis. New England Journal of Medicine, 314, 344-349.

Frierson, R.L., Lippmann, S.B., & Johnson, J. (1987). AIDS: Psychological stresses on the family. Psychosomatics, 5, 65-68.

Fullilove, M.T. (1989). Anxiety and stigmatizing aspects of HIV infection. Journal of Clinical Psychiatry, 50, 5-8.

Geis, S.B., Fuller, R.L., & Rush, J. (1986). Lovers of AIDS victims: Psychosocial stresses on the family. Psychosomatics, 5, 65-68.

George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. Gerontologist, 26, 253-259.

Gerberding, J.L., Bryant-LeBlanc, C.E., & Nelson, K. et al. (1987). Risk of transmitting the human immunodeficiency virus, cytomegalovirus, and hepatitis B virus to health care workers exposed to patients with AIDS and AIDS-related conditions. Journal of Infectious Diseases, 156, 1-8.

Giacquinta, B.S. (1989). Researching the effects of AIDS on families. American Journal of Hospital Care, 6(3), 31-36.

Glaser, B.G., & Strauss, A. (1967). The discovery of grounded theory: Strategies for qualitative research. NY: Aldine.

Glaser, B.G. & Strauss, A.L. (1968). Time for dying. Chicago: Aldine.

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

Grief, G.L., & Porembski, E. (1988). AIDS and significant others: Findings from a preliminary exploration of needs. Health and Social Work, 10, 259-265.

Goerning, P.N., Wasylenki, D.A., Farkas, M., Lancee, W.J., & Ballantyne, R. (1988). What difference does case management make? Hospital and Community Psychiatry, 39, 272-276.

Goode, W. (1960). A theory of role strain. American Sociological Review, 25, 483-.

Grad, J. & Sainsbury, P. (1963). Mental illness and the family. Lancet, 1, 544-547.

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 followup. British Journal of Psychiatry, 114, 265-278.

Grady, C. (1992). HIV disease: Pathogenesis and treatment. In J.H. Flaskerud and P.J. Ungvarski, (Eds.), HIV/AIDS: A Guide to Nursing Care, (pp. 30-54). Philadelphia: W.B. Saunders Co.

Greene, V.L. (1983). Substitution between formally and informally provided care for the impaired elderly in the community. Medical Care, 21, 609-619.

Grief, G.L. & Porembski, E. (1988). AIDS and significant others: Findings from a preliminary exploration of needs. Health and Social Work, 10, 259-265.

Gwyther, L.P. & George, L.K. (1986). Caregivers for dementia patients: Complex determinants of well-being and burden. The Gerontologist, 26, 245-247.

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

Hardy, M.E., & Conway, M.E. (1978). Role theory: Perspectives for health professionals. Norwalk, CT: Appleton-Century-Crofts.

Henderson, D., Saah, A., Zak, B., Kaslow, R., Lane, H., Folks, T., Blackwelder, W., Schmitt, J., LeCamera, D., Masur, H., & Fauci, A. (1986). Risk of nosocomial infection with human T-cell lymphotrophic virus type III/lymphadenopathy associated virus in a large cohort of intensively exposed health care workers. Annals of Internal Medicine, 104, 644-647.

Hepburn, K. (1990). Informal caregivers: Frontline workers in the chronic care of AIDS patients. AHCPR Conference Proceedings. Community-Based Care of Persons with AIDS: Developing a Research Agenda. Rockville, MD: U.S. Dept. of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research.

Holland, G.N., Buhles, W.C., Mastre, B. et al. (1989). A controlled retrospective study of ganciclovir treatment for cytomegalovirus retinopathy: Use of a standardized system of disease outcome; UCLA CMV Retinopathy Study Group. Archives of Ophthalmology, 107, 1759-1766.

Hoeing, J. & Hamilton, M.W. (1966). Elderly psychiatric patients and the burden on the household. Psychiatria et Neurologia, 154, 281-293.

Holmes, T.H. & Rahe, R.H. (1974). Life change and illness susceptibility. In B.S. Dohrenwend and B.P. Dohrenwend (Eds.) Stressful life events: Their nature and effects, (pp. 45-72). New York: John Wiley & Sons.

Holmes, T.H. & Rahe, R.H. (1967). The Social Readjustment Rating Scale. Journal of Psychosomatic Research, 11, 213-218.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist, 25, 612-617.

House, J.S. (1974). Occupational stress and coronary heart disease: A review and theoretical integration. Journal of Health and Social Behavior, 15, 12-21.

Intagliata, J. (1982). Improving the quality of community care for the chronically mentally disabled: The role of case management. Schizophrenia Bulletin, 8, 655-674.

Institute of Medicine, National Academy of Sciences, (1988). Confronting AIDS: Update 1988. Washington, D.C.: National Academy Press.

Jabs, D.A., Enger, C., & Bartlett, J.G. (1989). Cytomegalovirus retinitis and acquired immunodeficiency syndrome. Archives of Opthalmology, 107, 75-80.

Kaplan, R.M., Bush, J.W., & Berry, C.C. (1976). Health status: Types of validity and the Index of Well-Being. Health Services Research, 11, 478-507.

Katz, I. (1978). Some thoughts about the stigma notion. Personality and Social Psychology Bulletin, 5, 447-460.

Kelleher, P. (1988). Coming to terms with diabetes: Coping strategies and non-compliance. In R. Anderson and M. Bury (Eds.), Living with chronic illness (pp. 132-156). Boston: Upwin Hyman.

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, 789-791.

Kemper, P. (1986). The evaluation of the National Long Term Care Demonstration: final report. Princeton, NJ: Mathematica Policy Research.

Kennedy, S., Kiecolt-Glaser, J.K., & Glaser, R. (1988). Immunologic consequences of acute and chronic stressors: Mediating role of interpersonal relationships. British Journal of Medical Psychology, 61, 77-85.

Kiecolt-Glaser, J.K., Glaser, R., Shuttleworth, E.C., Dyer, C.S., Ogrocki, P., & Speicher, C.E. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease victims. Psychosomatic Medicine, 49, 523-535.

Kingsley, L.A., Kaslow, R., Rinaldo, Jr., C.R., Detre, L., Odaka, N., VanRaden, M., Detels, R., Polk, B.F., Chmiel, J., Kelsey, S.F., Ostrow, D., & Visscher, B. (1987). Risk factors for seroconversion to Human Immunodeficiency Virus among male homosexuals. Lancet, 1, 345-351.

Knickman,J.R., Harnett, E. & Kohn, S. (1989). Case management for persons with AIDS: A comparison of hospital-based and community based approaches. Paper delivered at the American Public Health Association Annual Conference, October, 1989. Chicago, IL.

Kosberg, J.I., Cairl, R., & Keller, R.E. (1990). Components of burden: Intervention implications. The Gerontologist, 30, 236-242.

Lane, H.C. (1989). The role of immunomodulators in the treatment of patients with AIDS. AIDS, 3(suppl 1), S181-S185.

Larsen, D.L., Attkisson, C.C., Hargreaves, W.A., & Nyguyen, T.D. (1979). Assessment of client/patient satisfaction: Development of a general scale. Evaluation and Program Planning, 2, 197-207.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. Journal of Gerontology, 44, p61-p71.

Layzell, S., & McCarthy, M. (1992). Community-based health services for people with HIV/AIDS: A review from a health service perspective. AIDS CARE, 4, 203-215.

Lazarus, R.S. (1986). Stress: Appraisal and coping capacities. In A.E. Eicher, M.M. Silverman and D.M. Pratts (Eds.), Handbook of Medical Sociology, 4th Ed. (pp. 69-87). Englewood Cliffs, NJ: Prentice Hall.

Lazarus, L.W., Stafford, B., Cooper, K., Cohler, B., & Dysken, M. (1981). A pilot study of an Alzheimer's relatives discussion group. The Gerontologist, 21, 353-358.

Levine, N.B., Dastoor, D.P., & Gendron, C.E. (1983). Coping with dementia: A pilot study. Journal of the American Geriatrics Society, 31, 12-18.

Lubkin, I.M. (1986). Chronic illness: Impact and interventions. Boston, MA: Jones and Bartlett Publishers.

Maes, S., Vingerhoets, A., VanHeck, G. (1987). The study of stress and disease: Some developments and requirements. Social Science Medicine, 25, 269-289.

Mann, J.M. (March, 1988). For a global challenge. World Health (pp. 4-8).

Martin, J.P. (1988). Hospice and home care for persons with AIDS/ARC: Meeting the challenges and ensuring quality. Death Studies, 12, 463-480.

Matza, D. (1964). Delinquency and drift. New York: John Wiley & Sons.

McArthur, J., Palenicek, J., Bowersox, L. (1988). Human immunodeficiency virus and the nervous system. Nursing Clinics of North America, 23, 823-842.

McCormick, W.C. (1989). Home care for persons with AIDS: A rational approach. AHCPR Conference Proceedings. Community-Based Care of Persons with AIDS: Developing a Research Agenda. Rockville, MD.: U.S. Dept. of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research.

McNair, D.M., Lorr, M., & Droppleman, L.F. (1971). POMS manual for Profile of Mood States. San Diego: Educational and Industrial Testing Service.

Mead, G.H. (1938). Mind, self, and society. Chicago: The University of Chicago Press.

Merz, D.C. (1991). Clinical management of the acquired immunodeficiency syndrome. Unpublished manuscript.

Mischel, M.H. (1984). Perceived uncertainty and stress in illness. Research in Nursing and Health, 7, 163-171.

Mittenthal, S. (1976). Evaluation overview: A system approach to service integration. Evaluation, 3, 142-148.

Morrill, W. (1976). Services integration and the Department of Health, Education, and Welfare. Evaluation, 3, 52-55.

Morrow-Howell, N.C. (1984). Functional change in the elderly: Results of the multipurpose Senior Services Project, Social Work Research and Abstracts, 20, 1050.

Moss, A.R., Osmond, D., Bacchetti, P., Cherman, J., Barre-Sinoussi, F., & Carlson, J. (1987). Risk factors for AIDS and HIV seropositivity in homosexual men. American Journal of Epidemiology, 125, 1035-1047.

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

Needle, R.H., Leach, S., & Graham-Tomasi, R.P. (1989). The Human Immunodeficiency Virus (HIV) epidemic: Epidemiological implications for family professionals. In E.D. Macklin (Ed.), AIDS and families, (pp 13-39). New York: Harrington Park Press.

Nickel, J., & Salsberry, P. (1988). Effects of Nurse Case Managed Care for HIV Patients. Unpublished grant application _ RO1 NR02281.

Nichols, E.K. (1989). Mobilizing against AIDS. Cambridge, MA: Harvard University Press.

Nyamathi, A. (1989). AIDS related heart disease: A review of the literature. Journal of Cardiovascular Nursing, 3, 65-76.

Nguyen, T.D., Attkisson, C.C., & Stegner, B.L. (1983). Assessment of patient satisfaction: Development and refinement of a service evaluation questionnaire. Evaluation and Program Planning, 6, 299-314.

Office of Technology Assessment (May, 1988). How effective is AIDS education? (DHHS Publication No. ADM88-6435). Washington, DC: U.S. Government Printing Office.

Pagel, M.D., Becker, J., & Coppel, D.B. (1985). Loss of control, self-blame, and depression: An investigation of spouse caregivers of Alzheimer's disease patients. Journal of Abnormal Psychology, 94, 169-182.

Parsons, T. (1951). The social system. NY: The Free Press of Glencoe.

Pasccoe, G.C., Attkisson, C.C., & Roberts, R.E. (1983). Comparison of indirect and direct approaches to measuring patient satisfaction. Evaluation and Program Planning, 6, 359-371.

Patrick, D.L., Bush, J.W., & Chen, M.M. (1973). Methods for measuring levels of well-being for a health status index. Health Services Research, 8, 228-245.

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

Phillips, L.R., & Rempusheski, V.F. (1986). Caring for the frail elderly at home: Toward a theoretical explanation of the dynamics of poor quality family caregiving. Advances in Nursing Science, 8, 62-84.

Pinder, R. (1988). Striking balances: Living with Parkinson's disease. In R. Anderson & M. Bury (Eds.), Living with chronic illness: The experiences of patients and their families. Boston: Unwin Hyman.

Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39, 230-239.

Presidential Commission on the Immunodeficiency Virus (1988). Chairmen's Recommendations. Washington, D.C.: Bio-Data Publishers.

Price, R., Brew, B., Sidtis, J. et al., (1988). The brain in AIDS: Central nervous system HIV-1 infection and AIDS dementia complex. Science, 239, 586-591.

Rabins, P.V. (1981). Management of irreversible dementia. Psychosomatics, 22, 91-97.

Rapp, C. & Chamberlain, R. (1985). Case management services for the chronically mentally ill. Social Work, 30, 417-422.

Raveis, V.H. & Siegel, K. (1989). Impact of caregiving on informal or familial caregivers. AHCPR Conference Proceedings. Community-Based Care of Persons with AIDS: Developing a Research Agenda. Rockville, MD: U.S. Dept. of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research.

Redfield, R.R. & Burke, D.S. (1988). HIV infection: The clinical picture. Scientific America, 259, 90-98.

Redfield, R.R. & Tramont, E.C. (1988). Toward a better classification system for HIV infection. The New England Journal of Medicine, 320, 1414-1416.

Robinson, B. (1983). Validation of a caregiver strain index. Journal of Gerontology, 39, 344-348.

Rogers, M. (1987). Transmission of Human Immunodeficiency Virus infection in the United States. In B. Silverman and A. Waddell (Eds.), Report of the Surgeon General's Workshop on Children with HIV Infection and their families (pp. 17-19). Washington, DC: Public Health Service.

Rose, J.M. (1990). Practice concepts: Symposium. The Gerontologist, 30, 692.

Rose, M.A., & Catanzaro, A.M. (1989). AIDS caregiving crisis: A proactive approach. Holistic Nursing Practice, 3, 39-45.

Rothenberg, R., Woelfel, M., Stoneburner, R., Milberg, J., Parker, R. & Truman, B. (1987). Survival with the acquired immunodeficiency syndrome. The New England Journal of Medicine, 317, 1297-1302.

Ryndes, T. (1989). The coalition model of case management for care of HIV-infected persons. QRB, 4-8.

Scambler, G. (1984). Perceiving and coping with stigmatizing illness. In R. Fitzpatrick, J. Hinton, S. Newman, G. Scambler, and J. Thompson (Eds.), The Experience of Illness, (pp. 203-226). NY: Tavistock Publications.

Schofferman, J. (1988). Care of the AIDS patient. Death Studies, 12, 433-449.

Schulz, R., Tomkins, C.A., Wood, D., & Decker, S. (1987). The social psychology of caregiving: Physical and psychological costs of providing support to the disabled. Journal of Applied Social Psychology, 17, 401-428.

Schuster, C.R. (1988). Intravenous drug use and AIDS prevention. Public Health Reports, 103, 261-266.

Schwartz, S.R., Goldman, H.H., & Churgin, S. (1982). Case management for the chronic mentally ill: Models and dimensions. Hospital and Community Psychiatry, 33, 1006-1009.

Seidel, J.V., Kjolseth, R., & Seymour, E. (1988). The Ethnograph: A user's guide. Littleton, Colorado: Qualis Research Associates.

Selye (1956). The stress of life. New York: McGraw-Hill.

Selye (1976). The stress of life (2nd ed.). New York: McGraw-Hill.

Sheehan, N.W., & Nuttall, P. (1988). Estimates of the direct and indirect costs of the acquired immunodeficiency syndrome in the U.S., 1985, 1986, 1991. Public Health Reports, 102, 5-17.

Siegel, K. & Krauss, B.J. (1991). Living with HIV infection: Adaptive tasks of seropositive gay men. Journal of Health and Social Behavior, 32, 17-32.

Simmons, K.H., Ivry, J., & Seltzer, M.M. (1985). Agency-family collaboration. The Gerontologist, 25, 343-346.

Smiley, M.L. (1988). HIV infection and AIDS: Definition and classification of disease. Death Studies, 12, 399-415.

Soldo, B.J., & Myllyluoma, J. (1983). Caregivers who live with dependent elderly. Gerontologist, 23, 605-611.

Stafford, M.C., & Scott, R.R. (1986). Stigma, deviance, and social control: Some conceptual issues. In S.C. Ainley, G. Becker, and C,M. Coleman (Eds.), The dilemma of difference: A multidisciplinary view of stigma. New York: Plenum Press.

Strauss, A. (1962). Transformations of identity. In A.M. Rose (Ed.) Human behavior and social processes (pp. 20-41). Boston: Houghton Mifflin Company.

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

Strauss, A.L. (1978). Negotiations: Varieties, contexts, processes, and social order. San Francisco, CA: Jossey-Bass, Inc.

Strauss, A.L. (1987). Qualitative analysis for social scientists. Cambridge, England: Cambridge University Press.

Strauss, A.L., Corbin, J., Fagerbaugh, S., Glaser, B.G., Maines, D., Suczek, B., & Wiener, C.L. (1984). Chronic illness and the quality of life. St. Lois C.V. Mosby.

Stulberg, J., & Buckingham, S.L. (1988). Parallel issues for AIDS patients, families, and others. Social Casework: The Journal of Contemporary Social Work, June, 355-359.

Test, M. (1979). Continuity of care in community treatment. In L. Stein (Ed.), Community support systems for the long-term patient, (pp. 15-23). San Francisco, CA: Jossey Bass, Inc.

Turner, R.H. (1962). Role-Taking: Process versus conformity. In A.M. Rose (Ed.) Human behavior and social processes (pp. 20-41). Boston: Houghton Mifflin Company.

Turner, H.A. & Pearlin, L.I. (Fall, 1989). Issues of age, stress, and caregiving. Generations, 56-59.

U.S. House of Representatives (1988). A generational in jeapardy: Children and AIDS. A report of the Select Committee on Children, Youth, and Families. Washington, DC: U.S. Government Printing Office.

Volberding, P., Lagakos, S., Koch, M. et al. (1990). Zidovudine in asymptomatic human immunodeficiency virus infection: A controlled trial in persons with less than 500 CD4 positive cells per cubic mm. The New England Journal of Medicine, 322, 941-949.

Watkins, J.D., et al. (1988). Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic. Presidential Commission, 655 15th St. NW, Suite 901, Washington, DC 20005.

Weiner, B., Perry, R.P., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. Journal of Personality and Social Psychology, 55, 738-748.

Weiss, S.H., Goedert, J.J., Gartner, S., Popovic, M., Waters, D., Markham, P., Veronese, F., Gail, M.H., Barkley, W.E., Gibbons, J., Gill, F.A., Leuther, M., Shaw, G.M., Gallo, R.C., & Blattner, W.A. (1988). Risk of Human Immunodeficiency Virus (HIV-1) infection among laboratory workers. Science, 239, 68-71.

Weitz, R. (1989). Uncertainty and the lives of persons with AIDS. Journal of Health and Social Behavior, 30, 270-281.

Wilson, H.S. (1989). Family caregiving for a relative with Alzheimer's dementia: Coping with negative choices. Nursing Research, 38, 94-98.

Wolcott, D.L., Namir, S., Fawzy, F.I., Gottlieb, M.S., & Mitsuyasu, R.T. (1986). Illness concerns, attitudes towards homosexuality, and social support in gay men with AIDS. General Hospital Psychiatry, 8, 395-403.

Wolfensberger, W. (1972). The principle of normalization and its implications for psychiatric services. American Journal of Psychiatry, 127, 291-297.

Young, R.F. & Kahana, E. (1987). Conceptualizing stress, coping, and illness management in heart disease.

Zarit, S.T. (1989). Do we need another "stress and caregiving" study? The Gerontologist, 29, 147-148.

Zarit, S.H., Reeves, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-655.

Zarit, S.H., Todd, R.A., & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26, 260-266.

Zarit, S.H., & Zarit, J.M. (1982). Families under stress: Interventions for caregivers of senile dementia patients. Psychotherapy: Theory, Research & Practice, 19, 461-471.

Zich, J., & Temoshok, L. (1987). Perceptions of social support in men with AIDS and ARC: Relationships with distress and hardiness. Journal of Applied Social Psychology, 17, 193-215.

Zimmerman, J.H. (1987). Negotiating the system. Public Welfare, 45, 23-27.

APPENDIX A

INFORMAL CAREGIVER QUESTIONNAIRE:
Part 1 and Part 2

ID # ________
Date ________

INFORMAL CAREGIVER QUESTIONNAIRE - PART I

1.	Birth date	Specify:	________________ Mo. Day Yr.
2.	Age	< 25	____________
		25-34	____________
		35-64	____________
		> 65	____________
3.	Sex	Male	____________
		Female	____________
4.	Race/Nationality	Euro-American	____________
		Afri-American	____________
		Other(Specify)	____________
5.	Education	Specify:	____________ (Grade Completed)
		< High School	____________
		High School	____________
		Some College	____________
		College	____________
		> College +	____________
6.	Employment Status	Full-Time	____________
		Part-Time	____________
		Unemployed	____________
		Retired	____________
		Disabled/ Disability	____________
7.	Occupation	Specify:	________________
8.	Annual Income	Specify:	________________
		< 10,000	____________
		10-14,999	____________
		15-19,999	____________
		20-29,999	____________

30-39,999 __________
> 40,000 __________

9\. Relationship to Patient

Partner __________
Friend __________
Legal guardian __________
Spouse __________
Mother __________
Father __________
Sister __________
Brother __________
Daughter __________
Son __________
Other(Specify) __________

10\. Years living with patient (consecutively)

Specify: __________ (mo.)
__________ (yrs)
0 = separate households

11\. Years living with patient (total)

Specify: __________ (mo.)
__________ (yrs)

12\. Length time helping/supporting patient with illness as needed

Specify: __________ (wks)
__________ (yrs)

13\. Number of people in patient household

Specify: __________

14\. Date of referral for patient home care services

Specify: __________

15\. Time since patient referred for home care services.

Specify: __________
(months)

Contact person: __________ Telephone #: __________
Address: ____________________

ID # __________
Date __________

INFORMAL CAREGIVER QUESTIONNAIRE
Part II

Nature of caregiving activities/Patient illness factors

1. What is it like caring for _______ (patient)?
   Describe ______________________________________

2. What is the most difficult or hardest thing for you about _______'s (patient) illness?
   Describe ______________________________________

3. How is _______ 's (patient) illness effecting him/her physically at this time?
   Describe ______________________________________

4. Are there any things that you do for _______ (patient) because s/he is unable to do them or becomes too tired doing them for him/herself?
   Yes ___ No ___
   Describe ______________________________________

5. How is _______ 's (patient) illness effecting him/her emotionally at this time?
   Describe ______________________________________

6. What are the things that you do for _______ (patient) to help him/her feel better emotionally?
   Describe ______________________________________

7. Which of the following things are you currently doing for _______ (patient) to assist or help him/her feel better?

   -- show Handcard A --

   List by number: ______________________________________

8. What are your major concerns at this time?
   Describe ______________________________________

Time spent in caregiving activities

9. On average, how much time do you currently spend each day with ______ (patient)?
Hours ______

Competing demands/role conflict-overload

10. Has ______ 's (patient) illness been disruptive to your personal life in any way?
Yes ___ No ___
Describe ________________________________

11. In addition to assisting ________ (patient), what other responsibilities do you have?
Describe ________________________________

12. Is it ever difficult for you to fulfill other responsibilities because of ______ 's (patient) illness?
Yes ___ No ___
Describe ________________________________

13. Are you work activities restricted in any way because of ______ 's (patient) illness?
Yes ___ No ___
Describe ________________________________

14. How does this make you feel and how do you manage this situation?
Describe ________________________________

15. Are your social or recreational activities restricted in any way because of ______'s (patient) illness?
Yes ___ No ___
Describe ________________________________

16. How does this make you feel and how do you manage this situation?
Describe ________________________________

17. Do you ever wish you could terminate your caregiving role? If yes, would you consider this seriously?
Yes ___ No ___
Describe ________________________________

Economic stressors

18. What are your financial commitments to _______ (patient)?
Describe ____________________________________

19. Has _______'s (patient) illness caused you any financial hardship?
Yes ___ No ___
Describe ____________________________________

If no, do you ever worry that _______'s illness could cause you financial hardship?
Yes ___ No ___
Describe ____________________________________

20. Have you done anything to avoid financial cost resulting from _______'s (patient) illness?
Yes ___ No ___
Describe ____________________________________

Amount of assistance with caregiving activities

21. Does anyone else assist/support _______ (patient) in any way?
Yes ___ No ___

22. If yes, who else helps (identify relationship) and what type of assistance/support do they provide?

Informal
Name ________________ Relationship ________________
Type support ________________________________

Name ________________ Relationship ________________
Type support ________________________________

Name ________________ Relationship ________________
Type support ________________________________

Formal

Name ________________ Relationship ________________
Type support ________________________________

Name ________________ Relationship ________________
Type support ________________________________

Name ________________ Relationship ________________
Type support ________________________________

23. What services that ______ (patient) receives are most helpful to you?
Describe ____

24. Does _________ (patient) receive all the assistance/help from others that you would like?
Describe ____

25. What additional assistance/services do you think would be helpful at this time?
Describe ____

26. Are there any services that _______ (patient) receives that you do not think are helpful?
Yes ___ No ___
Describe ____

27. Do you and __________ (patient) agree about what type of help/services are needed in your home?
Yes ___ No ___
Describe ____

28. Have the home care services that _______ (patient) receives changed your responsibilities in any way?
Yes ___ No ___
Describe ____

29. Are you able to communicate well with health care professionals about _______ (patient)?
Yes ___ No ___
Describe ____

30. Do you think health care professionals understand what _______ (patient) really needs?
Yes ___ No ___
Describe ____

Competence/qualifications for caregiving

31. How have you learned about HIV/AIDS?
Describe ____

32. Have you ever cared for or assisted someone else who was ill?
Yes ___ No ___
Describe ____

33. Where have you received most of your information about HIV/AIDS?
Describe ____

34. Has anyone ever instructed you about how to assist someone with HIV/AIDS?
Yes ___ No ___
If yes, who?
Name ________________ Relationship ________________
Name ________________ Relationship ________________

35. Do you think you have the technical knowledge necessary for supporting/caring for someone with HIV/AIDS?
Yes ___ No ___
Describe ____

36. Do you think you have the emotional capability necessary for supporting/caring for someone with HIV/AIDS?
Yes ___ No ___
Describe ____

37. Do you think you have the physical strength necessary for supporting/caring for someone with HIV/AIDS?
Yes ___ No ___
Describe ____

38. Do you currently provide any care that you are not comfortable with or feel you are not qualified to provide?
Yes ___ No ___
Describe ____

39. Do you ever feel you are not doing enough for _______ (patient)?
Yes ___ No ___
Describe ____

If yes, what do you do when you feel this way?
Describe ____

40. Do you ever feel uncertain about the right thing to say or do for _______ (patient)?
Yes ___ No ___
Describe ____

If yes, what do you do when you feel this way?
Describe ____

Quality of relationship

41. How would you describe your relationship with ______ (patient) before s/he became ill?
Describe ________________________________

42. Has your relationship with ______ (patient) changed since s/he became HIV positive?
Yes ___ No ___
Describe ________________________________

43. Are there things that you and ______ (patient) disagree on or are there things that are sources of tension between you and ______ (patient)?
Yes ___ No ___
Describe ________________________________

44. Do you and ______ (patient) ever discuss your feelings about death?
Yes ___ No ___
Describe ________________________________

45. Have you ever, or do you now have any doubts about your decision to assist ______ (patient) during his/her illness?
Yes ___ No ___
Describe ________________________________

Stigma

46. Do you think AIDS is looked down upon or stigmatized by our society?
Yes ___ No ___
Describe ________________________________

47. Do you think that persons with HIV infection are treated differently by anyone because of this diagnosis?
Yes ___ No ___
Describe ________________________________

48. Do you think because of AIDS stigma that the type or quality of health care that is available is different?
Yes ___ No ___
Describe ________________________________

49. Do you think that there is a tendency for others to look at you differently because of your association with _______ (patient)?
Yes ___ No ___
Describe ____

50. Does society blame _________ (patient) for his/her illness?
Yes ___ No ___
Describe ____

51. Do you think you would feel or behave differently toward ________ (patient) in anyway if s/he were ill with cancer instead of HIV/AIDS?
Yes ___ No ___
Describe ____

52. Do you ever feel ashamed or embarrassed that ________ (patient) is HIV positive (or has AIDS)?
Yes ___ No ___
Describe ____

53. Do you worry that people will treat you differently when they know that you are taking care of a person who is HIV positive?
Yes ___ No ___
Describe ____

54. Has anyone ever treated <u>you</u> differently because of __________'s (patient) AIDS?
Yes ___ No ___
Describe ____

55. How many people know about _________ (patient's) HIV/AIDS diagnosis?

	All	Most	Some	Few	None
Immediate Family					
Other Relatives					
Friends					
Co-Workers					
Other (Specify)					

56. How did they find out?
Describe ____

57. What have been their responses?
Describe ____

58. Did you and _________ (patient) agree about who should be told?
Yes ___ No ___
Describe ____

Social Support

59. Has your relationship with family/friends changed since _________ (patient) became ill?
Yes ___ No ___
Describe ____

60. Do you ever feel isolated or feel as if no one understands what you are going through?
Yes ___ No ___
Describe ____

61. Do you have anyone that you can talk to or who makes you feel better when you are upset or feeling low?
Yes ___ No ___
Describe ____

Fear HIV infection

62. Have you ever been tested for HIV infection?
Yes ___ No ___

63a. If yes, are you HIV positive?
Yes ___ No ___

When and where were you diagnosed?
Date: ______________
City/State: ______________

Do you participate in any clinical trials?
Yes ___ No ___

63b. If no, do you ever worry that you have been exposed to HIV infection?
Yes ___ No ___
Why? ______________________________

Do you take special precautions to avoid exposure to HIV infection?
Yes ___ No ___

If yes, what type of precautions do you take?
Describe ______________________________

If no, why do you not take precautions?
Describe ______________________________

Health Status

64. How would you describe your health status?
Poor ___ Fair ___ Good ___ Excellent ___

65. Are you able to go to a doctor or health clinic as often as you would like or need to ?
Yes ___ No ___
Describe ______________________________

66. During the last 2 weeks have you taken any of the following medications/drugs?

-- Show Handcard B --

If yes, list number and reason for taking.

Number Reason

____

____

____

67. Do you smoke currently?
Yes ___ No ___

68. Do you drink any form of alcoholic beverages including beer or wine?
Yes ___ No ___

If yes, how many alcohol containing drinks do you consume on the average?
per day ________
per week ________
per month ________

69. Do you exercise regularly?
Yes ___ No ___

If yes, what kind of exercise do you do and how much (frequency and length)?

Type Exercise	Frequency			Minutes (at time on ave.)
	x/day	x/week	x/month	

Open ended

70. What are your hopes for the future?
Describe ____

71. What is most rewarding for you about assisting someone with HIV/AIDS?
Describe ____

72. Has caring for someone with HIV/AIDS changed the way you think about your about yourself or your life?
Yes ___ No ___
Describe ____

73. Is there anything that we have not already discussed that you would tell other people about what it is like to care for someone with HIV/AIDS?
Yes ___ No ___
Describe ____

74. Do you have any questions that you would like to ask me?

HANDCARD A

1. Be available when or if needed.
2. Supervise/carry out prescribed treatment and general recommendations.
3. Evaluate options for treatment and/or services.
4. Monitor course of _______'s illness and evaluate significance of changes.
5. Evaluate strength/resources of _________.
6. Anticipate needs for future assistance and services.
7. Structure _________'s daily activities.
8. "Run interference" for _________ in social and community settings.
9. Try to keep _________'s life as normal as possible within bounds of his/her impairment.
10. Supervise/directly manage _________'s resources.
11. Perform personal care for __________.
12. Do extra housework.
13. Manage illness-related finances/paperwork.
14. Assist with mobility.
15. Do extra home maintenance work.
16. Provide transportation.
17. Do things to protect _________ from injury/accidents
18. Do things to bolster _________'s self-image.
19. Make sure _________ has right amount of social/recreational activity.
20. Make adjustments in housing arrangements.
21. Enable _________ to have desired spiritual support.

22. Touch (e.g., hold hands, hug).

23. Prevent and manage medical crises.

HANDCARD B

1. Pain relievers such as aspirin, Tylenol, or Motrin.
2. Cough medicines (e.g., Vicks, Robitussin, or Phenergan Expectorant).
3. Any other medicines or remedies for colds.
4. Asthma or allergy pills or medicines such as Benadryl, Dimetapp, or Sudafed.
5. Topical Steroids (e.g., hydrocortisone cream or valisone).
6. Other skin ointments or salves (e.g., Desitin, Calamine Lotion, Vaseline, or Clearasil).
7. Laxatives or any other medicines or remedies for the stomach (e.g., Ex-Lax, Rolaids, Colace, or Donnatal).
8. Vitamins or minerals.
9. Tranquilizers (e.g., Lithium).
10. Sedatives (e.g., Valium, Chloral Hydrate, or Seconal).
11. Antidepressants (e.g., Prozac).
12. Mood altering/Non-prescription (e.g., marijuana, cocaine, crack).
13. Antibiotics (e.g., Penicillin, Tetracycline, or Ampicillin).
14. Other

APPENDIX B

INFORMAL CAREGIVER QUESTIONNAIRE:
Follow-up

ID # ________
Date ________

INFORMAL CAREGIVER QUESTIONNAIRE
Follow-up

Nature of caregiving activities/Patient illness factors

1. What is the most difficult or hardest thing for you about ______'s (patient) illness?
   Describe ________________________________

2. How is ______ 's (patient) illness effecting him/her physically at this time?
   Describe ________________________________

3. Are there any things that you do for ______ (patient) because s/he is unable to do them or becomes too tired doing them for him/herself?
   Describe ________________________________

4. How is ______ 's (patient) illness effecting him/her emotionally at this time?
   Describe ________________________________

5. What are the things that you do for ______ (patient) to help him/her feel better emotionally?
   Describe ________________________________

6. Which of the following things are you currently doing for ______ (patient) to assist or help him/her feel better?

   -- show Handcard A --

   List by number: ____________________________

7. Are there any other things that are not on the card that you are now doing to assist or help ______ (patient) feel better?
   Yes ___ No ___
   Describe ________________________________

8. What are your major concerns at this time?
   Describe ________________________________

Time spent in caregiving activities

9. On average, how much time do you currently spend each day with _______ (patient)?
Hours ______

10. How much time do you actually spend doing the things (on card) you said you do for _______?
Hours ______

Competing demands/role conflict-overload

11. Has _______ 's (patient) illness been disruptive to your personal life in any way?
Yes ___ No ___
Describe ____

12. Is it ever difficult for you to fulfill other responsibilities because of _______ 's (patient) illness?
Yes ___ No ___
Describe ____

13. What other responsibilities do you have?
Describe ____

14. Are you work activities restricted in any way because of _______ 's (patient) illness?
Yes ___ No ___
Describe ____

15. How does this make you feel and how do you manage this situation?
Describe ____

16. Are your social or recreational activities restricted in any way because of _______'s (patient) illness?
Yes ___ No ___
Describe ____

17. How does this make you feel and how do you manage this situation?
Describe ____

18. Do you ever wish you could terminate your caregiving role?
Yes ___ No ___
Describe ____

Economic stressors

19. Do you have any financial commitments to _______ (patient)?
Yes ___ No ___
Describe ______________________________

20. Has _______'s (patient) illness caused you any financial hardship or caused you to worry about the possibility of financial hardship?
Yes ___ No ___
Describe ______________________________

21. Have you done anything to avoid financial cost resulting from _______'s (patient) illness?
Yes ___ No ___
Describe ______________________________

Amount of assistance with caregiving activities

22. Do any other family members or friends provide any assistance or support to ______ (patient) at this time?
Yes ___ No ___
Describe ______________________________

23. What community/home care (formal) services does _____ (patient) receive at this time?
Describe ______________________________

24. What medical (physician) services does _______ (patient) have at this time?
Describe ______________________________

25. What outside help (family/friends or professional services) do you rely upon the most or find to be most helpful to you?
Describe ______________________________

26. Are there any services that _______ (patient) receives that you do not think are helpful?
Yes ___ No ___
Describe ______________________________

27. Have the home care services that _______ (patient) receives changed your responsibilities in any way?
Yes ___ No ___
Describe ______________________________

28. Does _______ (patient) have a case manager?
Yes ___ No ___
Name(s)/Agency(s) ______________________________

28a. If yes, is the case manager helpful to you in any way?

List: ______________________________
Other? ______________________________

29. Are you comfortable talking to health care professionals about _______ (patient?
Yes ___ No ___
Describe ______________________________

30. Do you think health care professionals understand what _______ (patient) really needs?
Yes ___ No ___
Describe ______________________________

Competence/qualifications for caregiving

31. How have you learned about HIV/AIDS?
Describe ______________________________

32. Have you ever cared for or assisted someone else who was ill?
Yes ___ No ___
Describe ______________________________

33. Has anyone ever instructed you about how to assist someone with HIV/AIDS?
Yes ___ No ___
Describe ______________________________

34. Do you think you have the technical knowledge necessary for supporting/caring for someone with HIV/AIDS?
Yes ___ No ___
Describe ______________________________

35. Is there any information about HIV/AIDS that you would like to have?
Yes ___ No ___
Describe ______________________________

36. Do you think you have the emotional capability necessary for supporting/caring for someone with HIV/AIDS?
Yes ___ No ___
Describe ________________________________

37. Do you think you have the physical strength necessary for supporting/caring for someone with HIV/AIDS?
Yes ___ No ___
Describe ________________________________

38. Do you currently provide any care that you are not comfortable with or feel you are not qualified to provide?
Yes ___ No ___
Describe ________________________________

39. Do you ever feel you are not doing enough for _______ (patient)?
Yes ___ No ___
Describe ________________________________

40. Do you ever feel uncertain about the right thing to say or do for _______ (patient)?
Yes ___ No ___
Describe ________________________________

Quality of relationship

41. How would you describe your relationship with _______ (patient) at this time?
Describe ________________________________

42. Has your relationship with _______ (patient) changed since s/he became HIV positive?
Yes ___ No ___
Describe ________________________________

43. Are there ever any uncomfortable moments between you and _______ (patient) that seem to be related in some way to his/her illness?
Yes ___ No ___
Describe ________________________________

44. Are you and _______ (patient) able to enjoy similar activities or spend time together in similar ways now as before?
Yes ___ No ___
Describe ________________________________

45. Do you and ______ (patient) ever discuss your feelings about death?
Yes ___ No ___
Describe ____

Stigma

46. Do you think AIDS is looked down upon or stigmatized by our society?
Yes ___ No ___
Describe ____

47. Do you think that persons with HIV infection are treated differently by anyone because of this diagnosis?
Yes ___ No ___
Describe ____

48. Does the fact that ______ (patient) have HIV/AIDS make you uncomfortable in any way?
Yes ___ No ___
Describe ____

49. Do you think that there is a tendency for others to look at you differently because of your association with ______ (patient)?
Yes ___ No ___
Describe ____

49a. If yes, how do you handle/manage with this?
Describe ____

50. Over the past 3 months, has anyone new learned of ______'s (patient) HIV illness?
Yes ___ No ___
Describe ____

51. If yes, what have been their responses (consider initial vs. present)?
Describe ____

Social support

52. Do you attend a support group for SO's of someone with HIV/AIDS or get counseling of any sort (note whether related specifically to HIV/AIDS counseling)?
Yes ___ No ___
Describe ____

52a. If no, would you be interested in receiving counseling or attending a social support group?
Yes ___ No ___
Describe ____

52b. If yes, do you find this helpful?
Yes ___ No ___
Describe ____

53. Do you have any family or friends you can talk to who helps you feel better when you are upset or feeling low?
Yes ___ No ___
Describe ____

Health Status

52. Have you ever been tested for HIV infection?
Yes ___ No ___

53. If yes, are you HIV positive?
Yes ___ No ___

54. Do you find it difficult or stressful to care for/assist someone with HIV/AIDS?
Yes ___ No ___
Describe ____

55. If yes, what do you do to alleviate your stress?
Describe ____

56. Do you feel you have had any new health problems because you are taking care of _______ (patient)?
Yes ___ No ___
Describe ____

57. Have any existing health problems gotten worse because you are taking care of _______ (patient)?
Yes ___ No ___
Describe ____

58. Have you neglected your own health because of the care that _______ (patient) needs (e.g., not had time to go to physician, not had time to think of own health or unable to afford to go to the physician)?
Yes ___ No ___
Describe ____

Open ended

59. Has caring for someone with HIV/AIDS changed the way you think about your about yourself or your life?
Yes ___ No ___
Describe ____

60. Is there anything that we have not already discussed that you would tell other people about what it is like to care for someone with HIV/AIDS?
Yes ___ No ___
Describe ____

HANDCARD A

1. Be available when or if needed.
2. Supervise/carry out prescribed treatment and general recommendations.
3. Evaluate options for treatment and/or services.
4. Monitor course of _______'s illness and evaluate significance of changes.
5. Evaluate strength/resources of _________.
6. Anticipate needs for future assistance and services.
7. Structure _________'s daily activities.
8. "Run interference" for _________ in social and community settings.
9. Try to keep _________'s life as normal as possible within bounds of his/her impairment.
10. Supervise/directly manage _________'s resources.
11. Perform personal care for __________.
12. Do extra housework.
13. Manage illness-related finances/paperwork.
14. Assist with mobility.
15. Do extra home maintenance work.
16. Provide transportation.
17. Do things to protect _________ from injury/accidents
18. Do things to bolster _________'s self-image.
19. Make sure _________ has right amount of social/recreational activity.
20. Make adjustments in housing arrangements.
21. Enable _________ to have desired spiritual support.
22. Touch (e.g., hold hands, hug).

23. Prevent and manage medical crises.

HANDCARD B

1. Answers any questions I have about ____________ (patient's) care.

2. Assists me in locating appropriate services for _______ (patient).

3. Arranges appropriate care/services for __________ (patient).

4. Educates me about HIV/AIDS so that I am more knowledgeable about how to assist/care for ________ (patient).

5. Provides me with information about HIV/AIDS transmission so that I am confident about how to avoid exposure to the virus.

6. Encourages me/provides ongoing emotional support.

7. Discusses/provides me with information about health care options/alternatives.

8. Helps me manage stigma/discrimination.

9. Facilitates reconciliation among family members and significant others.

10. Helps me learn how to negotiate or deal with health care agencies/community services.

11. Is available if I just need to talk to someone.

12. Assists me with financial concerns or provides information about how to lessen/avoid financial hardship.

13. Helps me to understand what _________ (patient) is feeling/going through.

14. Helps me understand my needs and what I can do to feel better.

15. Provides me with information about available social support groups for family members/significant others.

APPENDIX C

INFORMAL CAREGIVER QUESTIONNAIRE:
Patient Deceased

ID # _______
Date _______

INFORMAL CAREGIVER QUESTIONNAIRE
Follow -up (deceased)

Nature of caregiving activities/Patient illness factors

1. What has the time since ______ 's (patient) death been like for you?
   Describe ______________________________________

2. What was it like caring for _______ (patient) before his/her death?
   Describe ______________________________________

3. What was the most difficult or hardest things for you about _______'s (patient) illness at that time?
   Describe ______________________________________

4. How did _______'s (patient) illness effect him/her physically?
   Describe ______________________________________

5. How did _______'s (patient) illness effect him/her emotionally?
   Describe ______________________________________

6. Which of the following activities did you do in an effort to assist or help _______ (patient)?

   -- Show Handcard A --

   List by number: ______________________________

7. Are there any other things that are not on the card that you did to assist or help (patient) feel better?
   Yes ___ No ___
   Describe ______________________________________

Time spent in caregiving activities.

8. On average, how much time did you spend each day with _______ (patient)?
   Hours _________

9. How much time did you actually spend doing the things (on card) you said you do for ______?
Hours ________

Competing demands/role conflict-overload

10. Prior to his death, was it difficult for you to fulfill work or other responsibilities because of ______'s (patient) illness?
Yes ___ No ___
Describe ________________________________

11. Prior to his death, were your social or recreational activities restricted in any way because of ______'s (patient) illness?
Yes ___ No ___
Describe ________________________________

Economic stressors

12. Has ______'s (patient) illness/death caused you any financial hardship or caused you to worry about the possibility of financial hardship?
Yes ___ No ___
Describe ________________________________

Competence/qualifications for caregiving

13. Is there any information about HIV/AIDS that you would have liked to have or would like to have now?
Yes ___ No ___
Describe ________________________________

14. Prior to his/her death, did you ever feel emotionally/mentally fatigued as a result of assisting ______ (patient)?
Yes ___ No ___
Describe ________________________________

15. Do you feel emotionally/mentally fatigued now?
Yes ___ No ___
Describe ________________________________

16. Prior to his death, did you ever feel physically fatigued as a result of assisting (patient)?
Yes ___ No ___
Describe ________________________________

17. Do you feel physically fatigued now?
Yes ___ No ___
Describe ________________________________

Quality of relationship

18. What was your relationship like with _______ (patient) at the time of his/her death?
Describe ____

19. Were there ever any uncomfortable moments between you and _______ (patient) that were related in some way to his/her illness?
Yes ___ No ___
Describe ____

20. Were you and _______ (patient) able to enjoy spending time together or doing any activities together prior to his/her death?
Yes ___ No ___
Describe ____

Stigma

21. Since the last time we spoke, did anyone new learned of _______'s (patient) HIV illness?
Yes ___ No ___
Describe ____

** Determine if before or after patient death

22. If yes, what were their responses (consider initial vs. present/pre vs. post death)?
Describe ____

23. Does the fact that _______ (patient) died from HIV/AIDS make you uncomfortable in any way?
Yes ___ No ___
Describe ____

24. Do you think that there is a tendency for others to look at you differently because _______ (patient) died of AIDS?
Yes ___ No ___
Describe ____

24a. If yes, how do you handle/manage with this?
Describe ____

24b. If yes, do you think that people will continue to look at you differently when they learn that ______ (patient) died of AIDS? (How long?)
Yes ___ No ___
Describe ______________________________________

25. Are you reluctant to tell anyone that ______ (patient) died of AIDS?
Yes ___ No ___
Describe why ______________________________________

Social support

26. Have you attended a support group for SO's of someone with HIV/AIDS or get counseling of any sort (note whether related specifically to HIV/AIDS counseling)?
Yes ___ No ___
Describe ______________________________________

26a. If no, would you be interested in receiving counseling or attending a social support group at this time?
Yes ___ No ___
Describe ______________________________________

26b. If yes, do you find this helpful?
Yes ___ No ___
Describe ______________________________________

27. Do you have any family or friends you can talk or who helps you feel better when you are upset or feeling low?
Yes ___ No ___
Describe ______________________________________

Health Status

28. Did you find it difficult or stressful to care for/assist ______ (patient)?
Yes ___ No ___
Describe ______________________________________

28a. If yes, what did you do to alleviate your stress?
Describe ______________________________________

29. Do you think you developed any new health problems as a result of caring for ______ (patient)?
Yes ___ No ___
Describe ______________________________________

30. Did any existing health problems get worse as a result of caring for _______ (patient)?
Yes ___ No ___
Describe ____

31. Did you ever neglect your own health because of the care that _______ (patient) needed (e.g., not had time to go to physician, not had time to think of own health or unable to afford to go to the physician)?
Yes ___ No ___
Describe ____

Amount of assistance with caregiving activities

32. Did any other family members or friends provide any assistance or support to _______ (patient) around the time of his death?
Yes ___ No ___
Describe ____

33. What community/home care (formal) services did ______ (patient) receive at that time?
Describe ____

34. What medical (physician) services did _______ (patient) have?
Describe ____

35. What outside help (family/friends or professional services) did you rely upon the most or find to be most helpful to you?
Describe ____

36. Did _______ (patient) have a case manager?
Yes ___ No ___
Name/Agency ____

36a. If yes, what types of assistance did <u>you</u> receive from the case manager?

List: ____
Other? ____

Open ended

37. When you think over the course of ______'s (patient) illness, what were the most difficult times for you?
Describe ____

38. How are you doing now?
Describe ____

HANDCARD A

1. Be available when or if needed.
2. Supervise/carry out prescribed treatment and general recommendations.
3. Evaluate options for treatment and/or services.
4. Monitor course of _______'s illness and evaluate significance of changes.
5. Evaluate strength/resources of _________.
6. Anticipate needs for future assistance and services.
7. Structure _________'s daily activities.
8. "Run interference" for _________ in social and community settings.
9. Try to keep _________'s life as normal as possible within bounds of his/her impairment.
10. Supervise/directly manage _________'s resources.
11. Perform personal care for __________.
12. Do extra housework.
13. Manage illness-related finances/paperwork.
14. Assist with mobility.
15. Do extra home maintenance work.
16. Provide transportation.
17. Do things to protect _________ from injury/accidents
18. Do things to bolster _________'s self-image.
19. Make sure _________ has right amount of social/recreational activity.
20. Make adjustments in housing arrangements.
21. Enable _________ to have desired spiritual support.
22. Touch (e.g., hold hands, hug).

23. Prevent and manage medical crises.

HANDCARD B

1. Answers any questions I have about _______ (patient's) care.
2. Assists me in locating appropriate services for _____ (patient).
3. Arranges appropriate care/services for _______ (patient).
4. Educates me about HIV/AIDS so that I am more knowledgeable about how to assist/care for _______ (patient).
5. Provides me with information about HIV/AIDS transmission so that I am confident about how to avoid exposure to the virus.
6. Encourages me/provides ongoing emotional support.
7. Discusses/provides me with information about health care options/alternatives.
8. Helps me manage stigma/discrimination.
9. Facilitates reconciliation among family members and significant others.
10. Helps me learn how to negotiate or deal with health care agencies/community services.
11. Is available if I just need to talk to someone.
12. Assists me with financial concerns or provides information about how to lessen/avoid financial hardship.
13. Helps me to understand what _______ (patient) is feeling/going through.
14. Helps me understand my needs and what I can do to feel better.
15. Provides me with information about available social support groups for family members/significant others.

APPENDIX D

HUMAN SUBJECTS APPROVAL

THE OHIO STATE UNIVERSITY Protocol No. ________

CONSENT TO INVESTIGATIONAL TREATMENT OR PROCEDURE

I, ____________________, hereby authorize or direct Carole A. Anderson associates or assistants of her choosing, to perform the following treatment or procedure (describe in general terms), to obtain from me information on my health status, satisfaction with services, and experiences as a person who provides care to someone with HIV/AIDS.

upon ____________________.
(myself or name of subject)

The experimental (research) portion of the treatment or procedure is: to compare case managed home care with standard home care.

This is done as part of an investigation entitled: Effects of Nurse Case Management on HIV/AIDS Caregivers.

1. Purpose of the procedure or treatment: to determine if supplemental care makes a difference in the health and satisfaction of caregivers.

2. Possible appropriate alternative procedures or treatment (not to participate in the study is always an option): standard home care -- my decision to participate or not participate in this study will in no way effect the home services provided to the person for whom I care.

3. Discomforts and risks reasonably to be expected: None, except for time required for an interview each month.

4. Possible benefits for subjects/society: this could benefit me as an opportunity to explore my feelings/thoughts regarding the caregiving experience; it can benefit society by providing information for planning home care services to better meet the needs of HIV/AIDS caregivers.

5. Anticipated duration of subject's participation (including number of visits): Throughout the time in which home care is provided; approximately 30 minutes each month.

I hereby acknowledge that ______________ has provided information about the procedure described above, about my rights as a subject, and he/she answered all questions to my satisfaction. I understand that I may contact him/her at Phone No. ___________ should I have additional questions. He/She has explained the risks described above and I understand them; he/she has also offered to explain all possible risks or complications.

I understand that, where appropriate, the U.S. Food and Drug Administration may inspect records pertaining to this study. I understand further that records obtained during my participation in this study that may contain my name or other personal identifiers may be made available to the sponsor of this study. Beyond this, I understand that my participation will remain confidential.

I understand that I am free to withdraw my consent and participation in this project at any time after notifying the project director without prejudicing future care. No guarantee has been given to me concerning this treatment or procedure.

In the unlikely event of injury resulting from participation in this study, I understand that immediate medical treatment is available at University Hospital of The Ohio State University. I also understand that the costs of such treatment will be at my expense and that financial compensation is not available [redacted]

I have read and fully understand the consent form. I sign it freely and voluntarily. A copy has been given to me.

Date: ____________________ Time ______ AM PM Signed ______________________________
(Subject)

Witness(es) ______________________________ ______________________________
If
equired ______________________________ (Person Authorized to Consent for Subject, If Required)

certify that I have personally completed all blanks in this form and explained them to he subject or his/her representative before requesting the subject or his/her representative to sign it.

Signed ______________________________
(Signature of Project Director or his/her Authorized Representative)

BIOMEDICAL SCIENCES REVIEW COMMITTEE
RESEARCH INVOLVING HUMAN SUBJECTS
THE OHIO STATE UNIVERSITY

X Original Review
____ Continuing Review
____ Five-Year Review
____ Amendment

ACTION OF THE REVIEW COMMITTEE

With regard to the employment of human subjects in the proposed research:

90H0244 EFFECTS OF NURSE CASE MANAGEMENT ON AIDS CAREGIVERS,
Carole A. Anderson, Pamela J. Salsberry, Jennie T. Nickel,
Nancy R. Reynolds, Family and Community

THE BIOMEDICAL SCIENCES REVIEW COMMITTEE HAS TAKEN THE FOLLOWING ACTION:

X APPROVED

____ APPROVED WITH STIPULATIONS*

____ DISAPPROVED

____ WAIVER OF WRITTEN CONSENT GRANTED

*Stipulations stated by the Committee have been met by the investigator and, therefore, the protocol is APPROVED.

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the University, signed consent forms are to be transferred to the Human Subjects Review Committee for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the Review Committee, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: August 20, 1990

Signed: [redacted]
Chairperson

HS-025H (Rev. 8/90)

BIOMEDICAL SCIENCES REVIEW COMMITTEE
RESEARCH INVOLVING HUMAN SUBJECTS
THE OHIO STATE UNIVERSITY

____ Original Review
_X_ Continuing Review
____ Five-Year Review

ACTION OF THE REVIEW COMMITTEE

With regard to the employment of human subjects in the proposed research:

90H0244 EFFECTS OF NURSE CASE MANAGEMENT ON AIDS CAREGIVERS,
Carole A. Anderson, Nursing Administration

THE BIOMEDICAL SCIENCES REVIEW COMMITTEE HAS TAKEN THE FOLLOWING ACTION:

_X_ APPROVED	____ DISAPPROVED
____ APPROVED WITH STIPULATIONS*	____ WAIVER OF WRITTEN CONSENT GRANTED

*Stipulations stated by the Committee have been met by the investigator and, therefore, the protocol is APPROVED.

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the University, signed consent forms are to be transferred to the Human Subjects Review Committee for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the Review Committee, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: July 15, 1991

Signed: [redacted]
Chairperson

HS-025H (Rev. 3/85)

BIOMEDICAL SCIENCES REVIEW COMMITTEE
RESEARCH INVOLVING HUMAN SUBJECTS
THE OHIO STATE UNIVERSITY

___ Original Review
___ Continuing Review
___ Five-Year Review
_X_ Amendment

ACTION OF THE REVIEW COMMITTEE

With regard to the employment of human subjects in the proposed research:

90H0244 EFFECTS OF NURSE CASE MANAGEMENT ON AIDS CAREGIVERS, Carole A. Anderson, Nursing Administration

(Amend the protocol as outlined in letter dated March 18, 1992.)

THE BIOMEDICAL SCIENCES REVIEW COMMITTEE HAS TAKEN THE FOLLOWING ACTION:

___ APPROVED
_X_ APPROVED WITH STIPULATIONS*
___ DISAPPROVED
___ WAIVER OF WRITTEN CONSENT GRANTED

*Stipulations stated by the Committee have been met by the investigator and, therefore, the protocol is APPROVED>

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the University, signed consent forms are to be transferred to the Human Subjects Committee for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the Review Committee, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: April 2, 1992

Signed [redacted] Chairperson

HS-025HA (Rev. 11/91)

BIOMEDICAL SCIENCES
HUMAN SUBJECTS REVIEW COMMITTEE
THE OHIO STATE UNIVERSITY

Meeting Date: April 2, 1992

RESEARCH PROTOCOL:

90H0244 EFFECTS OF NURSE CASE MANAGEMENT ON AIDS CAREGIVERS, Carole A. Anderson, Nursing Administration

presented for review by the Biomedical Sciences, Human Subjects Review Committee to ensure the proper protection of rights and welfare of the individuals involved with consideration of the methods used to obtain informed consent and the justification of risks in terms of potential benefits to be gained. The Committee action was:

Request to amend the protocol as outlined in letter dated March 18, 1992 was administratively APPROVED WITH THE FOLLOWING STIPULATION:

1. Provide letter of support from the Columbus AIDS Task Force.

Your approval is contingent upon your agreement to comply with the above stipulations. Please SIGN this form in the space(s) provided and RETURN WITH ANY ADDITIONAL INFORMATION REQUESTED TO THE HUMAN SUBJECTS REVIEW DESK, 300 RESEARCH FOUNDATION, 1960 KENNY ROAD, CAMPUS, within one week. Upon such compliance, the approval form will be mailed to you. In the case of a deferred protocol, please submit the requested information at your earliest convenience.

Date ____________________ Signature(s) [redacted]

Principal Investigator(s)

HS-105 (2/91)
Stipulations/Comments

CATF
Columbus AIDS Task Force
1500 W. Third Ave., Suite 329, Columbus, Ohio 43212-2843 (614) 488-2437

April 29, 1992

Ms. Nancy Reynolds
[redacted]

Dear Ms. Reynolds:

Please accept this letter as our authorization for you to conduct confidential interviews with caregivers associated with the Columbus AIDS Task Force.

We understand that this study done in conjunction with The Agency for Health Care Policy and Research will continue through the summer of 1992.

The Columbus AIDS Task Force is excited about the assistance this can provide us and other AIDS service providers in planning future programs that benefit primary caregivers.

Sincerely,

[redacted]

Gloria J. T. Smith
Executive Director

GJTS:bcal

APPENDIX E

CASE MANAGEMENT PROTOCOL

The protocol delineated in the parent study (Nickel & Salsberry, 1988) is detailed below. This protocol reflects the functions of nurse case managers as discussed in the ANA document, Nursing Case Management (1988).

A. Conduct an initial comprehensive assessment of the patient and patient condition within 48 hours of referral.

B. Develop a plan of care based upon the assessment. This plan will include strategies to strengthen the self-care ability of the patients, as well as addressing the immediate and episodic needs of the patient. This plan is to be completed within 48 hours of the assessment.

C. Meet with the interdisciplinary team within 5 working days to review and revise the plan of care. The members of the interdisciplinary team include a physician, the case manager, a social worker, home health care nurse, and when appropriate, the patient and family. Other clinical specialists are available to the team as consultants. These specialists include infectious disease, clergy, nutritionist, mental health worker, pharmacist, and dentist. The team will meet every two weeks to review and modify, as needed, the care plans for all patients in the experimental group.

D. Initiate the plan -- the time frame here is less structured, and is directed by the needs of the patient. The case manager authorizes services from other agencies as needed to meet the needs of the patient and family.

E. Monitor the progress of the patient through weekly phone contacts, at least monthly visits with the patient and family, and regular conferences with the home health care nurses providing direct care.

F. Reassess the patient and family monthly or more frequently if the situation dictates.

G. Revise the plan as needed.

H. Evaluate and monitor the quality of services provided throughout the entire contact.

I. Communicate at least monthly with the patient's primary care physician regarding the patient's progress with medical care management.

J. Facilitate transfer to and from the inpatient setting. The case manager may assist the inpatient nursing staff in the development of a plan of care and assist with discharge planning to assure that transitions into and out of the inpatient setting are relatively smooth.

APPENDIX F

HIV PROJECTIONS -- FRANKLIN COUNTY

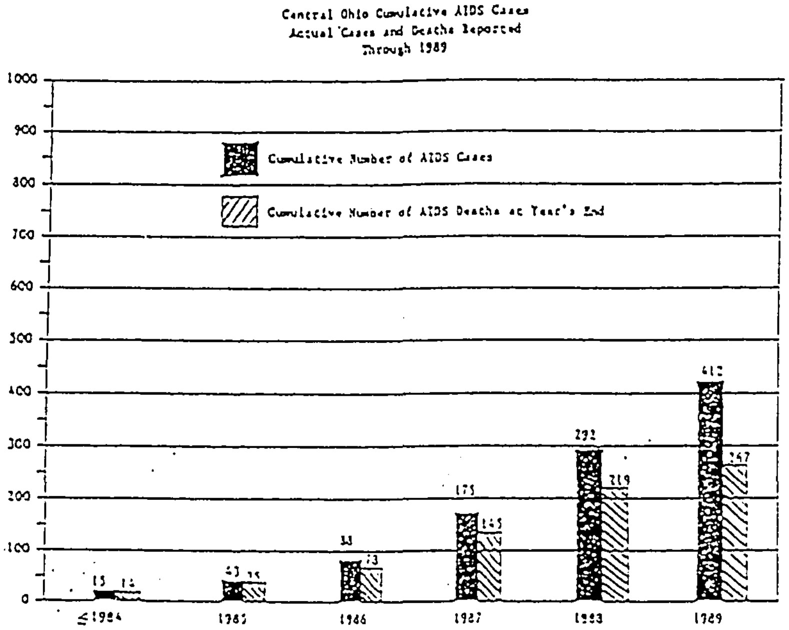
AIDS AND HIV INFECTION IN CENTRAL OHIO

July, 1990

Barbara J. Cooke
Health Planner
Central Ohio Regional AIDS Services
Planning Project
[redacted]

Cumulative Cases and Mortality: AIDS

AIDS was first recognized in 1981 and Central Ohio reported its first case in 1982. From 1982 through July 2, 1990, Central Ohio has reported a total of 442 cases.(1) Of these, 272 are known to be dead showing a mortality rate of 61.5%. The following graph illustrates the cumulative impact of AIDS and the cumulative number of AIDS deaths at year's end by year of dignosis.



Source: "Acquired Immune Deficiency Syndrome (AIDS) Data for Ohio and the United States," Ohio Department of Health, July 2, 1990.

As of June 1, 1990, the United States reported 136,204 cases of AIDS diagnosed since 1981. Ohio ranks 13th of all states and territories with 1999 cases reported as of July 2, 1990. Franklin County ranks second of all Ohio counties with 391 cases (Cuyahoga is first with 479 cases).(1)

AIDS exerts a substantial impact on young adult mortality. Nationally in 1987, AIDS deaths accounted for 11% of all deaths in men 25-34 years of age and 9% of all deaths in men 35-44 years of age.(3)

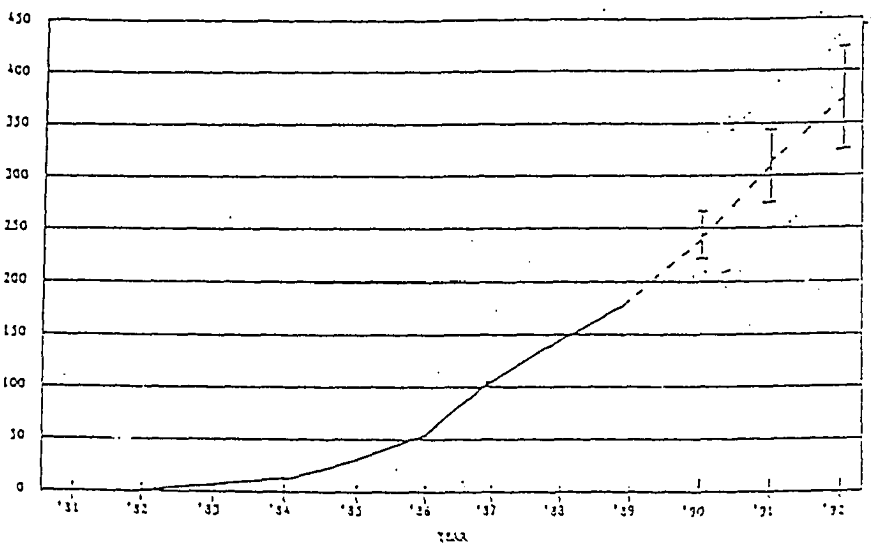
Projections of AIDS Cases Through 1992

Projections of the number of AIDS cases that will be diagnosed and reported in the future are made through the use of mathematical models. Using a proportion model, the Columbus/Franklin County Community Plan projected in April, 1989, that 950 AIDS cases would be diagnosed and reported for Franklin

County by the end of 1991.(4) That projection is consistent with the forecast made here which incorporates case reporting to date.

Using the proportion model and power transformation model, the following historical data and projection intervals are offered to illustrate the changing incidence rate and to predict new AIDS cases in Central Ohio.(7)

New Cases of AIDS by Year of Diagnosis
for Central Ohio*
1981-1992



*Adjusted for reporting delays and non-reporting

NOTE: Bracketed projections encompass spread of data from three different projection methods.

Using recommendations from the Centers for Disease Control (CDC) which adjust for both reporting delays and non-reporting, the following table shows a projection of the number of persons living with AIDS in Central Ohio.(5,6)

Projected Numbers of AIDS Cases, Deaths Attributable to AIDS, and Persons Living with AIDS
Central Ohio Data
1989 - 1992

Year	AIDS Cases New Cases	Alive (average)	Deaths	(rate)	Cumulative Cases (inc death)
1989		300			528
1990	244	343	201	(37%)	772
1991	310	431	222	(34%)	1082
1992	382	529	284	(35%)	1464

Status: HIV Infection

Information on the levels and spread of HIV infection is essential for planning prevention and control efforts and for predicting future health care needs. This data, however, is largely unavailable. Only a small percentage of infected persons know their HIV status and reporting for these tests (all except at anonymous test sites) have only recently been mandated in Ohio.

In order to provide reliable national estimates of HIV infection, CDC conducts a comprehensive family of HIV surveys. Using these results, CDC estimates that approximately 1 million persons are infected nationwide.(5) For local estimates, CDC suggests using a 1:8 cumulative AIDS cases to HIV prevalence ratio. The following are estimates for Central Ohio.

	Cum. Living with AIDS	HIV Prevalence
1989	300	2400
1990	343	2744
1991	431	3448
1992	529	4232

Conclusion

Estimates of the number of HIV-infected persons and the projected number of persons with AIDS are used to assess current and future health care, mental health, and social service needs. Several factors influence these projections -- factors which we can not yet measure reliably, such as the incidence of new HIV infection, the distribution of drug therapies and their effect on the incubation period from infection to AIDS, and the completeness and/or timeliness of reporting. Estimates must be continuously refined if we are to use them to measure the growth of the epidemic and the effectiveness of prevention efforts.

REFERENCES

1. "Acquired Immune Deficiency Syndrome (AIDS) Data for Ohio and the United States," Ohio Department of Health, July 2, 1990.

2. "Population Projections Ohio and Counties by Age and Sex: 1980 to 2010," Ohio Data Users Center, July, 1986.

3. "Update: Acquired Immunodeficiency Syndrome -- United States, 1989," MMWR, Vol. 39, No. 5, February 9, 1990.

4. Columbus AIDS Community Advisory Coalition, Columbus/Franklin County AIDS Community Plan (1989-1991), Columbus, Ohio, 1989.

5. "Estimates of HIV Prevalence and Projected AIDS Cases: Summary of a Workshop, October 31-November 1, 1989," MMWR, Vol. 39, No. 9, February 23, 1990.

6. Rosenberg, Philip S. "A Simple Correction of AIDS Surveillance Data for Reporting Delays," Journal of AIDS, Vol. 3, No. 1, pp. 49-54, 1990.

7. Voorhees, Ron, MD, MPH, "Transformation Method for Short-Term AIDS Projections," New Mexico Health and Environment Department, Office of Epidemiology, unpublished.

APPENDIX G

DESCRIPTION OF PARTICIPANTS--GROUP 1

Description of Group 1 Participants

B. 33 year old Euro-American HIV positive gay male who cared for partner with whom he shared home. They had lived together for 5 years. The partner was HIV positive throughout that time and had AIDS during the last 1 1/2 years.

L. 46 year old African-American female with chronic health problems. Separated from husband. Cared for HIV-positive daughter, K, and K's 2 year old child in her own home. Child was HIV negative. K was apparently infected by ex-boyfriend who was an intravenous drug user. K had been living independently until AIDS diagnosis at which time she returned home to live. L worked part-time at home.

D. 47 year old Euro-American male who cared for HIV positive friend D.S., in own home. D.S. was a quadrapalegic with a history of alcohol abuse. D.S. had little contact with his own family. D worked full-time in the evening.

E. 33 year old African-American male who cared for girlfriend, E.H., with whom he shared an apartment with their 2 year old child and E.H.'s four year old child from a former marriage. E and children were HIV negative. E.H. was apparently infected by a former boyfriend and was not diagnosed until she was symptomatic with AIDS. E.H. had limited contact with her own family. E worked full-time in maintenance at night in local hospital.

J. 26 year old Euro-American gay male who cared for partner with AIDS in apartment which they shared. J was HIV negative and worked part-time in a bar in evenings.

A. 44 year old African-American female who cared for brother with AIDS in his apartment. A lived at home with her husband and three children, one of whom had developmental problems. A was a full-time office worker.

S. 42 year old Euro-American gay male who cared for partner in house which they shared. S was HIV negative and worked full time in the military.

APPENDIX H

DESCRIPTION OF PARTICIPANTS--GROUP 2

Description of Group 2 Participants

N. 57 year old Euro-American female who cared for son with AIDS in own home. Her husband, who was laid-off from work, and their grandson also lived in the home. The son returned home to live when his HIV partner became too ill to assist with care.

B. 41 year old Euro-American gay male who cared for partner with AIDS in townhouse which they shared. B was HIV negative and worked full-time as banker.

L.B.. 35 year old African-American female who cared for sister with AIDS in apartment which they shared with their children. L.B. worked full-time as secretary.

C. 33 year old Euro-American gay male who cared for partner with AIDS in apartment which they shared. C had not been tested for HIV. He worked full-time as manager of small business.

J. 28 year old Euro-American gay male who cared for partner with AIDS in apartment which they shared with patient's mother. J was HIV positive and worked full-time as dance instructor.

APPENDIX I

DESCRIPTION OF PARTICIPANTS--GROUP 3

Description of Group 3 Participants

T. 33 year old Euro-American HIV-positive gay male who cared for partner with AIDS in apartment which they shared. T worked full-time for agency that provided transportation and laundry services to home-based AIDS patients.

R.J.. 50 year old Euro-American female who cared for gay son with AIDS in house which they shared. R.J. moved to area to care for son. Worked full-time as waitress. Son died ... before interview was conducted.

R. 39 year old Euro-American gay male who provided care to partner over course of HIV illness. Worked full-time as hair-dresser. R was HIV negative. His partner died ... months before interview conducted.

M. 52 year old Euro-American gay male who cared for partner over course of HIV illness. M was HIV negative. He was a professional who took year off from work over last year of patient's life. His partner died ... before interview conducted.

W. 29 year old Euro-American female. She cared for her gay brother who was also intravenous drug user in her home which she shared with husband and their three young children.

K. 27 year old Euro-American HIV negative gay male who cared for partner over the course of HIV illness in home which they shared.

M.N. 61 year old Euro-American female who cared for gay son with AIDS in own home which she shared with husband. Son returned home to live from another state when became too ill to care for self. Son had died ... before interview conducted.

M.L.. 62 year old Euro-American female who cared for gay son who returned home to live from another state when diagnosed with AIDS. Son had own apartment in same apartment complex as mother. He shared his apartment with his sister who was blind from diabetic retinitis. He died ... before interview conducted.