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Becoming a couple affected by HIV infection

Powell-Cope, Gail Marie, Ph.D.

University of Washington, 1992

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Becoming a Couple Affected by HIV Infection

by

Gail M. Powell-Cope

A dissertation submitted in partial fulfillment
of the requirements for the degree of

Doctor of Philosophy

University of Washington

1992

Approved by Marie Annette Brown
(Chairperson of Supervisory Committee)

Program Authorized to Offer Degree School of Nursing

Date August 6, 1992

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Abstract

Becoming a Couple Affected By HIV Infection

by Gail M. Powell-Cope

Chairperson of the Supervisory Committee: Professor Marie Annette Brown
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The purposes of this study were: (1) to describe the experiences of gay couples when at least one was diagnosed with symptomatic HIV infection or AIDS, and (2) to explain couples' experiences in the context of heterosexism. To address the first study purpose, grounded theory provided the methodological basis for data gathering and data analysis. The second study purpose was achieved through a structural analysis that explained the relationship between couples' actions, their acknowledgment, or lack thereof, of heterosexism as an important dimension of their social environment, and the intended and unintended consequences of their actions on heterosexism.

The sample consisted of 9 gay couples. Becoming a Couple Affected by HIV Infection was perceived as a major life transition as each individual was challenged with confronting multiple losses including possible death of the PWA, the pre-AIDS lifestyle, relationships with friends and family members, the future, finances, and health. The beginning of this transitional began with "hitting home," or the awareness and subsequent emotional shock that life as the couple knew it before HIV was gone. "Mutual protection" is the mechanism by which individuals in the couple governed their activities toward one another. The major motivation for actions taken by study participants was the protection of the self and the other by forestalling losses such as threats to the relationship, health, and privacy, and

preserving important relational characteristics such as independence, social boundaries, and intimacy. "Moving on" marked the end of the transition and included acceptance of a world in which loss and uncertainty were expected, if not commonplace, and moving on with one's life within the relationship, having renegotiated its meaning. Study participants settled on one of two different perspectives for the future: succumbing to AIDS or surviving HIV infection.

Structural analysis revealed that although study participants defined their experiences using the term homophobia, their experiences could also be understood in the context of heterosexism, or the socially constructed belief that heterosexuality is superior to homosexuality. Heterosexism asks heterosexuals to consider their privileged position which serves to perpetuate the constraints placed upon gay couples coping with HIV infection. Employing this term helps us to understand the institutionalized and systematic constraints placed upon gay couples, as compared to the concept of homophobia, which tends to focus on the individual personality traits of gays and those who harbor negative feelings toward them.

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ACKNOWLEDGMENTS

I wish to express sincere appreciation to the chair of my supervisory committee, Dr. Marie Annette Brown, and to the committee members, Drs. David Allen, Kathryn Barnard, Lewayne Gilchrist, and Kristen Swanson for their guidance through my program of study and through the dissertation process. Also, I acknowledge Dr. Jeanne Quint Benoliel for the support, guidance, and intellectual challenges she gave to me throughout the doctoral program. For their unending support and love, personal thanks to Terry, Zachary, Mom, Heather, Pete, Elaine, Karen, Julie, and Kim. You know who you are. I appreciate the assistance of Lindsey Turner and Mary Ryan for the transcription of interviews and Mary for her editorial assistance and valuable critique. Also, I would like to extend a special acknowledgment to the couples who were participants in this study for their candor, courage, and fortitude. I acknowledge the funding agencies without whose help this research would not have been possible: Sigma Theta Tau International; Sigma Theta Tau Psi Chapter; the Hester McLaws Scholarship Fund from the School of Nursing University of Washington; and the National Research Service Award Predoctoral Fellowship from the National Center for Nursing Research, National Institutes of Health.

Dedication

To the many people who daily cope with HIV infection in their lives and to their partners, family members, and friends who support and love them through their lives' journeys.

CHAPTER I

INTRODUCTION

Nursing as a field of study can be conceptualized in diverse ways, yet most nurses would agree that any sufficient definition must include the following concepts: nursing, environment, client (or individual), and health (Chinn & Jacobs, 1987; Kim, 1987). This research addresses two of those major components: individuals and environments. Specifically, the focus of this study is individuals' experiences in the context of a committed relationship where one partner has been diagnosed with HIV infection and their social environment.

Caring for a sick family member has received considerable attention in the populations of the frail elderly, Alzheimer's disease, and chronic illness such as cancer. More recently human immunodeficiency virus (HIV) infection has been recognized as a chronic illness in which family members play crucial roles in caring for loved ones at home. As HIV infection becomes more prevalent and as people with HIV infection live longer, families will increasingly be called on to assist in caring for the person with AIDS (PWA) at home. Family caregiving for PWAs is an increasingly significant issue, particularly for nurses. In order to enhance the quality of care to PWAs and support family home care, nurses must understand the individual experiences of the sick person and the significant other. In addition, attention to the social, political, and cultural context of caregiving will assist nurses in developing strategies that serve people with HIV infection, their primary family caregivers, and society more broadly.

Purposes

The major objective of this study is to extend a substantive theory of family caregiving, "AIDS Family Caregiving: Transitions Through Uncertainty" (Brown

& Powell-Cope, 1991) by exploring family caregiving that occurs between gay partners, at least one of whom is infected with HIV. Specific aims directed toward achieving this objective are to:

1. Describe partners' experiences of caregiving in the instance of HIV infection;
2. Describe PWAs' experiences of receiving care from their partners in the instance of HIV infection; and
3. Explore perceived salient aspects of the social context that influence and are influenced by the couples' experiences.

Given that social interaction occurs within a broader social context, a secondary objective of this study is to critically examine the emergent grounded theory in light of salient sociostructural dimensions. More specifically, this study is concerned with unintended consequences of couples' actions as they give rise to and reinforce unacknowledged sociostructural conditions.

Caregiving is conceptualized as a social process, primarily involving the caregiver and the recipient of care, that occurs within a social context. HIV infection was chosen as an illness context for this study because it provides features similar to other caregiving situations (e.g., death, chronic illness) and unique features that vary considerably from other caregiving situations (e.g., death at a young age, fear of contagion, and sociocultural challenges associated with sexual orientation and stigma).

Significance

This study is significant because it will yield data about caregiving and care receiving for an important clinical problem. Data obtained will be useful in planning health services and developing health policy for people with HIV

infection and their families, and in assisting caregivers and PWAs to cope with the demands of caregiving, and HIV disease.

HIV Infection

Human immunodeficiency virus (HIV) is the causative agent of acquired immunodeficiency syndrome (AIDS) (Gallo et al., 1984). HIV infection refers to a spectrum of clinical manifestations from the initial acute infection to asymptomatic disease and symptomatic disease, and progression to AIDS. The diagnosis of AIDS is clinically based on the presence of pre-defined criteria, mainly opportunistic infections, and represents a more progressive disease state on the spectrum of HIV infection. It remains unclear what proportion of individuals infected with HIV will go on to develop AIDS. For example, in one study 50% of HIV infected gay and bisexual men developed AIDS within 10 years after seroconversion (Lifson et al., 1990). One's chances of developing AIDS increase with the length of time infected with HIV. However, the longer people with HIV infection are studied in follow-up studies, the longer the period of asymptomatic disease is likely to last. Currently, estimates of the incubation period range from 9 to 12 years (van Griensven, 1990).

HIV is primarily transmitted through sexual contact when there is an exchange of body fluids (blood, semen, and vaginal fluids), among injection drug users through the sharing of contaminated needles, and perinatally from infected women to their infants (Allen & Curran, 1985). Initially AIDS was identified among gay men, and in fact, gay and bisexual men were the first group identified at high risk of developing AIDS (CDC, 1983). Nationally, gay and bisexual men account for 56% of all cases of AIDS (CDC, 1990b), and 82% in Seattle-King County (Washington State/Seattle-King County, 1991). Injection drug users are

the second highest risk group for HIV infection (CDC, 1989a), representing approximately 17 to 23% of all AIDS cases (Osborn, 1988). HIV infection is therefore associated with sexuality, homosexuality, and intravenous drug use, phenomena that are culturally linked to moral, social, political, and legal issues.

In January 1988 the World Health Organization estimated that 5 to 10 million people were infected with HIV worldwide, and between 500,000 and 3 million new AIDS cases would occur during the following five years (Samuels, Mann, & Koop, 1988). The incidence of individuals diagnosed with AIDS in the United States has escalated from 220 in 1981 (CDC, 1986) to more than 100,000 by the end of 1989 (CDC, , 1990b) and 206,392 by the end of 1991 (CDC, 1992a). According to the CDC (1992b), the first 100,000 cases of AIDS were reported over a period of eight years, whereas the second 100,000 cases were reported during a two-year period. These statistics emphasize the rapidly increasing magnitude of the HIV epidemic (CDC, 1992b). Although the rate of reported cases of AIDS continues to increase each year, the rate of increase in the United States has declined somewhat in certain populations such as gay and bisexual men (CDC, 1989b; Visscher et al., 1990). For example, the proportion of AIDS cases in the first 100,000 cases of AIDS compared to the second 100,000 cases among gay men without a history of injection drug use was 61% and 55%, respectively. In 1989 increases in diagnosed AIDS cases were the greatest for injection drug users, heterosexual contacts, and perinatally transmitted cases (CDC, 1990a).

In Seattle-King County, over 1,990 cases of AIDS were diagnosed by the end of 1991, 37% of whom are still alive (Washington State/Seattle-King County, 1991). It is generally accepted that the total reported cases of AIDS reflect 10% of people actually infected with HIV infection. Therefore, 1 million people may be

infected with HIV nationwide (CDC, 1990b), and 15,000 to 20,000 people in Seattle-King County.

Although approximately half of all those diagnosed with AIDS have died (CDC, 1989b), the course of the illness is changing and becoming chronic in nature as treatment becomes more effective in preventing opportunistic infections and in controlling viral activity. People are living longer with AIDS due to advances in treatment, such as Zidovudine (AZT) (Broder & Fauci, 1988; Creagh-Kirk, et al., 1988), and earlier diagnosis and treatment of opportunistic infections (Broder & Fauci, 1988). In a report of HIV prevalence and projected AIDS cases, officials at the Center for Disease Control (1990b) concluded:

. . . the nationwide burden of HIV-related disease will continue to grow, requiring further prevention efforts and increased medical, and social services for the next several years for persons with HIV infection. (p. 119)

Family caregiving is one service that will continue to increase in its demand. In the interest of caring for PWAs, it is critical for nurses to become more skillful in working with families, who continue to provide a major share of care to people with AIDS and HIV infection.

In summary, HIV infection is associated with issues which our society has approached with great discomfort including death in young, productive people (nationwide, 68% of people with AIDS are between the ages of 20 and 39 years [CDC, 1990a]), sexuality and particularly sexuality within gay relationships, and illegally defined activities such as intravenous drug use. In light of the increasing prevalence of HIV infection, the severity of AIDS, and the complex social context surrounding HIV infection, family caregiving for persons with HIV infection is

expected to increase, and may be problematic for those involved. This study will help to answer questions raised by people with HIV infection and their primary family caregiver given the high mortality of AIDS, and unique social conditions surrounding AIDS. Nurses are in positions to assist caregivers and their family members with AIDS by providing and planning services for caregivers that are sensitive to their needs and concerns. The study will help to elucidate avenues for nursing interventions at the individual and environmental levels.

Family Caregiving

Family caregiving has been studied most extensively within the context of Alzheimer's Disease and the frail elderly. Family caregiving remains relatively unexplored in the instance of HIV infection. To date few studies have been identified that address family caregiving during HIV infection (Brown & Powell-Cope, 1990; Geis, Fuller, & Rush, 1986; Giacquinta, 1989; Greif & Porembski, 1987; Greif & Porembski, 1988; Pearlin, Semple, & Turner, 1988; Raveis & Siegel, 1989). More empirical data is needed about caregiving in the specific instance of HIV infection.

According to Horowitz (1985), who reviewed over 200 research publications of caregiving, research to date primarily has focused on: a) demographics and characteristics of caregivers; b) caregiver behavior and tasks; and c) effects of caregiving on the caregiver. In general, caregivers of the elderly tend to be spouses (most commonly women caring for husbands) or adult children (more commonly daughters than sons). In contrast, caregivers of people with AIDS are likely to be gay partners or friends. For example, 36% of the sample (N=53) in the Brown and Powell-Cope study (1991) were friends, and 34% were current lovers. Raveis and Siegel (1989) found that 100% of PWAs who had

lovers named them as a source of emotional support, 89% named friends, and only 63% named family members. Because of the importance of gay partners as caregivers for PWAs, this study will focus on gay couples in which one member is a person with HIV infection and the other is the primary family caregiver.

Because caregiving is defined by the person's need for assistance, much of the research to date has focused on caregiving behavior and tasks such as emotional support, direct service provision, mediation with formal organizations and providers, and financial assistance (Horowitz, 1985). In slowly progressing diseases, such as Alzheimer's, caregiving tasks often become increasingly important and time-consuming for the caregiver as the care recipient becomes more physically impaired. In diseases like HIV, characterized by acute exacerbations and a wide range of symptoms from dementia to anorexia, the amount and type of caregiving tasks are likely to be quite varied over the course of the illness (Brown & Powell-Cope, 1990).

Bowers (1987) maintained that much of the caregiver research has been focused on caregiver tasks and the related effects on the caregiver. For example, data regarding effects of caregiving indicate that family caregivers experience problems related to mental health (George & Gwyther, 1986) and feelings of burden, strain (Morycz, 1985; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986), anger, depression and fatigue (Rabins, Mace, & Lucas, 1982), and uncertainty (Stetz, 1986). As a result, Bowers (1987) maintained that most research, theory development and intervention has been limited in scope, thereby possibly masking other salient aspects of caregiving. In a grounded theory of intergenerational caregiving Bowers (1987) examined "invisible caregiving," that is, caregiving in the instance of mildly impaired elderly family members. Invisible

caregiving was aimed at protecting the elderly's self-image and the parent-offspring relationship. While tasks were a part of protective caregiving, the interpersonal aspect was the most important dimension in understanding the meanings attributed to caregiving from the perspectives of caregivers. Similarly, this research will help to clarify important caregiving issues that are not necessarily task-based but based on meanings attributed by actors to their social context.

Another significant limitation of caregiver research is that studies rarely incorporate the perspectives of the recipient of care. Horowitz (1985) stated:

It is somewhat ironic that when we discovered the family as caregiver we seemed to forget about the older person as the recipient of care. There is a very limited literature on what effects receiving assistance has on the frail older person (other than in the global sense of permitting continued community residence) or on which conditions define more satisfactory caregiving arrangements from the older person's point of view. (p. 226)

In this research study, examining the perspective of both care recipients and caregivers will yield data that are more relevant and presumably of more use to families and to nurses who work with families than data yielded by defining caregiving solely from the perspective of the caregiver. A major contribution of this study is that it will yield a more comprehensive perspective of caregiving by including caregivers and care recipients.

In summary, family caregiving during HIV infection is an important substantive and theoretical domain for nursing science and practice. Expected findings from this study will clarify salient issues about caregiving from the

perspectives of the caregiver and the person with HIV infection. Further analysis will explore environmental dimensions of caregiving related to relevant social structures.

CHAPTER II

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

The conceptual framework for this proposed study is derived from: a) symbolic interactionism; b) Giddens's social theory, "The Theory of Structuration"; c) the concept of psychosocial transitions; and d) a theory of caregiving, "Transitions Through Uncertainty: Family Caregiving During HIV Infection" (Brown & Powell-Cope, 1991). The focus of this chapter will be the conceptualization of the research problem, and a review of the literature as it pertains to family caregiving.

Symbolic Interactionism

Consistent with symbolic interactionism, family caregiving is conceptualized as a social interactive process that occurs between a family member and the recipient of care -- in this study, a person with HIV infection. Furthermore, the author acknowledges that caregiving as a social process occurs within a social context. Symbolic interactionism emphasizes both social and psychological processes that occur over time.

All social theories are concerned with individual human action and social structures, but the relation between the two has been a long-standing debate in social theory. At the root of the problem lies the question, "Can social structures be conceptualized independently of the microprocesses from which they are constituted, or must they be analyzed in terms of these microprocesses?" (Turner, 1986). Collins (1988) traced the origins of the macro/micro question to Emile Durkheim who, in the late 1800's, sought to establish sociology as a distinct field separate from psychology. Durkheim believed that autonomy and social structures should receive priority over individual action and that social structures were

characterized by exteriority and constraint (Collins, 1988). As a result, much early social theory focused on the analysis of social structures and de-emphasized the importance of individual human action. Functionalism and Marxism are two examples of theoretical positions that give primacy to social structures.

The symbolic interactionism school of sociology developed as a reaction to functionalism, another school of sociology that gives primacy to the influence of social structures on human action. Dissatisfied with the emphasis on macro social structures, interactionist perspectives (such as symbolic interactionism) focused on the micro process of face-to-face interactions as the critical field of study for sociologists. According to Goffman (cited in Scheibe, 1987) the study of the "interaction order," or unique aspects of interaction, deserves merit in its own right. Although Goffman did not develop his work as an attack on functionalism, he did assert that person-to-person interaction is the primary topic of substance for sociology.

George Herbert Mead, a philosopher, influenced most of the interactionist perspectives. The concepts of mind, self, and society were the focus of Mead's work. Mead viewed the mind as a uniquely human process that develops through social interaction. The uniqueness of the human mind lies in its ability to use symbols to refer to objects in the environment, rehearse actions toward symbols, and select proper courses of action (Turner, 1986). Because of the mind's ability to symbolically represent objects, individuals are able to represent and evaluate themselves as object. Mead postulated that through interaction an individual is thus able to achieve a sense of self (Blumer, 1969; Manis & Meltzer, 1967).

Role-taking enables the individual to reflect back on oneself and learn how to interact with another. According to Mead, reflectively viewing oneself is

important in developing a sense of self and in creating meaning in things and experiences in the world. Furthermore, Mead believed that society represents "organized and patterned interactions" among diverse individuals (Turner, 1986). Through interaction, and the ability to take the role of the other in relation to oneself, conceptions of the self become crystallized into a relatively stable conception of self as object (Bowers, 1988).

Mead's notions of mind, self and society were used by Blumer to develop symbolic interaction, a theory about human behavior that focuses on the meaning of events to people in natural settings (Blumer, 1969). Blumer emphasized Mead's idea that humans are symbol users and creators of meaning (Turner, 1986). Much of Blumer's theory was a polemic against functionalism, its assumptions and methodology. According to Blumer (1969) human action always takes place in a social context which includes other people as well as social structures (not surprisingly, social structures are viewed as emergent processes dependent on social interaction) such as family, community, society and culture. Humans are not merely passive reactors to stimuli (or social structures), but active creators of the world to which they respond. Human interaction is mediated by the use of symbols (which include verbal and nonverbal gestures as well as objects in the social world), interpretation of symbols, and ascertaining the meaning of others' actions (Blumer, 1969). Individuals develop and acquire common understandings of definitions which in turn influence their actions in a situation (hence the famous Thomas principle: "If men define situations as real, they are real in their consequences."). Common definitions and shared symbols enable people to act alike, understand one another, and engage in collective action (Blumer, 1969).

The major contribution of the interactionist perspectives in social theory is that they "brought the acting individual back" into social theorizing. According to Turner (1986) the major advantage of symbolic interactionism is that it allows for analysis of micro social patterns and their impact on the individual. Turner cited the important advances made possible through symbolic interaction such as the conceptualization of deviance, socialization, and stigma.

The major limitation of interactionist perspectives lies in their inability to analyze macro social patterns (Turner, 1986). Symbolic interaction gives only vague explanations of the emergence, change, and sustaining of social structures. From the symbolic interactionist perspective, society is viewed not as a structure which influences individuals, but as one which exists only because of symbolic interaction and interpretation of situations by individuals. Society then is based on consensus and shared meanings (Chenitz & Swanson, 1986). According to Blumer (1969, p. 147), "Social organization enters into action only to the extent to which it shapes situations in which people act, and to the extent to which it supplies fixed sets of symbols which people use in interpreting their situations." In symbolic interactionism the individual actor, or symbol user and definer of situations, is given primacy over and beyond society as a structure. Therefore, society itself is constructed, perpetuated, or altered through social interaction, the mind and the self.

Critiques of symbolic interactionism have been aimed primarily at the primacy of individual action over social structure. For example, in a critique of symbolic interaction, Stryker and Statham (1985) stated:

Ultimately what is needed is a well-developed theory that recognizes both the ways in which and the degree to which individual behavior, social

interaction and the social person are constrained by social structure as well as how it is that persons can construct their behaviors, individually and collectively, even to the point of altering the structures within which they act. (p. 311)

Similar to a common critique of other social theories, Stryker and Statham (1985) suggested that by neglecting social structures, such as social class and power, symbolic interactionism constitutes an ideological bias that favors the status quo of liberal democracy in American society. However, Stryker and Statham (1985) appear to focus on the constraining nature of society and disregard the enabling aspects of social structures. Moreover, symbolic interactionism is criticized for its inability to explain rapid social change (Bowers, 1988) and power relationships.

The Theory of Structuration

To more fully understand caregiving, such as conditions and consequences, perspectives of the caregiver and receiver, and social context must be accounted for. The theory of structuration provides a perspective that links caregiving as a social interactive process to its social context and allows for analysis beyond the phenomenological level of the caregiver and care-receiver.

A major trend in contemporary social theorizing is directed toward reconciling the "macro" and "micro" perspectives of human action and society. According to Turner (1986) the theory of structuration is an attempt to eliminate the shortcomings of functionalism (i.e., overemphasis on social structures to the neglect of agents in interaction), phenomenology (the lack of attention to social structures), Marxism (because it is functionalistic, evolutionary, focused only on

class structures, and ultimately not accurate) and portions of symbolic interactionism.

The theory of structuration combines interactionist concepts with concepts that allow for the understanding of structural properties of society. The concept of structuration is an attempt to eliminate the dualism that has plagued much of social theory: individual/society, subjective/objective, micro/macro (Turner, 1986).

About this theory, Turner (1986) stated,

One cannot understand action and inter-action without reference to the rules and resources of social structure, whereas one cannot fully understand large-scale, long-term institutional structures without knowledge of how actors use the rules and resources of these institutional structures in concrete interaction. (p. 458)

Action and structure are not different realities or dichotomies, but dualities within a common reality. Giddens (1984) defined the duality of structure as, "Structure is the medium and outcome of the conduct it recursively organizes; the structural properties of social systems do not exist outside of action, but are chronically implicated in its production and reproduction" (p. 374). Human action and social structures, therefore, are implicated in one another. Social structures are not separate entities that act upon human action, but are created and recreated through human action.

Giddens (1982) began with the question, how should we conceptualize "human action"? The very process of structuration incorporates human action. Human action includes discursive consciousness (the reasons people give for the things they do) and practical consciousness (knowledge embedded in skilled

action). Together discursive and practical consciousness constitute the knowledgeable ability of actors as they are engaged in social interaction.

Giddens (1982) used the terms "unacknowledged conditions and unintended consequences" to refer to social structures (e.g., institutions, resources, and power) as they affect action (e.g., intentions and reasons). According to Giddens, structure is more than constraining, as commonly conceptualized by mainstream sociology. Structures are not fixed entities, but are "recursively organized rules (norms, roles) and resources" (e.g. power, or the ability to mobilize resources) that exist only as properties. The key concept in Giddens theory, structuration, refers to the conditions that govern the maintenance or transformations of structures. "Structural properties of social systems, then, are the medium and outcome of practices that constitute the system and structures are both enabling and constraining of human action" (Giddens, 1982). For example, grammar, as a structural feature of language, enables people to generate utterances, and by producing a grammatically correct sentence the individual contributes to the reproduction of language (Giddens, 1982). According to Giddens (1984) to study constraint involves specifying the limits of agents knowledgeable ability because structural constraint always operates by way of agents' motives and reasons, thereby establishing conditions that affect options available to the self and others.

Giddens specified three types of constraints: material and structural constraints and those constraints associated with sanctions (Giddens, 1984, p. 174). Material constraints are those constraining physical aspects of the body as well as features of the environment that limit options available to agents. Secondly, sanctions are experiences derived from expressions of power such as the direct application or the threat of force or violence and mild expressions of

disapproval. Finally, structural constraints are "the limits upon the range of options open to an actor, or a plurality of actors, in a given [social] circumstance or type of circumstance" (Giddens, 1984, p. 177).

Like the symbolic interactionists, Giddens rejected law-like theories of society (Turner, 1986) and positivist notions about science and research. Giddens introduced the idea of "double hermeneutic" to explain the relationship between social science and everyday human activity. According to Giddens (1984), the "double hermeneutic" means that concepts and generalizations used by social scientists to understand the social world can also be used by actors to alter the very processes and concepts described; "there is a constant 'slippage' from one to the other involved in the practice of the social sciences" (p. 374). Therefore, laws about the social world are not possible because they are always open to revision by actors in their situations.

Because of this "slippage," social theory often contradicts the reasons given by people for the things they do. Giddens's perspective, then, affords equal treatment to discovering the explanations for action given by the perspectives of the actors, and the historical and social explanations and consequences of human action. Structuration would be explained by explicating the dialogical relationship between the two perspectives.

Giddens (1984) argued that social theory is inherently critical and that "structuration theory is intrinsically incomplete if not linked to a conception of social science as critical theory" (p. 287). Critical theory appears to be gaining more attention within nursing as evidenced by the increasing number of articles in nursing journals that address critical theory. Contemporary critical theory (which arose in Germany in the 1920s and 1930s and was concerned with explaining

historical conditions such as World War I, Nazism, and Fascism) seeks to understand all forms of domination, for example sexism, racism, classism, ageism, and heterosexism (Stevens, 1989). According to Stevens (1989) contemporary critical theory actually refers to a set of ideas, not one social theory. "The basic belief was that no aspect of social phenomena may be comprehended unless it is related to the historical whole and to the structural context in which it is situated" (Stevens, 1989, p. 57).

Giddens, however, has stated that he wishes to separate his work "fairly definitively...from the writings of the Frankfurt School" (Giddens, 1989, p. 289). It appears that Giddens's ideas about critical theory in relation to the theory of structuration are not fully developed. In response to a recent critique by Bernstein about Giddens's shortcomings in explicating the nature of critical theory, Giddens specified four levels of critique reflected in his theoretical positions. He referred to the first level of critique, the least controversial, as "intellectual critique" (Giddens, 1989). He explained:

Intellectual critique simply refers to the fact, emphasized by Popper among many others, that disciplined inquiry must be seen as carried on by a community rather than by an individual; any and all theories, concepts and findings brought forward are open to critical dissection and assessment. (p. 288)

Giddens (1989) referred to the second level of critique as practical critique. Practical critique is related to his belief that social science theories, concepts, and findings are routinely incorporated back into the communities they were developed to describe. Furthermore, the products of social science not only influence the

ways in which we think, but also "become in large part constitutive of the practices which form institutions" (Giddens, 1989, p. 289).

The third level of criticism of social science is termed ideological critique, that is, analysis of the role of claims to knowledge as aspects of systems of power. Giddens (1989) posited:

As I have argued elsewhere, ideology should be understood not as false knowledge, juxtaposed to the valid knowledge claimed by science (social or natural), but as the analysis of the conditions under which modes of signification or discourse are incorporated within exploitative systems of domination...A further answer to the question: 'who will use this knowledge, and for what ends?' is therefore that we can investigate, actually or counterfactually, how the knowledge generated from a particular research study is incorporated within asymmetrical power relations. (p. 290)

Finally, the fourth level of criticism is termed moral critique, or criticism concerning "the rights and wrongs of contrasting policies or courses of action" (Giddens, 1989, p. 290).

In conclusion, Giddens's view of society offers a new way to conceptualize environments in nursing. Overall, as White (1984) claimed, the study of environments has been underrated in nursing due to the historical commitment to the client-nurse basis of practice. According to White (1984):

The historical concerns of nurses for providing comfort and for supporting patients in what they cannot do, combined with current emphasis on self-care, tend to overshadow the environment as a variable that can be manipulated to promote health. (p. 330-331)

Although White emphasized the importance of environments in nursing, her conceptualization is not congruent with that of Giddens. White's conceptualization of an environment that can be manipulated reflects a functionalist orientation, that is, an environment that stands outside of individual human action instead of one that is the outcome and medium of human action.

Chopoorian (1986) perhaps was stronger in her criticism of nursing and felt that nursing as a profession gives token credence to the environment, yet fails to clearly conceptualize the environment as a basis for research, theory, and practice. She felt that the concept of environment has not been well developed in nursing because the environment is primarily regarded as a context in which people adapt. Moreover, she felt that nurses tend to focus on nurse/client interaction, and fail to consider environments other than the immediate surroundings of the client. The focus of nursing, therefore, remains on the individual's adaptation. The environment fades against the prominent recipient of care, and the client remains the object of change. Chopoorian (1986) offered direction for nursing by reconceptualizing the environment as: 1) social, political, and economic structures; 2) human social relations; and 3) everyday life. By including social structures, human social relations, and everyday life, Chopoorian's conceptualization of the environment approaches Giddens's view of the interrelatedness of social structures and human action.

In conclusion, the use of structuration theory in conjunction with symbolic interactionism allows for a more comprehensive understanding of the phenomenon of caregiving than either would alone. The theory of structuration will allow for analysis of environments as social, political and economic structures instead of reflecting the more traditional functional approach of sociology.

Psychosocial Adaptation and Transitions

Transition, as a concept, is relevant to the proposed study because the diagnosis of HIV infection is conceptualized as an event that challenges the assumptive world of those involved, including the person with HIV infection and his or her significant others. As a result of the diagnosis of HIV infection, plans for living in the world are questioned and modified. Family members assume new roles associated with giving care, and people with HIV infection assume new roles associated with receiving care (Brown & Powell-Cope, 1991).

Transitions, rather than the more familiar notion of "Individual Adaptations" guide the proposed study. The rationale for this approach will be discussed in this section. The concepts of Adaptation and Transitions reflect overlapping yet distinct domains of understanding. Change is the conceptual domain that links adaptation and transitions together, but in each perspective change is grounded in different conceptualizations of human action. The Webster New Collegiate Dictionary (1977) definition of adaptation includes: 1) adjusting to environmental conditions and 2) modification of an organism or its parts that makes it more fit for existence under the condition of its environment. As such, adaptation may include both process as an individual adjusts to environmental demands, and as an outcome of an individual who "fits" in with demands of the environment.

Adaptation is grounded in a biological model of human action that views humans as passive adapters to the environment. Therefore, those who study adaptation may do so without accounting for the person's perceptions of a situation (Lyon & Werner, 1987). Adaptation has become associated with psychosocial stress models, as evidenced in Lazarus's and Folkman's (1984) theory of stress,

appraisal, and coping. This model accounts for a person's contextual perceptions; however, Lazarus and Folkman (1984) restrict the definition of adaptation to an outcome, either social, psychological or physiological in nature. Lazarus's overall model is committed to appraisal and coping over time, yet as adaptation is most commonly applied, the contextual, processual, and multi-level nature of change is not often evident. Most commonly, the unit of analysis from an adaptations perspective appears to be the individual (Duffy, 1987). Duffy (1987) criticized nursing scholars for their tendency to define adaptation in terms of a person's passive conformity to prevailing societal norms. She maintained that focusing on the concept of adaptation encourages holding the individual responsible for change, thereby underestimating the role of the environment as a unit of intervention.

Until recently the concept of transitions was not constrained by the legacy of a passively responding individual; for this reason transition is an appealing way to understand human conditions. Transition implies an individual who can cope with environment in multiple ways. For example, the individual can: 1) change to meet demands of the environment (e.g., adapt); 2) live a lifestyle that is unaltered despite environmental demands (e.g. resign); or 3) live outside of prevailing norms thereby transforming them (e.g., resist) (Duffy, 1987). Marris (1974) suggested that "resistance to change is, then, as fundamental an aspect of learning as revision, and adaptability comes as much from our ability to protect the assumptions of experience, as our willingness to reconsider them" (p. 16). From Marris's perspective resistance is derived from the desire to preserve "threads of continuity" related to basic assumptions about one's life.

The Webster New Collegiate Dictionary (1977) definition of "transition" is a passage from one state, stage, or place to another. Time and or motion are implied in this definition of transition. Parkes (1971), one of the first theoreticians to describe psycho-social transitions in the literature, used the term to identify a field of study that would be different from stress and crisis models. He criticized the stress literature because of the tendency to define stress in terms of outcomes thereby becoming tautological and not useful as an analytic tool. In addition, stress and crisis models tend to focus on the negative aspects of change, thereby underplaying normative changes which occur as part of "normal life." Parkes (1971) therefore introduced the concept of psychosocial transitions to clarify stress and crisis theories and to understand human change from a different perspective.

Parkes (1971) maintained that individuals normally live within a predictable, familiar environment, which he referred to as the life space. During one's life, changes occur within the life space that are minor and require no shift in assumptions or way of living in one's world (Parkes, 1971). However, at other times changes in one's environment require adjusting, refocusing one's world view and assumptions, and changing plans for living in the life space (Parkes, 1971). Psychosocial transitions, then, are major changes in one's life which have long-term effects, occur over a relatively short period of time, and affect one's assumptions of the world (Parkes, 1971). Jacobson (1986) concurred that the key feature of a transition, compared to other types of change, is in the shifts that occur in one's assumptive world as a result of change.

Chick and Meleis (1986) noted that transitions models are used to describe and integrate complex change within developmental and stress theories. There seems to be consensus in the literature that transition is a "multiple concept" that

embraces elements of process, time, and perception. Transition reflects a processual orientation to change, that is, change that occurs in stages. For example Bridges (1980) indicated that transitions involve stages of endings marked by loss, periods of confusion and disorientation, and new beginnings characterized by reorientation to one's life. A transitions conceptualization of change is compatible with a sociological interest of social processes from a symbolic interactionism perspective, for example, interactions that change over time or occur in stages.

The concept of transitions allows for the recognition of continuity as part of change. As Hall (1983) indicated, stability, or nonchange, is associated with culturally negative terms such as inertia, tradition, and stagnation. Western cultural beliefs tend to support the notions that growth or change is good and continuity is bad. Hall (1983) derived the concept of persistence (defined as promoting continuity, or enduring in the face of obstacles) to reflect the importance of change and stability. Transition as a concept is compatible with persistence because it embraces change and continuity as people live through situations. In highlighting continuity during transitions, Bridges (1980) stated,

Not everything vanishes in the ending process, of course, and some people find it very important to experience the continuities in their lives when so much else is changing...Psychologically the process of return brings us back to ourselves and involves a reintegration of the new identity and elements of the old one. (p. 157)

Marris (1974) used a "thread metaphor" and stated that loss and change will lead us to "repair the thread, tying past, present, and future together again with rewoven strands of meaning" (p. 21).

As a concept for nursing science, transitions allow for freedom from the common notion of adaptation, that is, a passive individual reacting to a relentless environment. As such, adaptation underemphasizes the ability of people to alter their environments. In developing nursing science, then, the study of transitions increases options for working with clients because it directs the focus of change to multiple levels of individual experience and the environmental context.

Transitions allow for envisioning the complexity of human action in context. According to Benoliel (1988) "the human condition is characterized by the situation of undergoing multiple transitions which overlap and interact in a variety of complex ways" (p. 9). Thus, a goal in developing nursing science and nursing interventions for human conditions involves investigating overlapping and intersecting transitions. Chick and Meleis (1986) emphasized the importance of delineating dimensions of time, patterns, and types of transitions in order to study the timing of interventions. For example, Benoliel's (1985) conception of nursing care in terminal illness is built on the assumption that dying patients and their families require assistance in undergoing the shifts and discontinuities associated with stages of dying as they live through the experience of a terminal illness. She maintained that such an orientation requires individualized care, accessibility of practitioners in greatest time of need, and a partnership between nurses, patients and families, who may hold conflicting values and expectations about the most desirable way to die (Benoliel, 1985).

From a transitions perspective a major goal of nursing science is to elucidate the dynamics of people's lives during major life transitions as a basis for nursing care. The very notion of nursing intervention and the nurse/patient relationship is colored by our perspective of change. A transitions perspective

places the role of the nurse as a facilitator of change but also as one who supports clients as they undergo transitional experiences. About facilitating others' transitions, Bridges (1980) stated:

And most of these journeys must be taken alone. All our habits of caring for others (and seeing ourselves as people who would care for others) become self-defeating. We need to resist the old impulses to take care of others and instead to pay attention during this time to what we are doing and why we are doing it. (p. 157)

Results from Swanson-Kauffman's (1986) study of women who have miscarried provide an illustration of a transitions model in guiding the development of nursing practice knowledge. The categories of coming to know, losing and gaining, sharing the loss, going public, getting through it, and trying again capture the dynamic and processual nature of the life transition of miscarriage. Exploring the complex transitional nature of miscarriage provides an understanding of the types of caring that are most helpful for women undergoing this transition, as well as the timing of when different types of caring are most likely to be supportive. For example, when a woman is "coming to know" that she is experiencing a miscarriage, perhaps she is helped most by a skilled nurse or physician who can validate the loss clinically. On the other hand, perhaps the most appropriate "intervention" during "sharing the loss" is a friend who is willing to hear her story and take the time to be present to her. Jacobson (1986) maintained that "transitionalists" see social support almost exclusively in relation to the transition an individual is undergoing. For example, he proposed that until a person in transition has let go of a loss, advice offered as support will be unheard or misinterpreted as nonsupportive.

In summary, the sensitizing concept of transitions offers nursing a way to study human experiences characterized by change. Transitions allow for integrating continuity with change, for selectively focusing the gaze to the individual or the environment, and for developing nursing therapeutics. Therapeutics that are grounded in the life experiences of others and relevant to their transitional experiences will be more effective than those developed and applied acontextually.

Family Caregiving

In this section of the conceptual framework the concept of psychosocial transitions will be used to explain the experiences of AIDS family caregivers. In addition, a transitions framework will be used to present the findings of the Brown and Powell-Cope (1990) study of caregiving which provides the theoretical basis for the proposed study, and to integrate the literature on family caregiving in general.

Informal care has always existed, yet family caregiving is particularly salient during current times of economic restraint in health care expenditure. In this way national health and social policy intersect with the everyday realities of families affected by chronic illnesses. With the recent emphasis on home care to contain costs, families are increasingly expected to bear more of the concomitant responsibilities and burdens. Family caregiving therefore cannot be separated from the social context in which it occurs.

Much of the literature that addresses family issues in the instance of HIV infection is anecdotal or based on clinical impressions. Little systematic research is reported on caregiving although recently results from exploratory studies of families of people with AIDS are beginning to appear (Geis, Fuller, & Rush, 1986;

Giacquinta, 1989; Greif & Porembski, 1987; Greif & Porembski, 1988; Pearlin, Sample, & Turner, 1988; Raveis & Siegel, 1989). Caregiving in the instance of HIV infection may or may not resemble caregiving in other populations, yet similarities and differences are not well-articulated at this point in time.

The first distinctive feature of AIDS family caregivers is their age. Caregiving during HIV infection is different from caregiving in the elderly population because AIDS affects primarily the young adult population. Sixty-six percent of all cases of AIDS reported in 1989 were between the ages of 20 and 39, and 21% were between the ages of 40 and 49 (CDC, 1990a). Therefore family members, particularly lovers, are faced with assuming the caregiver role at a time in life that is not consistent with their previous expectations. In other words, caregiving during HIV infection is a "non-normative" transition, a transition that is out of sequence with the expectations young people have for the course of their lives. While an elderly individual may expect to take care of his or her spouse during later life or a middle-aged adult for a parent (Brody, 1985), a young gay man may not have considered the possibility of caring for a sick lover during his third or fourth decade of life.

Second, AIDS family caregivers differ from other populations in terms of the role relationship between the caregiver and care recipient, and the caregiver's gender. Horowitz (1985) in a review of almost 200 research articles noted that most family caregivers are women, and most frequently wives or adult daughters. Caregivers of people with HIV infection, however, are more likely to be gay partners (male) and friends; to date, gay men still account for the largest proportion of people with AIDS (CDC, 1992b). For example, in the Brown and Powell-Cope (1991) study, 64% of caregivers were men, 34% percent were

classified as friends, 34% current lovers, 10% former lovers, and only 18% as heterosexual partners or biological family members. Similarly, in the Raveis and Siegel study (1989) 82% of the caregivers were men, 37% lovers, 42% friends, and only 19% traditional family members. In addition Raveis and Siegel (1989) reported that 100% of PWAs with lovers named them as a source of emotional support, whereas only 53% named traditional family members. Therefore, the important role that gay men play in caring for people with HIV infection cannot be overemphasized.

Another distinguishing characteristic of AIDS family caregiving is the overwhelming nature of multiple losses at a time in life when young people do not expect them to occur. Family caregivers of PWAs, particularly gay men who are highly involved in gay communities, are not only faced with losses directly due to the PWA's illness, but may likely have experienced the death of many friends (Pearlin, Sample, & Turner, 1988). Pearlin and colleagues (1988) noted that multiple losses and deaths in gay communities were likely to result in anticipatory isolation and feelings of guilt, ambivalence, and vulnerability to death and disease.

Brown & Powell-Cope Study

We began our grounded theory study of AIDS family caregiving during 1988. During data analysis a transitions framework began to inform further data collection and concurrent data analysis. The basic social process of the substantive theory grounded in interview data of caregivers was "Transitions through Uncertainty." This theory provides the foundation for the current study of couples. This current research extends "Transitions through Uncertainty" by including the perspectives of care recipients, that is, persons with AIDS, and by

further exploring salient sociostructural dimensions relevant to AIDS family caregiving.

The purpose of our study was to describe the human experience of family caregiving during HIV infection. Fifty-three family caregivers who were currently involved in caring at home for a family member with AIDS completed in-depth interviews and lengthy questionnaires. Thirty six percent were classified as friends, 34% current lovers, 10% former lovers, 4% partners in heterosexual relationships, and 14% biological family members. Results discussed in this section refer to those produced by analysis of qualitative interview data only and focus on the transitional nature of caregiving. The following five substantive categories characterized the experience of caring for a family member with AIDS: 1) Living with Loss and Dying; 2) Renegotiating the Relationship; 3) Managing and Being Managed by the Illness; 4) Going Public; and 5) Containing the Spread.

The diagnosis of a major illness is one type of psychosocial transition (Parkes, 1971). A life-threatening disease, such as AIDS, is a transition for the individual diagnosed and for those in his/her life space, such as family caregivers and partners. Living with the PWA and AIDS on a daily basis precipitated the restructuring of one's view of the world and plans for living in the world if one was to take on the role of a caregiver. The PWA learned to adjust to being the care recipient and the significant other learned to adjust to becoming the caregiver. Although our study was cross-sectional, there was substantial evidence to support the claim that caregiving changed over time and involved several related, but conceptually discrete, themes. The sample of 53 caregivers included those whose PWA had been ill for a very short time and a few whose PWA was close to death. A transitions framework embraced the diversity of experiences and guided an open

exploration of concerns as defined by the family caregiver at any given point in time.

In summary, transitions was a useful concept in exploring the meanings of AIDS family caregiving. The value of a transitions approach was that it provided a conceptual scheme for analyzing a complex human experience characterized by change. The major concept explaining transitions in AIDS family caregiving, derived from our study, was uncertainty. Uncertainty will be discussed first within the context of AIDS caregiving and then within the context of caregiving in general. Second, within the overall transition of caregiving, specific issues surfaced within the primary relationship (Renegotiating the Relationship), within the caregiver's relationship to the world (Going Public), with the caregiver's experience of the past, present and future (Living with Loss and Dying), with the caregiver's relationship to the virus (Containing the Spread), and with the caregiver's relationship to the illness experience of the PWA (Managing and Being Managed by the Illness). Each set of changes will be described in more detail when discussing each dimension separately. In addition to a more detailed presentation of our study, comparisons will be made with the extant literature on AIDS family caregiving and caregiving for other chronic illnesses.

Uncertainty

Uncertainty pervaded the transition of caregiving during HIV infection in profound ways (Brown & Powell-Cope, 1991). Uncertainty was infused into every aspect of caregivers' lives for the duration of the caregiving transition. Uncertainty in "Managing and Being Managed" was most prominent and was related to the meaning of symptoms, the unpredictability of AIDS, and the newness of AIDS as a modern disease. The uncertainty of "Living with Loss and

Dying" was described as not knowing which illness would herald the PWA's death and coping with an uncertain future together. Uncertainty in "Going Public" was related to not knowing how others would react to the information that the individual was a caregiver for a person with AIDS. Uncertainty in "Containing the Spread" was related to not being confident in the effectiveness of preventive measures or the fact that scientific information alone was not always sufficient to reassure the caregiver about prevention efforts. Uncertainty within "Renegotiating the Relationship" was the least common type of uncertainty expressed by caregivers, but focused on being unsure of how AIDS changed the rules and process of negotiating issues within the relationship.

Uncertainty as a concept has recently gained attention in the nursing literature and has been studied primarily in relation to people's experiences with chronic or life-threatening illnesses (Mishel, 1984; Mishel & Braden, 1988; Cohen, 1989). While uncertainty has been noted in caregiving situations other than AIDS, it is not a common theme in the caregiving literature. In a grounded-theory study of family caregiving for a relative with Alzheimer's Disease, Wilson (1989) noted that the early stages occurred within a context of uncertainty and unpredictability about the consequences of the caregiver's decision to take on the role of caregiver. After the initial stage, marked with the uncertainty of taking on the role, uncertainty diminished and became specifically associated with the illness itself. In the Wilson study, uncertainty was noted predominantly in the initial stages of caregiving, in contrast to the omnipresence of uncertainty in the AIDS family caregiving (Brown & Powell-Cope, 1991).

In a study of 65 spouse caregivers of persons with advanced cancer, Stetz (1989) found that caregiver's level of uncertainty (conceptualized the three

dimensions of: predictability, controllability, and illness understanding) negatively predicted caregiver health. Stetz (1989) concluded that uncertainty was an important dimension to a life-threatening environment (i.e., caregiving at a later stage) because of its relationship to caregivers' health. In a study of home care needs of cancer patients and their caregivers, Blank, Clark, Longman and Atwood (1989) found that a series of needs resulted from treatment uncertainty related to the course of therapy and outcomes. It is likely that this form of uncertainty and the uncertainty noted by Wilson (1989) in later stages of caregiving were similar to the uncertainty experienced by caregivers of PWAs in the context of trying to manage the illness.

In a study of parents of children with chronic illnesses, Cohen (1989) found that uncertainty associated with managing the illness was a significant source of stress. Early in the course of the illness parents reported not being sure of which symptoms to monitor. With experience, parents learned to differentiate important from unimportant symptoms, but rarely were able to make assessments with absolute certainty (Cohen, 1989). Specific to AIDS caregiving, Greif & Porembski (1988) noted the difficulty of significant others' coping efforts due to the lack of scientific knowledge about AIDS.

Based on the literature review of caregiving, uncertainty appears to be an important dimension of the human experience, yet the contexts of uncertainty and the importance of various types of uncertainty at different stages of the caregiving experience remain unexplored. Further research would help to clarify the role of uncertainty in the overall transition of caregiving.

Living With Loss and Dying

In our study of AIDS family caregiving (Brown & Powell-Cope, 1991), Living with Loss and Dying reflected families' experiences with overwhelming loss, including possible death of the person with AIDS. This category was defined as the process of revising one's plans for living in the world based on the possible or probable death of a loved one and included the subdimensions of facing loss, putting the future on hold, and maximizing the present. While AIDS family caregivers faced multiple losses (for example, losses within the relationship, the future, social activities, and the support of family and friends), the major loss was clearly the anticipated death of the PWA.

Parkes (1971) proposed that "we build a set of plans to enable us to cope with a future which may or may not transpire...It is for our assumptions about the lost future that we grieve" (p. 110, 111). With the onset of AIDS or HIV infection the caregiving couple faced coping with the possible death of the person with AIDS, letting go of the future, ultimately letting go of the person with AIDS, reorganizing plans for the future, and learning to manage in the present. Before the onset of AIDS, caregivers, particularly lovers, assumed that the PWA would be an integral part of their future as a couple. With the diagnosis of HIV infection came the realization that in all likelihood the PWA would die young, and the future of the relationship was in jeopardy. Long-term plans were often put on hold, and the family caregiver assumed a way of life characterized by "one day at a time." Short-term plans were often abandoned or time frames compressed to allow for the realization of goals and to avoid the disappointment of not realizing one's long term goals. As family caregivers watched HIV infection change the PWA, they learned to expect more changes, more limitations and fewer realized

goals. The diagnosis of HIV infection, the first episode of *Pneumocystis carinii* pneumonia, and first signs of dementia were critical events that reminded caregivers of the tenuous nature of the future. As a result of an altered future, caregivers learned to "live one day at a time" and focus on the present as they cared for the PWA. A similar present orientation to life and maintaining normalcy have been noted in other groups of chronic illness caregivers, also (Corbin & Strauss, 1988).

Living with Living and Dying during AIDS family caregiving most likely was related to the stage of life in which AIDS strikes. Family caregiving during HIV infection describes a non-normative transition, that is, one that occurs unexpectedly within the life cycle. Neugarten (cited in Schlossberg, 1984) proposed that the timing of a transition will affect one's ease of adaptation because a socially prescribed timetable serves to organize major life events, such as caregiving for an elderly spouse. Caregiving in the context of a long life together as a couple is often viewed as a "normal" course of events because sickness, frailty, and death usually are associated with old age. However, caring for a partner who may die early in life, such as a couple affected by AIDS during their 30s, often leaves the couple feeling robbed of the future they had planned.

Loss, multiple loss, and grieving have been noted in the psychosocial AIDS literature (Gordon & Shontz, 1990; Govoni, 1988; Saunders, 1989); therefore it is not surprising that the caregiving experience during HIV infection is characterized by loss as well. Pearlin (1988) identified intrapsychic sources of stress during AIDS caregiving arising from the caregivers' attempts to view themselves in the future, their vulnerability to death and disease, and their experiences with multiple losses (e.g., deaths of friends and acquaintances from AIDS).

Loss during caregiving is not unique to the situation of HIV infection, yet it remains unclear whether or not loss is more prevalent or troublesome for HIV caregivers than caregivers in other situations. It is difficult to assess the degree to which loss is important in the experience of caregivers since loss, as such, has usually not been explicitly examined. When a family member assumes a caregiving role, it is not surprising that he or she may be forced to relinquish portions of a life before caregiving, resulting in feelings of loss. For example, Rabins, Mace, and Lucas (1982) found that a common problem experienced by family caregivers was the loss of friends and hobbies resulting in no time for oneself. In a sample of family members caring for a relative receiving outpatient radiation therapy for cancer, Oberst, Thomas, Gass and Ward (1989) examined the appraisal of caregiving in terms of: harm/loss (in which a potential stressor has already caused damage); threat (in which there is a potential for harm); challenge (in which there is a potential for growth despite difficulties); and benign (in which there are no consequences for one's well-being). Interestingly, mean appraisal scores were lowest for the harm/loss and threat subscales, indicating that loss may not be a critical factor for this group of caregivers.

The importance of coping with the past, present, and future has been noted in other caregiving studies focusing on different populations, but like loss, has not explicitly been examined. Barusch (1988), in a study of coping strategies of elderly spouse caregivers, found the fear of future was a major concern. In contrast, only 9% of caregivers in Stetz's (1987) study of caregiving during advanced cancer identified "not knowing what will happen in the future" as a caregiving demand. Perhaps concern for the future varies with respect to the stage of caregiving or severity of the care recipient's condition; Stetz's sample was caring

for a spouse with advanced cancer whereas Barusch studied family members of demented older adults.

Some researchers have addressed coping with future-related concerns. Barusch (1988) found that although cognitive restructuring was the most common coping strategy used for fear of the future, it was not a very effective coping strategy. More effective were the use of personal action to change a situation, managing a situation without changing it, and seeking information from others to change a situation (Barusch, 1988). In contrast, but similar to our findings (Brown & Powell-Cope, 1991), Quayhagen and Quayhagen (1988) found that existential growth was a common coping pattern of Alzheimer's caregivers. Finally, the consequences of coping with future concerns may have significant outcomes for caregivers. For example, in a longitudinal study of stroke caregivers (Schultz, Tompkins, & Rau, 1988), increasing concern for providing future care was associated with greater perceived burden, and initial concern for providing future care was predictive of depression.

The extent to which the possible death of the care recipient is a significant concern for caregivers is not clear from the caregiving literature. In a study of the needs of family members who care for patients with cancer receiving ambulatory care, Hinds (1985) reported that only 4% of the sample identified loss of the patient through death as a significant psychological problem area. Most family members were more concerned with physical care of the cancer patient, probably because the patients were receiving active treatment and therefore focused on living rather than dying. Other studies of cancer family caregivers indicate that fear of losing their loved one and fear of being alone were identified as significant stressors (Blank, Clark, Longman, & Atwood, 1989; Corbin & Strauss, 1988;

Perry & de Meneses, 1989). In comparing families involved in different stages of care, Cassileth and colleagues (1985) found that family members who were involved in palliative care experienced higher levels of anxiety and mood disturbances than those involved in the patient's care during active and follow-up medical treatment. They concluded that families involved in palliative care (or those actively coping with the death of a loved one) were at highest emotional risk and therefore in most need of psychological support.

Managing and Being Managed by the Illness

Managing and Being Managed by the Illness described the vigilant monitoring of the mercurial nature of HIV infection and the constant responding to the relentless demands and uncertainties associated with caregiving tasks. Subdimensions included: watching and analyzing, doing for, and coordinating help (Brown & Powell-Cope, 1991).

The focus of Managing and Being Managed was on the PWA's illness status. Not surprisingly, the transition from lover/parent/friend to caregiver was affected to a large extent by the illness status of the PWA, or the "illness trajectory." The trajectory concept is applicable to the AIDS caregiver in several ways. First, caregiving occurred over a significant period of time and was highly influenced by what happened to the PWA. Secondly, the "illness trajectory" of the PWA had implications for how the caregiver organized his/her work of caregiving and coped with caregiving activities. Caregiving activities are dependent upon what Martocchio (1982) characterized as four patterns during periods of living-dying: 1) peaks and valleys; 2) descending plateaus; 3) downward slopes; and 4) gradual slopes. Although Martocchio (1982) found that illness patterns were not disease-specific, the majority of AIDS caregivers in the Brown and Powell-Cope

(1991) study did describe HIV infection in terms of "peaks and valleys." The illness and caregiving experiences were accentuated by peaks of relatively good functioning and valleys that reflected health crises of the PWA. An example of a common "valley" was the dreaded and unpredictable onset of *Pneumocystis carinii* pneumonia. Many caregivers had been through acute episodes of pneumonia "with" the PWA as a near death experience, and consequently lived in constant dread that another similar event could happen at any time. Therefore, they watched vigilantly for early symptoms that could indicate another episode of pneumonia.

Many caregivers, therefore, lived with the constant threat of the PWA's volatile illness, even during "peaks," because the onset of an opportunistic infection was often sudden and dramatic. "Peaks and valleys" often served as markers in caregivers' lives. One respondent during an interview repeatedly referred to "the day John's face turned black." The near death of the PWA became a milestone in his illness and therefore an anchor point from which the caregiver evaluated the health/illness status of the PWA and her own caregiving actions directed toward Managing the Illness. Many caregivers described living with peaks and valleys as resembling life on a roller coaster.

Feelings of Being Managed by HIV resulted from the increasing needs of the PWA and his or her unpredictable health status (Brown & Powell-Cope, 1991). In Being Managed caregivers found it extremely difficult to take time out for themselves, to be alone, and to experience what Bridges (1980) called the "neutral zone." According to Bridges (1980) the neutral zone is a time of confusion yet renewal and reorientation occurring between the recognition of endings and the start of new beginnings. Bridges maintained that this "time out" is a necessary

time for the integration of loss incurred by transitions before one can "get on with life." Part of the difficulty in experiencing the neutral zone lies in our cultural expectations that we "do" something, anything, and in our discomfort with uncertainty and confusion. Caregivers often found it difficult to experience "the neutral zone" because of the constant demands associated with Managing the Illness.

Performing caregiving tasks was a major component of Managing and Being Managed by the Illness (Brown & Powell-Cope, 1991). According to Horowitz (1985) because caregiving is defined by the person's need for assistance, much of the research to date has focused on caregiving behavior and tasks. Tasks of caregiving have been conceptualized across studies in many different ways such as: emotional support, direct service provision, mediation with formal organizations and providers, and financial assistance (Horowitz, 1985). In slowly progressing diseases, such as Alzheimer's Disease, caregiving tasks often become increasingly demanding and time consuming for the caregiver to perform as the patient becomes more physically impaired. In a diseases like HIV, characterized by acute exacerbations and symptoms ranging from dementia to anorexia, the amount and type of caregiving tasks were likely to be quite varied over the course of the illness (Brown & Powell-Cope, 1991).

The consequences for family caregivers of managing the illness have been extensively studied. Both Chenoweth and Spencer (1986) and Cassileth and colleagues (1985) found that stress and emotional responses of caregivers may take different forms depending on the phase of illness of the care recipient. Cassileth and colleagues (1985), in a study of cancer patients and their next of kin, found that more anxiety was evident in the palliative phase of care compared to

early illness, when care duties were more physically demanding. Similarly, Stetz (1987) found that the most commonly reported source of caregiving demand during advanced cancer arose from managing physical care and carrying out the treatment regime associated with the illness. Chenoweth and Spencer (1986) noted different sources of stress associated with recognizing early symptoms, problems associated with diagnosis and information, and the impact of providing care at home. For example, the major problem reported in caring for a relative concerned the need for constant care, physical care and constant supervision, similar to the notion of "Being Managed" in HIV caregiving (Brown & Powell-Cope, 1991). Pearlin, Sample, and Turner (1988) similarly described the relentless nature of caregiving during AIDS that increases as the illness progresses.

There is no doubt that caregiving tasks are major concerns for family caregivers. For example, in the Barusch (1988) study 61% of spouse caregivers of the elderly reported that care-related tasks were a specific problem. Cantor (1983) found that the most prevalent source of strain reported in a group of family caregivers for the frail elderly adult was health of the care recipient.

Bowers (1987) maintained that much of the caregiver research has been focused on caregiver tasks and the related effects on the caregiver. Data regarding effects of caregiving indicate that family caregivers experience problems related to mental health (George & Gwyther, 1986) and feelings of burden; strain (Morycz, 1985; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986); anger, depression and fatigue (Rabins, Mace, & Lucas, 1982); and uncertainty (Stetz, 1986). Performing personal tasks for a family member can be particularly distressing. In a study of family home care Hooyman, Gonyea and Montgomery (1985) found that the performance of personal care or body contact tasks was a

stronger predictor of perceived burden than were less intimate tasks (such as shopping and laundry). Performing personal tasks can be particularly stressful for children, who may not be as used to intimate physical contact with their parent as the spouse caregivers would be. For example, Young and Kahana (1989) found that child caregivers were more likely than spouses to provide personal care but they also scored higher on a burden inventory than did spouses.

As a result of the emphasis on caregiving tasks, Bowers (1987) maintained that most research, theory development and intervention has been limited in scope, thereby possibly masking other salient aspects of caregiving. Horowitz (1985) and Bowers (1987) noted that much of the caregiving literature has been focused almost solely on caregiving tasks to the exclusion of other important issues. While caregiving tasks are an important issue in caregiving, grounded theory approaches such as those by Brown and Powell-Cope (1991) and Bowers (1987) serve to articulate important caregiving issues other than performing tasks. They offer different ways of understanding caregiving from the perspectives of those living the experience. Oberst, Thomas, Gass, and Ward (1989) found that in situations where little physical care is required, family members often spend considerable time in other caregiving activities, such as providing transportation, giving emotional support to the care recipient, and performing extra household tasks.

Renegotiating the Relationship

Renegotiating the Relationship was defined as the ongoing process of revising the rules and expectations of the caregiver/care-recipient relationship and striving to reach acceptable balances (Brown & Powell-Cope, 1991). The three subdimensions included: modifying give and take, coping with dependency, and managing conflict while choosing your battles.

According to Bridges (1980) during transitions the salience of interpersonal relationships often becomes magnified:

Whatever the current antagonisms and topics that a couple is trying to deal with, a life transition brings them to the point where each has the opportunity to discover the inner resources that have hitherto been expressed in the relationship through the other person. Each has the opportunity to be more whole, more complete as a person. Their relationship can then be renegotiated on a less restrictive basis. (p. 72)

Brown and Powell-Cope (1991) found that the primary relationship between the caregiver and receiver was a salient feature of the total caregiving transition. In general, family relationships are characterized by roles and expectations of one another. When a family member is diagnosed with HIV infection, roles shift and expectations about the relationship are forever changed. Family caregiving involves transitions in roles from friend, lover, or family member to caregiver.

Striving to reach acceptable balances within the relationship was an issue that periodically surfaced as circumstances changed, particularly health of the PWA. Relationships typically changed from mutual interdependence to responsibility for the life of the PWA due to his or her progressing illness and increased dependency. Striving to reach balances involved relinquishing aspects of the pre-AIDS relationship and changing expectations about the PWA's contribution to the relationship, yet still finding meaning in being a family caregiver.

Bridges (1980) referred to the first stage of transitions as endings, similar to Parkes's (1971) notion that transitions shatter one's assumptions and plans for

living in the world. Endings for family caregivers relevant to Renegotiating the Relationship included the termination of the pre-AIDS relationship with the PWA, a life of independence, and plans for life as a couple. Caregivers often struggled with these issues initially and then periodically as they resurfaced with changing circumstances.

All relationships are based on rules which may or may not be explicit. The explicitness of such rules often affected the quality of negotiations for AIDS caregivers. According to Moses and Hawkins (1982) rules pertain to such topics as finances and sexuality. People with AIDS and family caregiver dyads negotiated many of the same issues as other couples, from household tasks, to resolving conflict, but if couples had not worked out rules of the relationship prior to the onset of AIDS, the negotiating process was often complicated. The lack of clear rules was problematic for gay men in relationships or in nontraditional family situations (e.g., friends living together) because of the absence of legal and social definitions that clarify relationship roles. On the other hand, some in nontraditional family situations were more committed to specify rules in a relationship given the fact that socially sanctioned norms were irrelevant from the beginning. In relationships characterized by implicit rules, the illness often defined and changed rules that partners were not aware of in the first place. Couples in this situation seemed to have more difficulty negotiating than couples in relationships with explicit rules. Partners in a relationship with explicit rules still found that AIDS changed rules, but it was less difficult for them to distinguish AIDS-related changes from ones that were a result of a normally changing relationship.

According to Bridges (1980) a major transition in the course of human development is from dependency to independence. According to Silverstein (1981), reconciling dependency and independence may be particularly difficult for gay men as both attempt to reconcile their socialization as men (resulting in valuing independence) and their desires to be in an intimate relationship. As a result, gay men in relationships may confuse intimacy with dependence and feel threatened by situations that place them in positions of dependency. While independence and dependence issues can be troublesome for those in any relationship, it is not surprising that when one partner becomes ill with AIDS, dependency issues become magnified. For example, in our study (Brown & Powell-Cope, 1991) AIDS family caregivers often reported that the PWA feared abandonment by the caregiving partner. In addition, caregivers often felt overwhelmed at the increasing level of responsibility as the PWA became more and more physically dependent. Many gay men reported that AIDS highlighted issues of dependency and contributed to a process of constant negotiation with the PWA.

Changes in role relationships have been noted in the caregiving literature but, as with loss, are not the focus of much research or theorizing in general. In Barusch's (1988) study of caregivers of elderly spouses, 88% of the sample reported missing the way the care recipient (spouse) used to be. Commonly reported interpersonal problems included arguing with one's spouse and the spouse's failure to show appreciation toward the caregiver (Barusch, 1988). In contrast, only 7% of caregivers in the Stetz study (1987) reported alterations in the interpersonal relationship with the ill spouse as a significant caregiving demand. Using an exchange theoretical perspective Stoller (1985) studied the effects of

caregiving on the relationship between elderly adults and their live-in helpers in a sample of 753 noninstitutionalized elderly persons and their informal helpers. Stoller (1985) found that the amount and scope of help that caregivers provided had a negative effect on their relationship with the older person. Furthermore, greater levels of assistance required by the older person had a negative effect on the elder's presence on the household. It was concluded that the degree of disruption of household functioning (such as expressive functions of family and changes in social activity within the household), rather than the absolute level of assistance required by the elder, directly undermined the elder-caregiver relationship. Klein, Dean, and Bogdonoff (1967) examined the effects of a family member's illness on the marital relationship as perceived by the spouse caregiver. They found that the level of marital integration decreased during illness, particularly during periods of increased symptomology of the ill spouse (Klein, et al., 1967). Furthermore, types of symptoms may have differential effects on the relationship although this point is not entirely clear. Deimling and Bass (1986) found that impairment of activities of daily living and mental health impairment explained a significant percentage of the variance in the elder/family caregiver relationship. In particular, strongest effects were produced by the elder's disruptive behavior and social functioning, not by physical symptoms (Deimling & Bass, 1986).

Going Public

In the AIDS caregiver study, Going Public was defined as the process of letting others know that the caregivers were caring for a person with AIDS. Going public existed on a continuum from living with secrecy to living assertively.

Caregivers balanced the risks and benefits of going public in determining who to tell, when to tell, and how to tell (Powell-Cope & Brown, 1992).

AIDS family caregiving may be similar to other caregiving situations because it is a chronic life-threatening disease and results in the need for demanding physical care. However, AIDS caregiving may be very different because of the social context surrounding HIV infection. The social stigma surrounding AIDS and experienced by people with AIDS is well known (Bennett, 1987; Holland & Tross, 1985; Morin, Charles, & Malyon, 1984; Sontag, 1989) but the stigma of those people indirectly affected by AIDS, such as family caregivers, is not well documented. It is not surprising, however, that AIDS family members experienced considerable stigma: a "guilt by association" type of phenomenon (Powell-Cope & Brown, 1992). Geis Fuller, and Rush (1986) in a study of lovers of people with AIDS found that societal stigma and isolation were experienced in a variety of ways: among friends and family, with those in the health care system, and from organized religion. Themes of stigma, rejection and isolation were also common among biological family members (Geis, Fuller, & Rush, 1986). Giacquinta (1989) noted that stigma often led to "family exile," an isolation of the affected family imposed by distancing of relatives and others.

Presumably, knowing that someone is a caregiver to a person with AIDS conveys messages about the person's private life such as sexual orientation, drug use, and sexual activity. Disclosing one's caregiver status can mean revealing one's own sexual preference to family or co-workers who were unaware that the caregiver was gay or caring for a partner with AIDS. As a result, caregivers reported a variety of ways to selectively disclose or conceal information to others in their lives (Powell-Cope & Brown, 1992). Goffman stated (1963):

The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. 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)

Going Public involved "passing" (Goffman, 1963) because caregivers devised ways to manage the information that they were caring for a family member with AIDS. Specific strategies included: making excuses, lying, withholding information, changing jobs or places of residence, and avoiding certain social situations (such as family gatherings). A common approach to safeguarding the risk of disclosure was exemplified by the process of staging the amount and type of information given (Powell-Cope & Brown, 1992). Initially caregivers may have talked about a sick friend. Later they may have elaborated that the partner or "a friend" had cancer or was dying. Eventually some caregivers chose to share with others the explicit diagnosis of AIDS and the extent of their caregiving roles. Staging usually coincided with the health status of the PWA, that is, as the PWA became sicker the caregiver disclosed more information to a greater number of people.

The management of information is common to other chronic illness situations, yet may reflect different motivations. Managing social interaction by deciding whom to tell, how much, and under what circumstances was found to be a major strategy used by parents of children with chronic illnesses to reduce stressful encounters (Cohen, 1989). While the style of social interaction is similar to that of family caregivers in the Brown and Powell-Cope (1991) study, the motivation was not limited to social stigma but attributed to stress reduction in general.

It is important to emphasize that Going Public was not always dominated by passing and concealing. In discussing chronic illness and stigma, Kleinman (1988) wrote, "The patient may resist the stigmatizing identity, or he may accept it; either way, his world has been radically different" (p. 160). Similarly, those close to the person with AIDS may choose to resist or accept the stigma. A number of caregivers in the Brown and Powell-Cope study attempted to alter the social context of AIDS by becoming activists or publicly vocal about AIDS stigma and discrimination. Many were proud of their association with AIDS and disclosed publicly more often than they concealed information (Powell-Cope & Brown, 1992).

As with changes in role relationships ("Renegotiating the Relationship") and loss ("Living with Loss and Dying"), stigma has been noted in the caregiving literature but is not the focus of research and theory development in general. The importance of stigma in any caregiving situation may be related to the stigma specific to the disease in question. For example, cancer has become increasingly accepted in our culture and may evoke feelings of compassion in others, but mental illness and dementia may evoke feelings of fear and repulsion from others. Birkel and Jones (1989) and Wilson (1989) found that due to the stigma, shame and embarrassment associated with mental illness in general, caregivers of those with dementia were reluctant to seek outside help from common resources.

Containing the Spread of HIV

Containing the Spread of HIV was defined as the fear surrounding the spread of HIV infection and the strategies used to prevent transmission to self and others (Brown & Powell-Cope, 1991). Subdimensions included: 1) confronting fear and personal vulnerability, and 2) doing things differently. Containing the

Spread reflected family caregivers' concerns, fears, and vulnerability associated with their own HIV antibody status, and strategies used to prevent infection in themselves and others.

In addition to the multiple losses inherent in HIV infection and the burden of caregiving tasks, family caregivers are also faced with the added burden of coping with the transmissibility of the virus. Fear of contagion related to HIV has been noted in the general public (Meisenhelder & LaCharite, 1989) and specific groups, such as health care workers (Blumenfield, Smith, Milazzo, Seropian, & Wormser, 1987; Imperato, Feldman, Nayeri, & DeHovitz, 1988; Link, Feingold, Charap, Freeman, & Shelov, 1988; Scherer, Haughey, & Wu, 1989). Therefore, it is not surprising that in our study (Brown & Powell-Cope, 1991) contagion was a concern of family caregivers who were sexual partners of the PWA and who frequently were exposed to body fluids as a result of performing caregiving activities.

Compared to other caregiver groups, concerns about transmissibility are probably unique to caregivers of people with HIV infection. Communicability is not typically an issue in other caregiving situations such as cancer, Alzheimer's Disease and the elderly adult. In the Raveis and Siegel study, 57% of gay caregivers of people with AIDS were somewhat or very worried that they might develop AIDS. While Containing the Spread was not the major concern for most caregivers in the Brown and Powell-Cope study (1990), it was present to some degree in all 53 caregivers interviewed for the study, and reflected the influence of transmissibility of HIV on the caregiving experience.

The manifestation of Containing the Spread was consistent with a transitions perspective of caregiving because caregivers' responses change over

time. Initially caregivers often experienced strong emotions such as fear of contagion or anger at having been exposed to HIV (in the case of partner caregivers). However, with time, education, and support most caregivers worked through initial fear and came to terms with their past exposure (for example, by testing for their HIV antibody status), and sought to prevent current exposure during caregiving activities by seeking education about universal precautions. What may have been a major concern at the beginning of caregiving usually faded into the background against the more pressing problems associated with caregiving.

Summary and Conclusions

In summary, for the purposes of the current study, caregiving during HIV infection is conceptualized as a psychosocial transition involving the caregiver and care recipient. The overall transition is marked by uncertainty and multiple issues including: probable death of the person with AIDS (Living with Loss); changes in the caregiver/care recipient's relationship (Renegotiating the Relationship); managing the illness of HIV infection (Managing and Being Managed by the Illness); disclosing one's association with HIV infection (Going Public); and confronting one's own fear surrounding the communicability of HIV (Containing the Spread of HIV). In this section the similarities and differences of caregiving during HIV infection and caregiving during other illnesses have been highlighted, including the context of stigma in which HIV infection occurs. Finally, because caregiving has been examined almost exclusively from the perspective of the caregiver, more research is needed that addresses the perspective of the care recipient.

CHAPTER III

METHODS

Study Design: Grounded Theory

Grounded theory is an approach to research with the goal of theory development. The theory is meant to explain action in the social context under study (Stern, 1980; Strauss, 1987). In this study, the theory concerns actions of couples in the context of HIV infection. Strauss (1987) described grounded theory as a style of data generation and analysis that includes theoretical sampling, constant comparative analysis, and the use of a coding paradigm to ensure conceptual development and density (Strauss, 1987). Grounded theory is mainly an inductive approach to theory development, yet it also includes elements of deduction and verification (Strauss, 1987).

Grounded theory as a methodological perspective was developed from symbolic interactionism. According to the symbolic interactionism perspective, the research process itself must be conceived as a symbolic process in which the researcher takes the role of those studied in order to understand the world as they do (Bowers, 1988). Grounded theory reflects a belief that there can be no abstract laws of social processes, therefore operationalized definitions are avoided. Instead, abstract concepts are amenable to revision by the ongoing process of researchers in exploring events in the empirical world (Turner, 1986). Blumer's argument for the use of sensitizing concepts reflected his belief in the fluidity of the empirical world, that is, constantly shifting processes of symbolic interaction among various actors in various contexts (Turner, 1986).

In this study, grounded theory was the major method of generating and analyzing data in order to extend a previously developed substantive theory (i.e.,

Transitions Through Uncertainty) and develop a more inclusive theory of AIDS family caregiving by including the perspectives of care recipients. According to Strauss (1987) grounded theory can be used to discover new theories about social situations from previous theories, providing that they, too, were carefully grounded in research. In the current study, a previously developed grounded theory was used to direct collection of new data with the goal of developing a new and more encompassing theory (Strauss, 1987). The use of grounded theory was consistent with the major objective of this study, with specific aims one, two and three of description and exploration, and with the theoretical framework. The secondary objective of the study was met through a sociostructural interpretation of the caregiving experience, explained later in this section.

Sampling

The sample included nine gay persons with HIV infection and their partners. To maximize sampling, both the persons with AIDS and their partners were approached to participant in the study. Persons with HIV infection were initially identified through support groups using study announcement fliers (Appendix A) and from advertisements in a local gay newspaper (Appendix B). Caregivers were identified through caregiving classes, support groups, and advertisements in local gay publication using the same flier. To extend sampling, notices about the study were placed in several newsletters of community AIDS organizations.

Inclusion criteria for those with HIV were that they were: (a) self-identified as gay, (b) diagnosed with Class IV HIV infection (that is, symptomatic HIV infection or AIDS), and (c) able to identify a partner who was willing to be in the study. Inclusion criteria for caregivers were that they were: (a) self-identified as

gay, (b) in a partner relationship with the PWA, (c) a partner of a person diagnosed with Class IV HIV infection, and (d) willing to ask the PWA to be in the study. Participants were reimbursed \$20.00 for each formal interview and \$10.00 for completing one telephone interview.

Theoretical sampling was used to locate informants based on emergent theory (Glaser, 1978) and by theoretically sampling within interviews (Strauss, 1987). The sample was not intended to be representative of a population, but rather serial and contingent upon previously gathered data and ongoing analysis (Lincoln & Guba, 1985). While attempts to locate study participants based on coding and analyses were made, the sample was technically more a convenience sample. To compensate for the problems in theoretically sampling people, diversity among participants was insured by recruiting from as many different community resources as possible. In addition, interviews were guided by theory generation. The questions asked and the probes used during interviews were methods designed to theoretically sample data within interviews, not for selecting participants for the study sample. Snowball sampling, a process by which informants locate potential informants (Biernacki & Waldorf, 1984), was attempted but proved to be of limited value in this study.

Data Gathering Procedures

Protocol

All participants, except for one couple, were interviewed on at least two occasions: one formal in-person interview, and one less formal telephone interview. One couple was lost to follow up and only completed the initial interview. Six couples completed follow-up in-person interviews. When potential participants called the researcher in response to recruitment fliers and study

advertisements and announcements, verbal telephone permission was obtained to schedule the first formal interview (Appendix C). After initial screening to determine study eligibility, participants were asked their preference for the location of the interview. Before the in-person interview began, the researcher explained the study and obtained permission to audio tape-record the interview for subsequent transcription. Informed consent was obtained and confidentiality insured. Participants were assured that specific matters discussed with the researcher would not be revealed to their partner.

Before the interview began, the researcher explained her role. The initial question, "What it is like to be receiving care from [family caregiver] since you've been sick," or "What is it like to be a family caregiver of a person with HIV infection" was chosen depending on whether the interview was with a PWA or caregiver. A conscious effort was made to prevent premature closure on topics relevant to new emergent theory, yet gather data relevant to the existing caregiver theory. New questions evolved as categories were developed during concurrent data analysis. Demographic, health, and functional status data were obtained at the completion of the interview (Appendix D). Health and functional status were used only for descriptive purposes. Specifying the health and functional status of the PWA was useful in delineating the limits of theoretical import and potential applications of the findings. Approximately one month after the formal in-person interview, all participants were asked to engage in an informal telephone interview. The purpose of the telephone interview was to clarify initial interview data, to "check out" provisional hypotheses, and to confirm more definitive conclusions.

On the basis of the telephone interview, six couples were asked to meet with the interviewer again to further discuss their experiences and emergent theory. For example, one couple experienced a major health crisis following the first interview, therefore a second formal interview was indicated. Also, second interviews were used to differentiate the intended from unintended consequences of selected caregiving activities in order to develop the sociostructural analysis. Data from this study comprised more than 50 hours of interview data.

Field notes were recorded immediately after all in-person and telephone interviews were completed to detail descriptions of participant's behavior, conditions of interview context and environment, and any unusual circumstances of the interview. Thus, field notes became another critical source of data.

Participant Observation

Participant observation augmented interview data. It was hoped that as participants came to trust the researcher, they would invite her to accompany them during daily activities (e.g., grocery shopping), social activities (e.g., dinner party), and AIDS-related gatherings (e.g., the annual Candlelight Vigil). Since these informal observation opportunities did not materialize, the researcher used alternative sites for observations that were more public, such as an annual AIDS fund-raising walk, a thrift store managed by an AIDS community service organization, an educational setting informing people with AIDS about new medical treatments, and a public showing of the AIDS quilt. Field notes about observational experiences were recorded as soon as possible after the event and became yet another source of data. Informal interviews (e.g., conversations with actors in their social settings) were conducted during observational sessions.

Instruments

Interview Guide

After the initial global question, an interview guide was used to obtain salient information relevant to study purposes (Appendix E). Some questions focused on specific aspects of the "Transitions Through Uncertainty" or the social context. The interview guide was flexible, thereby allowing the participant to direct the format and pace of the interview. On the basis of ongoing analysis, questions were added to the interview guide.

Health and Functional Status Indicators (Appendix D)

Health was measured by a single item measured on a 6-point scale ranging from excellent to poor. Functional status was measured using the Karnofsky Performance Status Scale (KPS) (Karnofsky & Burchenal, 1949), the Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969), and the Instrumental Activities of Daily Living (IADL) (Lawton & Brody, 1969).

The KPS is an 11-point rating scale ranging from normal functioning (100) to dead (0). The KPS is correlated with other measures of physical functioning (Schrag, Heinrich & Ganz 1984; Yates, Chalmer, & McKengney, 1980), the Katz Activity of Daily Living Index and measures of quality of life and health (Grieco & Long, 1984; Mor, Laliberte, Morris, & Wiemann, 1984) indicating construct validity. Significant correlations were also found between the KPS and length of survival in a group of cancer patients (Mor, et al., 1984) indicating predictive validity. Interrater reliability ranges from .69 to .97 (Grieco & Long, 1984; Mor, Laliberte, Morris, & Wiemann, 1984; Schrag, Heinrich & Ganz; Yates, Chalmer, & McKengney, 1980).

The PSMS (Lawton & Brody, 1969) consists of six 5-point scales ranging from total independence to total dependence using Guttman scaling methods. Toileting, feeding, dressing, grooming, walking, and bathing are assessed with the PSMS. Validity has been demonstrated with significant correlations between the PSMS, other functional measures, and the IADL. Interrater reliability was reported ranging from .87 to .91 (Lawton & Brody, 1969).

The IADL is a 5-item scale measuring ability to use the telephone, shop, use transportation, take one's medications, and handle financial matters. Interrater reliability was reported as .85. Validity was demonstrated by its correlation to other measures of physical functioning and the PSMS (Lawton & Brody, 1969).

The Use of Self in Interviewing and Participant Observation

The quality and outcome of qualitative interviews and participant observation were dependent on the researcher's use of self. According to the naturalistic paradigm the researcher and the one researched are inseparable. According to Lincoln and Guba (1985, p. 94), "The inquirer and the 'object' of inquiry interact to influence one another; knower and known are inseparable." From a symbolic interactionism perspective, the research process itself is a form of social interaction. Who the researcher is and how she presents herself will affect the type and quality of data obtained. Therefore, the following discussion includes reflections about who I was going into this study, how who I was may have influenced data obtained, and strategies used to overcome these limitations.

First and foremost, I was a straight woman and nurse attempting to discover how gay men receive and give care in the instance of HIV infection. Encountering a straight woman interviewing gay men, there might have been a tendency for participants to selectively share information with me and to screen their

conversations. Some may have attempted to please me or to limit revelations to what they thought I could "handle," or to avoid offending me. Alternatively, participants might have chosen candor in discussing their experiences to "check me out," insure my sincerity, and test my level of acceptance. Although in many ways I did not share their social circumstances, I entered into this study with extensive experience that proved to be an asset in interviewing gay men. Specifically, three aspects of my prior experiences were helpful in conducting the current study.

First, before embarking on the previous study (Brown & Powell-Cope, 1991), I was encouraged by consultants to think about my values and attitudes towards homosexuality. I accomplished this through extensive reading, discussions with gay and lesbian colleagues and friends, and personal reflection. This reflection proved crucial because it helped me to work through preconceptions and strive for acceptance by those with lifestyles different from my own. Reflection was also critical in helping me to examine and alter my language concerning AIDS and homosexuality. In interviewing gay men with AIDS my language has become more consistent with that of my population of interest and based less on professional terminology.

Second, I came to this study with prior and relevant interviewing experience. As part of the AIDS caregiver study (Brown & Powell-Cope, 1991) I conducted in-depth interviews with 6 gay caregivers of people with AIDS. As part of another study, I completed structured interviews with 31 gay men with AIDS. The success of these interviews may have lent me credibility with participants and among the gay community that straight women otherwise might not have, based on their different sexual orientation.

Third, I had been active in AIDS-related work since 1983. My long record of community and professional activities helped to establish my credibility and my commitment to working with people with AIDS and their significant others. During other research endeavors, I worked with people in the community agencies which facilitated study recruitment efforts. I hoped that my long record of commitment to working with people with AIDS and my success in navigating the AIDS community would outweigh any initial skepticism participants may have felt because of my professional status and lifestyle orientation. During interviews, demonstrating my acceptance of and openness about my biases continued to foster open discussions with study participants. Historically health professionals and institutionalized medical care have not been perceived as sympathetic to gay issues. Participants' distrust and skepticism of me as a nurse was a factor I anticipated; instead I found all participants regarded nurses and the nursing profession in a positive light.

Although I did not expect major problems during interviews, I strove to remain sensitive to my gender, sexual orientation, and professional status. As part of data analysis, I attempted to explore the effect of these characteristics on the type and quality of data gathered by keeping a journal of my feelings and experiences. I expect to be "checked out" by participants for sincerity, non-judgmental attitudes, and trustworthiness. Retaining these characteristics was crucial as I conducted the extensive interviews and data analysis.

Personal Journal

As part of the ongoing process of data collection and analysis, a journal was kept to record personal reactions, problems, mistakes and feelings that arose during the research. Spradley (1979, p. 76) noted that "making an introspective

record of field work enables a person to take into account personal biases and feelings, to understanding their influence on the research." In particular, a journal was important in accounting for my personal feelings about homosexuality, AIDS, gay coupling, death and dying, and chronic illness and their effects on the research process and outcomes. During analysis the journal became another data source. In addition, debriefing with my supervisory chair and a colleague facilitated my goal of achieving integrity as an AIDS researcher.

Protection of Human Subjects

This research was approved by the University of Washington Institutional Review Board of Human Subjects. Upon entry into the study, the researcher reviewed the informed consent form with participants (Appendix F) and obtained their written consent. Participants were given the option of withholding identifying information to secure their anonymity. Because people with AIDS constitute a vulnerable population, special care was taken to negotiate consent throughout the research process. Before conducting the telephone and second interviews, the researcher reviewed major principles of the informed consent with the study participant.

Data were handled to ensure confidentiality. Code numbers were used to identify audio tapes, transcripts, field notes, and memos. A master list of codes and participant names, phone numbers, and addresses were kept in a locked file. The importance of confidentiality was discussed with transcriptionists and their verbal cooperation was obtained. The master list and audio tapes were destroyed upon completion of the study. Individual participants were not identified in the write-up of the study. Because of the population, special care was taken when contacting participants by phone so that confidentiality was protected. For

example, messages were not left on answering machines unless permission was given by the participant. Because both partners were interviewed, each participant was assured that nothing he said to the researcher would be revealed to his partner. Interviews were conducted in private unless requested otherwise by the participant. One couple requested to be interviewed together.

It is believed that participants benefited from this study because they were given the opportunity to discuss personal matters in a confidential and comfortable setting. However, there was a risk that respondents could feel anxious or upset in response to discussing personal and emotional issues. During the few times that participants became visibly agitated during interviews, they were given the option of continuing, continuing after a break, or terminating the interview. In addition, the researcher was prepared to make referrals to community services if indicated. Only one interview was prematurely terminated at the participant's request. This PWA was very ill at the time and felt that he was too fatigued to continue. The interview was completed at a later date. All participants were extremely knowledgeable about community resources and no referrals were made.

Data Analysis

The first goal of analysis was to extend a substantive theory of caregiving in the instance of HIV infection (Major study objective). This was accomplished by comparing and contrasting experiences of PWAs and family caregivers (Study aims 1 and 2), and by attending to the contexts of caregiving (Study aim 3). The secondary study objective was met by conducting a social structural analysis of data.

Constant Comparative Analysis

Interviews were transcribed as soon after they were conducted as possible. Analysis began immediately following transcription. Analysis occurred concurrently with data gathering and further sampling. Coding of data was achieved through constant comparative analysis (Glaser & Strauss, 1971). As categories were identified, they were compared to categories previously identified from the Brown and Powell-Cope (1990) study, other tentative categories and other pieces of data, as well as subsequent interview data. Because extant grounded theory was used to partially guide data analysis, the researcher attempted to remain sensitive to new data and new coding. Intra-informant comparisons were made from time one to subsequent interviews, and inter-informant comparisons were made between informants.

Hutchinson (1986) described three levels of coding in grounded theory. Level one codes (also called in vivo or substantive codes) are words that closely match the data that describe the basic action in the setting. Level one codes are representations that are grounded in the data, "break the data into small pieces" (Hutchinson, 1986, p. 120), and are useful in retrieving exemplar quotes from the data. Examples of level one codes that arose from transcripts in the proposed study included sex (sexual relationship between the PWA and partner) and depend (issues of dependency and independence with the relationship). As described by Swanson-Kauffman (1986), the computer program, The Ethnograph (Seidel, Kjolseth, & Seymour, 1988) was used for level one coding. This program provided a convenient method of sorting and retrieving data.

After level one coding, transcripts were read again and analyzed for level two codes, or categories reflecting meanings of caregiving. Coding at this stage

was more conceptual in nature, and included raising questions and yielding provisional hypotheses about categories and their relationships (Strauss, 1987). For example, sex and depend were grouped together into a category called relationship characteristics. As categories were named, they were examined for linkages, particularly keeping in mind the couple as the unit of analysis. This is level three of coding, in which theoretical constructs were derived from a combination of academic and clinical knowledge (Hutchinson, 1986). For example, telling others about HIV infection was viewed as a means of protecting the boundaries of the relationship. A core category was sought that served to "hold together" lower level concepts (Strauss, 1987). During coding at all levels, questioning of data and hypotheses generation were guided by asking certain questions of the data and emerging categories. For example, the emergent category of mutual protection was examined for possible causes, contexts, contingencies, consequences, and conditions (Glaser, 1978). The final coding paradigm consisted of 172 first level codes that were collapsed into 5 major second level codes. The 5 major second level codes included: social conditions, health and illness, primary relationship, social network, and philosophy of life. Third level codes provided the organization of the substantive grounded theory.

Theoretic memos were compiled as insights and conceptual linkages occurred. From time to time, theoretic memos were sorted, compared and contrasted. The process became more focused as the study progressed, and saturation was approached (Strauss, 1987). Saturation occurs "when additional analysis no longer contributes to discovering anything new about a category" (Strauss, 1987, p. 21). Methodological memos were recorded on an ongoing basis in a notebook, separate from data. Methodological memos included concerns

regarding data collection and analysis, procedures, and ideas for changes in protocol (Catanzaro, 1988).

Validity and reliability were addressed in several ways consistent with the grounded theory approach. Validity was addressed by using the following three approaches: constant comparative analysis (Atwood & Hinds, 1986), literature review (Atwood & Hinds, 1986), and experts (Swanson-Kauffman, 1986). Validity was built into the constant comparative process because data as collected guided the conceptual development of category definitions, as well as relationships among categories (Atwood & Hinds, 1986). Concurrent literature review as data collection progressed served into give insight to conceptual definitions and relationships (Atwood & Hinds, 1986). Themes were compared to those already described in the literature. Content validity was addressed by asking participants to evaluate the extent to which emerging themes were relevant to their experience. Validity also was addressed through informal discussions with couples who had had similar experiences but were not in the study, and by presenting preliminary findings and receiving validating feedback from expert nurses and nurse researchers who work with people with HIV infection and their families. They were asked to determine how closely study findings reflected their own experiences, and how well the categories captured their own experiences (Swanson-Kauffman, 1986).

Interrater reliability was assessed by defining criteria for submission of data into each category, and by asking two nurses, one an expert in grounded theory and one an expert in grounded theory and psychosocial responses of families to HIV infection, to review and code portions of transcripts. Interrater reliability with the former expert for the coding of first and second level codes was 72%, and

100% for second level codes alone. Discrepancies in coding were resolved by clarifying definitions of codes and by slightly modifying the coding paradigm. Final refinement of categories was achieved through consensus. Internal consistency of categories was indicated by the high level of agreement between the researcher's and experts' assessments.

Threats to reliability and validity and methods to control threats in qualitative research were summarized by Woods and Catanzaro (1988, p. 136). The table found in Appendix G are derived from their presentation and summarize approaches that were used in this study.

Secondary Objective: Structural Analysis

The second goal of analysis was to examine couples' experiences in light of salient social dimensions that became apparent during the study (Secondary study objective). Giddens's theoretical perspective was used to: (a) identify sociostructural conditions that facilitated and constrained the experiences of couples coping with HIV infection, and (b) articulate the dynamics between interpersonal experiences and these sociostructural conditions, e.g., how did caregivers and PWAs maintain and/or attempt to change constraining and enabling social conditions?

Giddens's (1987) concept of "structuration" provided the basis for this portion of the analysis. Social structures were actually properties that existed because study participants were able to use rules of social interaction and resources. The goal of this portion of analysis was to elucidate the relationships between a phenomenological understanding of HIV infection and the maintenance or alteration of social structures, or the duality of couples' experiences of HIV infection and salient social structures.

In this second goal of analysis, then, the experience of couples was "situated" in its social context by elucidating the constraints under which couples knowingly and unknowingly operated and by explicating power relationships. According to Thompson (1987) the goal of a critical scholar is to expose power relationships since they lose some of their power once they become visible. Giddens (1982) proposed that all social theory is inherently critical because social actors have the ability to change theory, and therefore their realities, once they become aware of it. For example, the experiences of study couples was situated within a society in which heterosexism pervades. Heterosexism is an ideology that limited alternatives for action of gay men, and contributed to AIDS-related stigma. Those family members who chose not to "go public" as a person involved in AIDS care were perpetuating heterosexism and the stigma and fear associated with AIDS. On the other hand, those who "went public" risked tremendous negative personal consequences but also acted to demystify the illness, thereby decreasing AIDS stigma and limiting the constraining effects of heterosexism.

Validity of the structural portion of analysis rests on the strengths of arguments posed. The strengths of arguments are based on how well they are substantiated by study data, the historical context discussed, warrants (or hypothetical statements based on relevant social theory), and backings (categorical statements of fact, or further data to support conclusions). In other words, validity rest on the logical coherence of arguments posed (Toulmin, 1958).

In conclusion, gay couples' experiences of HIV infection were explored using grounded theory and a sociostructural interpretation. Ultimately, results of this study could enhance the provision of care to people living with this devastating illness by identifying and articulating important issues for those

involved. These issues could serve as a basis for nursing therapeutics targeted at the level of individual responses. Elucidation of the sociostructural dimensions of the situation could ultimately indicate foci for nursing therapeutics targeted toward creating supportive environments for those affected by HIV infection.

CHAPTER IV

RESULTS

The purpose of this chapter is to summarize results of the study. The first section is a description of the sample including demographic information and functional health. The second section provides a description of the grounded theory derived from study data, *Becoming a Couple Affected by HIV Infection*. The grounded theory fulfills the major objective of the study (aims one, two, and three). The secondary objective is achieved in the third section through an analysis of heterosexism as a dimension of the social context that influences couples, and is influenced by couples' activities.

Description of the Sample

Demographic, health, and functional status data for the sample were obtained from the demographic information form (Appendix D). Self perceptions of study participants were obtained from interview data in response to questions about family, caregiving, and care receiving, some of which were not on the original interview guide (Appendix C). For example, the question "How do you define family?" was added to the interview guide based on analysis of early interviews.

Demographic Characteristics

Demographic characteristics are summarized in Table 1. While the study sample was not meant to be representative of all gay men with HIV infection and their partners, the demographic information does highlight the diversity of the sample. Selected sample characteristics will be compared to state and national statistics in order to place description of the sample in a larger context, not for the purpose of statistical comparison or evaluation of the sample's representativeness.

Table 1
Demographic Characteristics of Persons with HIV Infection (n=9) and Their Partners (n=9) (Presented as frequencies unless noted otherwise)

	Person with HIV Infection	Partner of PWA
Age range (years)	26 - 47	25 - 43
Ethnicity		
Caucasian	7	7
Afro-American	2	1
Hispanic	--	1
Education		
Less than high school	2	0
At least high school	2	2
Some/completed college	5	7
Employment		
Full-time	2	5
Part-time	0	1
Unemployed	7	3
Length of HIV infection (years)	M = 2.9 Range = .75 to 9	Not available
Length of Symptomatic HIV Infection (years)	M = 1.6 Range = .5 to 4	None symptomatic

Individual Characteristics

The sample consisted of 9 couples in which at least one person was diagnosed with Class IV HIV infection, that is, symptomatic HIV infection or AIDS. The age of study participants, 25 to 47 years, reflected the distribution of AIDS infection in Washington State and nationwide. Statewide, approximately 85% of people with AIDS are between the ages of 20 and 50 years. In the United States, 62% of men with AIDS are between 20 and 50 years of age (DHHS, 1992). As a group, PWAs were similar in age to partners (mean of 36.2 compared to mean of 35.4). All couples' ages, except for two, were within five years of each other. One 47-year-old PWA was partnered with a 28-year-old, and one 26-year-old PWA was partnered with a 39-year-old.

Fourteen study participants were White, three were Black, and one was Hispanic. The ethnic makeup of the sample, too, reflected the racial distribution of AIDS in Washington State and nationwide, with approximately 90% of cases in gay men statewide occurring among White individuals. Nationwide, 80% of gay men with AIDS are White (DHHS, 1992).

As shown in Table 1, the economic status of study participants, based on reports of the family's gross income, ranged from less than \$10,000 per year to over \$50,000, thus reflecting a diversity of financial status. The ethnic and economic distribution of this sample was important because experiences of discrimination and perceptions of social inequality based on race and economic class influenced perspectives of AIDS-related stigma and discrimination. One PWA, who described his ethnicity as American (he lined through the "Afro" prefix on the demographic form), commented on his perspective by contrasting his experiences with non-Black PWAs. Also, this PWA's partner, who was White,

acknowledged that he had learned first-hand about prejudice since he became coupled with his partner because of the PWA's ethnicity. In the following discussion, the PWA contrasted the relationship between the visibility (such as the color of one's skin) or invisibility (such as a diagnosis of HIV infection) of a stigma symbol and the experience of discrimination:

PWA: I need to check them [the support group for people of color] out, just to get a sense of brotherhood. Because to me the vast differences in the races that exist, affect how you see things and how I see things.

Interviewer: How is your experience of AIDS different because you're black as opposed to somebody who's white?

PWA: Discrimination. I'm more conditioned to the discrimination than they are. With the AIDS...my closest friends, my closest associates, don't know, because it's none of their business.

Interviewer: They don't know...

PWA: - that I have AIDS because it's none of their business. Period. Bottom line on that is that it's none of their business - and this came up in the [support] group yesterday...Why should I make a public announcement, why should I wear a T-shirt around in public and proclaim my illness? I don't have to do that. I'm already doing that with the color of my skin. And that discrimination - discrimination is discrimination, no matter what it is.

Interviewer: But you can't hide the color of your skin.

PWA: Right. So I don't need to add [the stigma of AIDS]. "Oh, he's contagious, he's got a rotten log to the stigma that I already carry."

Interviewer: Do you think the experience of AIDS is different for you than for somebody who's white and has never experienced the stigma of color?

PWA: Yeah. It has to be...the people in the group when they talk about the discrimination they get when they walk up to a nurse or when they hear the whispers and being talked about behind your back, when they think you're not there, it hurts them. You can see it, you can hear it in their voice, and

they don't know what to do about it. They don't understand it. They can't comprehend that that's what discrimination is. I brought this up at the group a while back, and a lot of them had to stop and think about it, and it took them a long time to think about it, but I was correct. They were discriminated against in the past...they have discriminated against people and for that to finally come and roost, as we say, for it to come home for them, to know that they made a mistake, it's great, it's wonderful. You see, I try not to discriminate against anybody. I try to accept people for who they are and who they'll be, and to give everybody the benefit of the doubt, and everybody is my best friend when we first meet...Do me wrong and I'm going to let you know you did me wrong and I'm going to say something about it...

Interviewer: So is what you're saying that you know how to handle the discrimination better?

PWA: Yeah.

In interpreting the results of this study, it is important to keep in mind that not all gay men are alike. Experiences of gay men are as diverse as experiences of heterosexual men and are influenced by other factors such as ethnicity, economic class, and gender. For example, one PWA, a professional white man who was partnered with a full-time worker and reported an income of \$20,000 to \$30,000 per year, acknowledged his privileged economic and social position:

I don't consider myself lucky to have AIDS, but I'm one of the luckiest ones around. I've had extremely good emotional support, my health care has been first class...I cannot complain about my health care. And financially, we're doing okay. I have my Social Security, plus I had a long term disability insurance plan so that makes up. So all in all I'm getting realistically about 60% of my salary. And I just, here in the last couple weeks, I've gotten some guarantees from my company that if my insurance runs out, that they'll pay the bills. What more can you ask for?

In contrast, two other couples lived in public housing and relied on food stamps, Medicaid, and Social Security disability. Another couple who did not live in public housing was on the verge of being evicted due to their inability to pay rent.

Worries about housing and purchasing food were stressors that more affluent couples did not share with financially insecure couples.

The sample was relatively well educated, with 12 having completed at least some or all of college. Not surprisingly, 7 of the 9 persons with HIV infection were not employed as a result of disability from HIV infection. Two were still able to continue full-time employment, because neither had yet experienced major disability, although they were classified as having Class IV infection. Although 6 of the partners were employed full or part-time, 3 were not employed at all. One had recently quit his job to care for his partner full-time. Another recently quit his job because he was HIV-positive and he feared that his stressful job would contribute to his becoming symptomatic. The third stayed home to care for his partner, although the PWA remained employed full-time.

As expected, the mean length of HIV infection was longer than the mean length of symptomatic HIV infection. The mean length of HIV infection represented the period of time the person was aware of the HIV antibody positive status, not the absolute time from seroconversion. Most people in this study knew of his HIV-positive status before the PWA became ill, although there were a few cases in which the PWA discovered his antibody status at the same time he became sick. For example, one man was suspicious of his positive status based on his sexual history, but it was not confirmed until he was hospitalized with a serious episode of *Pneumocystis carinii* pneumonia.

The PWA's source of HIV infection was not asked on the demographic form. From my clinical experiences, I knew that many people with HIV infection feel that the mode of transmission is a private concern. Therefore I did not want to intrude on study participants' privacy, but waited for the opportunity to research

their backgrounds in the context of the in-depth interview after establishing rapport. Given the opportunity, all PWAs and HIV-positive partners discussed past risk behaviors and their beliefs about how they became infected with HIV. All HIV-positive participants, except one, attributed infection to sexual contact. The participant who did not attribute his acquiring HIV infection to sexual contact had a history of intravenous drug use. He believed that he had probably contracted HIV infection through sharing needles with an HIV-infected individual.

Couple Characteristics

The length of friendship with one another, and of the relationship as a couple ranged from 1 to 7 years in all cases (Table 2). The majority of couples in this sample became a couple shortly after meeting one another and all participants lived with their partners in shared households. According to McWhirter and Mattison (1984), gay men who couple tend to set up homes together in the second year of their relationships. As do many gay men (Berger, 1990), men in this study often referred to moving in together as an important marker signifying the beginning of their relationship as a couple and their commitment to one another.

In a frequently cited study of gay couples, McWhirter and Mattison (1984) developed a staged theory of relationships, each stage entailing specific developmental tasks. According to their typology, couples in this study represented those in stages 1 through 4.

Many of the issues discussed by study participants reflected those which characterize the first four stages of gay relationships. In stage 1, Blending, each individual focuses on merging together to form a new identity as a couple. Romantic love and sexual expression are high during this time. Stage 2, or Nesting, is focused on setting up a household together, finding compatibility with

one another, and a decline in romantic love combined with some ambivalence toward the relationship. In stage 3, Maintaining, couples are mainly concerned with each partner expressing himself as an individual, taking risks, dealing with conflict and establishing traditions. Finally, stage 4 or Building, is characterized by increased collaboration, increased tangible and intangible productivity, establishing independence, and learning to view each other as dependable. It is also interesting to note that some of the issues in the later stages, such as shifting perspectives as a result of aging or declining health, restoring the partnership, and remembering past experiences together, were also frequently discussed by study participants. These issues, usually faced by aging couples, were "forced" onto gay couples affected by HIV infection, thereby reinforcing the idea that they must undergo a transition out of sequence with the expected time line of their lives. Finally, the HIV status of the couple was important and was discussed by all study participants. Five couples were "mixed couples" and 4 were "two positive couples." Although a question about the partner's HIV status was not included on the demographic form, and these data were compiled from interview data, this information is included in this section since the partner's HIV antibody status was an important influence on each couple's experiences. For example, in "mixed couples" the PWA often suffered tremendous worry and guilt about possibly infecting his partner. In contrast, some partners in "two positive couples" worried about whether or not the PWA's illness forecasted his own fate, a factor that often resulted in anxiety or depression.

Table 2

Demographic Characteristics of Couples (n=9) (Presented as frequencies unless noted otherwise)

Length of Friendship (years)	M = 4.0 Range = 1 - 7
Length of Couple Status (years)	M = 3.7 Range = 1 - 7
Family Income (\$)*	
Less than 10,000	3
10,000 to 20,000	3
20,000 to 30,000	7
30,000 to 40,000	0
40,000 to 50,000	1
More than 50,000	3
Missing	1
HIV status	
PWA positive/Partner negative	5
PWA positive/Partner positive	4

* Each individual was asked to rate the family income, therefore each individual's perception is reflected in the frequency distribution.

Health and Functional Status

Illustrating the health status of PWAs is useful in that it more fully tells the story of what life is like for couples affected by HIV infection. Many of the activities involved in being a couple affected by HIV infection are dependent upon the PWA's health at any given moment. As with interpreting demographic information, the interpretation of health and functional status of the sample is cited only for descriptive purposes because of the small sample size and the methodology of the study. A description of health indicators is included for illustrative purposes and for uncovering trends in the data.

It is important to keep in mind that HIV infection is a disease often characterized by exacerbation of symptoms, acute crises, and periods of stable health. In general, analysis of health measures indicates that most couples were interviewed during periods of relatively good health. As shown in Table 3, 6 persons with HIV infection rated their overall health as excellent, very good, or good, and 4 partners gave PWAs similar ratings. The PWAs' health was rated fair by 3 PWAs and 5 partners, and poor by no one. Both PWAs and partners tended to rate physical performance status of the PWA similarly, with Karnofsky means of 70 and 71, physical self-maintenance 7.6 and 7.2, and instrumental activities of daily living 6.0 and 6.1 respectively. Examining means, however, may not adequately reflect the experiences of any one couple. For example, in one couple the partner perceived the PWA in poorer health and more dependent on 3 of the 4 measures of health and functional status than was perceived by the PWA. In another couple the pattern was reversed, with the partner rating health, physical functioning, and independence higher than the PWA's self-rating.

Table 3

Health and Functional Status of Person with AIDS as Perceived by PWA and by Partner

	<u>Current Study</u>		<u>AIDS Family Caregiver Study</u> (Brown & Powell-Cope, 1991)
	Rating by PWA	Rating by Partner	
Global Rating of Health			Data not obtained
Excellent	1	0	
Very Good	2	2	
Good	3	2	
Fair	3	5	
Poor	--	--	
Karnofsky Performance Status			
Self care with minor assistance	2	3	
Carries out normal activities with effort	2	1	
Unable to carry on normal activities	2	--	
Requires occasional assistance	1	4	
Requires considerable assistance	1	1	
Disabled, requires special assistance	1	--	
Mean Karnofsky Rating	70	71	62
Physical Self Maintenance (PSMS)	7.6	7.2	10.1
Instrumental Activities of Daily Living (IADL)	6.0	6.1	4.7

In the former couple, one major interpersonal problem identified by the partner was the PWA's denial of his illness. Consequently, the PWA felt that the partner worried excessively and unnecessarily. In the latter couple, the partner had just quit his job to care for his partner full-time and was just beginning to come to terms with the seriousness of the PWA's illness. The PWA acknowledged his partner's inevitable death from HIV infection and reported an acceptance of his terminal situation. This PWA died two months after his interview.

In illuminating the health and functional status of this sample, it is helpful to compare and contrast reports of physical functioning and levels of dependence and independence with those reported in other studies. As shown in Table 3, data from the Brown and Powell-Cope AIDS family caregiver study (1991) indicate that, as rated by partners, the current sample of PWAs was rated slightly more functional (mean Karnofsky 71.5 compared to 62, respectively) and engaged in more self care activities (PSMS 7.2 compared to 10.1 and IADL 6.1 compared to 4.7, respectively) than the sample from the AIDS caregiver study (Brown & Powell-Cope, 1991).

The Grounded Theory: Becoming a Couple Affected by HIV Infection

The grounded theory derived from this study was designated "Becoming a Couple Affected by HIV Infection." "Becoming" was chosen because it reflected the processual and time-dependent nature of study participants' experiences. This process orientation will be further discussed in the section on transition. The term "couple" was significant because the theory emphasizes critical experiences of the couple and activities of each individual as they are related to the shared experiences within a coupled relationship. More will be said about couples in the section on commitment.

Finally, the term "HIV infection" was deliberately chosen based on study data. While AIDS may be a useful term for case reporting or other purposes, it did not reflect the range of HIV infection from initial exposure to HIV, asymptomatic infection, and symptomatic infection. HIV infection replaced AIDS in early conceptualization of the study because it more accurately represented the spectrum of illness rather than an end point of a terminal condition. The distinction between chronic and terminal illness was very important for the couples. The importance of this distinction will become clear in the results section describing the process of "Moving On." In presenting data the term "PWA," person with AIDS, was retained for ease in discussion, and because it was an accepted term among study participants.

The overall model of Becoming a Couple with HIV Infection is presented in Figure 1. The grounded theory consists of one basic social psychological condition, Loss, and three processes and categories: Hitting Home, Mutual Protection, and Moving On. A discussion of transitions, commitment and loss will be presented, followed by a discussion of the processes, subcategories and strategies. Results will be concluded by a discussion of heterosexism, a social structural condition that is implicit in the experiences of gay couples as they cope with HIV infection.

Becoming - A Transitions Perspective

In the AIDS caregiver study (Brown & Powell-Cope, 1991) caregiving was conceptualized as a major life transition based on Parkes's (1971) work and defined as a major change in life circumstances accompanied by uncertainty, questioning one's basic assumptions, and reexamining plans for living in the world. Based on data from the current study, "transitions" was also useful in describing

the experiences of couples who were faced with HIV infection. According to Chick and Meleis (1986) events that precipitate life transitions include: pregnancy, illness, recovery, death, loss, migration, and retirement. Data from this study suggested that the gay couple's experiences of the illness of HIV infection and the multiple losses incurred were the precursors to, as well as recurrent themes in, the transition of "Becoming a Couple Affected by HIV Infection." In this section the nature of this transition will be explored.

Social/Psychological Condition	Processes	Subcategories and strategies
Multiple Losses	Hitting Home	<ul style="list-style-type: none"> • Awareness of risk • Mounting symptoms • Being tested • Pronouncement of diagnosis
	Mutual Protection	<ul style="list-style-type: none"> • Awareness: Overt/Covert • Maintaining, restoring, protecting, and preserving: <ul style="list-style-type: none"> • Physical and Emotional Health • Relationship Boundaries • Independence • Intimacy
	Moving On	<ul style="list-style-type: none"> • New world view • Surviving HIV infection • Succumbing to HIV infection

Figure 1. A Grounded Theory of Becoming a Couple Affected by HIV Infection

Becoming a couple affected by HIV infection represented a major life transition for those involved. HIV infection was a pervasive presence in the lives of both PWAs and partners. The pervasiveness of HIV infection never relented. It permeated every aspect of their lives, from their primary relationship to their views of themselves and of the world around them. One partner explained the omnipresence of HIV infection as follows:

You never know...things are going real fine and then all of a sudden Kurt wants to go to the doctor and I'll think, well, you know, maybe he'll go in again because he feels this way or feels that way, so it's just this non-stop thing. It's always some kind of problem, big or small, it's always something...seems to be either my family or his family, his health, are the food stamps going to be on time, is the next coupon going to be there, and the doctor appointments - it's just a non-stop thing.

Living with symptomatic HIV infection was evidently an experience characterized by exacerbations and remissions. Between episodes of life-threatening events (such as *Pneumocystis carinii* pneumonia) there were periods of well-being or a trajectory of chronic debilitation. A topographical metaphor became useful to describe the experience of becoming a couple affected by HIV infection. Terrain, or the configuration of land, is marked by peaks and valleys. Similarly, couples' responses to HIV infection was often a series of ups and downs mirroring the disease course. The terrain of becoming a couple affected by HIV infection, then, represented individual responses to HIV infection, not objective markers of the disease course.

Most study participants felt that transition was an accurate way of describing their experiences as a couple in light of HIV infection. Consider the following excerpt from an interview with a partner of a man who had been very sick, off and on, for the past year and a half:

Interviewer: Do you think that it might be helpful to talk about AIDS as a transition for couples?

Partner: Oh, I think that decidedly so (laughs). I mean, it has such a dramatic impact on your life. I think decidedly so....I don't think anyone can live through this type of experience and come out the other end and view life exactly like they did before. [pause] And I don't...particularly if there's any level of personal involvement with the individual.

As this partner explained, the intense personal involvement of being a partner of a man with HIV infection was a critical antecedent to undergoing the major changes inherent in this transitional experience. The following study participant more clearly articulated the relational impact of HIV infection:

Interviewer: Do you think AIDS and dealing with AIDS could be thought of as a transition?

Partner: Well, of course. I mean, I think it is more transitional, or changes a relationship more than losing a job, that's for sure....In our relationship we are very committed to each other. And imagine a heterosexual couple, one of them dealing with cancer. It would change the relationship, and that's what it has done in our relationship. It really has made us stronger as a couple, but then there are all those other things that go along with it. All these other frustrating things. From him being the soul of, the powerhouse of home, and me being the breadwinner, to now me being the powerhouse of home, and him being the person that's being taken care of...Not once has it ever made us not love each other or want to leave the relationship. I don't think that it has with me, anyway. Sexually I'm very frustrated, but - oh, well. There's not really much I can do about it.

Because transitional experiences are dependent on one's perceptions, not all PWAs and their partners, however, explicitly described their experiences as major life transitions. Much has been written about denial as a response to HIV infection. Based on data from this study, those in denial could be said to have not faced the reality that HIV infection is a reality in their lives. This topic will be further discussed in the loss section.

Alternatively, the concept of transition is admittedly an abstract one. In general, lay people tend to express their experiences, desires, and feelings in more concrete terms than do social scientists. Therefore, transition may not be a part of their everyday thinking and language. For example, instead of saying that "I have a different world view as a result of HIV infection," study participants were more likely to express how they had changed as a person as a result of HIV infection. Study participants described themselves as more present-oriented, more aware of their mortality. The following partner explained that his newfound sense of personal empowerment derived from his involvement with HIV infection:

Interviewer: Do you think AIDS has changed - made you, well, do you think you're a changed person because of AIDS?

Partner: Definitely.

Interviewer: And what would some of those things be? How do you think you're different?

Partner: I used to consider myself a boy and now I consider myself a man. I really felt that I was still this boy, learning how to cope and live with life. And now, I've already gone through what most people will never experience, and that's their partner having a terminal illness and eventually - I mean, I assume eventually going to die. I've already experienced that, so I've actually got more power than most people.....And yeah, AIDS has really changed me -- REALLY. I certainly won't put up with anybody telling me how I feel. They know what I'm going through, because I used to - I would just sit there and agree and agree to a lot of, and just shake my head - not agree, but just nod my head in approval. And not anymore. I mean, God dang, if I disagree with them, I tell them right then and there. And that didn't happen a lot before....I've grown 100 times over.

Conceptually, and reflecting the experiences of study participants, the transition of becoming a couple affected by HIV infection was not a linear process; it was not easily described by sequential stages or phases. While there

were a clear beginning and end, which will be described in the section on loss, in between, the recurring themes of loss and organization/disorganization were common. For example, participants described instances of "revisiting the same issue" each time a similar health crisis occurred. Moreover, they felt increasingly skillful in coping with the challenges presented in each "revisited" situation.

Reflecting on his experiences over the past year, one partner described the iterative process of coping with HIV infection as follows:

Interviewer: Do you think people go through stages or phases after the diagnosis of AIDS?

Partner: Oh, yea, oh yea...Denial is a big one [stage]. Anger is a big one. I don't want to say acceptance. I hate that word, I can't really say you can ever accept this, but deal with it. In some sense that's a sense of acceptance. And I think that you repeat those cycles too, in various stages, and it's not like one day I'm doing denial today, and then I'm done with it. It doesn't work like that. It's like peeling an onion. You go through each layer and you have this same structure again. You gotta go through denial in this phase, and acceptance and anger, and cooperation, bargaining and all that stuff comes out. But yeah, you do that, and you do it again and again and again.

Interviewer: Do you think that there is one thing or type of thing in particular that prompts you to go through the same reactions, to peel off another layer of the onion?

Partner: Yes. It is milestones...And maybe not so much for him [my partner], but certainly other people that I've known, too, and how their relationships, interpersonal relationships are going, too. Their lover leaves, or they find somebody and they want to start a new relationship. All of them, the biggies in life, trigger these reactions.

In between the peaks and valleys of living with HIV infection, study participants described plateaus, or relatively long periods of wellness during which "life went on as usual," times during which the couple could act as if HIV

infection were not in their lives. Study participants described feeling relieved and grateful that life could assume a more normal quality. During plateaus both PWAs and their partners tried to maintain a sense of normalcy as they tried to get on with their lives without HIV infection as the sole focus. Couples attempted to maintain normalcy by focusing on each other and on their relationship during times of better health as expressed by the following partner:

Since he's been off of AZT and DDI he's been doing much better health-wise and he feels much better and his energy level is better, and he just - psychologically and emotionally he's been better. So that's been kind of nice, and - not this last weekend but the weekend before we took a trip out to Orcas Island. It was nice....the tourists were all basically gone and it was quiet and we stayed in just this funky cabin and took the dogs, and it just was really a nice time. We just had a genuinely nice relaxing time. Didn't do anything exciting, but it was just nice. So I think that our relationship has been better just from the standpoint that he's felt a lot better.

The unfairness of HIV infection was a very common theme throughout interviews, a contextual feature that distinguished this transition from others and a feature that complicated coping efforts. HIV infection, and therefore the accompanying life transition, was viewed as unwelcome and unjust because of the young age of each partner in the couple. The belief that chronic life-threatening illness should not happen to young people was expressed by many study participants. One PWA, who was in his twenties, commented:

I shouldn't have to worry about this yet! (laughs) I should be 70 or 80 or something, you know? I think it's scary.

In addition, young people often felt they should not have to care for chronically ill partners. One person with HIV infection described the unfairness of caregiving to his 28-year-old partner:

The other thing that bothers me is the unfairness, he [my partner] should not have to - I mean, he is only 28, he is a lot younger than I am, there's almost 20 years difference between us - he shouldn't have to be responsible. My getting the disease was through no fault of his.

One unique feature of becoming a couple affected by HIV infection that distinguished it from most other life transitions is, that for partners who are HIV-positive, the illness of the person with HIV infection was often viewed as forecasting their own fate. Watching the PWA's health decline was particularly distressing for their HIV-positive partners, who worried about what would happen if they too became ill and began to come to terms with their own mortality and fate as defined by HIV infection. One partner summarized these feelings as follows:

It's kind of depressing because you don't know if he's going to get really ill, and you think about that. I know I do, I think about what if he gets really sick and he gets in the hospital. It's depressing. It hurts to see somebody sick like that because you can understand what they're going through, especially if you're going through the same thing.

A Couple - Experiences Grounded in Interpersonal Commitment

When I embarked on this study I conceptualized the phenomenon of interest as family caregiving. After interviewing a few couples, I realized that this conceptualization was problematic for two reasons. First, family can be defined in a myriad of ways, each definition with its own strengths and limitations. Second, the notion of caregiver is restrictive because by definition it implies a relationship based on the needs of someone in a physically, emotionally, or developmentally dependent position. Because of my own frustration with the term caregiver, and because I sensed that the term did not fully capture couples' ranges of experience, I began to ask participants for their definitions of family and of caregiver. In response, I was told by participants that I was actually studying something broader

in scope than merely caregiving, that is, couples' experiences of HIV within the context of committed and intimate relationships. Moreover, when study participants were asked to define family, without hesitation all study participants named their partners as members of their immediate family. More will be discussed about perceptions of family in the section on heterosexism.

A caregiver is someone whose role is defined based on care given and on the needs of the care recipient. It became very clear early on in this study that PWAs and their partners defined their relationships much more broadly. Some participants reserved the term caregiver for professional caregivers, health care providers, and others who are paid to give medical care or domestic services. The following partner summarized some of these points:

Interviewer: What comes to mind when I use the word caregiver?

Partner: Well, caregiver... One who gives care, obviously, but I think of the word caregiver as someone in a medical situation, maybe a hospital or a hospice, something like that.

Interviewer: Do you consider yourself a family caregiver?

Partner: No, not really. Because I tend to put the more medical connotations in caregiver, and I suppose - although technically - okay, technically I suppose I am, but those aren't the words I would use to describe myself or the role, I guess, I play.

Interviewer: What are some of those words? What are some of the words you'd use to describe the role you're playing?

Partner: Well, as far as I'm concerned, I'm Carl's lover, we're still a couple, and I suppose that definition includes caregiving. I suppose in traditional wedding vows, for better or worse, for sickness and in health, you know, that goes along with it. Well, we're not legally married...but I still consider that in our relationship, [we are] lovers, a couple...

Although the lover of this partner had been critically ill once and experienced more minor illness since, the partner did not define their relationship on the basis of giving and receiving care. A similar sentiment was expressed by the following PWA when asked to define a family caregiver:

Brother or sister, mother or father. Caring for one or the other. I don't necessarily think of it as like me and Kevin [my lover]. Let me rephrase it. I didn't, or I wouldn't have, unless I was sick, you know what I mean?

While the PWA often was in a care-dependent position due to illness, because HIV is a chronic disease characterized by remissions and exacerbations, dependency was not a constant condition. Therefore, participants did not define their relationships by the types and amounts of care needed by the PWA. More commonly, both PWAs and partners defined their relationships based on commitment, love and responsibility. Commitment and love were the "glue" that held these relationships together despite the enormous challenges presented by HIV infection. Stated by a partner whose lover had previously experienced many acute health crises:

Being a couple affected by AIDS means a lot of love, a lot of caring, and a hell of a lot of work....Caregiving is a demanding position to be in. I don't think I would want to do it if I was not emotionally in love with the person, personally....If my heart wasn't in it, I couldn't do it....I wonder myself why people do it. Is it for the money or the job, or what?...You know, I do it because we're lovers, that's why I do it.

As proposed by Stanley and Markman (1991), commitment is a combination of two different constructs, personal dedication and a constraint commitment. Although Stanley and Markman studied commitment in heterosexual couples, data from this study suggested that their conceptualization is relevant to the lives of gay couples who are coping with HIV infection. Study participants

most often explained commitment as a personal dedication that reaped priceless rewards. One partner explained his personal dedication as follows:

Partner: I'm here, and doing for him what I do simply because I love him and we're in that committed relationship. I don't know how else to put it. As far as I'm concerned, that's basically it. If that love isn't there, oh, it gets trying, but if it's not there...

Interviewer: It keeps you going on?

Partner: Mm-hmm. Yeah, it gives me strength. It's - I guess I do what I do because of it, not because of anything else, not out of any obligation or duty or pity....I don't think about why I'm doing it, I just do it because - I don't know, it's hard to put an explanation on it. Why do you breathe? You know, it's just natural. It's hard to put any other external force on it. There is no other external force making me - quote, "making me" do what I do. I just do it because it's, you know, it's as natural as breathing, I suppose.

Stanley and Markman (1991) suggested that personal dedication to a partner is derived from a variety of sources. Sources cited most frequently by participants in this study included relationship agenda, alternative monitoring, and couple identity. Relationship agenda referred to the degree to which couples wanted their relationships to endure over time (Stanley & Markman, 1991). The desire for the relationship to endure over time was a common theme throughout the data in this study. Couples acknowledged the hard work already accomplished in overcoming difficult situations and periods in their relationship, ("If anything was gonna split us up it would've already done so"), and they anticipated the steadfastness of their lives together "no matter what happens," "until the end," or "through thick and thin."

Dying alone was a major fear of the PWAs, and the partners frequently expressed their desires for the PWA not to die alone. In part, their deep sense of commitment to one another was related to these fears and desires. Commitment to

one another gave each partner courage to face a future fraught with uncertainties, potential losses, and possible death of the PWA. Many participants recounted stories of witnessing neighbors, acquaintances, and friends dying alone of HIV infection. No one who had witnessed the despair of dying alone wanted the same for himself or for his partner. PWAs invested heavily in their relationships to prevent the suffering of dying alone; partners made commitments to "stick it out to the end" to protect the PWA from the same suffering. One PWA commented:

He just loves me. Who can ask for anything more than that....I feel very fortunate. I know a lot of people who have AIDS and they're by themselves. You know, they have mothers and stuff, but basically they're by themselves. Which I think is kind of sad....We've become a lot closer to each other. Death is a very scary thing and....we're very much in love with each other, and I know a lot of people who don't have that, who are sick, that are alone. And that really bothers me, that they would be by themselves. And I've known some people who have died by themselves.

And from another PWA:

Um, he's pretty well told me that, assured me that he will be there to the end, no matter what. And I've pretty well done the same thing. And it's now a matter of which one's first. Six years is a long time for me. I mean, trust me, you could bring anyone in here that knows me well at all and they would go, Aha, you've lasted that long? And so it's been, I don't know what it is, I can't just say it's love, but you know, we've really stuck it out, and there have been some real bad times. I mean, we've had our little fights, and he moved out and I moved out and we moved out, but we've always gotten back together.

Alternative monitoring, another source of personal dedication within relationships (Stanley & Markman, 1991), is the attractiveness to or awareness of other potential partners. This issue surfaced for different reasons in couples who were both HIV-positive and in which one was positive and the other negative. Some PWAs and HIV-positive partners felt unwanted or unlovable by virtue of

their HIV status. If they were both positive, one or the other may have wondered if that was the sole motivation for being in the relationship. Particularly true for HIV-positive/negative couples, the PWAs tended to worry about the motivations for the partner staying in the relationship, given that the negative partner had more likelihood of success in finding another partner. Particularly in mixed-HIV status relationships, PWAs felt their options for finding a partner were limited because of their HIV status and worried whether or not their partner would leave them for someone healthy. As expressed by one partner:

This is one of Carl's biggest fears that I'm sticking around when I could be doing other things, when I could be around healthier people, when I could be getting committed with someone who's healthy, I could be having sex again.

PWAs also worried about the motivations that kept their HIV-positive partners in the relationships. PWAs worried that their HIV status was the major reason that their HIV-positive partner was with them, either because the partner's choices were limited to HIV-positive individuals or because they felt sorry for them. This was explained to me by a partner in the following quote:

One issue we had together was because we're both HIV-positive, he kept on thinking that since he was HIV-positive, that's why I was with him. I told him, no, that's not it. I'm with you because I love you, you know? There's plenty of HIV-positive people out there that you could have or you could be with. And that stuck in his mind for a long time. No, it doesn't affect my decision at all. I care for him for who he is, not because he's HIV-positive. Yea, I want us to be together for a long time.

Couple identity, a third source of personal dedication, is the degree to which couples thought of themselves as a team with shared goals (Stanley & Markman, 1991). Many study participants related their convictions of "being in this together." HIV infection was a source of emotional bonding for many

couples. However, couples varied in the strength to which they identified themselves as a couple or as two separate people. Some were totally enmeshed with each other whereas others lived relatively parallel and separate lives. Most commonly study participants viewed themselves as two individuals in a life situation together who functioned as a team. Each attempted to maintain strong individual identities while at the same time retaining a clear identity as a couple. They spoke of living separate yet unequivocally connected lives. One PWA explained this perspective using an interesting metaphor:

I'm in the driver's seat of the car, and he's in the passenger seat and we're about to have an accident, and there's nothing that he can do about it, and that's what happens to people who are parents or caregivers, or lovers of people with AIDS...whoever your friend, your lover is, they're sick or there's something going on and you can't do anything, all you can do is help them become comfortable. Help them through life and death.

Study participants tended to emphasize the personal dedication component of commitment and to de-emphasize the constraint of commitment. The reason for this is unclear. Perhaps partners did not want to admit to feeling trapped for fear of hurting the PWA or because feeling trapped was not congruent with their self perceptions as a lover dedicated to someone sick and in need. Alternatively, they sincerely did not feel constrained in their relationships. One partner became angry with me when I asked him about his sense of obligation to his lover. He vehemently rejected the possibility that his commitment was constraining and against his volition. He sharply stated:

I don't feel obligated. I'm here because I love Carl, I'm in a relationship with him, so I don't feel like I'm under any obligation or duty. You can run around definitions as much as you want, I suppose you could say, well, yes, I have an obligation and duty to take care of him, but where that obligation and duty comes from, well, it's because I love him, and we're a couple,

therefore I don't consider it an obligation or a duty - because obligation and duty does imply that you're doing something you HAVE to do and you don't necessarily want to do. I'm here because I want to be here for both myself and for him.

Alternatively, three of the constraining factors proposed by Stanley and Markman (1991) - - social pressures, procedural difficulty in terminating the relationship, and morality of divorce - - clearly were not important to study couples. Because of the noninstitutionalized nature of gay relationships, study couples stated they did not feel trapped in their relationships but remained together out of deep personal dedication.

Views of marriage and commitment ceremonies varied among study participants. Some reported that they would be married if they could, others said that they would never marry if they legally could, and still others had not even considered marriage. The aversion to marriage reflected a rejection of a model that is historically based on patriarchal power structures. Data from studies about gay couples suggest that they strive for equality in primary relationships (Bell & Weinberg, 1978) and that egalitarian styles of coupling are related to relationship satisfaction (Kurdek, 1988). In addition, marriage implies organized religion and in doing so reminds gays of the condemnation of homosexuality that has been fostered by religious groups in the name of morality (Clark, Brown, & Hochstein, 1990). Also, many study participants commented on their experiences of growing up in families of divorced parents or of witnessing the failure of friends' and siblings' marriages. These experiences were likely to result in a rejection of marriage as a desirable solution to solidifying a committed relationship. One man explained:

I'm not that into marriage, because I've seen friends, so many of my friends before who got married and - my brother, married one year. What's the

sense in even getting married? I had one relationship that lasted for seven years, and I've had this relationship for six years. And to me that's what it's about. Marriage is symbolic, it's not going to make you happy, it's not going to make your union work, just because you went and somebody bought a few things and somebody said a few words, that doesn't mean anything to me.

Two couples formalized their relationship by means of a "commitment ceremony" to which they invited friends and family. For these two couples, the commitment ceremony was a public, but not legal, declaration of their love and commitment toward one another. One partner described it as "a public acknowledgment and telling everybody - we've done this, and here we are!" Perhaps public commitments served as a constraining force, yet a definitive answer to this question remains unanswered by this study.

Basic Social Psychological Condition: Loss

Loss was the basic social psychological problem faced by gay couples coping with HIV infection. As explained in Chapter II, the symbolic interactionism perspective posits social conditions as macro social patterns that influence individuals' actions. These patterns exist because of the symbolic interaction of actors in context and the interpretation of situations by individuals.

Multiple losses characterized the transition of becoming a couple affected by HIV infection and heralded its onset. Loss signified that something the couple had was being taken away, such as financial security, or that they were deprived of something they ought to have, such as a future together. The range of losses experienced by study participants is presented in Figure 2. As explained by the following partner, even prior to their personal involvement in HIV infection, gay men are often immersed in communities and networks in which loss and death from HIV infection are pervasive:

Prior to Randy getting AIDS, I just vaguely knew of some people that had died of AIDS. I didn't know anybody with AIDS. Now that he's been diagnosed I find out that two of my very good close friends have died - have contracted it and died already. And numerous people around me now have started dying. So I sort of see it as if it came to a big head all of a sudden. I went to a benefit croquet tournament 5 years ago, and the guy that was running it said, "You may not know anyone that has AIDS today, but you will next year. By the time this comes next year, you'll probably know somebody." It turns out that I do. That my partner, the person closest to me, had AIDS. Like, wow. It was just the time was right.

Life (death)	Primary Relationship
Family	*Independence
Friends	*Role and role expectations
Health/health beliefs	*Intimacy/Sexuality
Functional Status	*Reciprocity/Mutuality
Lifestyle	*Boundaries of relationship
Employment/financial status	*Future
World view (certainty, predictability, denial of death)	

Figure 2. Multiple Losses of Becoming a Couple Affected by HIV infection

The very neighborhood in which this couple lived was immersed in HIV infection and death, an environment that was common to several of the couples interviewed. Loss and death were visible in these neighborhoods and therefore made it difficult to deny. The neighborhood was described by a study participant as follows:

We've seen other people in this building die. In this building...and being taken in the [ambulance] lots of times. It's, you know, this neighborhood is kind of like what we call the gay ghetto, or whatever you want to call it.

That's just what we call it. And so, we've seen a lot of sickness and death.

Every transcript was filled with examples of losses that began with the onset of HIV infection. Because the focus of this study is on the relationship between the PWA and partner, the remainder of the results section will focus on how couples came to terms with losses relating to their own relationship. These losses are noted with an asterisk in Figure 2.

HIV infection is transitional for couples because it resulted in losses affecting every aspect of their relationship including intimacy, roles and role expectations, reciprocity, their future together as a couple, and their lifestyle as a couple as they once knew it. One partner explained the loss of his previous lifestyle as he knew it prior to his lover's diagnosis, that is, as a couple not affected by HIV infection:

Our lifestyle was really - I loved it. I loved both of us working and coming home and going out for dinner in the city, and having the city life. My sisters see it as being real, uh, exciting...we won't even eat dinner until 9 o'clock at night, and my sisters by 9, the kids are already in bed and they are ready for bed. But I just loved it, I mean, I wish he didn't have AIDS. I wish that our life was the same, but - we're just adapting and trying to live our life the best we can.

By far the most devastating loss for couples to face was the potential death of the PWA. Death was perceived as the most threatening loss. In fact, when I asked study participants, "Is the notion of living with loss relevant to your experiences as a PWA [partner of someone with HIV infection]?" each person immediately interpreted loss as death. The following discussion with a young man with HIV infection was typical of many of the responses to direct questioning about loss:

Interviewer: Is the notion of living with losses relevant to your experiences as somebody with AIDS?

PWA: I don't understand.

Interviewer: Have you felt any sense of loss in any areas of your life since you've been sick?

PWA: Hmm, that's a hard one. Because I know a lot of people with AIDS that haven't passed away. I can't answer that.

Interviewer: Do you feel like you've experienced any losses with respect to your relationship with Sam since you've been sick?

PWA: No, I don't, anyway. He might.

The second most threatening loss was the dissolution of the relationship, either due to the PWA's death, or to breaking up for other reasons. Despite deep levels of commitment expressed by all study participants, many had their share of troubles at some point and questioned their abilities to stay in the relationship. Shortly following the diagnosis of HIV or AIDS was a particularly vulnerable time for the survival of the relationship. Two years after his diagnosis one PWA recalled his initial fear of abandonment:

I understand a lot of people who contract AIDS after the relationship has started, their partner has left them. And I was really afraid of that at first. But not now. I know he loves me.

And a partner expressed his lover's initial trepidation during which time the PWA "gave his partner an out":

Partner: And I think in the beginning more or less he was real concerned with the fact that I might want out, and afraid to really let out how things are for fear I might leave or something.

PWA: I don't have that fear, though. I absolutely haven't. A lot of people - even today the people that's had partners for year...I've heard people say that "I'm scared my partner's going to leave." You know? What kind of a partner is that? [PWA turned toward his partner and looked at him.] And I did give you the option lots of times, didn't I?

At the time of interviews two couples were having difficulties maintaining their relationships. One said that he "thought the unthinkable," that is, of leaving the relationship. In one situation the PWA thought about leaving his partner because he did not want to be a burden to his lover. For this couple the threat of breaking up was a constant pressure for both partners and was made very difficult because of their deep love for one another. In another situation, the partner did in fact leave the relationship, in between the time of his first and second interview. His reasons were not clear; he did not discuss them with me, but the PWA attributed the separation to a variety of factors, including the partner's recent diagnosis of HIV infection, ongoing sexual frustration, and the added stress of a recent death in his family. As I talked with the PWA, he spoke with trepidation and was not sure if his lover was back to stay:

PWA: We've been doing okay. Recently here, I guess at the middle of the month, we weren't doing so well and he had moved out for a little while. And that was hard but we worked things out since then. He was going through some things when his grandmother had just died, and then me

being diagnosed, and he was confused about a whole lot of things, and that was hard on him. We had a lot of personal problems. So in the past couple of weeks it's been going okay, though.

Interviewer: What did that have to do with your being diagnosed, though?

PWA: Well, stamina in my sex life, it's the same thing I talked to you about last time. You know, with me being tired all the time and stuff so I just... well, we have kind of sort of worked that out. Kinda sorta. And so I don't know where it's going from now, but I, like I say, I try and take things on a day-by-day basis....But it was kinda rough there for a while, cause he was gone for a couple of days. And it was kind of rough on me cause, you know, for us to be together for so long, and then him leaving was, you know, kind of rough. But we seem to work it out, so....And he was confused about a whole lot of things, you know. Where I'm going, where our life is going. Then his grandmother had just passed away, I think like three or four days before that. So he was confused about a whole lot of things. But we've worked it out somehow, the best way we can, I guess.

Often study participants recognized events other than death as losses only when further questioned. Over a ten-minute period during the interview, one person with HIV infection told me about the loss of his job due to increasing disability and about the personal effects of that loss. When asked if he had experienced any losses since being diagnosed with HIV infection, he initially said no. Upon further probing, I stated, "Well, for example, you told me about your financial problems since you left your job. Some would call that a loss of financial security," and he replied, "Yeah, that is a loss, and another one I've gone through is...."

The western cultural tendency to deny death transferred to the interpretation of loss by study participants. Losses were often labeled as change or stress, thus reflecting the infusion of current psychological discourse into everyday experiences and interpretation. As one study participant commented, "Being a couple with AIDS is about change...constant change. Adapting." Losses, other

than death, therefore were frequently unacknowledged conditions that affected the lives of gay men with HIV infection and their partners. However, when I asked study participants if the term, loss, fit their experiences, all agreed that yes, it did. As a social scientist I listened to participants' experiences and opened discussions of loss. I acknowledged that I contributed to the shaping of their experiences by giving them a framework to interpret their experiences. In effect, study participants and I were involved in the double hermeneutic of social science (Giddens, 1984), that is, of shaping each other's understanding of our social worlds.

The notion of multiple losses captured a critical dimension of couples' experiences while coping with HIV infection. Because of the interconnectedness of the PWAs' and partners' lives, losses did not occur in a vacuum; one loss precipitated other losses. For example, one partner I talked with was paid by the state as his partner's primary caregiver which meant that his housing and his financial status were dependent upon caring for his partner. In anticipating his life after his partner's death he commented about the probable financial losses he would incur:

Partner: And [my financial status] will be the biggest challenge I've had to face and probably most people don't have to ever do that. And that is because of the fact that I'll lose a loved one and lose our home and my job all at the same time.

Interviewer: That's a lot.

Partner: It is. It's going to be a lot, that's for damn sure.

According to Chick and Meleis (1986), the precipitating event of transitions may be undertaken voluntarily, such as in a planned pregnancy, or may be imposed from without, such as the disease of HIV infection. Losses, then, can be

conceptualized along the dimension of volition. The multiple losses as reported and described by couples affected with HIV infection included both types. HIV infection, the disease, was generally viewed as a loss that came from without and was outside of one's control. This perception was very much related to the tendency of study participants not to blame PWAs for their disease. However, other losses were very much under study participants' control and freely given up, such as friendships that became burdensome.

In the previously developed theory of AIDS family caregiving (Brown & Powell-Cope, 1991) uncertainty was named as the basic social psychological problem that exerted a profound influence on caregivers' lives. While a sense of uncertainty was pervasive for participants in this study, actual and threatened loss were precursors to feelings of uncertainty. Multiple losses shook the very foundation of couples' belief systems. Subsequently, their world and their relationship as they knew them before HIV infection became ambiguous and uncertain.

While caregivers and PWAs searched for new meaning in their lives, it was reasonable for them to feel unsure about various aspects of their lives. Feeling secure within their committed relationships was cited by study participants as a reason for feeling secure in the face of overwhelming losses and uncertainties. Most study participants reported feeling secure in their relationships. One PWA commented:

Occasionally, momentarily [uncertainty plays a role in my experiences with Les]. Like when we almost broke up. I was really uncertain. I know that there aren't any guarantees that we may be together the rest of our lives, because I guess there's always a possibility that he may find somebody else, maybe it was meant to be. I can only hope that we'll do the best we can with the time we have....So I have my days of uncertainty. Usually it

doesn't last any more than a day, cause he's there being very supportive, and vice versa when he has his days. But I don't feel there is any uncertainty between us. Our bond is becoming stronger, as we go...

Processes of Becoming a Couple with HIV Infection

Hitting Home: Awareness of Loss

In describing their experiences, study participants invariably described the events that precipitated the awareness that HIV infection was inescapable. These can be thought of as antecedents to their entry into the transition and early phases of becoming a couple affected by HIV infection.

Hitting home marked the beginning of the transition to becoming a couple with HIV infection. Hitting home was the awareness or the acknowledgment that HIV infection was an escapable part of life, and that life as the couple once knew it was gone. Hitting home occurred in different ways because different events or combinations of events were likely to trigger it, but the emotional response was the same, e.g., the emotional shock that accompanied this awareness was experienced as emotional upheaval and turmoil:

...there used to be a time when I couldn't mention [AIDS]. I couldn't even say that Randy has AIDS. I would just freak out, start crying. In fact I had to go to [a gay recovery network]....So all I did was freak out all the time. So I called to seek some counseling about this because all I would do was cry constantly. I mean, I could not do anything else....When he was first diagnosed, that was my major, my biggest slap in the face.

In this study most of the couples began their relationships before the PWA became symptomatic and before the diagnosis of HIV infection. Approximately half of the PWAs knew of their HIV-positive status at the onset of the relationship. Regardless of HIV status at the onset, all couples related stories about becoming acutely aware of the life-threatening nature of HIV infection. Couples who already knew of the PWA's HIV infection before they got together described the

impact on the relationship as less dramatic than did those who did not know the PWA was HIV-infected at the onset of the relationship:

I guess for most people it is a traumatic shock, out of the blue it happens. But Kurt's been dealing with AIDS for years before he met me, and I knew it before I got into the relationship with him, so it really hasn't been that big of a change, I guess, like it is for a lot of people. If he had gotten it after we were together, it probably would have been a big shock.

However, during a previous interview and toward the end of the second interview, this same partner related the experience of first realizing some of the consequences of his partner's declining health due to HIV infection and the shock associated with the realization that the PWA would die:

(Quote from first interview) Well...we did have this bone thing come on here a few months ago, and that kind of hit home with that - maybe he will be in a wheelchair. So that kind of puts a different light on the whole situation...things are happening which weren't there before. (Quote from the second interview) The only thing that really hit home is - I guess, it had probably been about 2 months down the line...I thought, you know, gosh, one day I'll be alone. You know, he will be dead. That was what took me a while to grasp on to...the fact that, you know, that's real. Because he sits there, and he doesn't look like he is going to be dead in the near future so it's easy to forget, or it used to be easy to forget that that's really what's going on. I've kind of gotten a grip on that's the way it is.

Reviewing HIV risk status, experiencing a variety of prodromal symptoms, being tested for HIV, and receiving a pronouncement of a diagnosis was the most common sequence of events which precipitated hitting home. For the following partner it was this combination of illness and a positive HIV test that confirmed his worst suspicions:

[At first] we were just in denial. Being homosexual I was very fearful of contracting the HIV virus and didn't really want to go have my test taken, and I'm sure he didn't either, even though he thought for sure that this was what he had. But we were in such denial, we did not want to have it. We had a great little relationship going, you know? It was prospering and we

loved each other, and it was really great. And so then he kept having a nagging cough and the night sweats and things like that, and so we went to the doctor, the doctor suggested that he have an HIV test, of course.... And so we went - we had the tests, and then there was a week that we had to wait. He still had his cough and his night sweats and all that kind of stuff, and his came up positive....So then about another week went by and he was back in the doctor's office with chest pains and all that, so they decided to do a chest X-ray. And that was on like a Friday, I think, or a Thursday, and I took him to [the clinic] to get his chest X-ray, then we came home that night and he started to really get tight and to really have a hard time breathing. The next morning I took him in. I should have taken him that night, but we were still in denial. We were still like, this is just bronchitis. That's what we thought. In fact, I even forced the doctor to tell me, 'This could be bronchitis, right?' You know, I kept saying, you know, it's not AIDS, it could be this, it could be that, it could be this. And so the next morning he had such a hard time breathing that I called the doctor immediately. They said his chest X-ray came back positive and "Bring him in now!" He was barely able to walk. And so we got him into the hospital and in a couple of days he improved, and then it was - okay, I cried outside the room because the doctor told me that he had full blown AIDS. That's how they were describing it then.... And so I cried a little bit, and I thought, okay, this is going to change our life.

The initial response to a diagnosis of HIV infection was not always instant awareness of loss as exemplified in hitting home. Many study participants described periods of denial either during remissions or immediately following diagnosis, particularly if the PWA's health was still relatively good. When one perception did not match that of the partner, the mismatch was likely to be quite upsetting to the one for whom HIV infection had not hit home. One PWA said:

Partner: He [PWA] used to get so upset at times because I'd be so carefree and act like nothing's really happening. I think he'd get mad at me at times because I wasn't focusing so much on him with the AIDS.

PWA: It wasn't so much that you weren't concerned and stuff, it wasn't so much that, I just wanted you to face reality so that instead of living in a dream world, that everything was going to be hunky dory forever....

Partner: You know, you have to think about it, but denial is probably what it is. I think everybody goes through that in the death process.

The initial diagnosis of HIV infection did not always herald the beginning of the transition to becoming a couple affected by HIV infection, because following the diagnosis life often continued as usual for the couple. In these cases it was the mounting evidence that HIV infection would affect their lives that signaled the onset of this major life transition. One partner contrasted his earlier experiences during the period following his lover's diagnosis of HIV with his more recent experiences following his lover's declining health:

Partner: Well, he's had AIDS for 3 years, and the first 2 years I didn't really have to do anything. Just kind of support him, I mean in an emotional way. And then the last year he's been really sick, so I have had to give a lot of care.

Interviewer: You mentioned at the beginning that you gave him a lot of emotional support. And I'm just asking you to think back to what caregiving was like in the beginning.

Partner: (laughs) Oh, it was easy! Because he still did all the housework, and I just worked, and I was kind of like - this is easy. This is living with AIDS? And so then once he got really sick, then it became a lot harder and very emotional (sighs)...

The Work of Maintaining the Relationship: Mutual Protection

Mutual Protection was identified as the basic social process of becoming a couple with HIV infection. Mutual protection is the mechanism by which individuals in the couple govern their activities toward one another. Each individual attempts to ward off losses that are perceived as within his control and to "let go" of forces outside of his control. The major motivation for actions taken by study participants was the protection of the self and the other by forestalling losses such as threats to the relationship, health, and privacy, and preserving

important relational characteristics such as independence and intimacy. Mutual protection included actions directed toward the self, and toward each partner by the other.

Mutual protection was often expressed by study participants as "holding on" and "letting go." Holding on and letting go was a process by which couples sorted out what was important in their lives and reordered their priorities based on the need to protect some aspect of their lives. One partner summarized this process as follows:

Partner: Well, [John's having AIDS has] just been an awakening of my awareness of mortality, and it gives me an awful lot of ability to throw off the excess and what's not really important. It's so much easier to focus on what's important now than it was before.

Interviewer: Getting your priorities in order?

Partner: Yeah. And just realizing that [AIDS] isn't something that I need to be upset about, and letting it go, and focusing on what is really important in life. It gives you a whole different perspective. And that's a good thing, actually.

Study participants appraised situations in different ways: dangerous versus non-threatening, harmful versus beneficial, or hindrance versus helpfulness. Based on these appraisals participants said that they decided upon courses of action that would attain the most beneficial outcome for the least cost, measured in emotional or physical distress. They made decisions about what to hold onto and what to let go of based on these appraisals. All participants agreed that their relationship was the most important thing to hold onto because of the multitude of benefits incurred from the relationship:

Partner: Right now it's important for me to hold on...to Wes. He's the first person other than my mother that I've ever actually loved. And my mother's gone, and he's the only one left and that's really important to me. I'll stick to him like crazy glue. And when it's time to let go, I think we'll

both realize it. And then I will let him go. I will let go of the physical body, but what I've got in here [places hand on chest], I'll never. I won't live my life as though he's still existing, but right now it's holding on.

In weighing the options of holding onto something or letting go, study participants stressed the need to "take care of myself," a phrase commonly used in the popular health and illness literature. Study participants held onto or let go of beliefs, relationships, ideals, values and life situations such as jobs. Often these decisions were not taken lightly. They deliberated, weighed the options, but learned to favor that which would result in the most benefit for the self, the partner, or the relationship. While these were often very difficult decisions to make, once they felt comfortable with this process they learned to not regret decisions they had made.

Often decisions were complicated by friends and family who found it difficult to support decisions they did not agree with. One study partner told the story of his difficult decision to decline a promotion at work:

Partner: I'd come out here [to this city], in a lot of respects to reduce stress in my life, I had a very high paying, high-pressure job in Miami and I didn't want to pursue that any longer. My boss in Miami had recently retired, he had an ulcer, he had all kinds of medical problems. And they were going to offer his job to me. And I turned them down and resigned. No thank you, I don't want ulcers, I don't need that. Even though the money there was twice what I'm making now...I make fairly good money now, it's pretty amazing that I would [turn down that job]. A lot of people think I'm crazy, but it's not to me a good choice to make a lot of money and put yourself in a position where your body is going to give out on you....I no longer desire to be a CEO.

Interviewer: Did you at one time?

Partner: Oh yeah, at one time that was certainly within my grasp. I could very well have been an officer, if not THE officer of that company if I had stayed there. And I let go of that fairly easily. Well, I wouldn't say fairly easily, it was [difficult at the time]....But I did let go of it, I don't dwell on

that anymore. In fact I think that I made the wisest choice and really congratulate myself for doing that. Gosh, I've let go of a lot of things. Things that I have no control over, mainly.

Mutual protection occurred along two dimensions: the object of concern and awareness of actions. Figure 3 summarizes these dimensions and provides examples from the data. The object of concern was either physical or emotional health. The distinction is useful for analytical purposes, but it should be noted that this distinction was not absolute. Most study participants subscribed to a health belief system that emphasized the connections between the body and the mind, and between emotional stress and physical health. Depending on the circumstances, either protecting physical health or protecting emotional health usually took precedence over the other. For example, during a health crisis protective actions taken by partners toward PWAs were most likely directed toward the physical well-being of PWAs. Alternatively, during disease remissions partners were more likely to attend to the PWAs' emotional needs.

		OBJECT OF CONCERN	
		<u>Physical Well-being</u>	<u>Emotional Well-being</u>
AWARENESS	<u>Covert</u>	Putting wheat germ into casserole without PWA's knowledge	Pretending to take partner's advice about something but on own course of action
	<u>Overt</u>	Keeping partner HIV negative	Expressing gratitude and thanks to partner

Figure 3. Mutual Protection, Object of Concern and Awareness

Awareness. The visibility of actions taken by the PWA or partner, and therefore the level of awareness by the other party, was a critical dimension of mutual protection. Three scenarios of visibility were represented in the data:

1. Protective action taken by either individual and both aware;
2. Intentionally covert protective action taken by an individual that was not recognized by the other; and
3. Intentionally covert protective action taken by an individual that was recognized by the other.

For example, partners often orchestrated elaborate pretenses in order to preserve the PWA's dignity. Commonly, a partner would attempt to give the PWA an air of "independence." However, in many cases the PWA was aware of the pretense but did not divulge to his partner his knowledge of the partner's deliberately executed covert activities.

Actions were most likely to become overt in cases where the stakes were very high, such as in keeping the partner HIV-negative. During stable periods of HIV disease, protective actions were more likely to be covert because the stakes were not perceived as high. An unintended consequence of covert actions was that they could undermine trust within the relationship because one partner would have difficulty understanding the reasons for the other partner's behavior. Suspicion of the other's motivations was a common response to recognizing covert protective actions. While a fourth scenario is theoretically possible, that is, intentionally overt action that is covert to the other, it was not represented in the data.

Object of Concern: Physical and Emotional Health. The object of concern of mutual protection was either physical or emotional health. The motivation for protecting the PWA's health was obviously to extend the length of life and to

maintain an optimal quality of life. If the partner was HIV-positive, there was also a motivation in protecting his level of health. In addition, both individuals protected the partner's well-being so that he could continue to provide care and support to the PWA with as little stress and strain as possible. Common themes of mutual protection directed toward physical health included keeping the PWA as healthy as possible, keeping an HIV-negative partner from becoming infected with HIV, and preserving energy. Each will be discussed separately.

Preventing opportunistic infections in the PWA was a major goal in protecting physical health. In order to prevent infections couples devoted considerable attention to their diets and health habits, levels of exercise, personal hygiene, and the cleanliness of their household environments. Many, but not all, made significant changes in these areas. One HIV-positive partner described his incessant efforts to protect himself and his lover from developing infections and other illness:

Partner: Well, I've become really anal about cleaning, I guess. I clean all the time. I clean everything, I disinfect everything. I make sure that we don't use the same toothbrushes, the same razor, or at least I try to. He's not as intense about it as I am. And I just clean everything. I just wash everything we eat, I try to cut down on whatever foreign matter might come in and infect us. I don't allow us to have any pets, although some people think that's going a little too far. Larry thinks that. But I don't want anything in the house that creates more waste. That may sound really strange, but...I just get this vision that I'm gonna die with some weird bird disease, and that would be just awful. Some weird South American bird disease.

Interviewer: That would be horrible.

Part: Yeah, this is just not worth it, I'm not going to do that. And cats, I've never been a cat fan. I grew up on a farm and the cats were relegated to the barn where they caught mice, and that's what cats were for. And I don't

need a cat litter box, Jesus, how disgusting. And [the doctors] told us that if [you're HIV-positive and] have a cat and you clean the box, make sure you wear a mask and rubber gloves. And I'm going, what is the point? Why would you bring something in your house that you have to handle like nuclear waste? I'm not gonna do that. And we can't have a dog. I told him if he wants fish, maybe we can get a fish tank. That's only because I haven't read of any weird diseases you get from fish.

Interviewer: So you're being ultra clean, it's to protect both you and Larry?

Partner: Oh, absolutely.

Interviewer: And what about the not sharing your razors, I think you said, and your toothbrushes.

Partner: Sometimes you cause lesions in your mouth when you're brushing your teeth, or gums, poke through your gums and whatnot. So I worry about that, that there's a possibility of transmitting other infections that he may have, that I may have, back and forth. So I don't want us to do that. I've developed some other habits, too. I rinse my mouth after each time I brush, with hydrogen peroxide, which I've read can be very helpful in controlling periodontal disease and thrush. So I do that, and I've just become a lot more conscious of hygiene....since I found out I was HIV-positive.

Over time, both PWAs and their partners became quite sophisticated in managing their own health. They learned to monitor their progress and health status, interpret symptoms, take action to prevent minor problems from becoming major problems, administer treatments, interpret test results, and negotiate health care systems. PWAs and their partners monitored complex combinations of symptoms such as fevers, general malaise, shortness of breath, rashes, nausea, headaches, lethargy, swelling, pain and other unusual sensations, weight loss, forgetfulness, diarrhea, the condition of the mouth, swollen glands, and depression. All these symptoms were represented in the data from this study of 9 persons with HIV infection. Termed "vigilantly monitoring" in the AIDS family

caregiver study (Brown & Powell-Cope, 1991), PWAs and their partners became expert in watching for signs and symptoms occurring in themselves and in their partners. The belief that any symptom alone or in combination could herald an acute health crisis or even death made their monitoring extraordinarily crucial. Over time both PWAs and their partners became adept at interpreting symptoms, but symptoms were always constant concerns. One partner said he was "always on the prowl for signs of trouble." Another partner explained his caution as follows:

[I am much] more cautious now. Because at first it was kind of scary because - well, I mean, at first it's like if they're sick you don't know what to do, or maybe you don't notice things as much, but once you've had experience with it, you know if something's wrong you gotta take care of it right away. And you tend - like I tend to look at Larry as far as his body, as far as his weight, as far as any cuts or any bruises. I just pay more attention to him, to see how he's feeling, how he's reacting, his memory, things like that. Because usually when he's in a bad mood, he usually doesn't feel good. Or mentally he doesn't feel good. I watch out for things like that.

A factor that often complicated symptom monitoring was the tendency of a PWA to hide symptoms from his partner to protect him from undue worry or concern. Sometimes partners were aware of the PWA's attempts to conceal his condition, and other times they were not. Once partners discovered that the PWA had been keeping his symptoms "under cover," however, they often became more vigilant in their monitoring efforts because they felt they could no longer trust the PWA to tell them the truth.

One PWA explained his reasons for hiding symptoms from his partner:

I manage my symptoms by hiding them from Stan. Sometimes he catches me with a look when I have a wince of pain or a shortness of breath or a dizzy spell, a stumbling spell, but basically I hide them because I don't think

that he can deal with my pain as well as HE thinks he can. It causes him great emotional distress. And I don't want to heap that up on anybody. It's very personal and very private and I don't know how to share it with him....I hide my pain a lot from him. Because I don't want to see him hurt....It's very hard to do, but you've got to do what you have to do in order to keep a balance.

Deciding on a course of action based on the interpretation of symptoms was another significant source of stress for PWAs and partners as they attempted to protect the PWA's health. Many study participants reported that trial and error was the method by which they learned the management of any given symptom:

[I've learned by] trial and error. Just watching - I've always been a hypochondriac. Okay? I've always been, oh, gee, I've got a scratch, I run to the doctor. I've always been that way. Consequently I watch - I notice things about myself and about my body and stuff like that. And if I see something that's different, then I want to know why.

Research and self-education were as important as trial and error. Study participants made use of a variety of resources such as newsletters, gay magazines and newspapers, special seminars and classes, physicians and other health care providers, a drug and treatment information network, support groups, and informal sharing with friends and acquaintances to manage the PWA's symptoms.

Sometimes available information seemed as extensive as the symptomology of HIV infection. One partner explained how he and his partner worked together to keep abreast of new information.

Interviewer: How do you keep up with all of this information about AIDS?

Partner: Oh, I get a lot of it through the gay press and [community AIDS organizations]. And there's just an amazing amount of stuff going on right now. And I do spend a lot of time reading stuff. I read a lot, even for pleasure. [Keeping up on everything can be a full-time job itself.] You have to pick and choose. There's some stuff that seems redundant. Then you just kind of discard the rest of the article and then go on to the next one. There's just so much information right now, it really is amazing how

much effort is going into dealing with this crisis. [I collect information for both Larry and I.] I bring stuff home all the time.

Interviewer: Does he do the same for you?

Partner: Not quite so much, but he does bring things home too.

Most study participants emphasized the importance of educating themselves and keeping their partner informed, particularly if the partner was HIV-positive also. Participants viewed the people and agencies who helped them access information about HIV infection and treatments as invaluable resources. Although information gathering was critical in order to protect the PWA's health, some participants felt that much of the information available to them was "over their heads" or "too technical to be useful."

In addition to monitoring signs and symptoms, the list of medical tests PWAs and their partners learned to anticipate, undergo and cope with was exhaustive: t-cell counts, red blood cell counts, chest x-rays, biopsies, angiograms, and spinal taps, among others. Partners provided significant amounts of support in helping the PWA to cope with the myriad of tests. Many PWAs felt they could not have made it through testing ordeals had it not been for the encouragement and support of their partners.

One partner described the difficulty in helping his partner through a spinal tap and an angiogram. While supporting his partner he remained careful to hide his own pain from his lover so that he would not add to his distress:

Partner: So we had to do all these tests, like a spinal tap, that was pretty horrible. I was in the room holding his hand while they poked this needle in his back to draw out spinal fluid and he was obviously in a lot of pain with that. It's not easy to do on a person who carries any extra weight, cause they couldn't find the correct place....So, they were poking and

probing with this needle and that was pretty painful, and I witnessed that....Then they did an angiogram, which is a pretty nasty procedure too. It didn't seem to bother him as much. But I was in the room, the doctor let me stay in the room.

Interviewer: You were for the angiogram?

Partner: Yeah. And I sterilized myself and stayed in the room. It helped him a lot. He kept looking at me and saying, "What's going on? Are we done yet?"

Interviewer: How do you hold yourself together during those times? It sounds like it would be very difficult to watch the person you love in pain.

Partner: It is difficult. I don't think about it until afterwards, that's how I do it....I just do [what needs to be done]....After I'd come home from the hospital, I would sit here and cry. Because I couldn't do anything, I couldn't make it stop. The disease is going to progress in spite of my best efforts, there isn't anything I can do about that. And that's the hardest part, just the being out of control. But I don't let him see that, because that would be more difficult for him to do what part of it he has to do.

In coping with the health of one another, most study participants reported that they went through a period of questioning their health beliefs. Many reformulated their basic assumptions about health from a medical model to a more holistic model. In response, many altered their lifestyles accordingly. Participants engaged in a variety of "alternative" modalities such as massage, acupuncture, meditation, yoga, naturopathy, and the use of herbal remedies.

Protecting Relationship Boundaries. Preserving and protecting the boundaries of the relationship was a major feature of mutual protection. Boundary maintenance was most likely to be overt, and directed toward either physical or emotional health. Kantor and Lehr (1975) proposed a spatial metaphor to answer the basic question, How does a family set up and maintain its territory? According to this scheme, families set up and maintain architectural boundaries

and social-space perimeters. While the focus of this section is on social-space perimeter maintenance, it may be useful to briefly consider the architectural features of the families in the present study since these features often overlap. That is, families use the structural boundaries of their residences to maintain their metaphoric social perimeter.

All couples in this study lived together, i.e., shared a place of residence. While I did not specify living arrangement as a criterion for participating in this study, all of the couples who responded to the study advertisement shared a residence. In asking study participants to tell me about the history of their relationship with their partners all included descriptions of their meeting, dating, and then subsequently moving in together. Berger (1990) suggested that moving in with each other has special significance among gay couples because they lack a socially sanctioned event, such as a marriage ceremony, to signify the initiation of their relationship. The living arrangement of couples in the present study were particularly important not only in signifying the beginning of their relationship, but also in establishing and preserving their commitment to one another in the face of the stresses of living with HIV infection.

Due to the significance of shared housing to the relationship, it is not surprising that maintaining places of residence in the face of disability and job losses was a major concern for some study couples. A threat to housing symbolized a threat to their ability to stay together as a couple and therefore to the very foundation of their relationship. One PWA, who was currently unemployed, receiving disability income, and in the midst of recovering from pneumonia, expressed his frustration and anger toward his partner, who had recently quit his job without, in his mind, making adequate provisions.

The most recent problematic situation that comes to mind would be when he quit his job. And he just decided to quit because when I was sick, and I was laying in bed, and I had a 105 degree fever, I was worried about losing the house, losing the place to live. Where are we going to go? How am I going to take care of this guy, you know, the bills were piling up, the electricity is going to be turned off, we have no food to eat, it was just a nightmare. And he just couldn't take it anymore. He couldn't deal with anything....I did not mind him leaving the job, because it wasn't making him happy, but he didn't plan for it.

This PWA's partner also felt under tremendous pressure to see that their housing needs were met because he was also HIV-positive. However, the partner was more optimistic than the PWA. The partner felt that because they had been homeless before, they could survive even if they were forced to give up their house:

Yeah, it was real difficult when he had Pneumocystis because - I was afraid I was going to get sick and then if we both were sick at the same time, we'd be in bad shape. I was still working then - I would not have had any income if I had gotten sick. We'd be liable to end up out in the street. We're not that far from it now. Just up until Friday we thought we were going to lose this place. That's why we bought that trailer out there, to have something to fall back on. And we lived out on the street for a year and a half after we both moved here. We lived in a bus. We lived around town here. We were both working, we just couldn't kick up enough money for first month and last month. So, who knows? Might live on the street. I lived in my car probably three years out of my life altogether, at different times, so I know what that's like.

Protecting the physical boundary of a household was a concern for all study couples, but particularly for those couples with few monetary resources. Two couples felt that keeping adequate housing was a constant pressure due to their marginal income. In one couple, both were unemployed, and in the other couple, while the partner worked, it was in a low-paying service position that provided no

benefits. Housing provided safety for the PWA and an environment conducive to the partner's ability to provide food, comfort, and medical treatments for the PWA.

While housing symbolized the couple's physical boundary with the outside world, their commitment as a couple symbolized their social boundary with the outside world. Kantor and Lehr (1975, p. 41) proposed that all families negotiate interior spaces and exterior spaces so that family members can move about without having to fear harm. In the case of couples in which one is infected with HIV, protection from outside harm was a major task faced by PWAs and their partners as they made decisions about their social boundaries. Because of the stigma that still surrounds HIV infection, both PWAs and their partners feared repercussions from friends, acquaintances and family members if they tried to "open the boundaries" surrounding the safe haven of their relationship. Protection of relational boundaries was for the sake of the couple and it was usually negotiated between partners. PWAs and their partners were supportive of the other's need to turn outside of the relationship for help or support because they appreciated the incredible difficulties of their situations. As one partner viewed others' support:

Interviewer: Can you think of anything that is important for you to hold onto, as part of your experiences as a partner of someone with AIDS?

Partner: Oh yes, absolutely. It's important to hold onto your friends. Pull them in closer around you if you can. Family if you have it. And I have very little family. So, that isn't much of an option for me. But it would certainly be important. Most of the intangibles of life are important to hang onto.

Early on in the transition most couples found it relatively easy to regulate the social boundary of the relationship. However, with increasing illness, both PWAs and partners found it increasingly difficult to control the flow of people into their lives because of their increased needs. While many couples welcomed the

additional visitors, health care providers, and other helpers into their lives, some were not always received gratefully. Sometimes PWAs and their partners were suspicious of others' interest in them. Some study participants perceived the onslaught of people into their lives as distressing, particularly one partner who described himself as a loner.

Partner: When Brad got sick, I had all these people coming into the house - people after people after people - and it was hard for me to accept that...it was like, last week you didn't give a damn about me, didn't give a shit whether I lived or died, now all of a sudden that I'm sick it's, you're expressing your concern, you weren't concerned when I was depressed and couldn't get a job and you weren't concerned about keeping me from living on the street, but now that I'm going to die all of a sudden I'm important to you. You're interested in me now - don't get me wrong -

Interviewer: I hear what you're saying.

Partner: ...I don't feel like you're a bad person, that you're doing it, I'm just saying that it's such a change. Before I could be laying out on the street, and have nothing to eat, and people would just step over you, but now something has occurred to bring me to your attention, all of a sudden you want to help. It's just kind of hard to take, because after all those years [when no one wanted to help me].

Interviewer: Does that make you angry at all?

Partner: You bet....Well, it did at first, not so much now.

Ironically, at the same couples experienced an influx of people into their world, they often experienced the loss of family and friends who for a variety of reasons did not stay in their lives. Either the PWA or the partner feared the reactions of others to the news of HIV infection and therefore avoided them, or else they found that they did not have much in common with people who had once been friends. Study participants reported letting go of friendships which has once seemed beneficial to them but became less so as the PWA became more ill and as

the couple became more focused on themselves as a couple. One PWA described a situation with his partner's friend that resulted in the PWA deciding not to attempt to maintain his own relationship with this man:

PWA: Thomas has one friend who I dislike, who used to do AIDS volunteer work. He would take AIDS patients to the doctor, or pick up prescriptions, and he says he's had to stop doing it because it was just too emotional for him and he couldn't deal with it. I says to Thomas, "That's a crock of shit. He can't deal with it? He's not the one who's sick." When I got back from Europe where I was so sick, he called on the phone and I was telling him I had come down with a sinus infection. And he says, "Well, honestly, did you really think you could get through two weeks in Europe without getting sick?" And I said, "Yes, I did!" He says, "Well, I always get sick when I go away." I says, "Well, Chuck, you ought to stay home!" I was so annoyed with him. I told Thomas about what Chuck said, and Thomas just kind of shrugged it off. Thomas says to me, "You take things too seriously. You're being over-reactive to it." And I didn't really think I was being over reactive by getting so irate. I thought it was a cold, heartless remark to make. It was like, Oh, you should just stay home and wait to die and not do anything.

Interviewer: Which is clearly not how you're living your life.

PWA: No.

Interviewer: Do you find yourself avoiding people like this guy?

PWA: I try to, yeah. The last time we were invited over there for dinner, I told Thomas, "You know I'm not really comfortable going to dinner there." He said, "Why?" I said, "Because of Chuck's attitude towards people with AIDS. Chuck and his partner can't deal with it." And Thomas says, "Well, then you should talk to him about that." But I was so emotionally upset that I couldn't really hold a rational conversation with him.

Reasons for tightening the boundaries of the relationship included protecting each other from undesirable consequences such as acts of discrimination, the "burn-out" from involvement in the AIDS community, negative or nonsupportive attitudes and actions of others, or preventing losses of family and

friends. Despite the support that many study participants found in support groups, one PWA made the decision to withdraw due to what he viewed as the negativity of the group:

I'm distancing myself from the support group. The friends that I do have that have AIDS that are positive are very positive people, and becoming more and more. I'm not allowing myself any sort of relationship with just anybody that I meet, but I choose to surround myself with positiveness.

Another reason given by a partner for tightening the boundaries of the relationship was that by giving up his friend he would not have to "deal with his problems," and therefore have more time to devote to his partner. His relationship with his lover took precedence over any other relationship at this point in his life. As he explains, letting go of people who were once friends was very painful:

I have a friend that I've had for a long time that - we're not close right now. He's dealing with his own HIV problems and he can't seem to let Randy and I be. He wants to meddle in our business so I've recently had to give him up and say, "I can't deal with yours until I deal with mine, so just let me be for a while." I feel really torn about that, actually. I feel like I'm slapping him in the face and I'm telling him, get out of here, go deal with your own problems, but if he were more supportive of me, and wasn't so attacking and opinionated about me and Randy, then I'd be okay. But I just can't take negative - my family comes first and that is first and foremost in my life. So, I've had a hard time giving that up...a really hard time. But I've got to make this cut, you know?....He doesn't believe in western medicine so then he comes back from his eastern type philosophy and I'm coming in with my western type philosophy, and we clash. And that's a problem for me because I have somebody that I'm living this through, and by him not accepting that, that denies me, you know? It makes Randy and me null and void is how I see it. And so that's why I need to just say, okay, for me right now I can only deal with one thing at a time. And Randy is my one thing. And so you, my friend, are going to go on the back burner for a while.

Oddly enough, one partner said that telling others outside of the relationship about his involvement with HIV infection was also a way of

protecting himself from discriminatory acts. Indirectly he told his employer to protect his job, thereby creating a sense of security for the relationship. He stated:

Partner: [I told my boss] that I was HIV-positive because I wanted to protect myself. I told him, well, things are probably going to start changing. But I wanted to protect myself.

Interviewer: Protect yourself how?

Partner: So that if I was fired for not coming to work a lot, or for being sick a lot, if I wanted to collect unemployment or something I could have a case to fight them. Isn't that dumb? Most people I find around me don't - they're afraid to assert their rights. I'm not. I know law pretty good. I've been in trouble before, I've been in courts, I know how the system works.

Reasons for loosening boundaries of the relationship given by study participants included soliciting support from family, friends, and work associates, and obtaining professional services. A reason commonly reported by study participants for loosening the boundaries of the relationship was to seek support that was not available within the relationship, thus demonstrating the degree of enmeshment between the PWA and partner. This is illustrated in two very different responses, the first from a partner who said he received everything he needed out of life from his partner, and the second from a PWA who felt very strongly about acting on his need to receive support from outside of his relationship despite the difficulty it presented for his partner.

Interviewer: From your perspective, how has this been for Sammy, your reaching out, your having a support volunteer, and going to a support group?

PWA: It has been hard for Sammy. Because Sammy thinks that instead of me turning to him - see, I have that support, I have that foundation with him. As far as I am concerned, that's there and it can't be shaken - but all my needs are not met in that foundation [my relationship], all my needs, like I need time to where I can be the Fred Flintstone and I've got a Barney

Rubble, somebody to let me be crazy, who I want to be with, with no connection. That's where my support volunteer comes in. We deal with things, we laugh a lot over serious issues.

In contrast, another couple remarked on their complete dependency upon one another and therefore their lack of need to turn outside of the relationship for support. Interestingly, however, this couple did turn outside of the relationship for instrumental support and made extensive use of a variety of community agencies:

Partner: [We function] more as a unit instead of two separate people. We live our lives as one, more or less. We're together 24 hours a day so I think you have to be pretty down to earth and pretty up-front and right to the point to be able to get along with somebody at that close, for that amount of time.

PWA: Yeah, and it's not really because we have to be, it's just we're both - it might sound silly - but we're both - we don't like to be apart. You know, we just - if we're going to do something, we do it together....so we're pretty compatible there. If one of us is away from the other, we're lonesome. We're just not happy. We don't enjoy being apart - even if we just sit here and don't say nothing the entire day.

Past experiences in how each couple protected their boundaries based on their sexual orientation often influenced boundary maintenance based on HIV infection. In general, those who had previously "been out" with their sexual orientation felt more comfortable in turning outside of the relationship for support and health. They had already developed strategies for divulging sensitive information and responding to the negative responses of others compared with those who had not made public their sexual orientation. However, regardless of their past experiences with telling others about sexual orientation, telling families, particularly parents, about HIV infection was almost always a very difficult task for study participants.

Preserving Independence. Before HIV infection hit home, couples reported feeling comfortable with the informal agreements they had reached about each partner's level of independence within the relationship, and their expectations about how each was to fulfill his role as a partner. With the onset of HIV infection the balance of giving and receiving was upset and this threatened each individual's sense of independence. Interview transcripts were filled with examples of the struggles to retain a sense of independence in the face of the PWA's changing health status and resultant uncertainty about the future. The following conversation sums up many of the issues related to balancing needs, dependency, and independence:

PWA: Well, I don't like being dependent on anybody. You know. That was a real hard quirk for me to get over because - he is my payee for my Social Security - technically I don't handle that anymore. I don't drive a car. They pulled my license because of a seizure, so I can't do that, so I have to depend on somebody else for that. Depending actually for most, for everything.

Partner: I think there was a little bit of resentment. Once in a while it still comes around, the fact that I - not that I run everything, but as far as taking care...

PWA: It can go so far.

Partner: In the beginning it was all up to him, running around getting housing by himself and the doctor this, doctor that, the food stamps, all that was - he had to do everything...and then I come in the picture and then I got about half of it...then I got all of it...and I got real...

PWA: You got too much of it

Partner: Pushed a little bit back. But I think he gets a little bit resentful sometimes that I do a lot of stuff..

PWA: It's that I want to do as much as I can while I can do it. That is real important for me. And it's - I don't care who it would be, that is part of your life that is taken away. A great big part of it, that's being independent.

Because gay men are socialized first as men in western culture, they learn to value the traditional masculine traits of independence and self-reliance and to foster those traits within themselves. At the same time, however, stereotypes of gay couples have informed us that one partner fulfills the dominant role (or male model) and the other the submissive (or female) role. Most of the couples told me this was not how their relationships were constructed. Many strove toward more egalitarian relationships but found the achievement of equality increasingly difficult as the PWA became more symptomatic. Because HIV infection threatened each individual's sense of independence and reciprocity within the relationship, many actions were directed toward maintaining the PWA's independence and functional status; protecting the PWA's self esteem when dependency was inevitable by creating illusions of independence; and offsetting the partner's loss of freedom and the constraint which came with providing 24-hour care to his lover.

Protecting the PWA's sense of independence was a complicated endeavor in that it often conflicted with protecting his physical health. As the PWA's physical needs increased and the partner provided more physical care, the PWA was placed in a dependent position and felt a loss of independence. Partners therefore often encouraged as much self care as possible, such as encouraging the PWA to take his own medications while "keeping a watchful eye on him" to insure his safety. One participant was particularly concerned when his partner took mind altering medications:

Partner: He does forget, he really does. Especially when he's taking any kind of pain medication, and he has had a lot of pain. He's had pretty serious headaches, so the doctors gave him Dilaudid, and Dilaudid is like a heavy narcotic. So it's a serious narcotic, so it's easy to forget that you got to take it. Or he sometimes forgets that he did take it, so I count them out, and that stuff.

Interviewer: So when he's taking pain medications, particularly something like Dilaudid, you have to be a little bit more on top of things.

Partner: Oh, absolutely. I don't let him cook or anything. Just kind of keep an eye out for him. And like he was saying before, we slept apart for a while because it's just easier on me and him too, I get much better sleep, and now that he's had so much going on in the last month or so, I don't want him to be in the other room where something might happen and I wouldn't know about it. So I stay close to him....It's quite likely something might happen and I wouldn't even know about it [if I were in the room down the hall]. And especially since his having this stroke, a seizure is a possibility. That worried me, so we're sleeping in a room together now. So those things are how I watch out for him.

Partners frequently resorted to covertly attempting to make the PWA think he was acting more independently than he actually was. Often they were reluctant to do this because they felt it was not fair to the PWA, and they adopted covert actions with considerable ambivalence. On the other hand, since physical health was such an important concern, most of the time partners justified their covert actions based on the PWA's more immediate need for physical protection. One partner described how he got his partner to eat more healthfully, yet let his partner continue to think that he remained in control of his diet:

Partner: I put things in his food that he wouldn't dare eat if I told him he was eating it.

Interviewer: Make a lot of casseroles, huh?

Partner: Yeah, I make casseroles all the time. And lasagna, I like to make lasagna cause I can throw a lot of tofu in it and he thinks it's cheese. And I

do the same thing with like yeast and bee pollen and stuff. He's had a B vitamin deficiency problem, and I can't convince him to take vitamins, can't convince him he should eat things like brewers yeast in a milk shake or something, so I just make it that way. "Here, eat this."

The PWA's decreased functional ability and increased emotional stress, then, placed him in a dependent position, requiring greater help and assistance from his partner. Many partners, in turn, reported taking on more functions or duties within the relationship. The division of labor within the relationship was a commonly reported example of adjustments made as a result of increased illness. The following partner explained the insidious shift of responsibilities as the PWA's health gradually declined:

Partner: Well, I think [his sickness] has slowly started to shift balance of who's giving more and who's taking more type of thing.

Interviewer: Do you have an example for that?

Partner: Yeah. Before Dennis and I started talking about his illness and his getting sick, it was... "Well, you want something? There's the kitchen. Go get it. I'm not your maid." I mean, I am tired too, you get out there and cook. But now with his health and seeing him come home from work and sitting down and falling asleep, or falling asleep on the bus because he was so tired, it's like, "Okay, well, you make the money and so I'll do what I can."

The couple's shifts in responsibilities and duties were not nearly as difficult for the partner as they were for the PWA. Usually partners were willing to assume responsibilities and to put more into the relationship. Since they were committed to the relationship and to helping their sick partner, they often assumed new responsibilities with relative ease. One partner expressed his willingness to help in any way he could:

Well, there is nothing I can do for him with the disease. Nothing at all. So I've just got to sit here and watch his life diminish and watch him get

weaker and slowly die, and there's nothing I can do. So the things I can do for him, I try to give him things that I wish somebody would give to me if I were in those shoes, do for me. What can you do for somebody? Try and make them as happy as possible. I think, "Well, what makes me happy?"

However, giving did take its toll, particularly when the needs of the PWA escalated. Some partners said that because of increased caregiving activities they felt "tied down" and felt a loss of their own independence and freedom. They found it difficult to meet their own needs because protecting the PWA's health became paramount. In addition, the increased caregiving activities often left partners feeling fatigued, overwhelmed, and sometimes angry and frustrated due to the sheer magnitude and relentlessness of the needs they had to meet. The following partner described some of the frustration and ambivalence he had recently been experiencing:

I don't get angry at him for caregiving to him. When I get angry with him it's when he's all settled and I've just settled and he says, oh, I need a blanket. Oh, come on! It's like I just brought you your drink and your straw and your medicine and everything (laughs) - you need to remember these things before I actually get settled. And that's been the only real, you know, problem that we've had is this, try to remember these things. Now, before I - you know, make a zillion trips back and forth, back and forth.

PWAs were by far more upset by the changes in reciprocity within the relationship as their need for care increased than were partners, as explained from the partner's perspective:

Partner: [Dependency] is difficult for him. It's easy for me.

Interviewer: It's easy for you to take care of him?

Partner: Yeah, to take care of him. It's no big deal. But yeah, it is difficult for him. He's really stubborn about it, too. And he doesn't want to surrender any control to me. We've had a couple of issues about that already....I really have a difficult time suggesting things directly to him,

because for him [my doing things for him means] that he's surrendered. And so I usually [am less direct in my approach.]

PWAs reported a loss of independence, humiliation, decreased self esteem, anger and depression as they relinquished responsibilities to their partners. One partner recalled his PWA's anger and frustration during an episode of pneumonia, but felt powerless to do anything about it or to change his behavior. The partner's main goal was to nurse his lover back to health:

Partner: ...that time when he had the pneumonia...I was always asking him, what do you want? and I was probably pestering him, too, you know. I want to help so much, I think I overdo it. Just constantly asking, do you want me to do this, want me to do that, and I don't think he even minded so much asking me the stuff as he didn't want to make the decision himself. Just do it. He didn't feel like making any decisions. Just bring me something to eat, put it there, if I want to eat it, I'll eat it, if I don't, I won't.

Interviewer: Would that be easier for you, like, to deal with or - ?

Partner: No. (laughs) Yeah, because even after he got better he was still in a weak condition, and I still had to do the cooking and stuff. And he doesn't like my cooking. [He is a tough person to cook for.] Even if you made something that's relatively good, it's - well, you could have done this, or you could have done that. I think it's probably more of a problem for me as the caregiver than it's for him as the receiving end.

Giving and receiving care were complicated by the fact that time lines of illness episodes were often vague and ill-defined. Neither knew if there was "a light at the end of the tunnel" or if the PWA was "really" ill and should be excused from responsibilities. After health crises passed, couples struggled with rebalancing the give-and-take within the relationship. PWAs generally wanted and needed to be able to give back to their partners when they could. Partners were either agreeable or had difficulty letting go of duties and responsibilities they had assumed. Pride in mastery sometimes overrode their desire to relinquish

responsibility back to the PWA. Also, some partners found that they enjoyed being needed during disease exacerbations and therefore had difficulty in letting go of activities that made them feel good about themselves. Therefore, during disease remissions partners struggled with learning to accept help from the PWA, just as the PWA had struggled to accept help during his times of greatest need. It was during these "good times" that the partner was most likely to engage in covert actions designed to foster independence while maintaining a watchful eye on the PWA.

Particularly for men, acceptance of help and expressing appreciation for help received can be interpreted as signs of weakness and vulnerability. It is not surprising, then, that men in this study often found it difficult to express gratitude for help received from their partners. Especially during times when the PWA already felt vulnerable due to impaired health, showing appreciation to a partner often made him feel even more dependent. Ironically, these were also the times when partners felt overwhelmed by caretaking responsibilities and afraid that their partners might die.

Some partners felt that they could have really used some encouragement in the form of gratitude from the PWA. However, given their weakened conditions, PWAs were often not physically or emotionally able to offer support to their partner; likewise, partners were reluctant to ask anything of PWAs. One PWA described a very difficult time while recovering at home from pneumonia. He felt helpless to reciprocate, yet he could not act differently because of his own suffering:

PWA: When I was sick I was told I was a real pest - and I wasn't.

Interviewer: Who told you that?

PWA: [My partner] or the nurse, one of those persons. Yea, I was being real snotty. I just wasn't feeling good and I was trying to take everybody else's feelings into account and it was hard because I couldn't make them understand that I didn't mean anything, I just wasn't feeling good. Just trying to be considerate of others, even though I'm the one they're taking care of, still trying to be considerate...

In summary, balancing the give-and-take and dependency were sources of conflict between PWAs and their partners as they struggled to cope with the shifting demands of illness. The remissions and exacerbations of HIV infection further complicated efforts to work through these conflicts because the conditions for giving and receiving were so changeable. However, couples who successfully negotiated giving and receiving help seemed to emerge from their struggles with a deepened sense of commitment to one another and increased satisfaction from the relationship.

Preserving Intimacy. The amount of intimacy in a relationship reflects the warmth, closeness, and deepest association between partners. The basic problem for PWAs and their partners was how to achieve, regain, and maintain intimacy given the PWA's health status and desire to protect the partner from becoming HIV-positive. Factors which interfered with the couple's sexual relationship, and therefore their sense of intimacy, included the PWA's desire to keep the partner HIV-negative, the partner's fear of becoming HIV-positive, both the PWA's and partner's fear of "giving the PWA some kind of infection," and decreased interest on the part of the PWA due to fatigue, malaise, and declining health. On the other hand, the deep sense of commitment felt by couples was the major factor that helped them to weather threats to intimacy. Attempts to preserve intimacy were likely to be overt, since the costs of not preserving it were high, that is, resulting in dissolution of the relationship.

The first and foremost priority of most study couples was learning practices of "safer sex," that is, sexual activity that decreases the chances of transmitting HIV from one partner to the other. Keeping the HIV-negative partner free from HIV was often the most profound burden faced by PWAs. Since all participants in this study were well versed in how HIV is and is not transmitted, few feared casual spread of HIV but had reservations about sexual transmission. Despite the fact that all couples in this study were well informed about "safer sex," that is, how to preserve intimacy without compromising the HIV-negative partner, all PWAs of HIV-negative partners feared the possibility of transmitting the virus. Fear of transmission of HIV to a negative partner was thus given as a reason for celibacy. One man eloquently and painfully described what this was like for him:

PWA: As far as Jack is concerned, we could have just gone on normally the way we always had been, and things would have been fine. I can't accept that responsibility. I just cannot accept that responsibility.

Interviewer: What responsibility?

PWA: Of exposing him to HIV. Okay? As far as he was concerned, we could just go on our merry way. Having sex and being the same, okay? And everything being the same. As far as he was concerned, nothing changed when I came out of the hospital. And again I think that's mainly because he's always been sick. So as far as - oh, well, okay, you're sick, so big deal. Well, big deal. You should know! This'll kill you. And in his case, probably even quicker than anybody else because of his diabetes. And I just can't accept the responsibility of being the one to do it....I've been trying to push him away. Purposely, methodically. I guess in my own stupid idiotic way, I'm trying to protect him from the inevitable, which I can't do. We have not had sex in about two years. Not his choice, my choice. He's negative, was when we first met....After I got sick, we attempted to have safe sex, but I just couldn't - the thought of killing him, I couldn't handle. I still can't. I love him, I'll do anything that I can for him, and I've told him and we've talked about it - it's been a real bad 6 months, the last 6 months, because I've been trying to push him away and he's

trying to get closer. And I enjoy the affection but I'm afraid that I'm going to get to the point where I'm going to want to have sex and we're going to do it and we're going to become unsafe. Or God forbid something else would happen. I mean, that's the major concern.

While many couples practiced safer sex out of necessity, and learned to adapt, most found it less desirable and wished they could go back to more spontaneous sexual expression without having to worry about HIV and other sexually transmitted diseases. As one HIV-negative partner commented, "When we were having sex, [HIV] was always on the back of my mind...HIV took the fun out of sex." Couples mourned the sexual expression and affection they had enjoyed before HIV was a concern. One PWA who has not been sexually active in quite a while stated:

I miss the affection. I can remember in the hospital, I hadn't bathed in like two weeks. And they had a nursing student who came in one day, and she says, "How would you like it if I gave you a bath?" I said, "Oh, that would be great." And it was so wonderful. It was totally non-sexual, but it was just so wonderful having somebody physically touch me. It really meant a lot.

When coping with a loss of intimacy within their relationships, couples often attempted to redefine their relationships by decreasing the importance of sexual activity and focusing on other aspects. Many couples reported that their relationships had become stronger and more satisfying since the onset of HIV infection. Because in many cases their sex life had been taken away, they found other ways to express intimacy. As one partner described:

[Since Larry has been sick] we've gotten a lot closer, we're a lot more loving in a non-sexual way than we were. Definitely feel that we have more compassion for each other. It's really, that's the one positive thing out of all of this. Our relationship has gotten much deeper.

Most couples found substitutes for sexual expression which, prior to AIDS, had served to solidify a sense of closeness and intimacy. Substitutions included reveling in the "good times" when the PWA was feeling well and could enjoy simple pleasures, improving their communication with one another, and spending quiet time alone together, "creating memories." Companionship took on an increased sense of importance.

I was talking to my friend on the phone today, and we were talking about a mutual friend of ours - and this is a straight friend of ours - who has a very strange relationship with his wife. And I said, "Well, the problem with him is the fact that he's one of these type of people that he always thinks that rockets have got to be going off all the time." I think as you get older - it seems like companionship is much, MUCH more important. I watched too many friends or people that I've known who have been married and, you know, they got married - - this was great, it was very emotional and they had super sex and all of that, but they weren't really very good friends and then all of a sudden 3 years or 4 years or 5 years later they were all getting divorced. I don't think it's that much different for us. I think we probably tended - I think gay people particularly have greatly tended to over stress the sexual aspects of their relationship and have greatly underplayed the other aspects of it. So it's just not that big a deal. Plus I'm so stressed at the moment I'm not sure I care! (laughs loudly)

Couples learned to savor the good times together to protect what intimacy was possible in light of losing sexual intimacy. They often focused on other things that go into making a satisfying relationship. The partner of a quite debilitated man described the heightened importance of shared activities:

[Being in a relationship with someone with AIDS has] its good moments too. And you learn to appreciate the good moments and you learn to appreciate whatever duration of time where the person's feeling pretty good. You learn to appreciate simple things like being able just to walk 4 blocks to go to the local neighborhood restaurant and have a meal and be able to walk the 4 blocks back.

Even enjoying activities together often became more difficult as financial restrictions limited their ability to engage in activities or as the PWA's health deteriorated. One PWA who used to enjoy going out frequently with his partner lamented:

I don't feel up to going out and so Mike goes out by himself more. He would like me to be with him, but I think he understands when I am tired, but it is hard for him.

While most couples sought to preserve the intimacy within their primary relationship, some individuals turned outside of the relationship for sexual intimacy. While in each case the partner was aware of the other having sex outside of the relationship, it was something the couple did not talk about with one another. In one case it was an accepted arrangement from the beginning of the relationship; in the second case both partners felt that talking about it to one another would be too hurtful for both of them.

Moving On -- A New World View

The end of the transition of becoming a couple with HIV infection was marked by several emotional stages: acceptance of a world in which loss and uncertainty were expected, if not commonplace, and moving on with one's life within the relationship having renegotiated its meaning. As the transition ended, couples had reached new balances in their lives and had achieved a sense of integration of their experiences since the time HIV infection hit home (Bridges, 1980). Each individual renegotiated meaning in his life based on the meanings of the losses incurred. Couples moved on with their lives, having forged new conceptions of the future, the meaning of death, as well as the future of the relationship.

Stated conceptually, settling on a view of the future in light of HIV infection was the context around which couples organized their perceptions and actions toward a shared time line. As Kantor and Lehr (1975) explained, "The movements of family members can be traced across two different kinds of time structures, clock time and calendar time." Prior to HIV infection these couples accepted a world view based on implicit assumptions, perceptions, and expectations about the dimension of calendar time. The onset of HIV infection challenged study participants to redefine their relationships based on a different perception of calendar time and their expectations about themselves as a couple within a relationship that might or might not extend into the future. New approaches to life therefore arose from these new perceptions and expectations. Settling upon an acceptable view of the future, with HIV infection a part of that future, was a major task for couples affected by HIV infection.

Participants in this study settled on one of two radically different perspectives of the future: succumbing to AIDS or surviving HIV infection (Figure 4). Such views, however, were not static. Most study participants tended to express conflicting positions during the same interview. Succumbing to HIV infection was by far the more common conception of the future held by study participants. Succumbing to HIV infection was defined as living with HIV infection with the belief that the PWA would have a shortened life due to HIV infection. Succumbers believed that death from HIV infection, whether in the near future or in the distant future, was inevitable and therefore the duration of the couple would be shortened due to HIV infection. The statement of one partner (who was HIV-positive and asymptomatic) summarized the perception of succumbing to AIDS:

[My partner] always accuses me of this, too, I play it all the way to the end. I don't mean that [death] is gonna happen tomorrow. But it is going to happen. I mean there is nobody who has survived AIDS, yet. It's still a fatal disease. And so that is going to happen....and there isn't a damn thing I can do about it. But its time frame is so ambiguous, I have no idea. Is it going to be three years, is it going to be six months? Two weeks, I don't know. That's part of what drives my ability to really change my life. That I don't know how long I'm going to last, and need to make some decisions based upon that.

Succumbing to AIDS was also sometimes a surrendering to death, that is, facing the reality of a gravely ill partner (or of oneself), and an acceptance of death. After a long struggle against HIV infection, sometimes partners and PWAs felt comforted by succumbing to AIDS, knowing that "the end was in sight," or that they could finally be at peace. One PWA who had been very ill for a long time expressed his surrender to AIDS:

Interviewer: You seem much happier - you seem more comfortable or more at peace with yourself now than last time when I talked to you.

PWA: Well, I'm not afraid of dying anymore. I was afraid that I was going to die. And I thought, if you die, there's not going to be any more being sick and there's not going to be any more pain, like shots, or things like the MRI machine and stuff, and then you'll be at peace, and that really comforts me. In fact, sometimes I sit around here and I cry. But it's not sad anymore. The last couple of weeks I was really - it seemed to me that I was really sad all the time, and it didn't matter much what I did, I sat here and just watched TV all day long. And now it's important for me to go outside, even though it's cold, but I love the fall. And I really enjoyed it even though Sam - we live on this hill, so everywhere we go is a hill - but he pushes me without any complaints. And I even offer to walk sometimes. And he says no. He insists that I stay in that chair. (Case103)

	<u>Perceptions of Future/ Endpoint of Life</u>	<u>Emic example</u>
<u>Succumbing</u>	Death will be caused by AIDS	"My lover is going to have a shortened life due to AIDS."
<u>Surviving</u>	Unknown or uncertain	"Life itself is uncertain. I [PWA] could get hit by a car tomorrow and die, or I could die from HIV infection next month or 20 years from now."

Figure 4. Moving On Based on a New Conception of the Future: Surviving or Succumbing

Alternatively, surviving HIV infection was defined as living life with the belief that HIV infection was not necessarily fatal. These individuals held very strong beliefs in the power of hope to overcome the threat of HIV infection. Survival meant that there was hope of "beating the odds" and "defying the statistics." Surviving HIV meant that there could be a continuance of the couple's relationship into the future. Surviving HIV infection was exemplified by one PWA as follows:

PWA: ...we went to a positive loving meeting last night, a workshop, and one of the first questions they asked was 'How long do you expect to live.'

One end of the room was two years or less and the other was 50. I stood at about 20 to 30. So it's very survivable, it's just a matter of surviving it.

Interviewer: I thought you were going to tell me you don't know the answer to that.

PWA: Actually, I don't know, but you know, if I had to guess...Based on my age now, I figure 25 or 30 years would be max anyway. So you know, I can only hope for a complete life. I don't know that, I mean I could walk out of here and get hit by a bus, that's my famous line.

Both people with HIV infection and their partners were represented in the category of surviving HIV infection. They cited the increasing length of time from diagnosis to death; improved detection and treatment of opportunistic infections; encouraging research on vaccines; parallels of HIV infection to cancer (a disease that is increasingly viewed as survivable), and vigorous research that could lead to a cure as evidence that it might be possible to be cured of AIDS one day in the future. As one participant succinctly stated, "My goal is to keep alive until a cure is found." Factors that study participants thought to be responsible for increased survivability of HIV infection included: positive attitudes; assertiveness in obtaining medical care; money and other resources necessary to obtain care and support; supportive friends and family; and a solid primary relationship. In fact one, PWA felt that his participation in an "AIDS Caregiver Study" could indirectly enhance others survivability:

I think the caregiving is a very important factor in HIV related illnesses. I think the experiences of people giving care and receiving care is a real big issue, and I think if some improvements can be made in the caregiving, there might be a better survivability rate.

The position on surviving HIV infection was by far the more difficult for participants to maintain than that of succumbing to HIV infection. Survivors acknowledged that the public discourse on HIV infection is focused on AIDS, the

final and most severe form of HIV infection, without giving attention to earlier disease. Participants often blamed the pervasiveness of media messages that HIV infection is a fatal disease. Because of the media's messages, Survivors contended, the media often undermined their confidence in surviving HIV infection.

However, study participants acknowledged pockets of resistance, such as a book entitled Surviving AIDS by Michael Callen (1990). The following conversation with a PWA who had just read Surviving AIDS emphasized key elements in the cultural expectations about the survivability or terminableness of AIDS:

Interviewer: I think what people like Callen are saying is that the dying phase may be needlessly expected by people, I mean -

PWA: Oh, absolutely. The media has played that aspect of the disease up to the point where you can't pick up a newspaper without seeing the statistics on how many people have been diagnosed and how many have died from it.

Interviewer: It's true, you don't pick up a paper and see long term survival statistics.

PWA: The media's expectation is that nobody survives....I mean, it was just a few years ago where the expectation was that you would die from AIDS within 2 years, but now with the medicines that they're using for the OI's [opportunistic infections] seems to have prolonged your ability to live with the disease rather than look at it as a foregone conclusion that there's nothing they can do.

Interviewer: In fact, the messages that are in the media, that people talk about, I mean, that people think about when they think about AIDS as a terminal illness, really has - there are important implications for those people who have AIDS. I mean, in how they live their lives. Doesn't it?

PWA: Yeah. I mean, it's like coming down with cancer. Cancer had such a negative connotation that if you told somebody, as a physician, that they had cancer, the immediate thing that would come to mind would be death. I mean, the two were on the same level. Cancer equals death. But now, with the drugs that they've come up with, it's terminal - it's a treatable

disease. Certainly, there are certain types of cancer that aren't as treatable...

Interviewer: What I've found - while what you say is true about people living longer with AIDS, I wonder why the popular image still is this death sentence. It's that people just don't know there's some kind of - ?

PWA: It's lack of information. That's the only thing I can figure out.

Interviewer: Another thing that might, what I just thought of now is that I think a lot of people - I think a person or people are more likely to know somebody with cancer than they are with AIDS, right now. I mean, cancer - it's so broad, and it's a more common disease right now than AIDS. So maybe they are more used to seeing people who have survived cancer, you know, who have been cured of cancer, who have been doing really well for many years in spite of cancer. But if you don't know somebody with AIDS, then it's kind of easy to hold onto those images that you had at the beginning. You know, so that when you don't see people living with it, coping with it, dealing with it - so you just kind of don't think about it? You might not have any reason to change your opinion - if it's not in the media and you don't know people, that's a choice, you know, you just kind of hang onto that - that death sentence -

Some study participants did not hold the media solely responsible for perpetuating the belief that AIDS was terminal. The partner of the PWA quoted above explained his understanding of the interrelatedness of the media, the medical profession, and the general public:

Interviewer: Instead of a death sentence, it really can be surviving AIDS. I mean, it's like a different orientation to -

Partner: Exactly. And one of the things they point out in Surviving AIDS is that a lot of the attitudes that we have about that is really an attitude that's been promoted by the media. And we all are subject to media because we all read papers and read magazines and we watch television. And it's really an attitude that's been fostered very heavily by the media, and the people in the medical community aren't any more immune from that than anybody else in the general populace. So you kind of get infected with this idea, no, you're going to come down with AIDS, you're going to have one or several horrible infections, and then in a short period of time you're gonna

be dead. And they never concentrate, or very little is done in terms of talking to people, finding out about people, who have had the illness long-term. There's a guy in New York, I think he's still the longest surviving AIDS patient.

Interviewer: Do you know how long that is?

Partner: I know he's had it for at least ten years....And he's survived it! So who knows what's on the horizon? I don't know. My feeling is that every day you survive it is hopeful they will be closer to being able to do something about it. Just ahead of time.

Those who believed that HIV infection was survivable were often branded by friends, families, and partners as being "in denial" or dismissed as living in a "fairy tale world." Sometimes these types of reaction were difficult for survivors to tolerate, but one study participant reported a different reaction to those who belittled him for his optimism surrounding HIV infection:

[My response to those who say I have a Pollyanna view about AIDS is]....I guess I'd rather be optimistic than pessimistic! (laughs heartily) I mean, it's pretty easy to be pessimistic - about that type of thing. I mean, I guess my attitude is sooner or later, most things in life, they find a cure for. Or they make significant progress in. I mean, look at what they've done with cancer. A number of people that years ago would have died from a lot of the things that they certainly don't die from today. So my attitude is well, why should this be any different? I just don't know, as does anybody, what the time frame is [for AIDS]. Twenty years away or fifty years away? It could be five days away. I don't know.

Telling a partner that he was in denial often was received as an accusation. In response, study participants who were accused of being in denial generally responded with either anger or by ignoring the accusation to avoid an argument.

The wording of these phrases, surviving HIV infection and succumbing to AIDS, was chosen deliberately to reflect different perceptions of HIV infection as a spectrum of illness versus AIDS as a terminal condition. Public discourse that focuses solely on AIDS misses the distinctions between HIV illness and AIDS.

Asymptomatic illness and less severe forms of HIV infection are therefore conflated into an inevitably terminal condition. Sontag (1988, pg 29) said:

...AIDS is not a single illness but a syndrome, consisting of a seemingly open-ended list of contributing or "presenting" illnesses which constitute (that is, qualify the patient as having) the disease, makes it more a product of definition or construction than even a very complex, multiform illness like cancer. Indeed, the contention that AIDS is invariably fatal depends partly on what doctors decided to define as AIDS--and keep in reserve as distinct earlier stages of the disease.

People in this study who chose to use the term HIV infection did so in part to weaken the notion that the inevitable end point of HIV disease is death.

Although many actions taken by those who hold Survivor versus Succumber positions may seem similar, they are motivated by different underlying assumptions about the future. Therefore, to understand the behaviors of individuals it is critical to understand the meanings they attribute to their situations. Examples of similar behaviors motivated by different conceptions of the future can be found in the strategies which study participants used in making death preparations and the decisions study participants made to live one day at a time and to keep a positive attitude.

Although most persons with HIV infection in this study had made preparations for their deaths, such as writing living wills and granting their partners durable powers of attorney, Succumbers did so because they were preparing for their inevitable or impending death from HIV infection. Survivors, on the other hand, did so because they realized that death could come at any time from any number of sources, and that making preparations for one's death was the

prudent thing for any responsible adult to do. As one PWA, whom I classified as a survivor, declared:

...once somebody is 18 and gets out on their own they should do all these things, they should have a will, they should have a directive to physicians. You know, once you're legally no longer under your parents obligations, all those things should be done. Because you never know...That's pretty difficult.

Other actions by Survivors or Succumbers were more distinct and characteristic of their views of the future. In general, partners who were Survivors tended to be assertive in their relations with the PWA's health care providers and strove toward forming partnerships with them. In addition, Survivors who were PWAs were likewise more assertive in their own medical care than were Succumbers. One man was quite assertive in his care and willing to look for alternative therapies and take risks:

Interviewer: Before, you mentioned the victims of AIDS. Can you tell me a little more about what you mean by that? Are they describing the people that feel victimized and who shun maybe yoga and all alternatives you are pursuing?

PWA: They go to...there's nothing wrong with going to a doctor. But what is your intention of going there, are you going there with the intention of him healing you, or are you going there with the intention of him helping you heal yourself? And [for victims] it's a sense that a lot of these people are not taking control of their situation. They're just letting themselves out there - here, use me like a guinea pig.

The approaches Succumbers and Survivors used in making decisions about AZT were specific examples of health care decisions based on different views of the future. Every couple discussed experiences with AZT, since at the time of this study, it was the only drug readily available to halt the progression of HIV infection. Succumbers tended to passively accept AZT from their health care

provider because they felt that they had no alternatives or say in the matter. In contrast, Survivors tended to question the benefits of AZT. They often made the decision to forgo AZT therapy or to take it in a manner that they decided for themselves. Survivors tended to adjust doses of AZT on their own, with or without their health care provider's knowledge, based on how they were feeling. Many noticed that they felt "run down" when taking higher doses of AZT and were willing to take it "as needed" or "as tolerated," realizing that they might or might not be receiving the full benefits of the drug. Similar to many attitudes of PWAs, the following quote is from a study participant who regulated the dose of AZT based on his level of well being:

PWA: I realize that I may have to try some [conventional medicines], and there's no right or wrong with that...it's all another belief system. A couple times I've been very close to giving up the AZT because the rest of my diet is so clean, in that I eat as many organic vegetables and fruits and foods as I can, and when I put AZT in my body I can really sense the effects of it. It's like liquid Drano sometimes.

Interviewer: You feel different, you can tell?

PWA: Oh, AZT just basically messes with my intestinal tract, makes me become nauseous. I'm supposed to be taking 500 milligrams a day, I tried 300 and now I'm taking 100 milligrams a day and still having some difficulties with it but, it's tolerable, so that's where I'm going to stay. It's helped to raise my blood platelets. What classified me as class 4, is my blood platelets were 50,000. And I think a normal person's platelet count's 100-120,000. And so it has benefits there. But I don't think that I could take 500, 300 milligrams a day, and not be a bitch, cause I fê:t like shit. And that's okay, there are so many other things, like shitake mushrooms....I have a arsenal of vitamins and herbs, and some kinds of holistic things that are natural antibiotics.

As study participants settled on an acceptable view of the future, they began to think about the goals that they had held for themselves, both individually and as

a couple, before HIV came into their lives. In general, succubers tended not to live for the future and were likely to abandon what had been important goals in their lives. One partner who was HIV-positive said that he was not going "to bother to go to electronics school because I probably won't be around that long." This attitude seemed to inhibit actions and limit their view of their future and their possibilities for the future.

Survivors evidently live with long-term goals in mind; they were realistic enough to know that these might not be realized, but this did not stand in the way of living for their future dreams. Surviving embraces a future orientation, succumbing does not. Succubers were more likely to give up on their dreams for the future. Because those PWAs and partners who succumbed to AIDS anticipated a shortened life span for the PWA, they reflected on what that meant in terms of the future of their relationship and on their ability to make plans for the future as a couple. This idea was expressed by one couple as follows:

Partner:Most people I assume plan for the future - plan to grow old together, and that's something that we can't do.

PWA: That's true.

Partner: So it's getting used to a short-term relationship. Trying to make the best of it, and for as long as you can....So usually people in this age bracket think about making plans for the future as a couple, well, it's different in this situation. Can't really make any plans for the future as a couple, that's for damn sure. So - I'm pretty content. This is all people do anyway is live, this is all there is to it.

Another partner, who was also HIV-positive, was even more resigned to the loss of goals that he felt had been robbed from him because of HIV infection:

Interviewer: So is your dream, then, of going to school pretty much gone?

Partner: I know it'll never happen. Even up until this [HIV infection], I thought it was still possible. Maybe something will happen, maybe I'll find another job that does pay, or it has some kind of educational benefits, you know, or I'll be able to go back to college. That'll never happen. And even more in the last year or so, I've gotten [HIV infection] - and I try to fight it, but I just can't, I just got this thing in my head that why even bother now? Why even bother? Even if I go through and I learn all this stuff, I'm going to die anyway, so - why waste the effort? [blows nose]

Interviewer: Well, what does that do to you? It sounds really as if something's been robbed almost.

Partner: Yeah, that's what I feel.

"Living one day at a time" defines the gestalt of moving on and was echoed by virtually all study participants whether survivors or succumbers. While the words might sound trite, living one day at a time was a major strategy used by study participants to cope with multiple losses. They sincerely believed in the power and value of living by this rule. Study participants sometimes said that people in their networks accused them of taking a one-day-at-a-time stance to justify "being in denial." Study participants felt that accusations of denial trivialized the difficulty and hard work associated with focusing on the present and living life to its fullest.

Among Survivors and Succumbers, taking one day at a time meant different things. For the succumbers, taking one day at a time meant that they had let go of goals and future dreams, realizing that they would never be fulfilled. In contrast, survivors took one day at a time because they now had the wisdom to realize that life for everyone is happenstance. They tended to view their worlds as more probabilistic than absolute (Mishel, 1990).

Finally, Survivors tended to believe that retaining a positive attitude was an essential ingredient for survival. For this reason they tended to surround

themselves with positive people and to avoid those who "brought them down." As with living one day at a time, focusing on the positive could sound like a trite prescription for life, but survivors earnestly believed in the power of keeping a positive attitude in order to resist AIDS. One PWA related his feelings about keeping positive in the face of HIV infection:

PWA: Because maybe I'm trying so desperately to survive and you don't want to deal with altercations with people, you don't want to deal with anything negative, you want everything to be positive...and living in a city you have to deal with stress, especially working with the public. I don't think I'm dealing with anything more than anyone else.

Interviewer: Probably a lot of people who disagree with you on that. Because you seem to have a very positive attitude.

PWA: I try. It's hard sometimes.

Interviewer: What do you do to maintain that positive attitude?

PWA: I try to have faith in what I do, no matter how bad things may be or may get, there's always positiveness that can come out of everything. If I ever were to give you my life story then I might be able to explain it, but it was something that I learned that you have to be, even if this particular segment of life is negative, you still have to have a positive outlook that eventually things will get better. And I've got a very supportive relationship, and we have our troubles like anybody else, but Ian is showing me that people can be trusted, that he won't run off, that he's here to stay, he's very supportive in a lot of ways. He's a wonderful man.

As the PWA indicated, having a supportive relationship helped PWAs to keep a positive attitude. Partners often said that one of their main roles in caring for their lovers was to help them keep a positive attitude in the face of HIV infection. One partner described the lengths he went to encourage and support hope in his partner in the face of his own fear and uncertainty:

I may sound confident and resolute about what's lying ahead, but I'm afraid. And you have to make that work for you instead of against you. If you're the primary support person for the HIV or the AIDS person, it's okay to show weakness, but not too much. You have to be strong for the other person, and you have to make them believe, as much as you believe.... You have to make them believe in themselves, in the hope that maybe there will be a cure, or that they're doing the right thing, they're making the right decision, whatever decision they make about their own health care.... But I'll always be afraid.

Data from this study suggest that the transition to becoming a couple affected with HIV infection ends in a conception of the future as surviving or succumbing to HIV infection; it does not necessarily end with the actual death of the person with HIV infection.

While the death event was not the focus of this study, it deserves comment because preparing for the event was such a strong theme in the data. Death of the person with HIV infection defines another transitional experience because it is a major, if not the most meaningful and difficult, loss for partners to endure. One study participant, a partner, had previously been in a relationship with a man who had died from HIV infection. His story of the death of his previous lover exemplified that the death experience characterized another profound transitional experience in his life. As with any transition, the moment he realized his lover was going to die was described as a period of confusion and uncertainty, followed by a period of grieving, and finally of moving on with a new life without his lover. His perceptions were congruent with Benoliel's (1988) assertion that the human condition is characterized by multiple overlapping and interacting transitions.

As with other aspects of loss among gay men, moving on with a new conception of the future is different for gay couples because of society's assumptions about couples, that is, that heterosexuality is the basis for coupling.

In a society that does not validate gay couples, little formal recognition is given to the grief process as experienced by gay men. This lack of formal recognition complicates efforts to move on with one's life because it creates environments that are unsympathetic and nonsupportive to the needs of gay men as they struggle with the pain of losing their lover.

In summary, hitting home, mutual protection, and moving on are three processes in a grounded theory that define the transition of becoming a couple with HIV infection. Loss is the social psychological problem implicated in these three processes. Furthermore, the unique position of study couples as gay men in our society makes their experiences more problematic as they struggle with a threatened loss of life or the loss of the most important person in their lives.

Heterosexism:

A Social Structural Condition of Becoming a Couple Affected by HIV Infection

This section of the results focuses on the secondary objective of the study: to explore perceived salient aspects of the social context that influence and are influenced by the couples' experiences. In explaining human actions it is often helpful to contextualize personal experiences in ways which explain the acknowledged and unacknowledged forces that act upon social actors. Additionally, to gain a deeper understanding of human action it is helpful to differentiate between the unintended and intended consequences of those actions on social structures. Thus, a structural analysis makes possible both understanding and explaining action beyond individual attitudes and behavior to the conditions that sustain them. From a structuration perspective the focus of analysis is a dynamic interplay between social structures and the actions of people within their social context as they are implicated in one another. Thus, social structures are the

medium by which action is possible, and also the outcome of the action they recursively organize (Giddens, 1984, p. 374).

In this study, therefore, I am interested in the extent to which the activities of becoming a couple affected by HIV infection influence and are influenced by the social structures relevant to those experiences. Social structures are viewed in duality: as conditions and consequences of patterned actions over time and across space.

As I listened to the narratives of the study participants, I began to understand the powerful impact that heterosexism as an ideology had upon their personal experiences. Heterosexism is defined as a socially constructed belief that heterosexuality is intrinsically and totally superior to homosexuality (Biery, 1990). Also, I began to think of their personal experiences as reflections of their social context as well as voices that were implicated in changing the very structures that affected them. Therefore, heterosexism was not a discrete entity that acted upon couples' actions, but a structural dimension of society that was created, recreated and altered through their actions.

Because I have introduced a conception of social structure that departs from the traditional symbolic interactionism perspective, heterosexism does not appear in the grounded theory derived from this study. Moreover, a methodological shift is necessary. From a symbolic interactionism perspective, social conditions are macro social patterns that influence individuals' actions. These patterns exist only through symbolic interaction and the shared interpretation by social actors. In applying Giddens's theory of structuration, interview data, that is, the voices of study participants, are treated as narratives that mirror and create the social context of which they are a part. The meaning that individuals attribute to their actions are

socially produced and institutionalized because they are reproduced in individual interactions. Understanding the behaviors of study participants requires understanding the conditions and motivations that they recounted. However, this is not sufficient to explain the roles social structures play in affecting behavior. A more complete understanding can be achieved by contextualizing the narratives in the social world of which they are a part and whose social structures serve to explain their actions. Gayness, therefore, must be treated as a social construction, not as a variable to be correlated or studied out of context. The following analysis is an attempt to understand the gayness within becoming a couple with HIV infection and as a social phenomenon that is grounded in the ideology of heterosexism.

Heterosexism and Homophobia: The Unacknowledged and The Acknowledged

In this section my intention is to be one voice that seeks to accurately reflect and validly interpret the perspectives of study participants as told to me, not the sole voice that claims to speak universally for all gay men affected by HIV infection and their partners. Although study participants often gave explanations for their behavior, there were also unacknowledged conditions that explained their behavior. As Giddens explained (1984, pg. 27) human knowledge is always bounded. In this section, I will articulate one social condition, heterosexism, that was both acknowledged and not acknowledged by study participants. My intention is to facilitate dialogue and insight by making explicit the unacknowledged conditions which shape the lives of gay couples who live with HIV infection and to articulate some of the unintended consequences of their actions. Gay men whose lives are affected by HIV infection may choose to use my writing to shape their own experiences as I have used their dialogue to shape

my understanding. This intersection between study participants' experiences and the metalanguage I have developed as a result of studying them is the double hermeneutic of social sciences about which Giddens (1984) wrote.

According to Giddens, important dimensions of structuration are time and space because the routinization of actions within regions of space are the patterns that we recognize as institutions. This study reports on a snapshot of gay relationships, but it represents gay relationships in their inescapable historical context. Although this study was conducted in one city, it is reasonable to assume that gay couples affected by HIV infection in other cities are similarly influenced by the condition of heterosexism.

What is the relationship between becoming a gay couple affected by HIV infection and the social structure as it is organized by heterosexism? Power structures, such as heterosexism, were generally the unacknowledged conditions that affected couples' experiences, yet the impact of heterosexism was profound. Biery (1990) defined heterosexism as follows:

[Heterosexism] is the same as racism and sexism. Heterosexism elevated heterosexuality from a sexual orientation to the status of institution that becomes enforced through ideology, theology, and other social institutions. In effect, "straight society" has consciously or unknowingly defined and maintained a view of sexuality which assures it a position of superiority (pp. 88-89).

Although study participants did not use terms such as heterosexism, oppression, and power, they implicitly acknowledged the presence of heterosexism by framing their discussions within the context of homophobia. According to Biery (1990, pg. 89) homophobia is rooted in heterosexism, "...but goes well beyond heterosexism. This basic feeling of superiority becomes exaggerated, irrational. Most people become unable to even explain why they feel the way they

do about homosexuality -- they just do. When this happens, heterosexism becomes a phobia: homophobia." Homophobia has become the common language to express heterosexism, in part because expressions of fear, such as the increasing incidence of hate crimes, violence against gays and lesbians, and "gay bashings," are highly visible, and understandably highly threatening to gay men. According to a study of 1,281 gays and lesbians living in Seattle, 16% of all respondents reported having been physically attacked (Seattle Commission for Lesbians and Gays, 1991). While 75% of respondents reported having been the target of either verbal or physical attacks, physical attacks are the most threatening outward consequences of irrational fear and homophobia since attacks on the physical body are concrete and real. Study participants frequently cited homophobia as a reason for acts of violence and discrimination directed toward them and their friends. One man gave a chilling account of his friend's and his own experiences as targets of gay bashing:

Partner: I would like to see homophobia gone. I would like to see that gone. I would like to see straight people and gay people interacting together, not being scared of each other. It'll take a while. There's a lot of prejudice out there. One thing I cannot stand, like I told you the other night, gay bashing. It's not right. To hate somebody just because of their style of life or their sex or what they do with themselves. That's their own - freedom. Just like the other day, my boyfriend said, take the knife with you. I said why? That's really going to help. I've got my keys, I know what to do with keys, and he's like, take it with you just in case there's some skinheads and they come through the park. I said, no, there's gonna be people out there. I'm the best runner and nobody gonna catch me.

Interviewer: I tend to think of this part of town as being a safe place for gays, but what you're telling me...

Partner: It's not, it's not. I had a friend who was dragged down the street, named Ray, she's a man - she's in between - and they robbed her, what they

did was they grabbed her purse and dragged her down the street, and they ran over her leg, she got caught under the truck, they ran over her legs and broke her legs. She was in the hospital for a while. Real nice person, you know. I guess basically they wanted her purse, they wanted her money, but I really can't say if that was gay related or not. It could have been because you can tell she's a drag queen, she always wears makeup all the time....Just like the other night, these guys were going to be beat us up for no reason, just because they didn't like us, because we were gay, that's why. It is a mad feeling because - what did we do to you, you know? We didn't do anything, we were just walking down the street. Of course, I had these shorts... They said, oh, look at that one, he's got those fucking tight shorts on....They were like making fun of us and they were doing it for a reason because they wanted to bash us, they wanted to start some violence.

This man's account was framed within the language of homophobia, fear and hate. But as study participants continue to focus on individual attitudes or beliefs, they are likely to remain naive about heterosexism as a social construction that is systematic in its application and its consequences. Niesen (1990) proposed that redefining homophobia as heterosexism facilitates the examination of the social environment in which we live. Furthermore, as long as social observers continue to focus on homophobia as a variable to be studied, the longer we are likely to remain distracted from the privileges enjoyed by heterosexuals. While homophobia targets homosexuals or the beliefs of some individuals, heterosexism raises the question of how heterosexuals sustain their position of privilege. Although homophobia provides a possible explanation for violence against gays, it is less successful in explaining not only the limits of homosexuals' actions but also the basis for the privileges associated with being heterosexual. McIntosh (1988, pg. 12) reminds us that "heterosexual privilege makes married persons comfortable and powerful, providing supports, assets, approvals, and rewards to those who live or expect to live in heterosexual pairs." Heterosexual couples forget that they have the privilege of walking down a public street holding hands, talking about their

spouses among business acquaintances, and asking physicians questions about the partner's health, without their sexual orientation becoming a topic of derision, a target of violence, a curiosity to be studied, a defect to be corrected, or a moral breach to be condemned. Furthermore, heterosexual couples facing a life threatening illness are privileged because they can openly express their pain and grief, function as a team within the health care system to obtain services and resources, and take time off from work to care for one another without their moral character being called into question.

Since HIV is a relatively new disease, identified in 1981, heterosexism preceded HIV infection. While HIV infection is not responsible for heterosexism, homophobia, and gay discrimination, many study participants felt that because of the demographics of HIV infection a heightened awareness of gay issues resulted. One participant explained the relationship between HIV infection and homophobia:

A lot of people say that AIDS has created a lot of homophobia. Granted, I think it has created some, but I don't think it's created as much as they would like to believe. And I think it was there, it's just a matter of its coming out more. And I think the answer to curing some of it is education.

And another PWA explained the double dose of shame, or internalized homophobia, that he felt because of being a gay man and a person with HIV infection:

PWA: There's a certain shame that goes along with having AIDS that I'm still dealing with. And I didn't realize it until [my support] volunteer had come over who's HIV-positive. We were talking, and he says, "Do you feel some shame still?" And I said, "Yeah, I do." It was around the time that I got the reaction from my brother, when he told me that he wasn't going to let me see him or the kids. That reinforced it for me.

Interviewer: The shame must be really hard to deal with.

PWA: It is. I mean there's such a stigma surrounding AIDS. You know being gay is difficult enough to deal with in this society. And then having a disease on top of it that is so closely related to being gay is really difficult.

HIV infection made homophobia more apparent because HIV infection is a visible condition by virtue of its outward manifestation of symptoms and because as people get sick they are more likely to turn outward for support, services, and health care.

A second reason heterosexism remained outside the language of study participants relates to the public discourse on HIV infection. As Bellah and colleagues (1985) explained, the language of individualism is the first language for the majority of Americans because it is deeply rooted in American history. Individualism embraces the values of an individual's ability to get ahead on his or her own initiative and putting aside the search for wealth in favor of cultivating a deeper sense of self.

Bellah and colleagues (1985, pg. 25) posited that while America's value of individual freedom has stimulated creativity, initiative, and tolerance of diversity, it has also resulted in a stubborn fear of recognizing power structures and interdependence in society. Heterosexism as an ideology fosters separation between groups of people, that is, between heterosexuals and homosexuals, and emphasizes power differences based on group differences. Yet heterosexism was generally overlooked by study participants when they attributed the consequences of heterosexism to individual differences and preferences. Bellah and colleagues (1985, pg. 143-144) suggested that:

Modern individualism has pursued individual rights and individual autonomy in ever new realms. In so doing, it has come into confrontation with those aspects of biblical and republican thought that accepted, even

enshrined, unequal rights and obligations--between husbands and wives, masters and servants, leaders and followers, rich and poor (pg. 143-144).

Heterosexuals and homosexuals could be added to this list of those with unequal rights and obligations.

Because of Americans' tenacity to revere individualism and individual freedoms, it is not surprising that from the beginning of the HIV infection epidemic much of the public discourse has focused on individual rights, including the rights to privacy and confidentiality, access to health care and treatments, and housing. Study participants echoed this language of rights in discussing how they coped with HIV infection. Data from this study suggested that personal experiences of HIV infection were often directed toward protecting those individual rights. What seems to be missing, or is at best weak, is the language of power and how the participants' experiences have been shaped by the distribution of resources as those are determined by power structures. Also missing was an understanding of the structure of legislation and policies that dictated those rights, such as federal (ACLU, 1991) and state legislation (Omnibus AIDS Legislation, 1988) that prohibits discrimination based on HIV status, the lack of federal legislation that prohibits discrimination based on one's sexual orientation, and the Seattle City Human Rights Ordinances that prohibit discrimination based on marital status or sexual orientation (Seattle Commission for Lesbians and Gays, 1988).

Heterosexism and Its Consequences

Heterosexism influences social organization through its effects on social institutions and resources. In the context of study participants' experiences the family is the institution of greatest immediate impact. Yet the family, as it is

defined and sanctioned by society, is a social institution that reinforces heterosexism. As one study participant observed:

I guess people that are in these high offices are basically heterosexual, and they're family oriented, and that's what this country is made of, is the family. And it probably wouldn't bother them in the least if a majority of the homosexuals are taken away. You're kind of stigmatized, being gay, and then to have this dreadful disease on top of that. It's just another shot in the arm.

Heterosexual union is assumed by many people, including policy makers and legislators, to be the most favorable basis for a family. Heterosexism results in the belief that the organization of family life, and therefore, that of the larger social life, is best served from a base of heterosexual union, procreation, and the nurturing of children. As a result, heterosexual unions are legally and religiously sanctioned whereas gay unions remain non-sanctioned and marginal to social organization. Consequently gay couples are not usually included in the enactment of family policy and family legislation.

The constraining and enabling factors associated with socially-sanctioned and non-sanctioned relationships in the context of HIV infection are presented in Table 4. This list of constraints was derived from both interview data and those suggested by Toriella (1989) in an article reviewing case law and legal statutes. Constraining factors limit the options for action, whereas enabling factors increase one's possibilities for action. In general the enabling factors of a socially-sanctioned relationship are the very factors which may constrain the actions of individuals within non-sanctioned relationships. Some of these enabling factors are based on the traditional rights, responsibilities, and resources that family members assume in caring for a sick family member.

Table 4

The Structure of Coupled Relationships: Constraining and Enabling Factors

<u>Structure of a Relationship</u>	<u>Constraining nature</u>	<u>Enabling nature</u>
Legally sanctioned, such as a heterosexual marriage	<p>Difficult to dissolve relationship</p> <p>Formalized role definitions that are implicated in oppressive social structures (e.g., non-paying role expectations such as caring for an elderly husband)</p>	<p>Benefits entitlement</p> <p>Sets up an environment which presumably supports caring for sick family members</p> <p>Increases access to health care providers and to health care information of partner</p> <p>Increases likelihood of participation of partner in health care decisions and bereavement decisions</p>
Non-legally sanctioned, such as a gay relationship	<p>Limits access of PWA to health benefits of partner</p> <p>Limits access to health care providers of PWA and therefore information</p> <p>Limits participation of partner in health care and bereavement decisions</p>	<p>Relatively easy to dissolve relationship</p> <p>Easy to keep non-public as long as PWA's health is good</p> <p>Allows individuals to focus on reasons to stay together other than constraining nature of a legally sanctioned relationship</p> <p>Increased facility of accessing AIDS services which were founded within context of gay community</p> <p>Sets up environment that will care for a sick family member, i.e., a partner</p>

For example, such formal, institutionalized definitions in part determine the distribution of health care dollars. Access to health care via private health insurance is a major problem faced by PWAs given shrinking health care resources and insurance companies that attempt to restrict benefits to individuals with terminal illnesses including HIV infection. Gay men may be further restricted from receiving benefits because they are not eligible for spousal benefits through their partners' coverage. Study participants were not alone in their grievance about restrictions of employment benefits to non-married partners. In a recent study of problems faced by gays and lesbians, the most common employment-related problem (reported by 71% of all respondents) was the inability to share benefits with a partner (Seattle Commission for Lesbians and Gays, 1991).

In the context of HIV infection, it is important to recognize that both heterosexual and homosexual relationships share one very important enabling factor: the creation of an environment that is supportive of caring for a sick family member. Commitment to one's partner provides a powerful motivator to care for him or her in time of illness or need. In this study, commitment was the major reason cited by partners for staying with the PWA "through thick and thin." Commitment was viewed as a necessary prerequisite for caregiving, yet it was often difficult for partners to do the things necessary to be effective care providers due to overwhelming constraints. Moreover, the lack of social and institutional support for gay relationships makes commitment an individual matter rather than a social role (i.e. social structure). Study participants often cited difficulties in obtaining information from health care providers to effectively care for their partner. In addition, they often feared that the PWA's parents or siblings, who benefit from socially defined roles, could usurp their authority if they desired.

Individual Actions: Reinforcing and Resisting Heterosexism

The ideology of interest in this discussion is the ideology of heterosexism, the systematic bias in American society that has as its goal maintaining the privilege of heterosexual couples. Although heterosexism per se was not mentioned by any study participants, many of their actions can be understood within the context of heterosexism. Table 5 reviews these actions and both their intended and unintended effects on heterosexism. Although not articulated as such, many actions taken by study participants can be viewed as confronting established power structures based on heterosexism.

In a feminist analysis of family definitions in nursing texts, Allen (1986) concluded that these texts "support and perpetuate a familial ideology that functions to oppress women" (pg. 15). In a similar vein, my thesis seeks to articulate the activities of gay couples with HIV infection as a practiced ideology which functions to either further oppress them or else empowers them to change the social system of which they are a social agent. For example, the activities of gay couples that keep their relationships invisible support a family ideology that functions to oppress them and limit their options. Other activities, such as openly caring for a sick partner, help to change traditional family ideology.

Because of study participants' tendency to focus on individual rights, many of their actions were directed toward securing rights to which they were entitled, thereby obscuring the effects of their actions on heterosexism as a social structure. Securing rights was viewed by study participants as critical in a society that does not acknowledge or sanction their relationship. For example, the right to decent and safe housing was often discussed by study participants, a right that became

Table 5

Intended and Unintended Consequences of Actions Taken by Study Participants

<u>Action</u>	<u>Intended Consequence as Expressed by Study Participants</u>	<u>Unintended Consequences on Heterosexism</u>
1. Silence about HIV infection	Protection from harm, discrimination	Increases heterosexism by allowing stereotypes to continue. Allows others to say, "I don't know any gay people."
2. Dialoguing about homophobia	Increase society's acceptance of homosexuality	Maintain status quo by masking heterosexism as a socially constructed condition
3. Community involvement and community identification	Gain support, to ease personal suffering, development of gay identity	Increases visibility thereby "forcing" others to think about their biases, or resulting in violence
4. Celebrating diversity among gays	Increased pride	Increases visibility of heterogeneity among gays thereby decreasing heterosexism
5. Displaying commitment symbols and commitment ceremonies	Demonstrate love and commitment to partner	Increases visibility of heterogeneity among gays thereby decreasing heterosexism

increasingly difficult to actualize as the PWA became sicker and as the couple's financial state worsened:

Partner: So we have a human rights case in the works right now against our former landlady for her actions. It was AIDS discrimination, because she did the same thing to somebody who lived next door to us, and it was harassing and bugging them next door, and then when he moved out, she started bugging us.

Interviewer: Did the other person have AIDS too?

Partner: Yeah.

PWA: And we had one moving sale before we left. When me and David got together he had stuff, I had stuff, we got rid of a lot - so she'd later say that we were out purchasing stuff and were running a business because she'd seen sacks of stuff going in almost every day - which is the truth, there was a lot of sacks going in there, but believe me, 80% of those sacks was groceries. You know? I mean, she would watch - even took pictures through our living room windows.

Interviewer: Oh boy.

PWA: [We could not get the help we needed to find housing] So we went out and did it on our own. Somebody with Section 8 pulled some strings to help us. And I'll never forgive the AIDS organization for not helping us for that as long as I live. We'll never forgive them for that. Because they would not find me housing, they would not help. They did suggest that I could go out in some crummy little place out on Aurora where there's knifings, at that time especially knifings and stuff. You know, what kind - they should get out there and know what that's like. The situation is we did it on our own and they're supposed to be doing that for you. Especially when you're - you have AIDS and you know, the strings and the paperwork can be a bit much. That's what they're there for to do, they didn't do it. We weren't even offered a ride down there. We went out in the cold weather...on a bus.

In addition to the right to housing, rights to health care decision-making were commonly discussed by study participants. They generally secured health

care decision-making rights by executing legal documents such as living wills and durable powers of attorney. Persons with HIV infection drew up living wills to insure their right to autonomous decision-making if they were no longer able to do so. Couples together established health care powers of attorney that would secure the right of the partner to make health care decisions on behalf of the PWA if he were no longer able to do so. One PWA came to the realization that he needed to legally secure his and his partner's rights concerning autonomous health care decision-making after an acute and life-threatening episode:

PWA: I was in the hospital, and my friend says, you know, you only have to put up with so much. It's your body. And you don't have a lot of life yet, and you want to live a good life, then you just have to do it. And tell everybody else to forget it. And so, that was the day I made the decision to stop treatment. And I told the doctor, and he asked me why I wanted to stop this and stop that, and I told him. And he said, well, I guess I understand that. So he's been very supportive about it....I definitely don't want to be on any machines or anything like that. If it's time for me to go, I just want to go. And if it hurts, I want something so it doesn't hurt anymore. But my partner said he'd make sure - I have a living will, but we found out I need to write a letter to go with it to make sure that my wishes are carried out.

Interviewer: What kind of a letter?

PWA: Just - I don't know, I think it's kind of strange, actually, to have to do it, because the will was drawn up by a lawyer and everything.

Interviewer: It's not the power of attorney, is it?

PWA: I've had that drawn up too. Sam has power of attorney and - Sam has control over everything. According to my will.

Although PWAs hoped that durable powers of attorney and living wills would work for them when the time came, some remained skeptical and took further steps to insure their rights with health care providers by helping their partners to become

more involved in their medical care. For example, one man made sure he introduced his partner to his physician thereby implicitly asking the physician to confront his own biases and privileged status:

I took Samuel with me to meet all [my health care providers] and I let them know that he's got absolute say if I'm unconscious or incapacitated and that he's got my power of attorney and my durable power of attorney and everything.

The level of visibility of gay couples is a key feature in examining the effect of individuals' actions because heterosexism prevails by rendering homosexuality and gay people invisible (Herek, 1990). This invisibility allows gay men to "pass" as heterosexuals and therefore enjoy the privileges of heterosexuality. Ironically, it is this very invisibility and use of privilege which succeeds in reinforcing the privilege of heterosexuality. In any case, visibility was frequently discussed by study participants. One partner explained the benefits of increasing visibility of gay people:

But really if they would only realize that it's - everybody - they're almost everywhere, homosexuals. Everywhere. And if they would just - you know what, if everybody were to come out, the general public would realize it.

Because the invisibility of gay couples reinforces heterosexism, actions taken by study participants to increase their visibility as a couple could thus have the important if unintended consequence of taking a stand against heterosexism. Defining themselves as a couple or family, publicly declaring their commitment, and using symbols are examples of actions taken by participants that challenged heterosexism. Calling themselves a gay couple, a family, questioned common definitions of family held by their straight friends, parents and siblings because those definitions include relationships based on either heterosexual marriage or blood ties (Allen, 1986). The San Francisco Task Force on Family Policy (1990)

proposed that the popularized conception of an American family "included a father who was the sole breadwinner and a mother who stayed home to provide support for the working husband, to care for the children, and to do the housework" (p. 14). While the number of women in the work force, the number of families headed by a single parent, and numbers of gays and lesbians who have domestic partners are all increasing, and therefore changing the configuration of families, there is still a critical need for the diversity of families to be recognized at policy levels (San Francisco Task Force on Family Policy, 1990). In a recent survey of Seattle lesbians and gays, approximately 45% of gay men reported that they were in a committed same sex relationship (Seattle Commission for Lesbians and Gays, 1991). By openly acknowledging their committed relationship, they are redefining the family as a social institution.

There is, however, a major difference in calling a gay partner a family member and publicly declaring that this is the case. Public declaration is a commitment witnessed by friends and family that formalizes the relationship. Couples in this study reported that taking vows in the presence of friends and family and exchanging rings was an act arising from personal desires and wishes. Two couples held commitment ceremonies because they loved each other and they wanted to make a commitment that reflected their desire for a relationship that would last over time. I propose that an unintended consequence of such declarations is to sensitize others to the existence of same-sex commitments. It is difficult for the public to be supportive of a position if they do not know the issue exists. Public declaration thus serves to erode the ideology of heterosexism, that spousal rights are reserved only for heterosexual couples, because it increases the visibility of non-heterosexual couples.

While a commitment ceremony between two people can be an important aspect of a relationship, it is still not necessarily visible to many others. On the other hand, tangible symbols are more likely to increase the visibility of non-heterosexual unions.

For example, a gold band worn on the finger is a tangible object that not only symbolizes a commitment between two people, but gives a clear message about one's status as part of a couple. Symbols such as a wedding ring worn on the right hand serve to increase non-heterosexual visibility, thereby challenging others' notions about committed relationships. Ironically, however, wearing the ring on the right hand also sets a gay man apart and allows heterosexuals to define themselves based on his being different, thereby reinforcing the heterosexual's position of authority. One study participant noted that his ring served as an invitation for others to ask the man about his "spouse," a consequence that he did not voluntarily offer but acknowledged once it was suggested. The following excerpt explains his perspective:

Partner: I would love to be able to wear my wedding ring on the 'right' [left] hand, although I sort of think it's really neat on this hand because people - right now, they'll say, "Oh, you're not married, but you have this wedding ring on?"If they ask me a question about it, I tell them. But if they don't ask me a question, I don't really go into great detail about my private life. And if they ask, "Oh, you have a wedding ring but it's on the wrong hand," I say, well, I'm married but not in a traditional way. And that usually just shuts them right up (laughs). And then if they want to pry or explore a little further, well, they can and I'll open right up to them. But if they ask me why my ring's on the wrong finger, I certainly tell them. So those people would know. But most people, if they didn't really know anything about my personal life, just would - you know, it's none of their business, really. I don't think most heterosexuals walk in and say, Hi, I'm Gail, I'm heterosexual....but for the most part, if they asked why my ring was on the wrong finger...mostly I would tell them, well, I'm in a

relationship, it's just not a traditional one. "Oh, really, Robert." Well, then I'd realize that okay, they're cool, they'll understand. And then if they didn't, then - and that would usually shut them up, right then and there. They usually wouldn't ask, "What do you mean, a traditional relationship?"

Interviewer: You both wear it [your ring] on your right. Do you do that in part, it's like a cue for people, like if they want to pick up on it, then they can? Or no?

Partner: No, we did it because we're not traditionally married, and so we just put it on our other fingers because this finger's sort of like a religious ceremony type finger [the left]. And we never went through that. So we did it on this finger. And a lot of homosexual men I know will do this, will have it on this finger.

Interviewer: But it does give people the opportunity to, like if they want to know more about you and your personal life and gee, are you gay or not, I mean, it does give them the opportunity of thinking, gee, I can ask him about that because obviously he wants people to know -

PWA: I've never been asked.

Interviewer: Really?

PWA: Never.

Interviewer: Have you ever been asked, either of you, why you wear your ring on your right finger?

Partner: I of course have a lot of times....They ask what it means but I've never been asked why I wear it on the right. I wear it on the right hand because it just was the one I put it on. And I'm right-handed, so I play with it....Well... I really didn't want a lot of my female clientele to assume that I was straight. They come on to me really heavy (laughs). And I've never really been good at telling them no. I mean, yes, I would tell them no. But I wouldn't want to leave - I just didn't want them to think that I was married. And by having it on this hand, most people would say, "Oh, you have a wedding ring, but it's on the wrong hand." And then when you tell them, they either don't pursue it at all or they want to be your best friend, you know? (laughs) So, yeah, that is interesting - - why we wear them on this hand.

In summary, the intended consequences of the partner wearing a gold band on his right hand were to honor the commitment made to his partner and to keep women from "hitting on him." In addition, an unintended consequence was to confront people with their biases toward coupled relationships, that is, that heterosexual unions are the only basis for committed relationships and consequently the rights and privileges associated with them. On the other hand, a ring worn on the right hand, not the left, serves to perpetuate the different-ness of gay commitments and of gay coupling thereby allowing heterosexuals to continue to define themselves as superior to the "other" (i.e., the homosexual).

Having commitment ceremonies, defining their relationship as family, being open to family and friends about sexual orientation, estate planning, and volunteering for this study are examples of actions taken by study participants that challenge the presumptive heterosexual basis for intimate adult relationships; i.e., the exclusive claim that heterosexuals have staked on the institution of family.

Establishing legal domestic partnerships is one mechanism used to solidify relationships, establish benefits entitlement, and increase the visibility of gay relationships. According to a report by the city of San Francisco, domestic partners "means two people who have chosen to share all aspects of each other's lives in an intimate and committed relationship of mutual caring and love" (The Mayor's Task Force on Family Policy, 1990, p. 2). This definition was based on the premise that: (a) relationships between committed couples are entitled to respect, regardless of marital status, and (b) since gays and lesbians are not accorded the right to marry, recognition of domestic partnership is the only way to treat their relationships with the equal dignity to which they are entitled (The Mayor's Task Force on Family Policy, 1990, p. 2) While legal in other parts of the

country, this mechanism was not used by anyone in the study because current legislation affecting Washington state and Seattle residents is limited to city employees only (City of Seattle Municipal Codes, Ordinance 114648, Chapters 4.24 - 4.30). Establishing a domestic partnership could be a means for translating verbal commitment between two people into a visible power resource through its effect on the distribution of economic resources. However, Washington state does not provide for such legal arrangements. Legal recognition (such as that obtained through the mechanism of a domestic partnership) of a gay couple as a family has implications that reach well beyond the personal experience to the development of social policy that determines the distribution of resources, namely health care dollars. Similarly, durable powers of attorney can be viewed as a resource used by gay couples to challenge the heterosexism of health care providers and to secure the rights of a partner in a committed relationship.

In addition to challenging the power vested in heterosexism, the effects of all actions, whether intended or unintended, that increase the visibility of gay men also have the potential for increased violence and structural constraints against gay men. In particular, many study participants felt that, although on some level they respected the militant AIDS activist groups, they also feared that their "radical" tactics could also harm gays as a group:

Partner: Some of their [the activists'] beliefs and policies I just don't agree with.

Interviewer: Like? Is there something in particular?

Part: One incident particularly, that occurred here. When Sam Kinneson was at the Paramount Theater. They went down to the Paramount, they spray painted the walls and graffiti. I don't agree that destroying public property or embellishing public property with your emblem is going to get

you anywhere but in trouble. I mean that's the reality of that. It doesn't accomplish anything. If you want to go have a protest, fine, go protest, but don't go spray painting on somebody else's property. It doesn't solve the problem. I really appreciate the fact that they were in the [gay pride] parade and that they were at the park at the rally. I however do not appreciate the fact that they spray painted one of their emblems on the base of a statue. I really can't see that does any good.

Interviewer: What's the harm that it does besides get you in trouble? I mean do you think as far as other people?

Partner: I think a lot of people will look at [what they've done] and resent, you know, a gay person did this - - another reason to hate. And that doesn't do any good. It doesn't solve the problem. You know, what we're trying for is understanding and affection in some stretch of the imagination, and that isn't gonna get it. So that group is one of the organizations that I agree very strongly with some of their points and issues, but I also disagree with them. So it's kind of a quandary for me, maybe I'll have to like start my own organization of radical fairies!

While gains may be made to increase the opportunities for gay men to live authentically as a couple, there is the real possibility of creating a "backlash" effect. If those in power feel threatened by the increasing visibility and therefore power among gays, a backlash would be an attempt for them to regain their advantage and reclaim power surrendered to gays. Gays may fear that heterosexuals could assert the primacy of heterosexuality by enforcing or enacting institutional constraints, such as Ross Perot's declaration that if elected President of the United States he would not appoint homosexuals to high level cabinet positions (Times News Service, 1992). Through legislative efforts states could decide to enforce sodomy laws already in place, or to pass legislation specifically excluding gays and lesbians as a group from receiving protection from discrimination, as is currently the case in Oregon (Barnard, 1992). As further evidence of backlash, one need only to examine the recent politics in Washington

State, where a National Guard nurse, Colonel Grethe Cammermeyer (who also served in Viet Nam and was highly decorated for her military service) was dismissed from the service because of her admission of lesbianism (Whitely, 1992). Her dismissal and subsequent decision to take the case to the courts have stirred up much controversy about the military's ban on homosexuals in the United States military (Jackson, 1992).

Shortly after this story became national news, the Washington State Republican party proposed their 1992 platform which calls for a ban on homosexuals working in the health care field or as teachers and day care workers, and barring them from the roles of foster and adoptive parents (Moriwaki, 1992). Moreover, the document states, "homosexuality is a deviant lifestyle, and as such should not be granted special privileges and protections" and "the definition of 'family' should not be extended to those living together outside of legal marriage, nor to homosexual relationships" (Washington State Republican Party, 1992, p. 2). One could ask if the action taken by the Republican party is a backlash in response to the Grethe Cammermeyer's outspokenness and decision to "fight" for the rights of gays and lesbians. Understandably, it is the fear of this type of backlash and repressive institutional change that has kept many study participants from increasing their visibility as gay couples affected by HIV infection, even if they acknowledge some benefit in doing so.

"Outing," one individual revealing another's homosexuality, is another action used to increase gay visibility and was discussed by one study participant. The point of outing assumes that people in positions of power and influence will become more helpful to "the cause" once their situation is known. For example, when Arthur Ashe went public with his HIV infection, his status as a board

member of Aetna Insurance, a company that does not insure HIV-infected persons, became to some a potential source for change. According to AIDS activists, Ashe is in an influential position and, because of his HIV status, now bears a public responsibility for questioning and reforming the health insurance system from within (Bull, 1992, pg. 20).

Because many people still erroneously assume that HIV infection is a "gay man's disease," outing someone who has HIV infection could be construed as an action that challenges heterosexism and ultimately the institutions that reinforce heterosexism. The controversy over outing lies in attribution of responsibility and the question of rights, making outing an emotionally charged issue. Protecting one's privacy by resisting outing reinforces invisibility which in turn reinforces the condition it is caused by: heterosexism. Thus the intended consequence of keeping private is no structural change and maintenance of the status quo. When asked about the practice of "outing," one PWA responded with conviction:

PWA: Oooh! That's kind of touchy...I think for each individual, that point comes, and if it doesn't then it doesn't, but I think you have, again, it's a matter of personal choice and freedoms. I can't... I don't agree with it. I can't see, in some cases, particularly, that the people that they've outed, some of them probably aren't.

Interviewer: So for you any benefit of outing is really..

PWA: Well, like I'm so far out for me personally, if somebody was to walk up to me and say, you faggot, I would say yes. I mean, you know that's what I would do! Actually, I've had people walk up to me and say, you faggot. It's like, so, why did you have to ask me? I mean, it doesn't bother me. But no, I would never force someone or even make accusations about someone that wasn't out that didn't want to be. I don't see that it benefits anyone. You know, the argument part is well, you know there are people in power, blah blah blah. Well, they will make their voice for, you know, they

will either do the right thing or they won't. But you forcing the issue is not going to make it any better. And I don't agree with that.

It may appear that I am placing the responsibility for changing social norms related to homosexuality on gay men themselves. This is not necessarily the case. Going public entails a great deal of personal risk including discriminatory housing practices and the loss of jobs, friends, and family. But the fact remains that shifting the discourse from homophobia to heterosexism can help to change the focus of study from which intrinsic traits of homosexuals are threatening to heterosexuals to the responsibility that heterosexuals bear (even subconsciously) in perpetuating the privilege associated with heterosexuality. As Neisen (1990) asserted,

With the focus on heterosexism, the need for heterosexuals to confront their heterosexism is reinforced. The prefix "hetero" establishes the origin of the prejudice. With greater clarity of origin emphasis is redirected toward heterosexuals reexamining their beliefs and attitudes about homosexuality.

(p. 27)

Besides the negative consequences of speaking out against heterosexism and homophobia, one study participant gave an alternative reason for not speaking out, that is, the individual right to privacy - - again, the voice of individualism. This participant resented the expectation that he had to announce his homosexuality, a standard that is not expected of heterosexuals since we assume others are heterosexual unless evidence indicates otherwise. Yet, this assumption of heterosexuality is at the core of heterosexism. This man explained his feelings about privacy as follows.

Just about everybody I deal with knows about my sexuality and knows about Randy - just about everybody. If they were just a casual account, they

really didn't know anything about me, like I don't bounce into an account and say, Hi, I'm Robert, I'm gay, how are you?....But most people, if they didn't really know anything about my personal life, just would - you know, it's none of their business, really. I don't think most heterosexuals walk in and say, "Hi, I'm Gail, I'm heterosexual. And you know, that's what I do at home."

In addition to increasing the visibility of gay couples, deliberately acknowledging and celebrating the diversity among gay people is another way in which study participants challenged heterosexism. While all study participants in this study commented that their homosexuality was an important aspect of their personhood, they were adamant in stating that they were much more than "just" a homosexual being thus confirming Bell and Weinberg's (1978, p. 23) observation, based on in-depth study of gays and lesbians, that "there is no such thing as the homosexual...and that statements of any kind which are made about human beings on the basis of their sexual orientation must always be highly qualified." Thus, acknowledging the diversity among gays combats the belief that homosexuality is an idiosyncratic anomaly of the individual -- not all gays are alike.

Acknowledging the diversity of gay men is a step toward combatting heterosexism and homophobia because the heart of any ideology aimed at a group of people presumes homogeneity.

I'm not out on the streets and I'm not what - you know, people that don't know a lot of gay people identify gay people as the ones that they can see and identify on the street as the stereotype. Well, they don't see the people like me who - I work, I'm educated, I work, I pay my taxes, you know - I'm not - I've never been arrested, you know? It's like I'm just a normal person wanting to live and live my life....Also, it kind of makes me upset that people who don't know a lot of gay people see us as just being sexual and it makes me upset that we are even identified as homosexual. You know, I'd like to be identified as, oh, there's two guys living next door, you know, or something like that, rather than oh, there's a couple queers or a couple of gay - or even homosexual men living next door. Homosexual means that

I'm the same sex, you know, it's like gosh, darn, I'm much more than a sexual person. I'm not even a sexual person right now! (laughs) It's like, come on, give me more credit.

And another participant offered the following observation:

[There are different factions] within the gay community. I mean, the fact that you have men and women for one, you know, and they usually don't intermingle that much, and the young crowd and the older crowd, the leather Levi crowd, country western crowd, a preppy crowd, and so there's all these little cliques, so to speak, these little groups that make up the whole community.

In addition to increasing visibility and acknowledging diversity, study participants identified a second important mechanism for resisting homophobia. They resisted not only external homophobia, but the negative consequences of internalized homophobia, self-doubt, and self-blame, by becoming involved in either the AIDS or the gay community. Because of the major effect HIV infection has had among gay men, many study participants found it difficult to draw a distinction between the gay and AIDS communities. Some participants felt as if the gay community had become a community of people with AIDS or people working to prevent HIV infection or care for people with HIV infection. Community involvement led to a sense of empowerment by increasing their self esteem and their pride in being gay. Within these communities study participants reported finding others with shared values and goals such as stopping the AIDS epidemic. By giving to others both PWAs and their partners felt that they were making an investment for when the time came that they might need services. One study participant commented:

There are a lot of people that are donating money and things to make it possible for those of us right now that are having problems to have that kind of financial aid, spiritual, emotional aid available. And that's a very good thing. One of the other things that I am very proud to say about the

AIDS crisis in general is that it has brought a lot of people together, not just gay, everybody, you know, black, white, yellow, orange, straight, children, everything....I am volunteering my time....there's several organizations I want to [volunteer for], that I see as very worthy things....I have not personally given a whole lot back, or given a whole lot to the community....I need to do it to feel good about myself. And it's something that I've always said that I will do.

As previously noted, study participants were more likely to say that they had changed personally as a result of HIV infection instead of reporting that their world view had changed (once again, the voice of individualism). However, when questioned directly, there were exceptions. Because of the effects of the illness, as PWAs became sicker they were increasingly forced to look beyond their primary relationship to health care services and community resources for instrumental and emotional support. As study participants became more involved in the communities around them, they began to develop a heightened awareness of the injustices surrounding not only HIV infection, but affecting issues such as health care financing and accessibility. In addition, they began to understand the interconnectedness among themselves as individuals and as members of communities and society, as well as the importance of these interconnections. As explained by a partner who was also HIV-positive:

I've become more aware of the gay community's relationship with the rest of the country, or the rest of the political system, I guess I should say. In light of AIDS, that has certainly changed, and I've become more aware of that. I've become aware of groups like ACT-UP and so forth. And what it is they're really trying to accomplish. And also groups that promote the right to die with dignity, and that's become more important to me than it was. Things like that.

In other words, the personal experiences common to people with HIV infection and their partners were in many cases experiences that thrust them into the public sphere. For others the heightened awareness of social and political

conditions of HIV infection, coupled with a personal history of poverty and disenfranchisement, resulted in feelings of bitterness, withdrawal, and resignation as expressed by the following angry man:

I got a lot of bones to pick with the government. (laughs) But I would have to say that most of them aren't related to AIDS... What bothers me about that is that they'll turn and they'll give money away to foreign countries that's never going to be paid back, and they don't complain about it. So when they ask for money for things like AIDS research, it's, well, I'll give it to you, but I don't really want to, you know? I don't understand it. Why they can spend 50 times as much money overseas but when you ask for something over here, it's like - they might give it to you if you complain enough but they have to make you feel guilty at the same time. They gotta make you feel like you're the lowest scum on earth for even asking in the first place.... Society in general I hate.... sometimes I just get so - mad that the way I see, like the government and the rich taking advantage of the masses, you know, and then I'll stand there and they'll be doing one thing, they'll be talking out one side of their mouth, saying how good it's going to be for the poor, and meanwhile they'll be sticking their hand back in your pocket on the other side.... That's the way it looks to me.

For other study participants, awareness of the social and political conditions surrounding HIV infection resulted in increased participation in public spheres of life such as in the gay or HIV infection community or in politics in general.

Increased public participation is an action that can result in altering heterosexism and other systematic sources of privilege which contribute to the marginalization of gays, thereby reinforcing their "other-ness," the very condition that gave rise to their activism in the first place. When asked if he had been a "letter writer" to politicians before HIV infection, one partner replied:

Partner: No. I wasn't, so there is something that has changed for me. There's certainly more sense of urgency now. I've been more an observer of the political process than I have been a participant, beyond voting. I never really got actively involved in working for a candidate or writing a lot of letters on issues and stuff, but I do that more now. There's a bigger

sense of urgency now. And I'm also naive enough to think that they read these letters and that you can sway them with persuasive arguments.

Interviewer:When there's an issue that's important to you, it changes how you feel about those things and what you do.

Part: Yeah. And it's something that's touched me so personally now that I have to do something. It's also a part of the control issue that I was talking about. I feel like I'm more in control when I'm making steps towards change.

Regardless of one's level of participation in public affairs, all study participants expressed a range of strong opinions about AIDS activists, the gay community, the non-gay community, the federal government's response to HIV infection, and current AIDS-related issues, such as the case of a Florida dentist (now deceased due to AIDS) who may have infected up to five of his patients with HIV (CDC, 1991), and the Washington State Death with Dignity Initiative of 1991, which would have allowed physician-assisted suicide in special circumstances.

In summary, heterosexism was found to be a generally unacknowledged structural component of society that profoundly affected the experiences of gay men with HIV infection and their partners. Although the source of oppression against gay men was unacknowledged as heterosexism and acknowledged as homophobia, many participants' actions could be explained by conceptualizing heterosexism as a social structure. Actions taken by PWAs and their partners both reinforced and challenged the power implicated in heterosexism as a structural constraint.

Summary of Major Study Findings

The results of this study were organized according to the objectives of the study and its specific aims. The description of the grounded theory is a reflection of study couples' thoughts, reasons for, and motivations behind their personal

experiences (specific aims 1, 2, and 3). The structuration analysis of heterosexism provided an alternative and complementary way of viewing their experiences as they were grounded in their social context (secondary study objective).

Although the phenomenon of study was initially conceptualized as caregiving and care receiving in the context of AIDS, interviews with gay men under these circumstances tended to reveal their situations in different ways and in broader terms. As grounded in the data, this study evolved toward "Becoming a Couple Affected with HIV Infection." Each term was meaningful because each was grounded in the data. Becoming reflected a dynamic, transitional perspective. Couple reflected the deep commitment felt for one another and the tendency for couples not to define their relationships simply based on care given and received. Finally, HIV infection was chosen to respect the different ways in which study participants approached the future, either by succumbing to AIDS as an endpoint or by surviving HIV infection as a chronic condition.

Loss was identified as the basic social psychological condition that affected the transition of becoming a couple with HIV infection. Losses were often multiple and far-reaching. Many losses, such as that of the future, the relationship, or a non-HIV infection lifestyle, were directly related to partners' perceptions of themselves as a couple who were committed to each other.

Three processes defined the transition from a couple without HIV infection to a couple living with HIV infection. The transition began with the awareness of the threatened loss of life for PWAs, and of the most important person in his life for partners. "Hitting Home" was the process that marked this initial awareness. In "mutually protecting" one another, each partner attempted to mitigate, prevent or accept subsequent losses that were a part of living with HIV infection.

Protective strategies were directed toward achieving physical and emotional health, setting the boundaries of the relationship, and maintaining independence and intimacy within the relationship.

Finally, in "Moving On," each partner settled upon an acceptable view of the future based on the fact that HIV was in their lives. These views, affected by the status of individuals as partners in a couple, and the views of surviving HIV or succumbing to AIDS, mediated the decisions about the future for the couple and how they were to live in the present given HIV infection.

Shifting from a symbolic interactionism perspective to a structuration perspective of the social environment allowed for analysis that was critical in understanding the actions of couples as they coped with HIV infection. Study participants referred to this social structure as homophobia whereas I suggested it could be analyzed as heterosexism and provided a rationale for doing so. Although couples did not frame their experiences in terms of heterosexism, this approach can accommodate the shift from studying homosexuals to asking heterosexuals to consider their privileged position, which serves to perpetuate the constraints placed upon gay couples coping with HIV infection. Heterosexism could also be a significant concept because it helps us to understand the institutionalized and systematic constraints placed upon gay couples, compared to the concept of homophobia, which tends to focus on the individual personality traits of gays and those who harbor negative feelings toward them.

CHAPTER V

DISCUSSION

In the previous chapter a theory of becoming a couple affected with HIV infection was detailed. The purpose of this final chapter is four-fold including the 1) contextualization of selected findings by relating them to relevant bodies of literature; 2) discussion of limitations of the study; 3) proposal of directions for nursing clinical therapeutics at the individual and environmental levels; and 4) possible avenues for further research in the area of HIV infection based on study findings.

Contextualization of Findings

The final step in developing grounded theory is to compare the theory to extant literature in order to discover similarities and discrepancies (Wilson, 1988). The purposes of comparison with other literature are to determine correspondence, divergence, comparative analysis, and integration into a body of knowledge (Strauss, 1987; Wilson, 1988). Using the literature in these ways helps to clarify the significance of the theory and to note specific contributions in furthering the understanding of a phenomenon. For the purposes of the current study, findings will be related to the literature on loss and grieving, couples' experiences of chronic illness, psychosocial responses to HIV infection, and family caregiving.

Two limitations of comparing study findings to these bodies of literature are evident. First, when comparing study findings with the loss and grieving literature, much of grieving theory appears to have been developed in response to death as a loss event. As noted in the results section, losses for couples affected by HIV infection were multiple, including many types of loss in addition to the threatened death of the PWA. A second limitation involves comparison to the

family caregiver literature; most studies tend to focus on spouses and children and underemphasize the role of families of choice as well as that of the care recipient. Thus, the family caregiving literature may be of limited value in contextualizing study findings.

However, two strengths in comparing findings from this study to other studies of family caregiving are evident. Firstly, since much of the family caregiving research to date has focused on caregiving behaviors and tasks (Horowitz, 1985), grounded theory studies are helpful in revealing important issues for families that are grounded in the meaning that they attribute to their situations. Secondly, since the caregiving literature tends to focus on the giver of care, findings from this study may yield a more complete understanding since the substantive grounded theory accounts for the care recipient's experiences and perceptions.

Loss is not a single entity, but a multidimensional concept encompassing elements of magnitude (major or minor), primacy (primary or secondary), actuality (actual or threatened), relationship to the self (internal or external, direct or indirect), volition (chosen or imposed) and timing (on-time, off-time) (Weenolsen, 1988). Results from this study suggest that for couples affected by HIV infection not only are losses multiple, but include those which that can be categorized by different combinations of elements.

Certain losses were commonly perceived in similar ways by participants. For example, death of the PWA was commonly perceived as major, primary, threatened, direct, imposed and off-time. However, since elements of loss are based on interpretation and meaning, the characteristics of other losses were more varied among study participants. For example, the loss of sexuality was viewed as

both major and minor, chosen and imposed. The complexity of losses and disparate perceptions between partners accounted for much of the variation in the couples' responses to HIV infection.

As responses to loss, hitting home, mutual protection, and moving on can all be viewed as elements of the grieving process. Examining responses to other losses and loss theory assists in interpreting the current study findings. However, one difficulty in attempting to integrate results of this study into the body of literature on loss and grief is that grief theories are either staged or, if not explicitly a staged process, contain wording that often reflects staging. For example, according to Rando (1984) there are numerous conceptualizations of grief, but overall three basic categories of responses: avoidance (encompassing shock, denial, and disbelief), confrontation (a highly emotional state), and reestablishment (the beginning of integration whereby the meaning of loss is incorporated into everyday life). Although Rando (1984, p. 28) resisted the notion of staged processes that imply invariance and sequence, each phase is unidimensional and overlooks the complex dialectic as people deny/confront, assimilate/resist, or hold onto/let go of. Similar problems occur with Bridges's stages of transitions (endings, the neutral zone, and beginnings), Bowlby's (1980) grief process (numbness, yearning and searching, disorganization and despair, and reorganization), and Kubler-Ross's (1969) descriptions (denial, anger, depression, bargaining, and acceptance). In contrast to a sequential phase, participants in this study emphasized the dialectic nature of coping with HIV infection, and the revisiting of similar and identical issues over time.

Because dialectic and nonlinear processes characterized the experience of HIV infection for study participants, it was common for couples to undergo several

different processes or reactions simultaneously within multiple and various types of loss. Dialectics is a thesis-antithesis-synthesis pattern by which two contradictory elements are transcended. The outcome of the dialectic process is a new idea on a higher level (Elbow, 1986). The nature of HIV infection set up polar oppositions for couples in this study. They were faced on a daily basis with contradictions such as the potential for allopathic cures versus the absence of an allopathic cure for HIV infection; life as absolute versus life as uncertain; I am going to live forever versus I will die of HIV infection or of something else someday; I love my family/friends versus they might reject me if I tell them; I live in an acquiring society versus I keep losing so much to HIV infection. Participants constantly struggled with affirming diametrically-opposed beliefs and reconciling the contradictions of living with HIV infection. The dialectic process is reflected in holding on and letting go, and the outcome is the wisdom gained, evidenced in moving on.

In the literature, denial is noted as a common response to loss (Bowlby, 1980; Kubler-Ross, 1969). For study participants, avoidance or denial was both a common and a controversial response. They often acknowledged times when they had been "in denial," yet reacted with anger when accused by others of "being in denial." In a review of the literature, Ersek (1992) found that the psychoanalytical tradition of denial is viewed negatively as pathology. According to the experiences of study participants, it would appear that this negative perception of denial has been transfused into popular beliefs and attitudes toward denial. In general, study participants voiced concerns about the tendency of others to judge denial negatively. They did, however, view denial as an extremely important process that allowed them to assimilate multiple losses gradually and to move into

the future as a couple. In addition, denial was often balanced with hope as they shifted their concerns from one object to another, this shifting being evidenced in the process of holding on and letting go. Holding on and letting go were similar to findings of a study of elderly persons with cancer (Dufault, 1981) in which subjects vacillated between focusing on realistic hopes while abandoning unrealistic hopes. In addition, couples felt angry when others misinterpreted hope as denial, thereby dismissing the difficulty of living in the present, taking one day at a time or hoping for a cure or a long life.

Hitting home is perhaps best reflective of Rando's (1984) second category of grief, that is, confrontation, which is a process of extreme emotions. Hitting home was an emic term and was used by several study participants; it emphasized the shock of realizing the circumscribed possibilities for each individual and for the couples as a result of HIV infection. Others have described similar processes in awareness of various types of loss. In a study of women's responses to miscarriage, Swanson-Kauffman (1985, p. 68) described coming to know as "the confusing, painful process of balancing mounting evidence of impending loss against hopes for a healthy pregnancy outcome." While participants in the present study underwent a similar process in assessing their risk, undergoing testing, and receiving the diagnosis of HIV infection, the precipitating events were not the same for all study participants and they did not occur in the same sequence for every couple. Furthermore, coming to know occurred over a period of hours to weeks (Swanson-Kauffman, 1985), but in the current study hitting home rarely encompassed hours. Hitting home was more likely to occur over a period of weeks, months, or even years. In addition, coming to know was described as a "roller coaster," whereas for couples in this study, the ups and downs of HIV

infection came to be seen later as a characteristic of the entire transition of becoming a couple affected by HIV infection.

Mutual protection was a category from the grounded theory of the current study that is not easily compared to theories of loss and grieving. Perhaps mutual protection is most reminiscent of Bowlby's (1980) descriptions of two phases in the grief process: yearning and searching, and disorganization and despair. Yet there seemed to be a more adaptive component in mutual protection whereby couples attempted to preserve the integrity of the relationship by reconciling losses not within their control and preventing other losses they felt they could control.

Yearning and searching as described by Bowlby (1980) were attempts to "hold onto" the loss object, and the study couples certainly attempted to do this. However, study couples also let go of losses they could not control. This tension between passionately holding on while simultaneously letting go was a key feature of mutual protection. This simultaneous, contradictory and interactional process is, to this author's knowledge, not well represented in formal loss and grieving theory. In a grounded theory study of adult children caring for their aging parents, Bowers (1987) found that caregivers engaged in three strategies for protective care, that is, care designed "to protect the parent from the consequences of that which was not or could not be prevented" (p. 26). The three strategies included: protecting the parent from awareness of an event; protecting the parent from the meaning of a situation; and actively reconstructing or changing the meaning of an event for the parent. While there was certainly an overlap of mutual protection with Bowers's typology, such as attempts to protect the other's self-image or physical health, certain differences were noted. For example, mutual protection is initiated by each individual and is directed towards the self and the partner,

whereas protective caregiving was caregiver-initiated towards the elderly parent. Comparisons raise the question of elders' perceptions of protective caregiving directed toward them by family members. Moreover, mutual protection is grounded within the context of loss whereas protective caregiving appears to be meaning-centered in a more general sense. Perhaps a process of mutual protection can be operative within contexts other than HIV caregiving. Had Bowers studied caregivers and care recipients, she might have also described a process of mutual protection.

Finally, the process of moving on can be compared with reconciliation (Marris 1974), acceptance (Kubler-Ross, 1969), reestablishment (Rando, 1984), reorganization (Bowlby, 1980), transcendence (Weenolsen, 1988) restoring continuity (Marris, 1974), or trying again, in the specific case of miscarriage (Swanson-Kauffman, 1985). While moving on is an emic term and the others are more conceptual (except for trying again), they all have in common an individual's movement to a higher level of functioning whereby the individual integrates the loss into a new world view and creates new meaning in his or her assumptive world. Weenolsen (1988, p. 66) described transcendence as a process by which the ultimate meaning of loss is integrated into how the self is changed or restructured.

For couples in this study the ultimate meaning of losses were integrated into the restructured perceptions of themselves as a couple as projected into the future. While most theorists indicated that these processes are end points, for participants in this study the attainment of new meaning based on losses incurred was not static. Moving on may have become more settled over time, but new losses were implicated in a continual process of deriving meaning that occurred over time.

The two ways in which study participants moved on (surviving and succumbing) is noteworthy as an important finding. Surviving HIV infection is a new concept for many. It challenges the widely-held assumption that HIV infection is inevitably terminal. In this study Survivors were often belittled for holding beliefs based on survivability. In fact, epidemiological evidence supports increased survivability of HIV infection, albeit a small increase. The median survival after the diagnosis of AIDS increased from 11 months, to 14 months, to 16.3, and to 18.7 months for individuals diagnosed before December 1985, from January 1986 to June 1987, and from June 1987 to September 1990, respectively (CDC, 1990c).

While uncertainty was not identified as a major construct in becoming a couple with HIV infection, it deserves comment because it was named the basic social psychological condition in the AIDS caregiver study (Brown & Powell-Cope, 1991). Moreover, uncertainty has recently drawn attention in the nursing literature and has been implicated in people's experiences with chronic or life-threatening illnesses (Mishel, 1984; Mishel & Braden, 1988; Cohen, 1989; Stetz, 1989); family caregiving for a relative with Alzheimer's Disease (Wilson, 1989); and in the home care needs of cancer patients and their caregivers (Blank, Clark, Longman & Atwood, 1989). Specific to AIDS caregiving, Greif & Porembski (1988) noted difficulty in coping for significant others due to the lack of scientific knowledge about AIDS, and Weitz (1989) described the responses to pervasive uncertainty. According to Brown and Powell-Cope (1991, p. 340) uncertainty was defined as "the caregiver's inability to predict future events and outcomes and the lack of confidence in making day-to-day decisions about the ill person's care." Moreover, uncertainty was a pervasive feature of caregivers' lives which never disappeared completely but varied in intensity, timing, and context. In the

description of the grounded theory from the current study, uncertainty is proposed as a response to loss. Because multiple losses were common, it follows that uncertainty was also common. Uncertainty as a response to loss is supported by the literature on loss and grieving (Bowlby, 1980). Uncertainty is implicated in the processes of grieving and in people's experiences of major life transitions regardless of the specific theoretical perspective. For example, uncertainty can be viewed as features of disorganization as proposed by Bowlby (1980), of the neutral zone as proposed by Bridges (1980), the questioning of assumptions of one's assumptive world proposed by Parkes (1974), and following losses that threaten one's integrity of the meanings on which the continuity of life rests (Marris, 1974). In summary, uncertainty was an important feature of becoming a couple affected by HIV infection but was secondary to loss. Moreover, the categories and processes involved in becoming a couple were theoretically linked to loss, not uncertainty.

Brown and Powell-Cope (1991) noted that the concept of loss is overlooked in the family caregiver literature because of the tendency to focus on care given and the effects of stress, strain, and burden on the caregiver. AIDS family caregivers faced multiple losses (for example, losses within the relationship, the future, of social activities, and of the support of family and friends), yet the major loss was clearly the anticipated death of the PWA (Brown & Powell-Cope, 1991). Findings from the current study of couples confirm that loss is also a significant characteristic of the experiences of couples facing HIV infection. Recently loss has been gaining attention in the area of family caregiving. In a qualitative study of elderly caregiving, Farran and Keane-Hagerty (1992) found that loss was one of the main existential themes expressed by family caregivers.

The major study finding of multiple losses, including actual or the threat of death, as a condition of gay men's experiences is well grounded in the psychosocial AIDS literature (Carmack, 1992; Gordon & Shontz, 1990; Govoni, 1988; Klein & Fletcher, 1986; Saunders, 1989; Weiss, 1988). In the literature of family responses to other chronic illnesses, loss of the loved one or the fear of being alone are also noted as significant stressors (Blank, Clark, Longman, & Atwood, 1989; Corbin & Strauss, 1988; Perry & de Meneses, 1989). While Carmack (1992) studied gay and lesbian responses to AIDS-related multiple losses, rather than focusing on people with HIV infection or partners, her results compared similarly to the process described in this study, holding/on and letting go. In a grounded theory Carmack (1992) defined a process of balancing engagement/detachment in which individuals struggled to reach optimal balances in their involvement with other individuals and in the community. Balancing engagement/detachment and holding on and letting go were dynamic processes that involved the redefinition of values, the desire to protect the self against emotional pain, and experiences at interpersonal and community levels.

Carmack's (1992) theory of engagement/detachment is grounded in the concept of multiple losses. While the focus of the current study was on losses which directly pertained to the couple's relationship, Carmack's description of multiple losses were strikingly similar to those found in this study: the pre-AIDS life style and culture, and the death of friends. In studying HIV caregivers, Pearlin (1988) identified intrapsychic sources of stress during AIDS caregiving arising from caregivers' attempts to view themselves in the future, their vulnerability to death and disease, and their experiences with multiple losses and with the deaths of friends and acquaintances from AIDS. Taken together, all of these findings

indicate that loss is a significant issue for families facing chronic illness and that multiple losses are a particularly significant feature of all people affected with HIV infection, be they PWAs, partners, or other family members.

Another important finding of the current study is the extent to which couples work together to protect each other's health. The range and depth of self care activities in which couples engaged was a distinctive dimension in becoming a couple affected by HIV infection, though similar to other studies of HIV infection. Allan (1990), in a study of asymptomatic HIV positive gay men, found that they engaged in a broad scope of activities such as stress reduction, dietary changes, exercise, and life-style and attitudinal changes for the purpose of maintaining health and preventing disease. Findings from this study confirm that these activities continue as HIV-infected individuals become symptomatic, and may take on even greater importance because the stakes are higher as the men become more debilitated and more vulnerable to potentially fatal conditions. Self-care activities occurred in the context of relationships, and partners were often as involved or more involved in protecting the PWA's health than was the PWA. Furthermore, as the person becomes symptomatic, self care activities are likely to include more symptom-monitoring activities, executing medical regimes, and illness-related care rather than being focused primarily on prevention as Allan (1990) observed. In another study of self-care among HIV positive gay men, Lovejoy, Paul, and Christianson (1991) found that feeling socially connected to their surroundings and friends was positively correlated with many HIV self-care behaviors. Participants in this study reported struggles with their connections to their social networks, but also demonstrated high levels of self-care. Perhaps these

high levels of self-care were a result of their strong primary relationship, that is, their feelings of connection to a significant other.

Limitations of Study

Three limitations of this study include the retrospective nature of interview data, the generalizability of findings, and the use of participant observation. The retrospective nature of data limits the researcher's confidence in the validity of recalled events. The effects of the passage of time on participants' perceptions are inherent in the study design. For example, data supporting the process of hitting home were exclusively retrospective. It is not known if descriptions of hitting home would be similar or different if couples had been interviewed while those experiences occurred. If the descriptions are in fact different, would it change the implications of findings for nursing clinical therapeutics?

A second limitation of the study involves the generalizability of findings. According to Chenitz and Swanson (1986), the greater the range and variation sought in theoretical sampling, the more generalizable a grounded theory is to others in similar situations. As explained in Chapter III, I attempted to theoretically sample as broadly as possible, however, findings of this study are limited to gay men who have HIV infection. I believe that the general concepts probably are applicable to other gay men in similar circumstances, however, the specific experiences and actions explained by a concept will most likely vary according to environmental conditions, such as geographic location. For example, the awareness of loss may be applicable to gay men with HIV infection regardless of geographic location. Yet, the specific experience would probably be different for a gay man who lived in San Francisco where the mortality from AIDS is high,

compared with the experiences of a gay man in a small rural town in the South where the incidence of HIV infection is very low.

A second issue about generalizability concerns heterosexism. Findings of this study related to heterosexism are limited to the experiences of gay men. No attempt was made to include lesbianism into the analysis. Although gay men and lesbians share a label of homosexual, their experiences are necessarily different based on their gender and the privileges associated with being male in our society.

A third limitation of the study involves the use of participant observation. Developing trusting relationships takes time. Although while conducting interviews I was able to elicit a measure of trust, it did not permit study participants to include me in their personal experiences. In addition, controlling the boundaries of their relationship was clearly a critical feature of their lives. By not insisting on gaining access to their personal activities, I strove to demonstrate respect and allow them to determine the extent of my intrusion into their lives.

In the proposal for this study, I suggested one form of participant observation would be to attend a dinner party with a study couple. While this and similar situations did not materialize, I was able to substitute nonintrusive observations by attending public events such as the annual Northwest AIDS Foundation benefit walk. Public observations contributed to the overall coherence and validity of study findings and helped to compensate for the lack of private participant observations.

Implications for Clinical Therapeutics

Interpersonal Level

Given the dearth of nursing research on care aspects of HIV infection (Larson & Ropka, 1991) as well as the Center for Nursing Research's emphasis on

research that addressed the bio-psycho-social aspects of HIV care, including testing models of care and symptom management strategies (Center for Nursing Research, 1990), it is vital that nurses develop nursing care studies. An important step in developing research on care-related issues, as well as research that tests different care strategies, is to evaluate the descriptive research for its potential contributions. Understanding the meanings people attribute to their actions and circumstances and the most salient social structures is essential in furthering the understanding of clinical therapeutics. Therefore, the contribution of the current study will be evaluated for its potential in guiding research for clinical therapeutics of HIV care.

Understanding the processes and strategies of couples affected by HIV infection is helpful in designing clinical therapeutics sensitive to their needs. Chick and Meleis (1986) proposed the study of transitions as a fruitful avenue for developing nursing clinical therapeutics. This study, in combination with the AIDS family caregiver study (Brown & Powell-Cope, 1991), details the processes and structure of a specific transition. First, findings indicated vulnerable times during which couples might need increased support and care. For example, study participants identified the period following the emotional awareness of HIV and acute health crises as times of increased vulnerability and therefore critical opportunities for support. These were also periods of high vulnerability in the integrity of couples' relationships.

Second, the interpersonal processes identified in this study, such as mismatches in perceptions and strategies that occur between PWAs and their partners during mutual protection (protecting boundaries, preserving independence, promoting intimacy), indicate the need for interpersonal

interventions that target couples, i.e., couples counseling or interpersonal skills training such as assertiveness, communication, problem-solving techniques, and conflict management. Since these critical junctures and interpersonal processes are not as easily measured as the biomedical aspects of HIV infection (such as t-lymphocyte counts), working with couples requires continuity of care from a provider who is knowledgeable about the physiological, psychological, and social dimensions of HIV care as well as the specific dynamics among the individuals involved.

Results of this study raise the question: What types of care services will best serve the needs of couples affected by HIV infection? While data to answer the question are still to be determined, models developed in caring for people with similar illnesses could prove to be beneficial for those affected by HIV infection. For example, in cancer care, Benoliel (1985) and Saunders and McCorkle (1985) proposed models of care based on nurses' availability during the highest times of need. Key features of these models include: partnership in care with the patient's personal support network; shared decision making; quick attention to symptomatic problems; prevention of complications; and monitoring of symptoms.

In a study of home nursing care of lung cancer patients based on these features, McCorkle and colleagues (1988) found that compared with a control group who received standard office medical care, patients in home nursing care groups experienced less symptom distress and increased independence. Because HIV is a chronic illness, it would appear that home care models which include these approaches could be useful for couples coping with HIV infection. The testing of care delivery models for people with HIV infection and their families is a critical need. Further research is required to determine the most effective

approaches in improving the quality of life for PWAs and the quality of care rendered by family members.

The importance of the commitment to each other demonstrated by couples in this study cannot be over-emphasized. In developing working partnerships with gay couples facing HIV infection, nurses must not only recognize but honor and respect the deep commitment which gay couples with HIV infection are likely to share. In a study of family caregivers, the desire to be recognized as a significant other by the PWA's health care provider was identified as a major concern (Powell-Cope, 1990). Ussher (1990) suggested that although counseling is an integral part of HIV care settings, the focus is most often on the individual. Paradoxically, many of the concerns felt by the HIV-infected person are in fact relationship concerns, such as the maintenance of relationship boundaries, balancing dependency and independence, and preserving intimacy. Ussher's pilot study suggested that couples who received counseling together showed improvements in relationship satisfaction (perhaps achieved by helping couples to communicate more effectively). Health care providers need to include significant others in caring for HIV-infected clients, especially as the partner begins to take on more care responsibilities.

Environmental Level

Findings from this study have the potential for assisting nurses in developing clinical therapeutics that create supportive social environments. The analysis of couples' experiences in light of heterosexism raises certain questions: How can we assist our clients to effect change in the social structures that constrict and limit their behavior? How can we assist clients to use the social structures and the resources that are available in order to attain desired goals? The results of the

structural analysis component of this study could be used to empower gays to participate in the creation of social change that would result in caring, compassion, and understanding toward those affected by HIV. While the motives and desirability of such goals are not a focus of this discussion they are important issues which demand scrutiny in and of themselves.

There is evidence to suggest that heterosexism is a part of the culture of nursing. In a study of lesbian phobia among nurse educators, Randall (1989) found that 24% of those polled thought that lesbianism is just plain wrong, 34% thought that lesbian behavior is disgusting, and 52% indicated that lesbianism is not a natural expression of human sexuality. Although my analysis of heterosexism was limited to gay men's experiences and did not include a discussion of lesbianism, Randall's (1989) findings are significant because 20% of her sample incorrectly thought that lesbians are a common source of HIV transmission. Randall (1989) proposed that "although lesbians are considered to be at low risk for AIDS, they are at high risk for discrimination and misunderstanding of their sexuality by sharing the label of homosexual with gay men."

Using heterosexism as a way to view lesbian phobia provides nurses with the understanding that heterosexism as an environment is ours to change. Valuing diversity in the sexual orientation of clients could result in increasing our acceptance of the variety of sexual orientation within our own ranks. Validating and valuing the homosexuality of our clients is a step toward creating an environment in which lesbian and gay nurses, nursing students, and faculty can feel supported and less alienated, without the need to conceal a part of themselves. Learning to appreciate the positive qualities of homosexual clients is a

demonstration of good faith that we are capable of valuing and perhaps embracing the diversity within our own profession.

The potential clinical uses of addressing heterosexism lie in using it to empower gay clients who may or may not have HIV infection, to help them to recognize the origins of prejudice and discrimination located outside themselves, and to assist them to learn ways to channel anger toward perpetrators of heterosexism rather than at the self (Neisen, 1990). Moreover, identifying heterosexism could be used to challenge heterosexual clients to think about their privileged status as a first step in relinquishing that status. Results could have the effect of assisting heterosexuals to become more compassionate toward gay men with HIV infection, to embrace cultural diversity of which sexual orientation is only one dimension, and to create systems of health care that are just for all citizens.

One way to foster empowerment would be for nurses to engage in building coalitions among community groups who share a common ground. Heterosexism shares with the other "isms" (racism, classism, feminism) two common features. First, these ideologies all possess the element of power embedded in social institutions which systematically sanction discrimination based on race, class, gender, or sexual orientation (Neisen, 1990). Second, they are based on unfounded prejudices and result in individual acts of discrimination (Neisen, 1990). These elements, then (power embedded in social institutions, prejudice and discrimination) are the common ground against which diverse groups might work together in coalition. Bereano (1991) clearly explicated the origin of AIDS activism in earlier social movements such as the Civil Rights Movement, the Gay Rights Movement, the Women's Health Care Movement, and the Disability Rights

Movement. Furthermore, Patton (cited in Wilton, 1990) indicated that societal responses to HIV seek to implicate and justify a range of "isms," that is, racism, sexism, classism, and heterosexism. Wilton (1990) explained:

Outside of the gay male culture, AIDS is commonly constructed as something which happens to other people *because* of their otherness. Injecting drug users, gay men and prostitutes have all been stigmatised [sic] in this way. In Britain, if you are white, 'other' is black and vice versa. If you are straight, 'other' is gay. If you are lesbian 'other' is a woman who has sex with men. If you are a woman who has sex with men, 'other' is a woman who has sex with more men than you do, or who is paid for it. (p. 234)

Despite the separation of people with AIDS into groups of 'others,' many of the concerns of gay male study participants are similar to those of other groups of PWAs and non-PWAs: affordable housing and health care, partnership and empowering models of medical care, access to and continued participation in health care, discrimination based on physical health, sexual orientation, gender, or color that limit health care options, and the eradication of HIV infection. Coalition building allows the pooling of resources, individual talents, and money to create widespread social reform. Building on nurses' rich history as public health reformers (Melosh, 1982) is a way for nurses in HIV care to reform social structures that limit health, housing and other options not only for gay couples affected by HIV infection, but also for lesbians, the poor, people of color, women and the disabled. Nurses are in a position to foster collaborative work among health and social activist groups with interests that support halting discrimination against people with HIV infection and increasing access and continued

participation in health care. Nurses could foster the building of bridges that connect diverse groups who share similar experiences, goals and values.

Structurally, study findings also indicate that there is still work to be done in creating environments in which people who face multiple losses and death can be supported. Nurses can become involved in movements to redesign western culture and American society to become more accepting of death and loss. Activities could include demonstrating care and concern for clients who face insurmountable losses, helping families to do the same, and becoming spokespersons to promote a society more open about death.

Grieving gay clients in particular may need more personal support, as they are often denied the right to openly grieve due to cultural attitudes toward homosexuality (Sowell, Bramlett, Gueldner, Gritzmacher, & Martin, 1991). In addition, bereavement may be complicated if the survivor is HIV-positive, and thus forced to face his own vulnerability (Sowell, et al., 1991). At the institutional level, nurses can serve as spokespersons for gay couples facing HIV infection or any other chronic illness who are denied rights, such as family leave. Nurses should be involved at local, state and national levels to make sure that formal definitions of family include nonmarried, gay and lesbian, or nonbiologically-related caregivers.

Findings of this study also raise questions about the funding of HIV home care and other family policy issues. A major contribution of this study is the finding that commitment is the basis upon which gay couples facing HIV infection defined themselves as a family. The concept of commitment is critical because it is the primary factor that contributes to a family environment conducive to the home care of people with HIV infection. Commitment is what kept couples

together through difficult periods and made possible a vision of their future as a couple regardless of what HIV held in store for them.

As the national health care system has restricted acute care services, while at the same time, home care has become an increasingly important component in maintaining the health of people with chronic illness, there is much debate on how best to finance home care and to support family caregivers who provide the bulk of it. In an analysis of the economic contribution of family members in providing home care Ward and Brown (1992) found that caregivers spent an average of 5 hours per week in performing housework directly for the PWA and 8.5 hours per day performing personal care tasks for the PWA. Moreover, the annual value of care provided for one PWA was calculated at \$25,857.88. Ward and Brown (1992) suggested that results of this and similar research are important because they challenge the assumptions underlying home care, that is, that care provided by family members is "free." Furthermore, it was posited that care systems based on unpaid contributions by family members result in inequities indicating health care delivery and government are not meeting their responsibilities in caring for the sick (Ward & Brown, 1992).

In another study of family policy, Linsk, Keigher, and Osterbusch (1988) conducted a nationwide survey to investigate the use of paid family caregivers for the elderly. They found that although 35 states permit some type of payment, there was a complex variety of limits restricting these payments. For example, 11 states allowed payments to spouses only, and 5 allowed payment to adult children only. The result of such restrictions is that in some states the elderly may be forced to accept personal care from distant relatives or non-relatives. While no data could be found regarding funding to AIDS family caregivers, there is an

implicit irony in these findings, namely that for gay partners who are not recognized as family, restrictions may turn out to be of benefit. Thus, their non-sanctioned status as a couple could conceivably result in their not being excluded from funding.

Finally, also at the structural level, results of this study are important because the analysis of personal experiences, homophobia, and heterosexism provides unique links to understanding HIV care. Homophobia is well-represented in the literature on HIV infection and is an integral part of the discourse about HIV infection (Poirier, 1988). Homophobia has been linked to negative attitudes of nurses and other health care providers toward people with HIV infection (Kalman & Kalman, 1985; Kelly, Lawrence, Smith, Hood, & Cook, 1987; Pleck, O'Donnell, O'Donnell, & Snarey, 1988; Scherer, Haughy, & Wu, 1989), to lack of knowledge about HIV infection (Doran, Laxson, & Pepper, 1990), and to acts of discrimination and prejudice against people with HIV infection and their families (Powell-Cope & Brown, 1992; King, 1989). Results of this study suggest similar effects of homophobia, but by framing them within the language of power, oppression, and heterosexism, new options are created for gay men with HIV infection as discussed in the individual level clinical therapeutics section. The discourse on HIV can be enhanced by sustained debate surrounding heterosexism.

Implications for Further Research

Longitudinal data are needed to determine the effects of couples experiences on subsequent bereavement of the survivor. Studies suggest that the level of difficulty in bereavement following the death of a partner may be related to the range of caretaking activities, degree of emotional distress, and amount of support received during caregiving prior to death, both in HIV infection (Lennon,

Martin, & Dean, 1990) and other populations (Bass & Bowman, 1990; Bass, Bowman, & Noelker, 1991). Based on a study of social support during caregiving and subsequent bereavement, Lennon and colleagues (1990) suggested that caring for the AIDS caregiver may lessen the distress after death of a partner.

Prospective study designs for bereavement, beginning well before the actual death event, would help to determine whether intervention before death would lessen the distress of grieving during bereavement.

Based on the findings related to moving on, long-term follow-up of survivors is critical. In urgent need of study are the relationship between styles of coping and managing one's health, and illness and survival. Do people who frame their experiences using a survivorship style experience higher levels of wellness than people who take a less active role in their own care? What are the key behavioral activities that increase survivability of HIV infection? In researching his book on AIDS survivors, Callen (1990) interviewed many researchers and found that very few are examining long-term survival. He also found that the reasons for this lack of research were unclear but probably attributable to a lack of interest on the part of scientists and the difficulties posed in studying multifactorial, bio-psycho-social phenomena. Callen (1990, pg. 50) concluded, "Unfortunately, much of the data on the influence of attitude on long-term survival is 'soft,' inconclusive and/or contradicting." While Callen offered a somewhat pessimistic view, perhaps nurses with their bio-psycho-social perspectives, are well-suited to researching the subject of AIDS long-term survival.

Of interest to me personally in pursuing a program of research is the relationship between social activism and AIDS activism, and the role of nurses in promoting empowerment among culturally diverse groups. If community identity

and connection are beneficial, how can we foster these among disenfranchised individuals? How can we foster them among privileged individualists? Moreover, how can nurses facilitate the development of coalitions to effect social change? Gay men have already made noteworthy accomplishments in their collective fight against AIDS. Among them are: (a) establishing successful Community Research Initiatives to test promising drugs more quickly than through traditional routes, such as the Food and Drug Administration and the National Institutes of Health (Kramer, 1988); (b) establishing information and service networks such as the Gay Men's Health Crisis in New York City, described by Larry Kramer (1988, p. 182) as "this country's first and largest community self-help AIDS organization;" and (c) on a local level, playing a major role in the establishment of a needle exchange program designed to prevent HIV infection by making clean needles available to those who use injectable drugs, and in the formation of major service organizations (Bereano, 1991). These accomplishments at the grassroots level raise the questions: what is nursing's role in collective action at the community level in HIV care. Should nurses be involved in these efforts, and if so, how?

The study of social activism within families facing HIV infection would benefit from the use of emancipatory models of research (Campbell & Bunting, 1991; Lather, 1988; Parker & McFarlane, 1991; Thompson, 1990) which seek to foster empowerment by exposing hidden power imbalances and enlightening social agents to act responsibly and autonomously (Allen, 1985). According to Lather (1988, p. 572) the purpose of empowering methodologies is to "contribute to consciousness-raising and transformative social action." Because of the double hermeneutic of social science research that Giddens suggested, emancipatory models of research are compatible with structuration theory, that is, examining the

relationships between personal experience and social structure, and using the results of such an examination for emancipatory purposes. In this study the use of grounded theory with symbolic interactionism as its theoretical underpinning was limiting and would seriously impede future efforts to study the political involvement of families affected by HIV infection because the basis for human actions in symbolic interaction is limited to those meanings explicitly expressed by social actors. For future research to be considered emancipatory, the specific goals and aims will need to be clearly stated for their political purposes (Campbell & Bunting, 1991), for example, to create emancipatory knowledge for families facing HIV infection, or to gain fuller participation in public life and political action for families affected by HIV infection. Emancipatory methods emphasize reciprocity between researcher and participant and equal power balances (Lather, 1988; Thompson, 1990).

Final Summary and Conclusions

This study began with the premise that the definition of nursing as a field of study must include the following concepts: nursing, environment, client (or individual), and health (Chinn & Jacobs, 1987; Kim, 1987). This research addressed two of these major components: individuals and environments. Specifically, the focus of this study was individuals' experiences of HIV infection in the context of a committed gay relationship, and the social environment as defined by heterosexism. Results of this study are important because they detail a theory of becoming a couple affected by HIV infection that is grounded in their experiences. Moreover, the structural analysis of heterosexism adds to the understanding of gay couples' experiences because it further grounds the theory within its social context. Results are useful in indicating directions for individual

and environmental clinical therapeutics in working with this vulnerable population. In addition, results provide a basis for further research that accounts for process and change over time as well as for emancipatory and empowering models of research.

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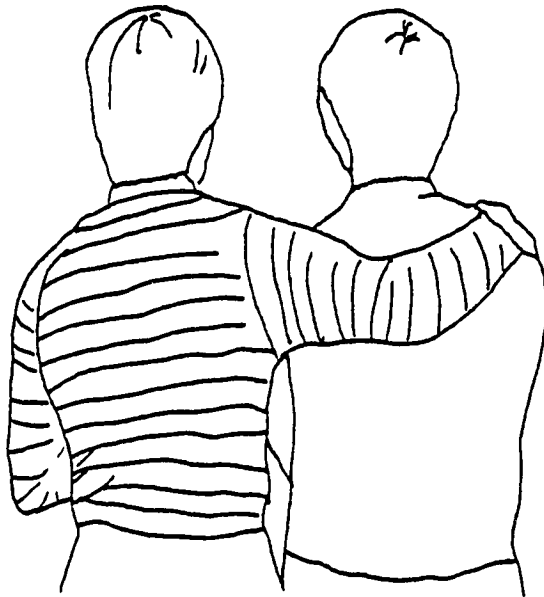
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APPENDIX A
Recruitment Flier

**FAMILY CAREGIVING BY LOVERS AND PARTNERS
DURING HIV INFECTION**



I am interested in interviewing gay couples, one of whom has AIDS or symptomatic HIV infection and the other is their lover/partner and primary family caregiver, to learn about your experiences. At most participants will be asked to complete 2 in-depth interviews (the first lasting approximately 4 hours, the second approximately 2 hours) and 1 shorter telephone interview. Each individual will be reimbursed \$20.00 for each in-depth interview completed and \$10.00 for the telephone interview. It is hoped that information gained will enable nurses and other health care providers to offer better care to persons with HIV/AIDS and their partners.

If interested please call:
Gail Powell-Cope, R.N., Ph.C.
School of Nursing, University of Washington
(206) 361-7084

APPENDIX B
Newspaper Advertisement

Advertisement placed in local newspapers and newsletters

University of Washington, School of Nursing research study recruiting gay couples: one of whom has AIDS or symptomatic HIV infection and one of whom is the primary family caregiver. Would like to know about your experiences. Study involves a maximum of 2 in-depth interviews and 1 brief telephone interview over a period of 2 months. You will be paid \$20.00 for each in-depth interview completed and \$10.00 for the telephone interview. Confidentiality insured. Call Gail Powell-Cope at 361-7084.

APPENDIX C
Initial Interview Schedule for Screening Purposes

Thank you for calling about the study, AIDS Family Caregiving. I am Gail Powell-Cope, a doctoral student in nursing at the University of Washington. This study is for my dissertation. I would like to ask you a few questions at this time to make sure you are eligible for this study and then I will explain the study to you in some detail. Whatever we talk about today is confidential. I am the only one who has access to information obtained. Is it all right to go on?

Are you a gay man who has been told by a health care provider that you have either symptomatic HIV infection or AIDS?

Yes No

Are you a gay man who is a primary caregiver for your partner who has been told by a health care provider that he has either symptomatic HIV infection or AIDS?

Yes No

For this study I am interested in interviewing both the person with AIDS, and his partner. Have you discussed this study with your partner? Is he interested in participating, also?

Yes No

[At this point I will determine eligibility. If the individual is not eligible . . . "Thank you for calling, but I am interviewing only gay men with symptomatic HIV infection of AIDS, and their partners." If eligible, "Now I'd like to tell you about the study."]

The purpose of this study is to find out what AIDS family caregiving is like for both the one providing care and the one receiving care. Results should be useful to health care providers to improve care as they work with families who are affected by AIDS. The study involves at least one face-to-face interview and one telephone follow-up. Based on the telephone follow-up you may or may not be asked to participate in a second face-to-face interview. The first face-to-face interview is expected to last approximately four hours, the second approximately two hours. The telephone interview is expected to be shorter. During the interviews you will be asked several open-ended questions about your experiences as a caregiver or a care recipient. For example, you will be asked to "Describe your experiences giving care to a person with AIDS" or "Describe your experiences as a person with AIDS who is receiving care from your partner." An

example of a more sensitive question is, "Tell me about the losses you have experienced since you have been caregiving." You will be reimbursed \$20.00 for completing each face-to-face interview and \$10.00 for each telephone interview, for a maximum of \$50.00.

Does this sound like a study you would like to participate in?

Yes No

[If no,] Thank you for your time.

[If yes, I will proceed in making arrangements for the interview.]

Other Relevant Information

1. Phone number: (home) _____
(work) _____

2. Best time to call: _____

3. Is it all right for me to leave a message on your answering machine?

Yes No

If yes, is there anything you would not like me to say on the machine such as my name, that I am calling about the "Family Caregiver Study," etc.?

4. Address: _____

5. Directions to home: _____

APPENDIX D

DEMOGRAPHICS INTERVIEW GUIDE
PWA VERSION: PARTICIPANT NO. _____

1. How old are you?
 Years Months
2. When were you diagnosed with HIV infection?
 Month Year
3. When were you diagnosed with AIDS or symptomatic HIV infection?
 Month Year
4. How long have you known your partner?
 Years Months
5. How long have you been in a relationship with your partner?
 Month Year
6. Are you currently employed?
 Yes, part time
 Yes, full time
 No
If yes, what is your occupation? _____
7. What was your 1990 combined yearly income before taxes?
 Less than \$10,000
 \$10,000 to \$20,000
 \$20,000 to \$30,000
 \$30,000 to \$40,000
 \$40,000 to \$50,000
 More than \$50,000

8. What is the highest level of education you completed?

1. Less than high school
2. GED
3. High School diploma
4. Trade or technical school
5. Some college
6. Baccalaureate degree
7. Graduate or Professional School

9. Ethnicity

1. Caucasian
2. Asian-American
3. Afro-American
4. Hispanic
5. Native American
6. Other _____

10. How would you describe your present health status?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

11. How would you evaluate your physical functioning? (Karnofsky & Burchenal, 1949)

- 100 Normal: no complaints; no evidence of disease
- 90 Able to carry on normal activity; minor signs or symptoms of disease
- 80 Normal activity with effort; some signs or symptoms of disease
- 70 Care for self; unable to carry on normal activity or to do active work
- 60 Require occasional assistance but able to care for most of my needs
- 50 Require considerable assistance and frequent medical care
- 40 Disabled; require special care and assistance
- 30 Severely disabled; hospitalization is indicated although death is not imminent
- 20 Very sick; hospitalization necessary; active supportive treatment is necessary
- 10 Moribund, fatal processes progressing rapidly
- 0 Dead

12. How would you rate your health status and functioning based on the following categories? (Lawton & Brody, 1969)

A. Toileting

- 1. Care for self at toilet completely; no incontinence
- 2. Need to be reminded, or need help in cleaning self, or has rare (accidents)
- 3. Soil or wet bed while asleep, more than once a week
- 4. Soil or wet bed while awake, more than once a week
- 5. No control of bowels or bladder

B. Feeding

- 1. Eat without assistance
- 2. Eat with minor assistance at meal times, with help in preparing food or with help in cleaning up after meals
- 3. Feed self with moderate assistance and am untidy
- 4. Require extensive assistance for all meals
- 5. Do not feed self at all and resist efforts of others to feed me

C. Dressing

1. Dress, undress and select clothes from own wardrobe
2. Dress and undress self with minor assistance
3. Need moderate assistance in dressing or selection of clothes
4. Need major assistance in dressing but cooperate with efforts of others to help
5. Completely unable to dress and resist efforts of others to help

D. Grooming (neatness, hair, nails, hands, face, clothing)

1. Always neatly dressed and well-groomed, without assistance
2. Groom self adequately, with occasional minor assistance, e.g., in shaving
3. Need moderate and regular assistance or supervision in grooming
4. Need total grooming care, but can remain well-groomed after help from others
5. Actively negate all efforts of others to maintain grooming

E. Physical ambulation

1. Go about grounds or city
2. Ambulate within residence or about one block distance
3. Ambulate with assistance of
 - a) another person
 - b) railing
 - c) cane
 - d) walker
 - e) wheelchair
 - e1. get in and out without help
 - e2. need help in getting in and out
4. Sit unsupported in chair or wheelchair, but cannot propel self without help
5. Bedridden more than half the time

F. Bathing

1. Bathe self (tub, shower, sponge bath) without help
2. Bathe self, with help in getting in and out of tub
3. Wash face and hands only, but cannot bathe rest of body
4. Do not wash self but am cooperative with those who bathe me
5. Do not try to wash self, and resist efforts to keep me clean

G. Ability to use telephone

1. Operate telephone on own initiative; look up and dial numbers, etc.
2. Dial a few well-known numbers
3. Answer telephone but do not dial
4. Do not use telephone at all

H. Shopping

1. Take care of all shopping needs independently
2. Shop independently for small purchases
3. Need to be accompanied on any shopping trip
4. Completely unable to shop

I. Food preparation

1. Plan, prepare, and serve adequate meals independently
2. Prepare adequate meals if supplied with ingredients
3. Heat and serve prepared meals, or prepare meals but do not maintain adequate diet
4. Need to have meals prepared and served

J. Housekeeping

1. Maintain house alone or with occasional assistance (e.g., heavy-work, domestic help)
2. Perform light daily tasks such as dish-washing and bed-making
3. Perform light daily tasks but cannot maintain acceptable level of cleanliness
4. Need help with all home maintenance tasks
5. Do not participate in any housekeeping tasks

K. Laundry

1. Do personal laundry completely
2. Launder small items; rinse socks; stockings, etc.
3. All laundry must be done by others

L. Mode of transportation

1. Travel independently on public transportation or drive own car
2. Arrange own travel via taxi, but do not otherwise use public transportation
3. Travel on public transportation when assisted or accompanied by another
4. Travel limited to taxi or automobile, with assistance of another
5. Do not travel at all

M. Responsibility for own medication

1. Am responsible for taking medication in correct dosages at correct time
2. Take responsibility if medication is prepared in advance in separate dosages
3. Am not capable of dispensing own medications

N. Ability to handle finances

1. Manage financial matters independently (budget, write checks, pay rent and bills, go to bank), collect and keep track of income
2. Manage day-to-day purchases, but need help with banking, major purchases, etc.
3. Incapable of handling money

DEMOGRAPHICS INTERVIEW GUIDE
 FAMILY CAREGIVER VERSION: PARTICIPANT NO. _____

1. How old are you?

Years	Months

2. When was your partner diagnosed with HIV infection?

Month	Year

3. When was your partner diagnosed with AIDS or symptomatic HIV infection?

Month	Year

4. How long have you known your partner?

Years	Months

5. How long have you been in a relationship with your partner?

Month	Year

6. Are you currently employed?
 - _____ Yes, part time
 - _____ Yes, full time
 - _____ No

If yes, what is your occupation? _____

7. What was your 1990 combined yearly income before taxes?
 - _____ Less than \$10,000
 - _____ \$10,000 to \$20,000
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 - _____ \$30,000 to \$40,000
 - _____ \$40,000 to \$50,000
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9. Ethnicity

1. Caucasian
2. Asian-American
3. Afro-American
4. Hispanic
5. Native American
6. Other _____

10. How would you describe your present health status?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

11. How would you describe your partner's present health status?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

12. How would you evaluate your partner's physical functioning? (Karnofsky & Burchenal, 1949)

- 100 Normal: no complaints; no evidence of disease
- 90 Able to carry on normal activity; minor signs or symptoms of disease
- 80 Normal activity with effort; some signs or symptoms of disease
- 70 Cares for self; unable to carry on normal activity or to do active work
- 60 Requires occasional assistance but able to care for most of my needs
- 50 Requires considerable assistance and frequent medical care
- 40 Disabled; requires special care and assistance
- 30 Severely disabled; hospitalization is indicated although death is not imminent
- 20 Very sick; hospitalization necessary; active supportive treatment is necessary
- 10 Moribund, fatal processes progressing rapidly
- 0 Dead

13. How would you rate your partner's health status and functioning based on the following categories? (Lawton & Brody, 1969)

A. Toileting

- 1. Cares for self at toilet completely; no incontinence
- 2. Needs to be reminded, or needs help in cleaning self, or has rare (accidents)
- 3. Soils or wets bed while asleep, more than once a week
- 4. Soils or wets bed while awake, more than once a week
- 5. No control of bowels or bladder

B. Feeding

- 1. Eats without assistance
- 2. Eats with minor assistance at meal times, with help in preparing food or with help in cleaning up after meals
- 3. Feeds self with moderate assistance and is untidy
- 4. Requires extensive assistance for all meals
- 5. Does not feed self at all and resists efforts of others to feed him

C. Dressing

1. Dresses, undresses and selects clothes from own wardrobe
2. Dresses and undresses self with minor assistance
3. Needs moderate assistance in dressing or selection of clothes
4. Needs major assistance in dressing but cooperates with efforts of others to help
5. Completely unable to dress and resists efforts of others to help

D. Grooming (neatness, hair, nails, hands, face, clothing)

1. Always neatly dressed and well-groomed, without assistance
2. Grooms self adequately, with occasional minor assistance, e.g., in shaving
3. Needs moderate and regular assistance or supervision in grooming
4. Needs total grooming care, but can remain well-groomed after help from others
5. Actively negates all efforts of others to maintain grooming

E. Physical ambulation

1. Goes about grounds or city
2. Ambulates within residence or about one block distance
3. Ambulates with assistance of
 - a) another person
 - b) railing
 - c) cane
 - d) walker
 - e) wheelchair
 - e1. gets in and out without help
 - e2. needs help in getting in and out
4. Sits unsupported in chair or wheelchair, but cannot propel self without help
5. Bedridden more than half the time

F. Bathing

1. Bathes self (tub, shower, sponge bath) without help
2. Bathes self, with help in getting in and out of tub
3. Washes face and hands only, but cannot bathe rest of body
4. Does not wash self but is cooperative with those who bathe him
5. Does not try to wash self, and resists efforts to keep clean

G. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers, etc.
2. Dials a few well-known numbers
3. Answers telephone but does not dial
4. Does not use telephone at all

H. Shopping

1. Takes care of all shopping needs independently
2. Shops independently for small purchases
3. Needs to be accompanied on any shopping trip
4. Completely unable to shop

I. Food preparation

1. Plans, prepares, and serves adequate meals independently
2. Prepares adequate meals if supplied with ingredients
3. Heats and serves prepared meals, or prepares meals but does not maintain adequate diet
4. Needs to have meals prepared and served

J. Housekeeping

1. Maintains house alone or with occasional assistance (e.g., heavy-work, domestic help)
2. Performs light daily tasks such as dish-washing and bed-making
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness

4. Needs help with all home maintenance tasks
5. Does not participate in any housekeeping tasks

K. Laundry

1. Does personal laundry completely
2. Launders small items; rinse socks; stockings, etc.
3. All laundry must be done by others

L. Mode of transportation

1. Travels independently on public transportation or drives own car
2. Arranges own travel via taxi, but does not otherwise use public transportation
3. Travels on public transportation when assisted or accompanied by another
4. Travel limited to taxi or automobile, with assistance of another
5. Does not travel at all

M. Responsibility for own medication

1. Is responsible for taking medication in correct dosages at correct time
2. Takes responsibility if medication is prepared in advance in separate dosages
3. Is not capable of dispensing own medications

N. Ability to handle finances

1. Manages financial matters independently (budget, write checks, pay rent and bills, go to bank), collects and keeps track of income
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.
3. Incapable of handling money

APPENDIX E

INTERVIEW GUIDE PARTICIPANT NO. _____

1. How did you hear about the study? And why did you volunteer to be in the study? (Lead-in questions)
2. What is it like to be receiving care from [family caregiver] since you've been sick? or What is it like to be a family caregiver for a person with HIV infection? (Overall grand-tour question)
3. Tell me about a time, or an incident you have experienced with [PWA or family caregiver] which you felt was problematic, important, or meaningful. (Intended to stimulate discussion)
4. How do you manage the illness and symptoms of HIV infection? (Targets "Managing and Being Managed by the Illness")
5. How do you relate to the outside world in light of HIV infection? (Targets "Going Public")
6. Tell me more about your decision-making process surrounding "Going Public." What did you expect to happen? And what happened that you did not anticipate? (Targets intended and unintended consequences of "Going Public")
7. How do you deal with the infectious nature of HIV infection? (Targets "Containing the Spread")
8. Is the notion of living with loss relevant to your experiences as a family caregiver [care receiver]? (Targets "Living with Loss and Dying")
9. How do you relate to one another now that you and you partner are in a caregiving [care receiving] situation? (Targets "Renegotiating the Relationship")
10. What role does uncertainty play in your experiences as a family caregiver [care receiver]? (Targets "Transitions Through Uncertainty")

11. To what extent do you feel unsure about aspects of life as a caregiver [care recipient]? (Targets "Transitions Through Uncertainty")
12. How has your sense of uncertainty or certainty about being a caregiver [care recipient] changed over time? (Targets "Transitions Through Uncertainty")
13. How have your experiences in caring for (or being cared by) your partner changed over time? (Targets "Transitions Through Uncertainty")
14. What are your thoughts about the political climate surrounding AIDS? (Targets context)
15. What has your experience been with community AIDS organizations such as: Shanti, Northwest AIDS Foundation, ACT-UP? Have you ever considered becoming involved in any AIDS organizations? What are your thoughts about community AIDS organizations? (Targets social and political context)

INTERVIEW SCHEDULE--ADDENDUM

1. I started out calling my study an AIDS Family Caregiver Study and I began to wonder how others define family and caregiving. How do you define family?

How do you define caregiver?
2. If you could sum up in one word or phrase what caregiving (being a person with AIDS, being a care recipient) means to you, what would that be?

Could you sum up in one word or phrase what it means to be a couple affected by HIV/AIDS?
3. Was there ever a time when you thought "AIDS has hit home with us," with you and your lover?
4. Do you do things to try to protect your lover's physical and emotional health?

Do you do things to try to protect your own physical and emotional health?

5. Does the phrase "Holding on/letting go" have any meaning for you as an AIDS family caregiver?
6. Those are all the questions I have. Is there anything else you would like me to know, or is there anything else that I should have asked you that I didn't?

APPENDIX F
Consent Form

School of Nursing
University of Washington
Seattle, Washington 98195

Family Caregiving During HIV Infection

Investigator: Gail M. Powell-Cope, R.N., Ph.C.
School of Nursing, SC-72
University of Washington
Seattle, WA 98195
Phone: (206) 361-7084

Investigator's Statement

I am inviting you to participate in a study about the experience of family caregiving by gay partners during HIV infection. The purpose of this study is to describe the experience of giving and receiving care when one partner is ill and the other is the family caregiver. The information you share will be helpful to others who are in a caregiving situation, and to nurses who assist people in making decisions about family caregiving.

If you agree to participate, you will be asked to participate in a minimum of one face-to-face interview and one telephone follow-up interview. Some participants will be asked to participate in one additional face-to-face interview. The purpose of the telephone and second interviews is to clarify topics discussed in the first interview. All interviews will be conducted by the principal investigator. All interviews will be conducted at your convenience in the setting of your choice. The first face-to-face interview is expected to last approximately four hours, the second approximately two hours. The telephone interview is expected to be shorter in length. You will be compensated \$20.00 for each face-to-face interview completed and \$10.00 for the telephone interview. (That is, payment will be to each individual per interview individually completed.) The face-to-face interviews will be audio tape recorded. You will be asked open-ended questions about your experience of giving care such as, "What is it like for you caring for [PWA] at home?" (if you are the caregiver) or "What is it like for you being cared for by your partner at home since you have been sick?" (if you are the person with HIV infection). You will also be asked to respond to one short questionnaire that includes background information about yourself and your

relationship with your partner. You do not have to answer any question you choose not to answer. After the data have been analyzed, all participants will receive a summary of findings if desired.

Because you will be asked to discuss experiences in your life that may be painful or difficult, you may experience some feelings of sadness, anger, or hurt. Sometimes having the opportunity to talk about a stressful experience is helpful in working through your feelings. At any time you can ask that the interview be ended. The investigator's phone number will be made available to you if at a later date you should wish to talk about the interview.

Strict confidentiality will be maintained. Information you give during your interviews will not be shared with anyone including your partner. Your name will not be used on any of the interview forms or tapes and the interview will be conducted privately. The tapes will be stored in a locked file until they are transcribed by a professional transcriptionist. During the time the tapes are locked only study personnel will have access to them. Audio tapes will be erased after they have been transcribed. Also, your name, address and telephone number will be kept in a locked file and only be seen by the investigator and faculty sponsor. The interviews will be kept in a locked file for five years and will be available only to the investigator.

Gail M. Powell-Cope	Date
---------------------	------

Marie Annette Brown	Date
Faculty Sponsor	

"The study described above has been explained to me, and I voluntarily consent to participate in this activity. I have had the opportunity to ask questions and understand that future questions I have about the research or about subjects' rights will be answered by one of the investigators listed above."

Signature of Participant	Date
--------------------------	------

School of Nursing
University of Washington
Seattle, Washington 98195

Information Letter and Oral Agreement to Participate in the study entitled: Family
Caregiving During HIV Infection

Investigator: Gail M. Powell-Cope, R.N., Ph.C.
School of Nursing, SC-72
University of Washington
Seattle, WA 98195
Phone: (206) 361-7084

Investigator's Statement

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choose not to answer. After the data have been analyzed, all participants will receive a summary of findings if desired.

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Gail M. Powell-Cope	Date
---------------------	------

Marie Annette Brown	Date
Faculty Sponsor	

"The study described above has been explained to me, and I voluntarily consent to participate in this activity. I have had the opportunity to ask questions and understand that future questions I have about the research or about subjects' rights will be answered by one of the investigators listed above."

APPENDIX G
Threats to Reliability and Validity

Threat to Reliability	Control of Threat
Researcher's status position	Role of researcher was carefully explained to participants before initial and second interviews
Participant choice	Persons with HIV and their caregiver were recruited indirectly through advertisements Participants were asked why they volunteered for study; this become part of the data set
Social situation conditions	Because data collection took place based on participants' preferences, context of interviews were carefully recorded and included in analysis Field notes were recorded immediately after interviews
Methods of procedure	Precise methods of data collection and analysis were reported Interviews were transcribed verbatim within 5 days of interview Analysis began as soon as transcripts were available Nurse experts coded portions of transcripts, interrater reliability was assessed using a consensus approach Findings were compared to extant literature as analysis progressed Salient observations of time 1 interviews were validated during time 2 interviews

Threats to Validity	Control of Threat
History and maturation	Changes that were recurrent, progressive, cyclic, or historical in nature were identified
Observer effects	Data were corroborated from multiple participants and discrepant-case analysis was conducted (as part of constant comparative analysis)
	Data were compared to theories and models derived from literature (as part of constant comparative analysis)
	Substantive and theoretical coding was conducted concurrent with data collection to elicit contrived responses
	Emerging themes were validated with participants
Selection and regression	Theoretical sampling was attempted
	Salient observations of time 1 interviews were validated during time 2 interviews
Attrition	Participants were assured that their input is valued
	Results will be made available to appropriate local agencies and participants will each be given a summary of results if desired

BIOGRAPHICAL SKETCH

Name: Gail Marie Powell-Cope

Birth Date: August 24, 1957

Birth Place: Buffalo, New York

Education and Degrees:

- Bachelor of Science
Nursing, 1979
University of Florida
Gainesville, Florida
- Master of Science
Adult Health Nursing, 1984
University of Florida
Gainesville, Florida
- Doctor of Philosophy
Nursing Science, 1992
University of Washington
Seattle, Washington