Caring Practices in Families of Persons with AIDS

by

Linda J. Budan, MA, MSN, RN

A Dissertation

Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

September 16, 1994

APPROVED:

[redacted]

Christine A. Tanner, RN, PhD, FAAN, Professor, School of Nursing, Oregon Health Sciences University, Research Advisor

[redacted]

Patricia G. Archbold, RN, DNSc, FAAN, Professor, School of Nursing, Oregon Health Sciences University, Co-Research Advisor

[redacted]

Michael Garland, PhD, Professor, School of Medicine, Oregon Health Sciences University School of Nursing, Committee Member

[redacted]

Marie Annette Brown, RN, PhD, FAAN, Professor, University of Washington, School of Nursing, Committee Member

[redacted]

Carol A. Lindeman, RN, PhD, FAAN, Dean, School of Nursing, Oregon Health Sciences University

Financial Acknowledgements

The following sources of financial support are gratefully acknowledged: Sigma Theta Tau, Beta Psi Chapter; NINR Institutional Family Research Training Grant No. T32NR07061-04

Acknowledgements

First comes my family in the list of those I wish to thank for support and encouragement during this work. For nearly two decades, my dear John has been willing to forego whatever was necessary to promote my work. To help me finish this project, he moved the family across country, held down multiple jobs on the home front, and during the final months, he read and commented on interviews and chapters. Most memorably, he built in our woods a one-room summer cabin where I could escape to write the final drafts of this manuscript. Ten-year-old Hanna, my angel in disguise, stood along side dad and pounded nails as the structure went up. She was always ready and willing to help mom when I needed it. When they finished they brought me tea in the shaded little cabin where I wrote this analysis. I could not have finished this project without their love, constancy and active support.

I am indebted to the other families of this study who allowed me into their worlds, revealed to me their pain, their regrets, their strengths, and in many cases their faith and astonishing capacities for human care. I was allowed to enter their lives, solicit their stories and share their most difficult memories. Many tears flowed during this study. Sometimes, we cried together during the telling of a story. Sometimes, I cried alone when I read and wrote about their trials and triumphs. I would like to say to them, *Friends, I shall never forget any of you. I admire and thank each one of you for your generosity and models of care.*

Sharing worlds through the telling and hearing of stories was a research approach I had not known before. It was a marvelous experience made possible for

me by Dr. Christine Tanner, my advisor and co-chair of the dissertation. More than this, Chris was the person who made five years of doctoral study a truly rewarding life-changing journey. *Thank you, Chris, for all you have done on my behalf. Thank you for your skill as a caring guide.*

Dr. Patricia Archbold was co-chair of my dissertation committee. Pat generously shared with me her knowledge and years of experience in research on caregiving. She was the first one to encourage me to write a grant proposal under a very tight deadline. That encouragement was an important, affirming experience for me. *Pat, thank you for your practical support and for your initial and ongoing faith in my project.*

Dr. Michael Garland seized on the value of phenomenology as an important method for ethics research. He helped me articulate why and how phenomenology has much to contribute to contemporary moral discourse. As well as his positive support, Mike provided perspectives from the fields of ethics and the humanities. *Thank you, Mike, for your enthusiasm for this project and for your ability to push me toward articulating the essence of an issue.*

Dr. Marie Annette Brown, Professor of Nursing at the University of Washington, generously agreed to contribute her time as a content expert and member of the dissertation committee. Dr. Brown's work on AIDS family caregiving influenced my choice of a content area for doctoral research and provided a theoretical background for my study. Marie contributed crucial commentary on the overall organizing framework of the interpretive account. She readily shared background information from her own research. *Marie, thank you for your time, your important contributions, and your colleagueship in this research.*

A wider network of colleagues and friends also helped me during my research experience. I wish to thank the many doctoral students who read portions of interviews, critiqued analyses, and urged me on. I extend a special thank you to Dr. Peggy Wros whose earlier doctoral research provided a model for me. I am indebted to Dr. Virginia Tilden, who initially spurred my interest in family research while I was employed as a graduate assistant in the School of Nursing Office of Research. I gained immeasurably from working along side Tammy Schuman, Jonathan Fields, Chris Nelson and others who generously shared their research experience and computer smarts. To all of you and others I have not mentioned, I say thank you.

ABSTRACT

TITLE: Caring Practices in Families of Persons with AIDS

AUTHOR: Linda J. Budan, RN, MA, MSN

APPROVED: [redacted]

Christine A. Tanner, RN, PhD, FAAN

The aims of this interpretive phenomenological study were 1) to describe and understand caring practices and practical knowledge of AIDS family caregivers and 2) to explore and describe family members' concerns and meanings related to AIDS caregiving. Ten male and eight female primary family caregivers from rural and urban settings were interviewed about their AIDS caregiving experiences. Participants were interviewed from 1 to 3 times between 3 and 24 months after the death of the person with AIDS. Thematic analysis, exemplars and paradigm cases were methodological strategies used during the iterative processes of reading texts, comparing cases, and writing interpretive commentary.

Three broad aspects of experience were seen to shape caring practices and concerns for persons with AIDS--namely, the cultural contexts of care, the moral meanings and concerns of caregivers, and the particular course of HIV disease in the ill person. These three broad aspects of experience influence the continuum of care for the person with AIDS. Contexts of care include cultural practices, history, and linguistic meanings from the larger culture, influences of local communities, and the practices and specific history of particular families. Six patterns of family as both context and concern emerged. These were: involved families, estranged families, the reconciled family, families in conflict, families with children, and disenfranchised caregivers. Caregivers viewed loss as a context for moral concern. The related meanings of loss included loss of a life world, loss of future time, and loss of the controlling self. Major categories of moral concern included preserving dignity and a sense of self, keeping secrets and living with lies, and being there for the ill person. Stages in the general continuum of care included adjusting to the diagnosis, caring during periods of wellness, reevaluating concerns and practices during the progression to persistent illness, getting settled for more intensive periods of care, moving into high gear, accepting palliative care, and creating caring practices at the time of death. Limits of the study included insufficient representation of minority groups in the sample of caregivers and the retrospective design which may have hampered detailed recall of concrete episodes of care. The findings provided confirmatory stories for current theory on AIDS caregiving and expanded theory by emphasizing the central place of moral concern in family members' caring practices. Nurses and other providers are called upon to broaden their definition of family and deepen their understanding of the contexts, practices, and concerns of AIDS family care. Such understanding can enhance our ability to support, coach, and collaborate with families in similar situations.

TABLE OF CONTENTS

CHAPTER PAGE

1 Introduction 1

  Aims of the Study 2

  Significance of the Study 4

  Strengths of Interpretive Phenomenology as the Method of Study 6

  Overview of the Research Report 10

2 Review of Literature 13

  AIDS Caregiving 13

  General Caregiving 19

  Caring Practices and a Relational Ethic of Care 23

3 Methodology 28

  Overview of the Research Design 28

  The Heideggerian View of the Person 29

  Assumptions of the Phenomenological Research Paradigm 36

    Knowledge 37

    Background Meanings 38

    Concern 39

  Consequences for Conducting Phenomenological Research 40

    The Aims of Phenomenological Research 40

    Methodological Implications 41

      Understanding Through Participation 42

TABLE OF CONTENTS (con't)

CHAPTER PAGE

Grasping the Forestructure 44

Investigating Experience as it is Lived 46

Establishing a Communicative Context 47

Looking into Background Meaning 48

Revealing One's Own Values and Assumptions 49

Fixing Action 50

Reflecting on Essential Themes 50

Analyzing Exemplars and Paradigm Cases 51

Engaging in Hermeneutic Writing 53

Additional Aspects of the Research Design 53

Recruitment Strategies 54

Sample 54

Human Subjects Protection 56

Data Collection 57

Setting 58

Data Management 59

Data Analysis 59

Evaluating the Interpretive Account 61

Summary 66

TABLE OF CONTENTS (con't)

CHAPTER PAGE

4 The Cultural Contexts of Care and Concern 67

Background Meanings of AIDS in America 68

The Gay Disease 68

The AIDS Metaphors 73

Stigma 75

Prosocial Responses 81

Local Community as a Context for Care and Concern 84

Gay Community 85

Care Teams 88

Rural Communities 93

Summary 94

5 Family as Context and Concern 96

Families of Choice and Families of Origin 97

Involved Families 98

Estranged Families 102

The Reconciled Family 107

Families in Conflict 109

Families with Children 120

Disenfranchised Caregivers 124

Summary 126

TABLE OF CONTENTS (con't)

CHAPTER PAGE

6 Moral Concerns and Meanings of AIDS Family Caregivers 127

Meaning, Concern, and Caring Practices in the Moral Domain 128

Moral Meanings 129

Moral Concerns 130

Caring Practices 131

Soliciting Stories of Moral Relevance 132

Loss as a Context for Moral Concern 133

Kinds of Loss in the Experience of Living with AIDS 134

The Related Meanings of Loss 136

Loss of a Life World 136

Loss of Relationship 137

Loss of Future Time 139

Loss of the Controlling Self 140

Summary 142

Moral Concerns and Caring Practices Related to Dignity and a Sense of Self 143

Protecting from Humiliation and Shame 144

Keeping the Ill Person in Control 146

Respecting Decisions 151

Keeping Things the Same 152

TABLE OF CONTENTS (con't)

CHAPTER PAGE

Respecting the Spiritual Self 154

Summary 156

Keeping Secrets and Living with Lies 156

Margaret and Mark, a Paradigm Case 158

The Effects of Secrecy 167

Being There 169

Summary 172

7 Concerns and Practices Across the Continuum of Care 174

The Trajectory of Illness 174

Transitions 176

The Continuum of Care 177

Adjusting to the Diagnosis 180

Denial and Avoidance 180

Maintaining Hope 183

Care During Wellness 187

Maintaining Balance and Normalcy in Daily Life 188

Making the Most of Present Time 189

Making the Shift to Persistent Illness 191

Getting Settled for Caregiving 193

Moving into High Gear 196

TABLE OF CONTENTS (con't)

CHAPTER PAGE

Going it Alone 197

Organizing Care Teams 199

Accepting Palliative Care 202

Summary 205

Caring Practices At the Time of Death 205

Cultural Views on Death in Everyday Life 206

Preparing for Death 209

Attending to the Dying Space 213

A Special Way of Being at the Time of Death 217

Letting Go 220

Summary 224

8 Summary and Discussion 226

Limitations 227

Discussion of Findings and Implications of Results 228

References 239

Appendices 255

LIST OF TABLES

TABLE PAGE

1 Caregiver Sample 55

LIST OF FIGURES

FIGURE PAGE

1 Organization of Interpretive Account 11

LIST OF APPENDICES

APPENDIX PAGE

A Consent Form 255

B Interview Guide 259

C Demographic Data Collection Form 261

D Tagging Scheme Used to Mark Text for Data Retrieval 263

CHAPTER 1

INTRODUCTION

Now well within the second decade of the AIDS epidemic, we are increasingly aware that we have no foreseeable end to the personal and social crises presented by this disease (Buehler, Petersen, & Jaffe, 1995). As the number of people with AIDS continues to increase, we face an ever more pressing challenge to provide both formal and informal care for persons progressing through the stages of HIV disease (McDonell, Abell, & Miller, 1991). This study is about family members and friends, who took on the challenge of becoming informal primary caregivers for a person with AIDS. Family caregivers, such as the ones who participated in this study, have become the cornerstone of society's response to AIDS (Brown & Powell-Cope, 1991). Since the beginning of the epidemic, they have played a critical role in providing care to persons with AIDS, yet knowledge about the concerns and practices of these caregivers is in an early stage of development (Brown & Powell-Cope, 1991; Raveis & Siegel, 1990).

The crisis created by an AIDS diagnosis profoundly impacts the family members and friends who may be called upon for care (Macklin, 1989). Social reactions to AIDS as well as the nature of the disease itself create a difficult climate in which to sustain the work of care. Fear of contagion and death; feelings of shame, guilt and social isolation; social intolerance of homosexuality and nontraditional family structures; the emotional toll of witnessing physical and mental decline; and the psychological burden of concealing a stigmatized condition contribute to the difficulties that family members face when caring for a person with AIDS (Brown & Powell-Cope, 1991; Macklin, 1989).

Aims of the Study

Only relatively recently has family caregiving for persons with AIDS been considered a priority in the AIDS research agenda (Hepburn, 1990). AIDS family caregivers in both traditional and nontraditional family structures remain understudied (Macklin, 1989). With the exception of the qualitative research on AIDS family caregiving by Brown and Powell-Cope (1991), few researchers have documented the lived experiences of family members who have cared for a person with AIDS. Thus, studies using varied theoretical and methodological orientations such as the ones used here are needed to understand the depth and breadth of the phenomenon of AIDS caregiving in order to enhance our ability to support the work of these caregivers.

In this report, I present the results of a phenomenological study of the experiences of family members who cared for a person with AIDS. The specific aims that guided this research were:

1) to describe and understand the caring practices and practical knowledge of AIDS family caregivers; and
2) to explicate family members' concerns and meanings, including moral concerns and meanings, as they related to the experiences of caring for a person with AIDS.

The notion of caring practices is borrowed from Benner and Wrubel (1989), whose definition reflects an integrated sense of the two concepts of caring and caregiving. Caring practices are defined as "organized, specific practices related to caring for and about others" (Benner & Wrubel, 1989). "Caring for" connotes the everyday, practical activities of caregiving, often referred to as the instrumental dimensions of care; "caring about" connotes the affective, meaning, and moral dimensions of care, which give direction, purpose, and motivation to the practical activities of caregiving. The term caring practices successfully melds the multiple meanings of these two aspects of care which have often been studied as two separate areas of knowledge (Pepin, 1992).

Practical knowledge is a way of knowing that differs from theoretical knowledge. Practical knowledge refers to the "know how" that is acquired through experience.

It is a kind of knowledge that develops over time and involves the acquisition of skills and abilities that arise from everyday engagement in a particular practice or activity. Practical knowledge has been referred to variously as tacit knowing, skilled know how, or knowing in action and has been recognized as knowledge embedded in practices. It is seldom formalized in language, is solicited by particular situations, and is dependent on context for meaning (Benner, 1984; Benner & Wrubel, 1989; MacIntyre, 1984).

For this study, family is defined in broad terms. Family is distinguished not only by blood and legal ties but also by affective qualities of relationality, continuity, care, and commitment. Family includes family of origin, family of procreation, committed partners, and caring friendship networks that fulfill the function of family (Tiblier, Walker, & Rolland, 1989). Family caring and family caregiving are used synonymously and are understood as interchangeable terms which reflect a unified phenomenon of caring for and caring about another person (Pepin, 1991). AIDS family caregiver refers to a family member who actively engages in the care of a person with AIDS.

Moral concerns and meanings are overlapping phenomena of the human moral domain, which references issues of right and wrong or good and bad in human conduct (Harman, 1977). For this study, these phenomena were understood as caregivers' considerations about what was good or worthwhile for self or others, or what may have caused harm to self or others in the caregiving situation.

Significance of the Study

The characteristics of many AIDS family caregivers differ markedly from those of caregivers in other situations (Folkman, in press). In the gay community, caregivers are frequently young male partners or friends, a pattern which differs from the common finding of older women caring for an elderly parent or an elderly person caring for an ill spouse (Stone, Cafferata, & Sangl, 1987). The premature assumption of caregiving responsibilities among relatively young caregivers may be out of step with expected life trajectories (Folkman, in press). Alternative family structures and the involvement of the gay community are distinct features of some AIDS caregiving situations (Sebesta, 1992). Cumulative loss due to multiple deaths in the gay support network may affect AIDS family caregivers in ways uncharacteristic of other situations. Caregivers may share the same illness with the person cared for. The presence of children as caregivers in the family is another understudied phenomenon not uncommon in the AIDS epidemic. Caring for a person with an infectious disease may create fears or concerns that are not relevant in other caregiving situations. Further, since AIDS is a new disease, rapidly changing treatment protocols, drug trials, and numerous complementary nontraditional forms of therapy may make treatment decisions more complex for some patients and caregivers. These differences make AIDS family caregiving sufficiently distinct from other caregiving situations to warrant research that looks specifically at the concerns and caring practices of family members who care for persons with AIDS.

The social and cultural context surrounding AIDS and the cascade of illnesses that characterize the progression of the disease make AIDS caregiving unique in several ways (McCusick, 1993). Because of stigma and the fear of AIDS, family caregivers may not receive informal support in their social networks (Giacquinta, 1989; Sebesta, 1992). In AIDS caregiving, there are both real and perceived needs for secrecy regarding one's caregiver status. The issues of infectivity and stigma linked with AIDS cause family caregivers to fear ostracism and multiple negative social consequences; therefore, many conceal their identity and activities as AIDS caregivers (Giacquinta, 1989; Macklin, 1989; Tiblier, Walker, & Rolland, 1989).

A phenomenological interpretive approach was used to provide a perspective on AIDS family caregiving that has not appeared in the literature. This study focused on family members' retrospective views of their experiences. As demonstrated by Benner and Wrubel (1989), caring practices are best described through exemplary stories of care. Such stories are reflections of lived experience that is already passed or lived through (Van Manen, 1990). The power of the narrative is in the hearing of the whole story. Thus, a retrospective view allowed the telling of stories that reflected the whole of the caregiving experience, making it possible to see the consequences of actions and the changing nature of caring practices.

An explication of the concerns and meanings, caring practices and practical knowledge evident in AIDS family caregiving may suggest possibilities, examples, or models of care that have yet to be explored or described in the literature on AIDS care. Such knowledge may encourage future family caregivers or may improve the quality of health care delivered by nurses and other professionals who assist family caregivers. Additionally, an understanding of moral concerns and meanings is needed to sensitize nurses to the moral dimensions of the experience of AIDS caregiving. Such an understanding may enhance the ability of nurses and others to discuss moral issues with family caregivers and may improve their ability to assist caregivers who are facing complex dilemmas related to AIDS caregiving.

Strengths of Interpretive Phenomenology as the Method of Study

Narrative methods such as interpretive phenomenology have been accepted as the appropriate approach for the study of everyday practical activity and phenomena in the realm of human understanding and meaning (Benner & Wrubel, 1989; Polkinghorne, 1983). Narrative approaches are useful for discovering knowledge in areas where little is known and for refining theory and extending knowledge in areas that are well researched.

Using a narrative approach in the present study was appropriate because the experiences of AIDS family caregivers remain understudied. Much remains to be understood about what family members do or how family members approach the care of a person with AIDS (Brown & Powell-Cope, 1991; Hepburn, 1990; Macklin, 1989). Since practices in the private domain of family caregiving are difficult to access and typically not open to observation, soliciting stories of care is an important way to enter the private world of family caregiving. Since phenomenology uses a narrative approach that produces rich accounts of lived experience, it can provide access to overlooked, tacit aspects of everyday experience including practices, meanings, and concerns within the family sphere.

In the present study, it was my intent to access stories that reflected the entire spectrum of the AIDS caregiving experience--from the time caregivers became aware of HIV in a family member through the time of death. Narratives covering the whole caregiving experience were solicited in order to capture changes in concerns and caring practices or to discern the development of practical knowledge over time.

Retrospective narratives on the entire caregiving experience also made it possible to access caregivers' reflections on aspects of care that were most worthwhile and aspects that were regretted. Stories of regret or worthwhile care were taken to reflect caregivers' moral meanings and concerns, which can be accessed after the experience is lived through and the consequences of actions are known.

Studies on AIDS and moral issues have focused on ethical dilemmas created in the public domains of health care and social policy (Reamer, 1991). The ethical discourse on AIDS has centered on conflicting interests evident in issues such as mandatory screening; individual rights to privacy; the limits of confidentiality; reproductive rights of HIV-infected women; the ethics of clinical trials; insurance company policies toward persons with AIDS; and the duty to treat. This discourse takes as its starting point a rule-based understanding of moral theory (Reamer, 1991). Principles such as autonomy, individual rights, duties, and justice are utilized in analyzing the dilemmas presented by difficult choices among conflicting moral values.

Little attention has been given to how AIDS raises moral issues in the private domain of family care. Cameron (1993) used a phenomenological approach to study the moral experience of persons living with AIDS; her observations included moral problems reported by five family members. No other published study has focused on the moral issues arising for family members who care for persons with AIDS. The present study addresses this gap by describing the moral meanings and concerns of informal AIDS caregivers.

In recent years, the call has been to broaden ethical discourse to include issues of responsibility and care as a complement to the traditional focus on rule-and-principle based moral thinking (Dreyfus, Dreyfus, & Benner, 1990; Gilligan, 1982). Over a decade ago, Gilligan (1982) issued a challenge to the dominant model of detached, rule-and-principle based moral reasoning, arguing for equal consideration of the moral content found in narratives of responsibility and care.

Using a narrative approach to the study of women's moral lives, Gilligan (1982) and others (Lyons, 1983) uncovered a moral orientation which involved responding to concrete ethical situations from a position of connection, responsibility and care. This orientation is most likely to hold sway in the private domain of family care because, within the nexus of family life, moral agents respond to particular situations (not general ones) and rarely act from a detached stance. Family members, by definition, are connected and, in the ideal, stay involved with one another. Rights-based moral thinking therefore, is less likely to make sense in the context of family care and connection, where persons necessarily respond to the mutual moral claims they make on one another. Persons are already acting in the world as moral agents before formal moral theory enters their awareness--if at all. As moral agents, persons search for, find and inact meaning in relations with one another. Phenomenological methods provide one approach for uncovering these moral acts and meanings.

On the phenomenological view, most of our everyday moral experience is in "unreflective, egoless response to the current interpersonal situation" (Dreyfus, Dreyfus, & Benner, 1990). Phenomenology, therefore, makes possible a moral view that is not restricted to formal principles, moral reasoning, judgments, or justifications. Phenomenological research can extend ethical inquiry by elucidating moral concerns and actions that emerge in concrete situations. As opposed to a "top down" approach to ethics research, phenomenology starts with everyday activity in order to understand what moral agents perceive as good or worthwhile in practices such as family caregiving.

In relation to the moral meanings and concerns of AIDS caregivers, phenomenology can point out what caregivers see as worthy of preserving, protecting or avoiding in concrete situations of care. By soliciting stories, phenomenology makes available an insiders's account of moral experience. Interpretation can reveal skilled know-how in morally-relevant situations and can uncover qualitative distinctions encountered in a range of moral experiences and actions. For these reasons, an interpretive phenomenological approach was viewed as an appropriate and powerful method for studying practices, meanings, and concerns, including moral meanings and concerns, in the experience of AIDS family caregivers.

Overview of the Research Report

The following report includes a review and critique of research and other literature relevant to AIDS family caregiving. An explication of the interpretive phenomenological method is offered in Chapter 3. Beginning with Chapter 4, I have presented the major findings of the study, framed as an interpretive account consistent with the underlying phenomenological paradigm.

The interpretive account offered here follows a three-part thesis related to the concerns and caring practices of AIDS family caregivers. This is, namely, that caring practices and concerns are shaped, first, by the background meanings and cultural contexts in which caregiving takes place; second, by the moral meanings and concerns of caregivers; and third, by the specific progression of disease in the ill person. Cultural contexts, moral meanings and concerns, and the course of illness combine in ways to shape a general continuum of care which can be traced throughout the progression of HIV disease. A schematic representation of the interpretive account is seen in Figure 1.

Chapters 4 and 5 present data supporting the thesis that caring practices are

Organization of the Interpretive Account

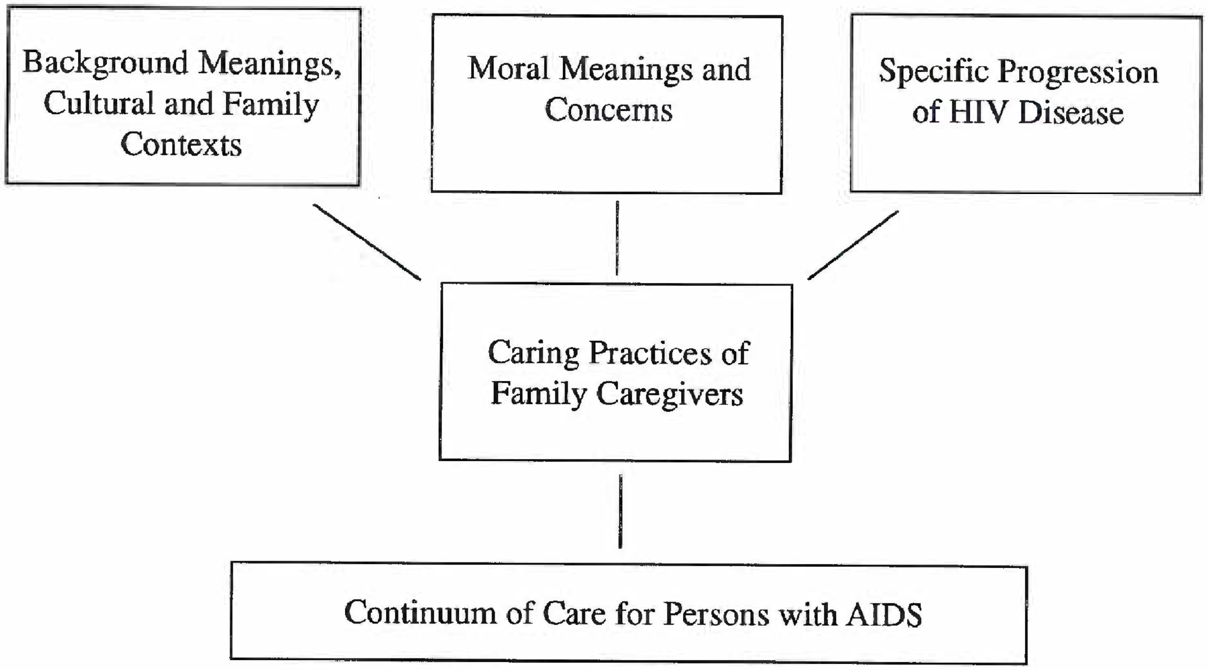

Figure 1. Organization of the Interpretive Account.

shaped in part by the broad cultural and specific family contexts in which caregiving occurs.

Chapter 4 looks at the cultural contexts of caring for a person with AIDS, while Chapter 5 presents family as both a context and a concern for the primary caregiver. Chapter 6 lays out a group of themes that suggest the dominant moral concerns of caregivers. Moral concerns are prevalent, and relatively constant throughout the stories of care. For example, while specific caring practices may change over the trajectory of illness, underlying moral concerns, such as the concern to preserve dignity, tend to remain constant throughout the caregiving experience. In Chapter 7, I present the outline of a general continuum of care common to the experiences of the AIDS caregivers in this study. This chapter also includes caring practices, concerns, and meanings of caregivers at the time of death. A final chapter presents a discussion of the findings and implications of the study for theory, practice and further research.

CHAPTER 2

REVIEW OF LITERATURE

This chapter presents a review and critique of literature on AIDS caregiving and relates the present study to gaps in this knowledge base. Additionally, relevant studies in general caregiving, including caregiving for the elderly, are reviewed as well as relevant research on caring practices and a relational ethic of care.

AIDS Caregiving

Much of the research on AIDS caregiving has focused on the negative consequences of caring for a person with AIDS and has not examined actual caring practices or moral concerns of caregivers. Originating mainly from the disciplines of psychology and social work, research to date has examined the stressors, burdens, coping strategies and sources of support utilized by AIDS family caregivers. The majority of studies have considered the experiences of caregivers who cared for urban gay men.

Geis, Fuller and Rush (1986) reported results of an early qualitative study which identified major areas of psychosocial stress for nine gay men who were caregivers for a partner with AIDS. Findings indicated that these caregivers experienced a significant degree of stress as a stigmatized and isolated group. Caregivers reported experiences of social stigma, isolation from family and friends, loss of sexual relationships, feelings of being punished, guilt and anger. Depression and suicidal thoughts among these caregivers were not uncommon.

Subsequent studies have indicated that AIDS caregivers face multiple psychosocial issues leading to marked stress and the need for both formal and informal supports (Folkman, in progress; Pearlin, in progress-b). Pearlin, Semple & Turner (1988) concluded that role overload finds its "quintessential expression" in AIDS family caregivers. The occupational, economic, and social lives of caregivers are progressively disrupted as the patient's disease advances. Three types of stressors were found in their study including 1) the demands and burdens of the caregiver role, 2) uncertainty regarding the future, and 3) problems in performing other roles (Pearlin, Semple, & Turner, 1988). These findings are corroborated by Folkman (in progress), Raveis & Siegel (1990); Matocha (1992); Giacquinta (1989) and Brown & Powell-Cope (1991).

Raveis and Sieger (1989) found that caregiving affected the caregiver's finances, work performance, socialization and physical and emotional health. Findings from a study of informal AIDS caregivers in San Francisco indicate that caregivers experience stress in relation to adjusting to the illness progression, the uncontrollable nature of the disease, the theme of loss, shifting responsibilities, role conflict, unexpected improvement, fatigue and the burden of being HIV positive themselves (Folkman, Chesney, & Christopher-Richards, in press).

A nearly universal finding has been the caregivers' experiences of a sense of isolation and distancing from other family members and friends as a result of the social stigma and discrimination associated with AIDS (Geis, Fuller, & Rush, 1986; Giacquinta, 1989; Gregory & Longman, 1992; Matocha, 1992; Pearlin, Semple, & Turner, 1988; Powell-Cope & Brown, 1992). Giacquinta (1989) reported caregivers' and other family members' experiences of emotional exile from relatives and friends, stifled communication about AIDS in the family, intense stress occurring with AIDS crises, and the family's emotional havoc. Matocha (1992) explored the effects of caregiving in the physical, psychological, economic, social and spiritual domains. Caregivers' needs and caregiving patterns were found to change over time.

In addition to research on AIDS caregiving, other publications report anecdotal experience with AIDS caregivers and the impact of AIDS on family structure and functioning. Bonuch (1993) commented that families have traditionally been the bedrock of support for ill members, influencing behaviors related to health and illness. Families continue to be the bedrock of support for persons with AIDS. AIDS has had a cultural, psychological and functional impact on the family, challenging traditional cultural definitions of family and shaping behaviors and language within the culture and the family. For families engaged in caring for a person with AIDS, caregiving brings about role reconfiguration, financial burden, social stigma, fear of contagion, guilt and psychological and physical fatigue (Bonuck, 1993).

Rait (1991) examined the family context of AIDS noting that HIV-related illness creates profound discontinuity in the lives of the ill person and the family. For caregivers, problems at every level of daily functioning arise, from completing mundane household chores to questions of fundamental existential importance. Family members report a relentless awareness that life hangs in the balance and may, because of the stigma attached to AIDS, work in isolation contending with secrecy, shame, guilt and discrimination.

Noting the social need to develop and strengthen support systems such as family caregivers, McDonnell, Abell, and Miller (1991) suggested an approach to assess family members' willingness and ability to provide care for a person with AIDS. The ability to provide care may depend on the caregiver's resources, coping strategies, perceived social support, familial obligation and affection, fears of the virus, and acceptance of homosexuality.

Both anecdotal reports and research literature attest to the enormous and varied stresses of AIDS caregiving. Several research efforts used the concepts of stress, coping, and caregiver role as the framework for understanding AIDS caregiving (Folkman, in progress; Folkman, Chesney, Christopher-Richards, in press; Grief & Perembski, 1988; Pearlin, in progress-a; Pearlin, Semple, & Turner, 1988). Hepburn (1990) commented that the focus of much AIDS caregiving research has been on the negative impact of caregiving and not on the nature or efficacy of the caregiver's work. Though knowledge about negative consequences and coping strategies of AIDS family caregivers cannot be dismissed, this focus tends to obscure the nature of AIDS caregiving itself. Hepburn (1990) contended that caregivers tend to be treated as victims of someone else's disease rather than as active participants in the care and treatment of someone who is ill. An exception to this orientation is found in the work of Brown and Powell-Cope (1991, 1993).

Unlike much of the published research in this area, the theory-building work of Brown and Powell-Cope has shifted the focus of study away from an emphasis on caregiver stress and coping toward an exploration of the nature of caregiving itself. The phrase "transitions through uncertainty" was used to label the core category of their theory on AIDS family caregiving. Their theory integrates the concepts of uncertainty and transition and conceptualizes the entire caregiving experience as a transition which may last for a few months or extend over several years. They viewed the caregiving transition as "a period of major change in life circumstances accompanied by uncertainty, questioning one's basic assumptions, and reexamining plans for living in the world" (Brown & Powell-Cope, 1991).

Uncertainty was identified as the basic psychosocial problem of caregivers and was explained in the context of five subcategories of caregiving. These subcategories included managing and being managed by the illness, living with loss and dying, renegotiating the relationship, going public, and containing the spread of HIV. Stages and strategies of each caregiving subcategory were identified. Managing and being managed by the illness was the category most directly related to the present study. It was the category in which uncertainty was most dramatic (Brown & Powell-Cope, 1991).

Caregiver strategies for managing and being managed by the illness included watching and analyzing, doing for, and coordinating help. Uncertainty was related to not knowing how the disease would progress, monitoring and determining the meaning of symptoms and behaviors, deciding about treatment options, and evaluating care. Caregivers became cautious so they would not overlook important symptoms. Constant vigilance and the feeling of "never being able to do enough" contributed to the perception of being managed.

Living with loss and dying was a second subcategory relevant to present study (Brown & Powell-Cope, 1993). This subcategory was linked with facing loss, putting the future on hold, and maximizing the present. The subcategory of going public was defined as managing social relationships and choosing a social identity based on disclosing information about oneself (Powell-Cope & Brown, 1992). Living with secrecy was a stage within this category that also emerged in the data of the present study.

The experiences of AIDS family caregivers reported by Brown and Powell-Cope reflect many indicators of transition (Schumaker & Meleis, 1994). During this transitional life phase, caregivers, for example, struggle to master new behaviors in order to manage the illness. Subjective well-being involves renegotiating relationships, attending to the well-being of relationships within the family, and attunement to coping with uncertainty. The second sense in which transition is used by Brown and Powell-Cope has to do with the transitional nature of caregiving itself as the nature of caregiving changes over the course of HIV disease.

AIDS caregiving studies have varied in terms of the sampling strategies used. Several studies restricted the caregiver sample to gay male caregivers (Folkman, in progress; Geis, Fuller, & Rush, 1986; Pearlin, in progress-a; Pearlin, Semple & Turner, 1988). Other studies included friends, lovers, spouses, parents, siblings, and other family members in the caregiver sample (Brown & Powell-Cope, 1991; Giacquinta, 1989; Grief & Perembski, 1988). Though efforts have been made to include African-American, Hispanic, and other ethnic groups, caregivers from minority groups have been underrepresented in many studies (Giacquinta, 1989).

What is missing from the AIDS caregiving literature is close attention to the actual caring practices that caregivers acquire. Brown and Powell-Cope have focused research in this direction; however, further studies are needed, using different samples and divergent methods, to corroborate and extend their work.

General Caregiving

Research on AIDS family caregiving tends to confirm early contentions that the stressors and negative consequences experienced by AIDS caregivers are similar to--though not entirely the same as--those experienced by caregivers for persons with other disabling conditions (Hepburn, 1990; Matocha, 1992; Pearlin, Semple, & Turner, 1988; Raveis & Siegel, 1990). Notable differences between AIDS caregiving and general caregiving are issues of contagion, the social stigma associated with AIDS care, and young male caregivers who frequently share the same illness with the one cared for. Nonetheless, consequences of caregiving are similar across disease categories. Negative consequences of caregiving for the elderly have been found to include guilt and emotional stress, depression, anxiety, restrictions on freedom, disruption of routines, disruptions in personal, family, and social life, decreased personal time, financial burden, physical burden, restricted mobility, uncertainty, isolation and loneliness (Abel, 1990; Given & Given, 1991; Horowitz, 1985). The general caregiving literature has demonstrated that many aspects of caregivers' lives are negatively affected by caregiving and that, across disease categories, the costs of caregiving are high.

In recent years, research in the area of general caregiving has focused increasingly on the nature of caregiving itself, recognizing that caregiving is a complex phenomenon involving affective, relational, and existential dimensions (Abel, 1990; Archbold, 1990; Archbold & Stewart, 1988; Bowers, 1987; Farran, et al., 1991; Phillips, 1989; Phillips & Rempusheski, 1986). Findings from general caregiving research about the relational aspects of caregiving, meaning in caregiving, and the quality of caregiving are relevant to the present study.

Abel and Nelson (1990) examined the experiences of caregivers for chronically ill adults and children in a collection of essays on general caregiving. They argued that the caregiver's identity is inherently relational and that caregivers must be attentive and responsive to the other. In our culture, good caregiving fosters the independence of people placed in dependent positions. Caregivers seek to preserve the dignity of care receivers and encourage their growth. Caregivers ideally gain knowledge through intimate understanding of a particular individual rather than through abstract principles. Though caregivers learn through practice rather than through instruction, they tend to formulate their own rules, hone skills, and seek to fulfill an ideal.

Fisher and Tronto (1990) commented that caring itself has yet to be fully examined in our culture, in part, because our world view holds to a theory of the self in which people are isolated, autonomous beings, independently accomplishing their life plans. From such a perspective, the interdependent relational work of caring is difficult to conceptualize or even recognize.

Abel (1990) identified important relational aspects of daughters' caregiving for elderly mothers. Caregiving was found to involve elements of pleasing, reviving and transforming a relationship, seeking to preserve an older person's dignity and taking over control. Several caregivers experienced caregiving as accentuating a sense of loss and found it difficult to take over responsibility for their mothers' lives. These caregivers saw themselves as "wounding" their mothers by taking over control (Abel, 1990).

Bowers (1987) defined caregiving by the meaning or purpose the caregiver attributed to a behavior. Through grounded theory methodology, Bowers uncovered some of the invisible work of caregivers not previously considered in compendia of caregiver tasks (Clark & Rakowski, 1983). Bowers found that a focus on instrumental caregiving obscured the family's most ardent focus--anticipatory, preventive, supervisory and protective caregiving (Deatrich, Knafl, & Guyer, 1993). Protective caregiving emerged as the most significant category of caregiving and the most powerful source of stress for caregivers. Caregivers worked to protect the ill person's self-identity, self-esteem, and sense of independence.

Phillips and Rempusheski (1986) investigated links between the quality of caregiving and caregiver-elder relationships. Images of caregiving and past and present images of the elder contribute to good or poor quality family caregiving. Personal standards, values and imperatives relative to a caregiving ideal are important components in determining quality of care. In this study, the nature of the past relationship between the ill person and the caregiver was viewed as a source of background meaning for caring practices.

Archbold and Stewart (1988) recognized enrichment as integral to the quality of family caregiving. Enrichment is related to feelings of mutuality and increased rewards of meaning in caregiving. Building on this conception, Cartwright (1993) explored enrichment processes used in family caregiving for the frail elderly. Enrichment was defined as the process of endowing caregiving with meaning or pleasure for both the caregiver and the care receiver. Two categories of enriching activities were identified: establishing routines to provide structure to daily caregiving and using routine breakers to change daily patterns. Core elements that transform ordinary activities into events with special meaning were labelled acquiring symbolic meaning, performing activity, and fine tuning. Music was cited as an element that brought symbolic meaning to caring. Performing activity referred to concrete, observable behaviors undertaken in the caregiving situation. Fine tuning involved changes in caregiving activities over time to accommodate the frailty trajectories which could involve both the care receiver and the caregiver (Cartwright, 1993).

Farran et al. (1991) used an existential theoretical framework to guide a qualitative study exploring how family members find meaning through caring for a person with dementia. Existential themes expressed by caregivers included fulfilling a sense of duty, cherishing family and social relationships, experiencing love, cherishing memories, and choosing to appreciate positive aspects of life. Keeping a promise to care for the ill person and cherishing memories of times past were aspects in the narratives of caregivers who cared for a person with dementia.

In sum, general caregiving research suggests conceptual categories that have relevance for the present study. Protecting dignity and preserving the ill person's sense of self, prolonging independence and control, enriching the environment or caring space, or constructing meaning from past or present events have been uncovered in general caregiving research and may provide insight into the caring practices of AIDS caregivers.

Caring Practices and a Relational Ethic of Care

The concept of caring practices has been explicated by Benner and Wrubel (1989) and used by others to research skilled practical activities of human care (Chesla, 1991, 1994; Gordon, 1994; Tanner, Benner, Chesla, & Gordon, 1993; Wros, 1994). The concept of caring practices was borrowed in part form MacIntyre (1984) who contends that a practice grows out of a tradition that is enriched by an ethic or notion of what is good. Thus, a practice such as family caregiving may be understood to have goods and instances of excellence that can be described and explicated. An understanding of such an internal ethic or notion of what is good informs the second aim of this study which includes an exploration of the moral concerns and meanings of caregiving.

Wros (1994) showed that it is possible to articulate moral concerns and a notion of the good embedded in caring practices by examining the practice of nurses caring for patients dying in critical care. Through examining skilled behaviors of nurses, Wros identified aspects of the moral sense of nursing within the cultural contexts of critical care. Moral concerns were identified as what nurses believed to be good or right in a particular context. These concerns were found to be centered on caring, respect for relationship, involvement, and connection. The focus of care was relief of suffering, respecting patients' wishes, and maintaining dignity, which included respectful care of the body and attention to the personhood of the patient.

Chesla (1994) also demonstrated the study of caring practices in her research on parents who cared for a schizophrenic child. Patterns in family care were uncovered and categorized as engaged care, conflicted care, managed care, and distanced care. Chesla provided narrative examples of how parents' ability to adapt caring practices had much to teach us about the care of the injured or chronically ill.

The scholars who have studied caring practices in nursing and in families have provided research data supporting the notion that caring practices are relational, concernful, skilled, and always understood in a context. They are enriched by practical knowledge and based on an inherent notion of the good (Chesla, 1994), which suggests Abel and Nelson's contention that human care conforms to a moral ideal.

In addition to studies on caring practices in specific contexts, the work of four theorists on care and caring have relevance for this study. Ruddick (1989), Noddings (1984), Swanson (1991) and Gadow (1985) suggest some of the goods, notions of excellence, and moral ideals inherent to human caring.

Though Ruddick (1989) studied issues central to the practice of mothering, her work on "maternal thinking" suggests themes that may also be seen as goods internal to the practice of caring for a family member who is seriously ill. These themes include protection and fostering growth. Protection involves attentiveness and preservative actions. As in Cartwright's (1993) observations on enriching routines, Ruddick suggested that the work of mothering involves small rituals meant to provide a measure of predictability in an unpredictable world (Ruddick, 1989). Minimizing risk, maintaining harmony, securing material resources and acquiring skills are involved in the work of preserving and protecting the world of those cared for. Fostering growth includes nurturing the spirit, finding supportive communities, and identifying and responding to needs.

Noddings (1984) characterized caring as a move away from the self in which the one caring is directed to act in concrete ways toward the welfare, protection, or enhancement of the one cared-for. Noddings characterized caring as a moral imperative. Noddings also noted that conflicts and guilt may be the inescapable risks of caring. Conflicts among commitments to the one cared for, to self, and to others constitute difficult moral dilemmas for the caregiver. As demonstrated by Wros (1994), Noddings asserted that from a position of care, one works through moral problems not by considering moral rules and principles, but by considering the concrete elements and particular others in the situation.

Gadow (1985) looked at the caring relationship between nurse and patient and, like Noddings, viewed caring as a moral ideal. Care entails a commitment to the enhancement and protection of human dignity (Gadow, 1985) and to the alleviation of vulnerability (Gadow, 1988). In the caring relationship, patients are protected from being reduced to the status of objects. Gadow examined the experience of "otherness" which is inherent in technological caring environments where technology imposes two forms of otherness: the apparatus and the professional. Both the apparatus and the professional expert can threaten or disrupt personal integrity and diminish dignity. Gadow asserts that a moral commitment to maintaining dignity can be supported through touch and through an intersubjective truth telling where the patient participates in constituting the truth of the situation.

Swanson (1991) contended that a universal conceptualization of caring does not exist. Caring has been described as a moral ideal, a way of being, an intent embedded in the behavior of a caregiver, and as a perception of the one cared for. Addressing this problem, Swanson inductively derived a factor-naming, middle-range theory of caring through phenomenological investigations of professional caregivers in three perinatal settings. She identified five processes or categories of caring, including knowing, being with, doing for, enabling and maintaining belief. Being with, doing for, and maintaining belief are useful categories for the present study. Being with is becoming emotionally present to the other as well as "being there" physically. Presence and sharing, however, are monitored so that the one caring does not burden the one cared for. Doing for entails doing for the other what he or she would do for the self, if possible. Maintaining belief is sustaining faith in the other's capacity to get through an event or face a future with meaning (Swanson, 1991). These categories and those suggested by Ruddick, Noddings, and Gadow provided rich sources of reflective thinking for the present interpretive study.

Studies on AIDS and moral issues have focused on ethical dilemmas created in the public domains of formal health care and social policy (Reamer, 1991). The ethical discourse on AIDS has centered on issues such as mandatory screening; rights to privacy; limits of confidentiality; reproductive rights of HIV positive persons; the ethics of clinical trials; and the duty to treat. Little attention has been given to the particular moral issues that AIDS incurs in the private domain of family care.

CHAPTER 3

METHODOLOGY

In this chapter, an initial overview of the research design is followed by a summary of the Heideggerian view of the person and the assumptions of the phenomenological research paradigm. Methodological implications of the philosophical assumptions of this paradigm and specific strategies used in this study are explained as well as the approaches used to evaluate the final interpretive account.

Overview of the Research Design

For this study, ten male and eight female self-identified primary family caregivers from rural and urban settings were interviewed about their AIDS caregiving experiences. In-depth conversational interviews took place at least three months but not more than 24 months after the death of the person with AIDS. The aim was to collect personal stories which would disclose as clearly as possible caring practices, practical knowledge, meanings, and concerns across the entire continuum of AIDS care. Interviews began with an orienting question about the particular trajectory of illness experienced by the person with AIDS. This trajectory was used to guide subsequent conversations about specific concerns and episodes of care. Interviews lasted from 1 1/2 to 6 hours. Each interview was tape recorded and transcribed verbatim after informed consent was obtained. Thematic analysis, exemplars and paradigms cases were the methodological approaches used during the iterative processes of reading texts, comparing cases, and writing interpretive commentary. The sections that follow will explain in greater detail the specific methods used for this research as well as the intellectual roots of interpretive phenomenology as the orienting philosophical framework of the study.

The Heideggerian View of the Person

For this study, I drew from Heideggerian existential philosophy and the phenomenological research tradition-- specifically, from the methodological work of Benner (1994), Addison (1992), Packer and Addison (1989), Packer and Richardson (1990) and Van Manen (1990). Because the method focuses on understanding the participants' meanings and practical knowledge within the context of their experiences, it was considered the appropriate approach for this study.

Interpretive phenomenology blends the European traditions of hermeneutics with the descriptive phenomenological schools of thought (Van Manen, 1990). The interpretive (or hermeneutical) element of the methodology aims at an interpretation of human meaning, whereas the descriptive (or phenomenological) element aims at explicating concrete aspects of "the thing itself" as it is encountered in the everyday world. The terms hermeneutics and phenomenology have been used interchangeably (Thompson, 1990; Van Manen, 1990) and have been combined in the term hermeneutic phenomenology. Interpretive phenomenology (Benner, 1994; Van Manen, 1990), hermeneutic phenomenology, and analytic hermeneutics (Packer & Richardson, 1990) have all been used to refer to a research approach that derives from Heidegger's ontological account of what it means to be human.

Hermeneutics has a long tradition in a number of disciplines including biblical exegesis, philosophy, law, and literature (Addison, 1992; Thompson, 1990). During the past few decades, the interpretive tradition has been introduced in the disciplines of psychology (Addison, 1992; Packer, 1985; Packer & Addison, 1989; Packer & Richardson, 1990; Polkinghorne, 1983), anthropology (Geertz, 1973); education (Van Manen, 1990); sociology (Rabinow & Sullivan, 1979; Schutz, 1972); and medicine (Coles, 1989; Kleinman, 1988). Within the past decade, the Heideggerian tradition of conceptualizing and researching human phenomena has gained influence in nursing (Benner, 1984, 1994; Benner, Tanner, & Chesla, 1992; Benner & Wrubel, 1989; Bishop & Scudder, 1990; Tanner, Benner, Chesla, & Gordon, 1993).

Though applications of the interpretive phenomenological approach may differ from one discipline to the next, central assumptions about human beings and about their world remain constant across disciplines. These assumptions can be traced to the philosophical tradition initiated by Heidegger and carried forward by Heideggerian scholars. Here, I will present a brief summary of the Heideggerian view of the person, followed by a list of assumptions basic to the phenomenological research paradigm and the primary aims of phenomenological research. I will then discuss how the implications for research have been applied in this study.

In Being and Time, Heidegger departed from the rationalist/empiricist concerns of science and philosophy and pointed out a new approach to understanding human being. Heidegger shifted the focus of philosophy from questions of epistemology (what it is to know) to questions of ontology (what it is to be).

Heidegger distinguished between two spheres of being. Human beings have a "public" sphere, called the sphere of the ontical, where we are preoccupied with our relationship to things, persons, and events (or "beings") in the everyday world. In this "public" sphere, we exercise concerns with the scientific, political, economic and technological world. In the second sphere of existence, referred to as the sphere of the ontological, we maintain a basic comportment toward Being (denoted with a capital "B"). Being is taken as the "is," the background of all beings, or the dimension of existence which lies behind the everyday world of persons, things, and events (Dreyfus, 1991).

Being-in-the-world, or Da-Sein, (there-being) is a term invented by Heidegger to signify his understanding of what it is to be human. Heidegger invented words, such as Dasein, to avoid the connotations of traditional language. Dasein, for example, avoids the Cartesian notion of an ahistorical, detached reflective self (subject) that stands apart from and mentally represents other objects in the world.

On this latter point Heidegger departed from his teacher Husserl, the German phenomenologist whose philosophical work is the more common basis for American forms of phenomenology (Thompson, 1990) and for most phenomenological work in American nursing (Morse, 1991; Munhall & Oiler, 1986; Oiler, 1982; Omery, 1985; Salsberry, 1989). Husserl searched for the logical structures of consciousness as the basis for human experiences and the medium through which we know objects. According to Husserlian phenomenology, for example, it is possible to grasp a phenomenon as it "truly appears" and to do so one "brackets" or consciously suspends one's preconceptions about an object prior to studying the object (Salsberry, 1989). Heideggerian phenomenology rejects this Cartesian notion of subject and object, taking the position that our being in the world is not characterized by the separation of subject and object (Thompson, 1990). Primarily, we grasp the world directly in that our experiences occur prereflectively. Language, culture, temporality, and historicity are the media through which we have our being in the world (Thompson, 1990). Further, the underlying Heideggerian view is that it is not possible to completely spell out the world (Dreyfus, 1991). It is possible to gain increasingly more sophisticated understandings, but ultimately phenomena are ineffable. Being historical, contextual, and multifaceted, human worlds are only grasped under finite, situated conditions (Benner & Wrubel, 1989).

As the activity of human existing, Dasein is an instance in which Being has become aware of itself. It's fundamental structure is that of care (sorge), which signifies that Dasein has concern about its own being. For Dasein, Being and things in the world matter. Being comes to the fore in different ways including languages, cultures, traditions, skills and human practices. Heidegger refers to these ways of understanding Being as by which Dasein shows itself (Dreyfus, 1991).

An essential characteristic of Dasein is that of having a "world." There are several senses in which we may understand "world." World may mean a totality of objects or things, such as the universe of physical objects, or world can be understood as our physical surroundings or environment. In a phenomenological sense, world means the relationships, practices, and language that human beings have access to by virtue of being situated in a culture (Leonard, 1994). In this latter sense, expressions such as "the world of science," "the world of fashion" or the "business world" convey an understanding of shared practices, concerns, skills and equipment which are common to the particular world of involvement. In Heideggerian thought, world is _a priori_. World is given in our history and in our cultural and linguistic practices and is the background against which beings, events, or things show up and are made intelligible to us. Thus we depend on being situated in our world for meaning and intelligibility. World is both constituted by and constitutive of the self (Leonard, 1994). The self is shaped by its world in the sense that the self takes up meanings, skills, practices and traditions by virtue of being "thrown" or always already finding itself in a distinct culture or situation (Dreyfus, 1991). Thus, the world is constitutive of the self by setting up possibilities for who a person can or cannot become (Leonard, 1994).

Though world circumscribes choices and possibilities, it does not strictly determine them. Human beings can open up and work out the possibilities that exist for them within particular cultures. Through working out possibilities and practices, the self also constitutes its world. This has been referred to as "situated freedom" (Benner & Wrubel, 1989) and differs from the modernist notion of an atomistic, radically free agent.

Heidegger referred to Dasein's way of being as "Being-in"--where "in" has the existential sense of "involvement" (Dreyfus, 1991). The phrase "being in love" conveys the sense of Dasein's being involved, as opposed to "being in a room." Being involved is definitive of Dasein. As Being-in-the-world, Dasein is involved in a definite world amidst a definite range of worldly entities and possibilities. Further, Dasein is primarily involved in the world in prereflective, organized, and purposive ways, evidenced in everyday skilled activities such as driving a car (Dreyfus, 1991).

Heidegger referred to three modes of being characteristic of Dasein's involvement with things. These have been translated as ready-to-hand, unready-to-hand, and the present-to-hand modes. When Heidegger looked at the way people are related to things he found that it was not normally as subjects are related to objects (Magee, 1987). Awareness does not necessarily play a role in the so-called subject-object relationship. Things are primarily encountered in a "ready to hand" mode which is a kind of transparent coping referred to as everyday skilled practical activity. Examples might be the activity of driving to work, taking all the right turns, going the right speed, stopping, starting, all in a smooth effortless fashion, while at the same time chatting with a passenger or listening in an absorbed way to the radio. This everyday kind of coping is contrasted with the unready-to-hand mode, which might occur if one were to run out of gas and had to stop and flag down help. The present-to-hand mode signifies those encounters with things or events which call for reflective thinking, and can be dealt with on the level of context-free, causal relationships such as chemistry, molecular science, or automotive engineering. While this third mode of being dominates scientific thinking, it cannot explain the everyday meaningful world of significance. Most of the time, we operate in the ready-to-hand mode which we take for granted, are not conscious of, and don't direct our attention to (Magee, 1987).

Involvement means that Dasein dwells within a context of meaning that plays a crucial role in a person's self-interpretation. Dasein dwells in a world in which things have significance and value and towards which Dasein is directed with concern. Persons have different concerns, however, based on their culture, language and individual situations (Leonard, 1994); thus, values and concerns may change with context.

Temporality is an additional aspect of being-in-the-world. It is constitutive of being in that what we have been and what we anticipate being are constitutive of who we are. Dasein is oriented toward the future, doing something now in order to be in a position to do something else later on. The past, as well as the future, belong to the very content of the present. Temporality is the way the person "is anchored in a present," which is made meaningful by past experience and by the person's anticipated future (Benner & Wrubel, 1989). Thus persons must be studied within the context of their past and future, by which they are constituted (Leonard, 1994).

In addition to temporality, Heidegger examined the nature of Dasein's spatiality, distinguishing between existential spatiality and physical space. Heidegger viewed spatiality as a function of existential concern. Spatiality is personal, lived space, centered in Dasein, with public and private regions, and degrees of availability. Things in the world show up as having a certain accessibility--which is to say, nearness or farness according to our ability to "grasp" them. In other words, Dasein brings things close in the sense of bringing them within the range of its concerns and interests (Dreyfus, 1991).

A final characteristic to be mentioned is referred to as embodiment, a notion elaborated by Merleau-Ponty who viewed the body as our way of being in the world (Dreyfus, 1991; Magee, 1987). In the phenomenological view, the body exhibits intelligible responses, grasps the world and moves with intention in a meaningful world (Leonard, 1994). Embodiment refers to "the way meanings, expectations, styles and habits are expressed and experienced by the body" (Benner & Wrubel, 1989). The habitual skilled body is the aspect of embodiment that includes all "culturally learned postures, gestures, and customs" and the capacity to acquire bodily skills (Benner & Wrubel, 1989).

Heidegger's notions about being-in-the-world undergird basic assumptions that are carried forward into the phenomenological research paradigm. Borrowing from the phenomenological tradition, Benner and Wrubel (1989), for example, asserted that human nature is relational and not fixed, that to be human is to participate in cultural, social and historical contexts, and that the study of human action must take cultural and historical contexts into account. Though the person is self-interpreting, the possibilities for self-interpretations are not limitless, because they are handed down in language and in cultural practices. Further, human beings have an effortless and nonreflective understanding of the self in the world. They are situated meaningfully in a context and grasp meaning directly and immediately because our bodies as well as our minds are knowers (Benner & Wrubel, 1989).

Assumptions of the Phenomenological Research Paradigm

The assumptions underlying the interpretive phenomenological research paradigm derive directly from Heideggerian existential philosophy. Assumptions about knowledge, background meanings, and concerns are derived from the Hedeggerian view of the essential characteristics of Dasein and lay the groundwork for specific approaches taken in phenomenological research.

Knowledge

On the phenomenological view, the primary origin of knowledge is taken to be practical activity, which exists prior to any theorizing and which is embedded in a distinct cultures and historical era (Packer, 1985). Accordingly, truth is not a matter of determining how closely beliefs correspond to some fixed, ahistorical or decontextualized reality. All facts are taken to be value-laden, and all researchers have values that are reflected in their research projects (Addison, 1992). There is a further assumptions that all knowledge cannot necessarily be made explicit (Benner, 1994); certain aspects of human being remain ineffable.

Practical knowledge is a way of knowing that depends in large part on the skilled body. Practical knowledge (or knowing how) is drawn from everyday practical activity and is contrasted to theoretical knowledge (or knowing that). The assumption is that there is knowledge in human practices that may give rise to theoretical knowledge. Thus, I approached this study with the assumption that there is practical knowledge in the caring practices worked out by AIDS family caregivers and that analyzing narratives of care would allow this knowledge to be explicated.

Embodied intelligence is a kind of knowing made possible by the body and is disclosed in skills, emotions, sensory knowledge, cultural habits, and ways of organizing the perceptual field. Embodied knowing allows human beings to move through situations in rapid, nonreflective ways (Benner, 1994) and includes capacities such as proprioception as well as habitual cultural knowledge and complex skills. The body as a whole is a knower, an actor, and an experiencer of situations.

Background Meanings

Background refers to the interpretation-laden practices and self-understandings handed down through language and culture. (Allen, Benner, & Diekelmann, 1986). The background provides preunderstandings that we can never be completely clear about. Because of this, purely neutral, value-free observation is not possible. Though it can never be made fully explicit, the background is always present, and we understand human action within a background of bodily, personal, and cultural practices (Packer, 1985). Thus, meanings are made possible by background conditions such as the human social structure, personal histories, and shared cultural practices and language (Addison, 1992).

Understanding meaning is part of our way of being (Packer, 1985). Human beings are brought up in meanings and understand the world in terms of these meanings (Benner & Wrubel, 1989). Meanings are shared and are handed down culturally through language, skills, and practices. Because of shared meaning, people come to a situation with a preunderstanding or forestructure of knowing and understanding. Moreover, meaning is a transaction between the individual and the situation so that the person both constitutes and is constituted by the situation (Allen, Benner, & Diekelmen, 1986).

Human meaning can be verbalized and can also be expressed in action and practices. For example, the meanings that a person with AIDS gives to his illness can be expressed in choices about health care. A sense of shame or self-blame, which is readily picked up from the background cultural meanings associated with AIDS, may be expressed in the avoidance of care. Thus, to understand meaning and human behavior, it is important to consider practices. Further, the meanings of human actions are not fixed, clear, or unambiguous, but are negotiated in ongoing interactions and change over time (Addison, 1992).

Benner and Wrubel (1989) emphasized that background meaning differs from the notion of subjective, private meanings accessible only to the individual. Background meanings are given to persons from their culture; they are shared, public understandings of what is. The analogy of light was used by Merleau-Ponty to explain background meaning (Benner & Wrubel, 1989). One does not see the light, but rather sees what it illuminates. Without light, one sees nothing. Background meaning then is the light provided by the culture, the subculture, and the family.

Concern

Another assumption borrowed from the Heideggerian tradition is that human beings become involved in the world through concern. Things matter to us. Because of concern, people grasp a situation in terms of its meaning for the self. Concern has to do with the way the person is oriented meaningfully in the situation and thus dictates what will show up as salient. Persons and things show up for us because of our concern with entities in the world (Dreyfus, 1991).

Consequences for Conducting Phenomenological Research

Several methodological implications for the study of human action flow from the preceding assumptions based on Heidegger's account of human being. Though an interpretive phenomenological approach to research is not a set of prescribed techniques, practices central to the approach can be elucidated.

The Aims of Phenomenological Research

Phenomenological research begins in the lifeworld and attempts to gain insightful descriptions of the world as we experience it--which is to say, the world as experienced prereflectively in contrast to the world as conceptualized (Van Manen, 1990). The aim of an interpretive phenomenological study is to make explicit our understanding of human action by providing interpretations and constructing an account that is sensible within the context of current concerns and interests (Packer, 1985). The interpretater seeks to provide greater access and understanding of the text in its own terms. The goal is not a search for ahistorical or timeless formal structures of human behavior. Rather than provide an account of private events or understandings, the goal is to uncover commonalities and differences among lived experiences (Benner, 1994).

Interpretive phenomenology does not offer the possibility of theory that is characterized by propositions or law-like statements by which we can attempt to predict or control the world. It does offer plausible insights into human experience that brings us in more direct contact with the world.

Meanings, concerns, cultural practices, skills, the role of the situation, and the role of the body in human behavior are of interest in the phenomenological study of human action. The focus of study is to understand the meanings, relational concerns and practices of the everyday world (Benner, 1994). Typically, the approach studies practical activity, or what people do when engaged in everyday practical tasks of life (the ready-to-hand mode of engagement). However, the approach can also be used to study breakdown situations, where smooth functioning has ceased, as in serious illness or other crises.

The philosophical assumptions underlying the interpretive phenomenological research paradigm have specific methodological consequences or implications that must be taken into account when planning a phenomenological study. In planning the present study, the methodological approaches used by several researchers in the phenomenological tradition were considered. The writings of Van Manen (1990); Packer (1985); Packer and Richardson (1990); Packer and Addison (1989); Addison (1992); and Benner (1994) were especially helpful.

Methodological Implications

In the following paragraphs, I wish to describe the steps taken to link underlying philosophical assumptions with methodological implications for the phenomenological research paradigm. Methodological approaches such as understanding through participation; grasping "forestructure"; investigating experience as it was lived; establishing a communicative context for the interview; looking into background meaning; revealing one's own values and assumptions; reflecting on essential themes; analyzing exemplars and paradigm cases; and engaging in hermeneutic writing were all part of the overall research effort. These will be amplified in turn.

Understanding through participation. One implication of the interpretive phenomenological paradigm is that understanding comes through participation (Addison, 1992; Packer & Richardson, 1990; Van Manen, 1990). Following the Heideggerian sense of "involvement," one immerses oneself in the world of the participant in order to understand shared meanings, skills and practices (Addison, 1992).

For this study, I took steps to gain a participatory understanding of the phenomenon of AIDS caregiving. I initially entered into the "world of AIDS caregivers" by volunteering to be a co-facilitator for an AIDS family support group which met biweekly in a rural community. The group included family members (sisters, wives, parents, and friends) of persons with AIDS. During this five month period, I began to note family members' concerns about issues such as disclosure, family conflict, family secrets, stigma and access to competent medical care. During this time, I also studied several published accounts of family caregiving for persons with AIDS (Eidson, 1988; Glaser, 1991; Macklin, 1989; Moffatt, 1986; Monette, 1988; Pohl, Kay, & Toft, 1991; Preston, 1988; Rieder & Ruppelt, 1988). These texts expanded my access to the lived experience of caring for a person with AIDS.

Since the "world of AIDS" is broad and diverse, I next sought access to that diversity through an urban experience in a community-based AIDS education and support group. I trained as a "Hot Line" volunteer and contributed four hours each week for one year on a state-wide AIDS hot line. This experience brought insight into the larger cultural and social milieu surrounding persons with AIDS and their family members. In the agency, I saw repeated examples of the prosocial responses to AIDS. On the hot line, I heard stories of concern, fear, stigma, and at times bigotry and homophobia. In contrast to the rural experience, I gained access to the world of urban gay activists engaged in AIDS support work, yet also "burning out" from multiple AIDS-related losses and the interminable character of the epidemic. I had contact with administrators, case workers, nurses, and community-based prevention workers engaged in various aspects of "AIDS work." During this year, I also tried to capitalize on my access to a vast amount of technical and scientific information about AIDS treatment and research.

During my last year of doctoral study, I continued to expand my participation by working as an on-call staff nurse in a ten-bed, in-patient AIDS hospice. This experience, more than any other, provided for me an experiential, embodied way of grasping issues of concern for AIDS family caregivers. I was struck, for example, by one experience of working with an ill person who had lost mobility due to progressive multifocal leukoencephalopathy. This patient, unlike many of the younger terminally ill persons at the facility, was born in the same month and year as I, which aroused in me a personal identification I had not experienced with many other patients. He could no longer walk and had also lost his ability to speak. With effort, he could utter single word replies to my comments. I experienced his loss of "voice" as particularly poignant. Reflecting on this situation, I was struck by the extreme vulnerability and dependency of this patient who was mostly unable to ward off unwanted intrusions of any kind and who looked to others even for a voice. One's voice is a most taken-for-granted and embodied way of disclosing oneself as a person in our culture. "Having no voice" is tantamount in our linguistic and cultural meanings to "having no say" or "having no rights" in one's own situation, equivalent in other words to losing critical aspects of one's adult self. Participants in this study described similar situations when the ill person had lost the ability to speak. Because of my own participatory experience as a caregiver, I began to understand in a more embodied way how this situation can be one of extreme sadness, frustration, and shared suffering for the caregiver and the ill person.

Though my participation in AIDS care could not be taken as direct involvement in the participants' world, the experiences brought me somewhat closer to that world. Participation in AIDS care provided access to the experiences of family caregivers and allowed me to assume a more engaged stance when interviewing or interpreting text.

Far from trying to avoid interaction in the participants' world, the phenomenological researcher makes efforts to come to understand that world through active participation. Though inquiry begins with a participatory understanding of the phenomena to be studied, the researcher must retain a full awareness that the initial understanding is tentative and incomplete (Packer & Addison, 1989).

Grasping the forestructure. Packer and Richardson (1990) asserted that interpretation is grounded in a "forestructure" of preliminary preconceptions. Forestructure derives in part from participatory understanding and provides an initial point of view from which to begin interpretation. It is similar to what Van Manen (1990) refers to as the researcher's "preunderstandings." The researcher already has an initial, though incomplete, understanding of "what the participants are up to." Though incomplete, the forestructure guides analysis.

The participatory activities described above contributed to the forestructure that I brought to this study. For example, I held the tentative understanding that the experiences of families in rural areas were markedly different from those of gay activists in the urban setting. Rural families appeared to have greater concerns relating to stigma, discrimination, secrecy, and appropriate medical care. At the same time, I wondered how their experiences might also be the same as those of urban gay males. I later discovered that these caregivers shared concerns about preserving dignity and a sense of self for the ill person, regardless of their rural or urban settings.

Reading published first-hand accounts of AIDS caregiving also contributed to a preunderstanding of the phenomenon. Paul Monette's Borrowed Time (1988), Elisabeth Glaser's In the Absence of Angels (1991), and John Preston's (1988) collection of essays titled Personal Dispatches provided "a preliminary sighting of the entity to be studied" (Packer & Richardson, 1990). Glaser's account, for example, underscored the concerns of stigma, secrecy, disclosure, pain, comfort, and suffering.

A preliminary analysis of these and other narratives suggested a fundamental aspect of the forestructure that I brought to the research--that the moral concerns of caregivers are foundational and primary to understanding the practical aspects of care.

I approached the research believing that such concerns can be conceptualized and studied in the everyday, practical world, staying close to the voice and language of the participants rather than the traditional language of bioethics.

The third source of "forestructure" was the published research of Brown and Powell-Cope (1991), who constructed the first theory of AIDS family caregiving. This work contributed to a preunderstanding of the experience of AIDS family caregivers. The basic social psychological problem of uncertainty and the core category of transitions through uncertainty were validated by the present study. Subcategories such as managing and being managed by illness, living with loss and dying, and going public were concerns seen in the narratives of caregivers in this study.

In summary, the "forestructure" or "preunderstanding" is the system of related concepts and experiences that will orient the researcher during the interpretation phases of the study. For this study, sources of forestructure included practical involvement in the "world of AIDS," reading and interpreting published narratives of AIDS caregiving, and the grounded theory of AIDS family caregiving developed by Brown and Powell-Cope (1991). Remaining open to new and divergent understandings is an important aspect of interpretive study (Van Manen, 1990). I tried to share my preunderstandings and initial interpretations in an on-going dialogue with dissertation committee members and other colleagues.

Investigating experience as it is lived. Interpretive phenomenology maintains that for the human sciences the proper object of study is people's everyday involved activity--not (or not only) their reflections about situations (Packer & Richardson, 1990). The researcher, therefore, strives to investigate experience as it is lived rather than as it is conceptualized. Story telling is one way to access accounts of involved activity.

Benner (1994) commented that the role of story telling is central to the phenomenological research approach. The interpreter seeks to hear and understand the voice of the participants through experiences described in stories. The story is remembered after it is lived through and is told in terms of the participants' concerns and understandings. The underlying assumption is that no one precise story exists; there are multiples stories and each is shaped by the particular interview situation.

For this study participants were asked to tell stories about their lived experiences of caregiving for a person with AIDS. Participants were encouraged to describe episodes of caregiving and examples of actual practices or care settings connected with particular events during the illness. In general, participants were encouraged to avoid abstract thinking or causal explanations about situations; but from time to time they volunteered or were asked to share their reflections about causal relationships within caregiving situations.

The focus was on collecting retrospective stories of care which spanned the entire caregiving trajectory, including the death of the person with AIDS. These stories tapped into the entire caregiving experience after it had been lived through, and thus the research could not include participant observation.

Establishing a communicative context. Benner (1994) referred to establishing a "communicative context" in which the participant feels comfortable about sharing their story. The interview context is set up in naturalistic ways so participants do not feel unduly constrained or awkward about telling their story. Van Manen (1990) referred to the research interview as a "conversational interview," which serves both as a means to explore and gather experiential narrative data and as a vehicle to develop a conversational relation with the participant about the experience. The communicative context and conversational relationship promote a relaxed atmosphere which is important to good story telling. To achieve these aims for this study, most interviews were conducted in the privacy of the participant's home and, when possible, participants were interviewed at lease twice in order to establish rapport.

During interviews, I attempted to maintain a strong orientation to the original phenomenological questions. However, interviews were also discovery oriented; and since the unfolding of personal experiences and concerns cannot be foreseen, I remained open to the participants' stories and avoided rigid adherence to an interview guide (Van Manen, 1990).

Looking into background meaning. There were different ways in which background meaning was taken into account for this study. Background included the larger historical and cultural referential whole in which the caregivers and the interpreter dwells; it means local communities; and it also means family specific histories and current interpersonal relationships (Addison, 1992; Benner, 1994; Benner & Wrubel, 1989). Throughout the study, I attempted to keep all of these senses of background meaning in view. During interviews, I asked caregivers to outline the history of their relationship with the person with AIDS and prompted participants to describe family backgrounds and current connections. Chapters 4 and 5 present commentary and narrative text on the cultural and linguistic background meanings affecting caring practices and family contexts of care.

Revealing one's own values and assumptions. True to Heidegger's notion that we can never get completely clear on the background within which we are situated, I found the aspect of uncovering my own taken-for-granted meanings, values and assumptions a most baffling aspect of the study. I was perplexed about how to gain any clarity at all on the values I was bringing to the study, and it seemed that I could only begin to understand them in retrospect. For example, according to my own value orientation, I placed a great deal of importance on the culturally and historically undervalued work of human care--which includes such varied kinds of work as parenting, teaching, nursing, tending the land, and sustaining family. My initial tendency, therefore, was to idealize caregivers by selectively listening for and elaborating on what stood out as instances of exemplary care. I eventually began to form a less idealized image, recognizing in the narratives instances of conflict, power struggles, anger, guilt and the undue submersion of self in caregiving.

I was also aware that as a middle-aged, middle-class, white, heterosexual female, mother, and wife, my own way of being in the world would both open up and close down aspects of the communicative context I was trying to establish with participants. An example of what might have been systematically closed down showed up during one of the final interviews. A gay male caregiver began to discuss ways in which maintaining sexual intimacy with the ill person had functioned in his care. Prior to this interview, I believed that caregivers had not raised the issues and concerns of sexual activity during caregiving. Further, I had not provided openings for this type of discussion. Holding the tacit assumption that sexual intimacy was not of major interest in a study on AIDS caregiving, I may have cut off these kinds of discussions.

Fixing action. Packer and Richardson (1990) asserted that human action and experience must be fixed before it can be studied. Interviews in this study were transcribed and thereby "fixed" into a narrative text. The text is a reflection of lived experience and not, of course, the experience itself. Ricoeur (1979) warned that as recollected experiences are fixed in a written narrative, changes take place. What is at stake in the transcribing of discourse is the dissociation of the speaker's original intentions and the verbal meanings of the written text. Ricoeur recognized that the tie between the speaker and the discourse is transformed by the written text and in some ways distorted. This is so because the speaker speaks within a particular context and time and with certain intentions, intonations, gestures, and rhythms--all of which are lost in the fixing of the text. The researcher, therefore, must be aware of the differences between the original event, the telling of the event, and the fixed action that is studied. Though one cannot access the lived experience directly, narrative accounts obtained from participants are taken to be reflections of the lived experience which can be accessed and accounted for through interpretative study of the text.

Reflecting on essential themes. Van Manen (1990) described phenomenological refection as trying to grasp the essential meaning of something. The notion of "essential theme" is used in phenomenological interpretation to suggest the point or sense of a story or the underlying structure, shape, or core of an experience (Van Manen, 1990). A "thematic statement" is a simplification that attempts to capture the main focus, point, or meaning of the essential theme or aspect of the phenomenon. This reflective process is also referred to as thematic analysis (Benner, 1994).

Van Manen (1990) discussed three approaches to the insightful discovery of essential themes: (1) attending to the text as a <u>whole</u> and asking what statements might capture the fundamental or main significance of the entire text, (2) reading a text several times to circle or highlight <u>phrases</u> that stand out as being particularly revealing about the phenomenon, and (3) using a line-by-line approach to reading while asking what each <u>sentence</u> reveals about the phenomenon. This back and forth movement between the whole text and parts of the text is referred to as progression along a "hermeneutic circle" (Packer & Addison, 1989) or "hermeneutic spiral" (Polkinghorne, 1983).

For this study, thematic analysis began with reading narratives after an interview was completed and transcribed. I constructed a tentative outline of emerging themes and thematic statements which were shared with members of the dissertation committee for review and discussion. Van Manen (1990) referred such interactions as "hermeneutic conversations" whereby the researcher generates thematic statements and categories through conversations with other researchers.

<u>Analyzing paradigm cases and exemplars</u>. Paradigm cases are whole stories that are "strong instances of concerns or ways of being in the world, doing a practice, or

taking up a project" (Benner, 1994). They offer the opportunity to engage in the practical world of the participant. The paradigm case shows up the interconnectedness of concerns, meanings and patterns of practical activity within a particular context or situation. Paradigm cases are used as a strategy of analyzing and understanding the text and are also used as a strategy for presenting interpretive commentary (Benner, 1994).

Exemplars are shorter segments of text that may be used to demonstrate similarities or contrasts once a pattern of meaning has been identified (Benner, 1994). Exemplars are drawn from the text to convey aspects of a paradigm case or thematic analysis. A range of exemplars may be used to add nuances or qualitative distinctions when explicating a thematic element that has emerged in the text.

Using paradigm cases and exemplars, the interpreter attempts to uncover commonalities and differences occurring across situations, over time, and within cultural contexts (Benner, 1994). Sources of commonality include the situation, concerns, meanings, skills, and practices (Benner, 1994).

In this study, paradigm cases and exemplars were extracted from whole narratives and used to write case summaries of caregiving situations. Exemplars were picked that highlighted the qualitative distinctions of major concerns and emerging themes. Comparisons were repeatedly made among exemplars as well as among paradigm cases and whole narratives. Commonalities and differences were noted and put together into larger patterns. Exemplars and paradigm cases were eventually used in presenting the final interpretive account.

Engaging in hermeneutic writing. Thematic analysis, exemplars, and paradigm cases give control and order to interpretive writing. Van Manen (1990) referred to interpretive phenomenological research as a writing activity. Written language is a central concern in phenomenological research; "responsive-reflective writing is the very activity of doing phenomenology. Writing and rewriting is the thing" (Van Manen, 1990).

Writing fixes thought on paper, making our understanding of the world concrete and letting us see what tends to hide itself (Van Manen, 1990). Through writing, the researcher offers a narrative account of participants' experiences that opens up new possibilities for understanding, self-reflection, and changed practice (Addison, 1992).

Since the earliest phases of this study, hermeneutic writing was a continual, ongoing activity. Writing included summaries of individual caregiving situations and illness trajectories, descriptions of themes and tag words, and the writing and rewriting of interpretive commentary and the draft manuscript of the final interpretive account. Themes were used as foci or threads around which to weave the presentation of exemplars and paradigm cases. Copies of the draft manuscript were read by members of the dissertation committee, who offered corrections, supported the writing, or challenged the direction of particular interpretations.

Additional Aspects of the Research Design

Additional aspects of the research design such as recruitment strategies, characteristics of the sample, human subjects protection, data collection, data management, and additional aspects of data analysis are outlined in the following sections.

Recruitment Strategies

Several strategies were used to recruit participants into the study. First, agency personnel from local AIDS support organizations and local hospice organizations were asked to identify potential participants. These personnel were instructed on including the aims, method of data collection, and means for protecting confidentiality in their explanations of the study to potential subjects. Participants were given a one-page abstract of the study and were asked if their names and phone numbers could be forwarded to the investigator. After potential participants agreed to be contacted, I telephoned them to arrange an initial interview.

Seven participants were recruited through a local hospice association; others were referred through AIDS support organizations or through nurses in AIDS care. Network sampling was used to gain referrals to two participants. During the initial telephone contact, I explained the purpose and procedures of the study, ascertained the person's eligibility for the study, and his or her willingness to participate. If a potential participant agreed to participate, I scheduled an appointment for the initial interview at a time and place that was most convenient for the participant.

Sample

The sample for this study was comprised of 18 self-identified family members who had been primary caregivers for a person with AIDS. Ten male caregivers and eight female caregivers volunteered to participate in the study. Table 1 presents demographic data for this sample.

Four caregivers lived in rural settings. Caregivers represented various relationships to the person with AIDS including partners, friends, mothers, wives, anc sisters. Fifteen of the caregiving situations involved caring for gay white men, and three situations involved caring for heterosexual men who died with AIDS. One situation reflected caregiving for an Hispanic male. All of the remainder were Caucasian males.

Table 1

Summary of Caregiver Sample

GG Gender: M = 10 F = 8

Age range of CGs: 29 - 52 years

Ethnic group of CGs: 18 = Caucasian

Age range of PWA: 29 - 50 years

Ethnic group of PWA: 17 = Caucasian; 1 = Mexican

Income range of family: <$16,000 - $120,000

Average time spent in caregiving: 15 months

CG's relationship to PWA: 8 = Partners; 5 = Friends; 2 = Sisters; 1 = Mother; 2 = Wives

---

CG = Caregivers, PWA = Person with AIDS

Participants represented family members from both the biological family and the chosen family. Primary caregivers were initially defined as persons who had assumed the major portion of the caregiving activities and responsibilities in the home through the last four to six months of terminal illness. Three participants did not fit this expected criteria. One of these participants was a caregiver who offered supportive care for an ill person in a hospice setting. In a second situation, two caregivers cared for an ill person during the last four weeks of life. In a third situation, caregiving occurred during the last three months of life, though a long-distance caring relationship had been sustained over several years.

The sample did not include sufficient racial or ethnic representation; however, participants included both male and female caregivers, from biological and chosen families in both rural and urban settings. None of the persons with AIDS were female. Additionally, about half of the sample of caregivers was HIV positive which added an aspect of variability to the sample of participants.

Human Subjects Protection

Before the interviews, participants were informed about the goals and methods of the research, the potential risks and benefits of participation, and their right to withdraw from the study or decline to answer specific questions at any time. At each initial interview, I reviewed the procedures of the study with the participant and answered any questions. The consent form (Appendix A) was signed before starting the interview. Each participant was again informed of his or her right not to respond to questions, to change the topic of conversation, or to terminate the interview at any time. These same reminders were made at the beginning of follow up interviews. The signed consent forms served as the method of documenting consent.

Potential risks to subjects included psychological discomfort related to recalling and disclosing aspects of caregiving or experiences of loss and grief. Many caregivers were tearful at times during the interviews; however, almost all caregivers stated that verbalizing their experiences and feelings was a useful experience. Confidentiality was maintained by removing personally identifying data from transcripts and destroying tapes once they have been transcribed.

Data Collection

In-depth conversational interviews took place at least three months and not more than 24 months after the death of the person with AIDS. This time frame was selected to allow for a reasonable period of time for bereavement, yet be timely enough for participants to recall the events and experiences of caregiving.

The aim of data collection phase was to collect personal stories, exemplars, and paradigm cases which would disclose as clearly as possible caring practices, practical knowledge, and moral concerns of AIDS caregivers. I used an interview guide (Appendix B) as a help in staying close to the purposes of the research but I tried not to let the guide obscure or interrupt story telling by the participant. Additionally, demographic data were collected to describe the sample (Appendix C).

Interviews began with an orienting question about the particular trajectory of illness in the person with AIDS. Some caregivers chose to sketch this out on paper; others preferred to describe the illness continuum verbally while I took notes. The resulting trajectory was used to guide subsequent parts of the interview by drawing attention to specific episodes of illness and care.

I next proceeded with a general question about the history of involvement between the caregiver and the person with AIDS. This question was intended to uncover background meanings which would provide a sense for the historical and cultural contexts in which the caregiver and the ill person were mutually situated.
As details of the caregiving experience were revealed, I used prompts to elicit as much concrete detail as possible.

Interviews were from one and one-half to six hours in length. When possible, participants were interviewed twice. Participants who lived at a distance agreed to a single long interview. One participant was interviewed three times.

Though not all participants were interviewed twice, at least two interviews were desirable to build rapport with the participant, to grasp an understanding of both the overall situation and the specific instances of caregiving, and to ask participants to comment on emerging themes or preliminary interpretive statements.

Interviewing was stopped when ongoing thematic analysis suggested a repetition of thematic elements in the accumulating data.

Setting

The interviews were conducted at a place and time that was most agreeable to the participant. Most interviews were in the participants' homes. Two participants were interviewed at their place of work, where private rooms were available.

Data Management

The interviews were tape recorded and transcribed verbatim. Field notes on the setting and the participant's emotional tone and nonverbal cues were taken to supplement the recorded narratives. Additionally, some narratives were supplemented by portions from participants' written journals or memorabilia.

A coding key connecting case numbers to participants' names was used to track data. All personally identifying information was removed from transcripts of the interviews and field notes, and the audio tapes were destroyed after the transcriptions had been verified. Pseudonyms were used in the transcribed narratives. Names and other identifying information were not connected with the textual data.

After transcription, files corresponding to each narrative were converted into Ethnograph (Seidel, 1994) files and numbered line by line. Hard copies of both the Word Perfect document and the Ethnograph numbered documents were stored in a file drawer arranged by case number.

As data analysis proceeded, tags words were generated to tag segments of data for later retrieval and analysis. Ethnograph files were tagged using the tagging scheme in Appendix D. I also found it useful to physically tag segments of data using stick on notes with written tag names. Selected exemplars and paradigm cases were printed out and stored by thematic label or tag name.

Data Analysis

Shortly after interviewing was initiated and narratives were transcribed, I began to read the texts to obtain a sense of participants' central concerns (Packer, 1985). As the interviews were read, I made marginal notes outlining my perspective on what was going on in the story. After several interviews, I generated an emerging list of thematic labels or statements and shared these with members of the dissertation committee.

The process of reading texts, generating commentary, and returning to interview participants continued until a more in-depth phase of interpretation was begun. Toward the end of interviewing, I began to write case summaries, which represented more in-depth analysis of exemplars and paradigm cases. Interpretive memos were expanded and tag words were reconsidered and revised.

After a period of considering parts of texts, whole interviews, groupings of interviews, and the entire collection of interviews, I devised an initial outline of the interpretive account again sharing this with members of the dissertation committee for discussion and critique.

After the initial outline was drafted, segments of text were retrieved using Ethnograph. These segments were read and compared to identify recurring themes, commonalities and differences in caregivers concerns and experiences. Interpretive commentary was written and rewritten to explicate the meanings embedded in the text.

During this phase of analysis, I met frequently with members of the dissertation committee and sought responses from participants regarding the developing interpretive account.

The draft manuscript was prepared and organized around thematic elements, using exemplars and paradigm cases as methods of presentation within the interpretive account.

Evaluating the Interpretive Account

Interpretive phenomenology aims at providing access to a "world" and at fostering insight and understanding of the human phenomena in that world. The focus of research is on human meanings and concerns as they are shaped in distinct contexts and historical eras. Interpretation, in the words of Heidegger, is "letting-something-be-seen" (Packer & Richardson, 1990).

Validation in the rationalist/empiricist model is tied to the view that a valid account is one that corresponds to "what really happened" or "the way things really are" (Packer & Richardson, 1990). The underlying assumption is that human beings can gain access to ahistorical, universal truths, and that this access can be validated through prescribed techniques.

The interpretive paradigm, in contrast, assumes that there are multiple constructions of reality, each depending upon one's situatedness, concerns, and access to the world of interest. There is no strict correspondence between an event as experienced and an event as reconstructed through telling (Polkinghorne, 1988). Interpretive descriptions, therefore, are not taken to correspond to timeless or universal facts about reality. Thus, in the interpretive paradigm, issues of validity have a different meaning and the matter of evaluating the interpretive account demands approaches that are different from the truth claims of the rationalist/empiricist model.

The absence of truth claims in interpretive research does not mean that interpretation is speculative conjecture or undisciplined guessing. The researcher enters the interpretive project with a forestructure or a preliminary perspective gained through participatory understanding and a beginning practical knowledge of the world to be studied. Though the preunderstandings are tentative and are held up for challenge by the data, they nonetheless provide an entrance into the world of study that is not arbitrary or merely subjective (Packer & Richardson, 1990).

Packer and Richardson (1990) outlined four approaches to evaluating an interpretive account that do not fall back into the positivist model of validity. These include 1) coherence, 2) seeking participants' responses to interpretations, 3) consensus, and 4) pragmatic usefulness. A coherent interpretation is one that is plausible. Coherence is enhanced when initial interpretations are critiqued, opened to challenge, revision, and counterinterpretations (Packer & Richardson, 1990). Thus, looking for discomfirming evidence is necessary to understand a text and generate a coherent account.

Seeking participants' responses to descriptions and interpretation is a second approach to providing an intelligible interpretive account. This approach has been labelled "member checks" by Lincoln and Guba (1985). The approach does not correspond to a check on "reality," however, since seeking participants' views on the appropriateness or accuracy of an account is seeking another interpretation of that account. Even participants cannot provide an objective standard against which to validate an interpretation (Packer & Richardson, 1990). It is reasonable to expect, however, that a coherent account will resonate with the participants' understanding of their own experience and it is accepted that participants may offer important correctives to the interpretation.

A third approach to evaluating the interpretive account is seeking consensus among researchers. Conducting interpretive sessions and having "hermeneutic conversations" (Van Manen, 1990) with researchers are essential aspects of interpretive inquiry. One must keep in mind, however, that agreement is no guarantee that one has arrived at the "best" interpretive account. First, there may not be one best account of human action. Second, seeking consensus, especially if it is among people who are unfamiliar with the topics of investigation, may simply be a way of "training" others to see things as the interpreter does. Packer and Richardson refer to this as "training up" into the researcher's interpretive perspective. "Group think" is another undesirable possibility.

A fourth approach to evaluation is consideration of the pragmatic usefulness of the interpretive account. Does the account prove useful for understanding related phenomena and for acting in the everyday world? Is the account convincing? And does it improve, challenge, extend or change practices? Evaluating the account in terms of its usefulness in the everyday world involves providing engaged practitioners access to the account. This may be done through publication or presentation. Seeking input from persons who were not participants but who meet the criteria for participating in the study is another possibility. Also, a coherent and pragmatic account should be expected to "fit" with other research on the same or similar phenomena.

In this study, specific actions were taken to develop an interpretive account that made sense and that was coherent and useful. These actions coincided with the approaches to evaluation proposed by Packer and Richardson (1990) and are explained in the following paragraphs.

First, extended interviews were conducted with participants to collect sufficient data for constructing a coherent account of their caring practices. A sufficient amount of data is needed for identifying patterns, commonalities, and differences among exemplars and paradigm cases (Benner, 1994). My approach was to elicit story telling and to listen to stories while trying to follow along and understand the issues and concerns being described. At times during the interviews, however, I adopted a dialogic stance, asking for clarification when a turn in the plot or main point was unclear, or suggesting an interpretation and asking for confirmation or discomfirmation.

I returned for second interviews with several, but not all, participants. Second interviews were not feasible, for example, when long-distance travel to participants' homes was necessary. One informant, who related a particularly complex family context of care, was interviewed three times. When followup interviews occurred, I asked participants to expand on emerging themes and occasionally to comment on my initial interpretive understandings. Interviews were scheduled over a time span of 9 months, which gave time to consider emerging themes from preceding interviews and question subsequent participants about their experiences in relation to patterns of experiences that emerged from other data. These aspects of the research process fit Lincoln and Guba's (1985) criterion of "prolonged engagement," the activity of investing sufficient time to build trust and learn the "culture."

Second, after data collection was completed and interpretations were written, I ask participants in the study to respond to written interpretive commentary in order to assess the fit between the interpretive account and their own reconstructions of the experience.

Third, in an attempt to gain consensus, I shared insights and interpretive commentary with members of the dissertation committee, who also had access to the original narratives. Interpretive summaries of participant cases were shared with committee member and in this way opened up for criticism or consensus on the appropriateness of the commentary. Interpretive sessions included discussion of essential themes and identification of appropriate exemplars and paradigm cases. The danger of "training up" to my own interpretive perspectives was avoided because members of the committee were experts in relevant content areas. Members brought expertise in AIDS caregiving, general caregiving, ethical concerns and in the phenomenological method and view of the person. Additionally, other colleagues not involved in the research were consulted and selected portions of the interpretive account were presented to faculty and doctoral students in a family research seminar and feminist method interest group.

The fourth approach of evaluating an interpretive account depends on whether or not the account is viewed as useful by practitioners. This aspect of evaluation occurs when the readers gain access to the report through publication or presentation.

Summary

In this chapter, I presented a synopsis of the Heideggerian view of the person and related Heideggerian phenomenology to assumptions about knowledge, meaning, and concern that are basic to the phenomenological research paradigm. I have detailed ways in which methodological implications flow from the Heideggerian world view and how these were applied in the present research. I explained the step taken to evaluate the interpretation, which aims for a sensible, coherent, and useful account of AIDS caregiving. In the following chapters, I turn to the presentation of the interpretive account itself, considering first the background meanings and social contexts within which caregiving occurred for caregivers in this sample.

CHAPTER 4

THE CULTURAL CONTEXTS OF CARE AND CONCERN

In this chapter, narrative data and commentary are used to illustrate how contexts of care influence caring practices and concerns in families of persons with AIDS. An assumption of the Heideggerian phenomenological tradition is that persons are situated in particular historical, cultural and social contexts that set up possibilities and create limitations of individual expression and being. Caregivers are both limited and supported by their particular situations and by the broader contexts in which they live.

Caregivers work out the possibilities of care within multiple contexts. On one level, the culture as a whole and various subcultures within the whole shape contexts for caregiving. On other levels, local communities, families, and interpersonal relationships between caregivers and persons who are ill constitute further contexts for care.

In this chapter, I will look first at ways in which broad cultural responses to HIV disease shaped contexts of care for participants in this study. Narrative data will be used to support the view that meanings embedded in the larger cultural whole affect individual meaning and action. Additionally, I will use narrative text to illustrate how responses in local communities modify caregiving situations. In Chapter 5, I will examine how family becomes both a context of care and a concern for caregivers.

The narratives in this study reflected concerns and practices situated predominantly in white, middle-class American culture. One caregiving situation reflected influences of the traditional Mexican culture.

Background Meanings of AIDS in America

Both negative and positive responses to HIV disease contribute to the social context of AIDS in late 20th century America. AIDS has been characterized as a "social disease" owing to the stigma, fear, and discrimination experienced by people who have the disease (Velimirovic, 1987). Persons with AIDS and their families have suffered the consequences of prejudice, discrimination, and social stigma; they have lost homes, been barred from schools and work settings; and have been denied medical care. At the same time, the negative social responses of discrimination and AIDS phobia have been countered by progressive social reactions. These include numerous voluntary organizations dedicated to the support and service of people with AIDS; the emergence of an AIDS hospice movement; the adoption of legal protections from discrimination and invasion of privacy; and large-scale scientific and technological efforts to understand the disease and develop treatments (Bayer & Kirp, 1994). In the following sections, I will look first at the stigmatizing effects of negative meanings of AIDS in the culture. Narrative data from participants in the study will be used to illustrate some of the effects of this cultural context on individual caregiving situations.

The Gay Disease

The manner in which a disease enters a population has been observed to influence social views of that disease. As with other diseases, the meanings associated with AIDS are embedded in distinct societies at distinct moments in their history (Bayer & Kirp, 1994). Meanings are socially constructed in that they are linked with and draw from past cultural experiences, meanings and practices already present within the culture. From a phenomenological point of view, caregivers and persons with AIDS cannot escape the shared meanings and cultural contexts in which they find themselves. They are constituted by their culture and take up the meanings and practices already present in their situation. These meanings have been influenced in part by the manner in which AIDS first emerged in the culture.

The first evidence of the disease that would eventually be called AIDS appeared in 1981 among homosexual men in the United States. Small clusters of gay men in California and New York were reported to have Kaposi's sarcoma, a rare form of cancer, and pneumocystis carinii pneumonia, an opportunistic infection associated with immune deficiency (Bennett, 1987; Shilts, 1987). AIDS was quickly recognized as a deadly infectious disease with no known cure and an unknown mechanism of transmission. Initially called gay-related immunodeficiency disease, or GRID, AIDS was, from the beginning, identified in the United States and in other countries as a "gay disease" (Bennett, 1987; MacIntyre, 1993; Shilts, 1987).

The emergence of AIDS in an already stigmatized population encouraged and perpetuated the negative social responses of stigma and discrimination. These responses were generalized to all persons who were affected by the disease. The initial associations between homosexuality, infectivity and rapid progression to terminal illness created fear, a powerful social stigma, and widespread hysteria. Homosexual men were identified as carriers and blamed for the spread of the new epidemic. Media reports of "unfettered gay sexuality," anonymous sex in gay bath houses, and gay men having large numbers of sexual contacts drew public attention and crystallized homophobic attitudes in the culture (Bennett, 1987; Shilts, 1987). Gay men were viewed as a social threat rather than as part of the suffering and coping brought forth by a devastating disease (MacIntyre, 1993).

AIDS quickly became the paradigmatic instance of a disease with moralistic cultural meanings--a disease of sexual excess and perversity visited upon its "victims" as a punishment for deviant behavior (Ross, 1988a). As an already stigmatized group, homosexual men were vilified even further and considered to be sources of both moral and physical contamination (Bayer & Kirp, 1994; Ross, 1988a).

Fairly soon after AIDS was reported in gay men in June, 1981, it was noted in the heterosexual population (Bennett, 1987). The virus was observed to spread through exchange of body fluids, similar to the modes of transmission of hepatitis B. IV drug users who shared contaminated needles and their sexual partners were added to the high-risk group. The stigma attached to IV drug abuse added to the mounting social prejudices against infected persons. Heterosexual transmission, blood transfusions, and intrapartal routes of transmission were soon documented (Bennett, 1987).

Despite evidence to the contrary, the social understanding that AIDS is a "gay disease" persists. Some caregivers in this study suggested that the connotation of AIDS as a gay disease was a significant concern for their families. Caregivers, the ill person and other family members dealt with homophobic feelings and associated issues of concealment. In some cases, gay men were concerned about disclosing their sexual orientation to parents; in other cases, heterosexual mean feared being labelled homosexual. The following narrative data illustrate how social meanings linking AIDS with homosexuality affected the context of caregiving. Margaret, a woman who cared for her 51 year old husband, Mark, explained Mark's fear of disclosure and of being identified as a gay man.

> Questions had been raised about his sexual orientation, and he was devastated by those accusations that he was gay or bisexual. I believe the reason that he was most concerned was that he believed that people would conclude that he'd contracted it from having sex with another man. He couldn't bear to have people make inquiry even as to how he contracted it.

Mark's fear of being exposed as a bisexual or gay man fueled the need to conceal his illness. He exacted a promise from Margaret that she would not disclose his AIDS diagnosis to anyone, including her children and closest friends. Fear of being identified as gay led to an intense need for secrecy that eventually isolated Mark and Margaret from friends and sources of support. As Margaret commented,

> He went to his death not having told a soul that he had AIDS. Because he went to his death believing that people would judge him and that he wouldn't be loved or accepted.

For Mark, having AIDS was a socially untenable position; the disease brought into question not only his sexual orientation but his social acceptability as well. AIDS conferred a deviant social identity which, if known, would encourage judgement and rejection by others.

After Mark died, Margaret openly discussed his illness with friends and family. She commented on the stigmatizing social attitudes that sort people with AIDS into two groups: the innocent and the morally guilty.

> One of my hopes for the future is that, as more and more persons who aren't part of traditionally discriminated against groups come forward and

> acknowledge they're sick, that when they're asked how they contracted it, that they'll say "It's none of your business. It shouldn't matter." Because if there are any innocent victims, then there must be some guilty people who by their behavior deserve to have this horrible illness and deserve to die...Afterwards, the first question out of people's mouths was: "How did he get it? Did he get it from an OK way?" I just give them my speech about "I don't know, and I was his wife and it didn't matter to me, how can it matter to you? Let's talk about why it matters."

Margaret understood questions about how Mark got the disease as inquiries into how he should be socially categorized. Was Mark an innocent victim? Or was he morally at fault? Believing that AIDS is a disease which can have both "innocent" and "guilty" victims may be a logically inconsistent position (Ross, 1988a); yet, this inconsistency does little to reduce the potency of the social view that certain groups, specifically homosexuals and drug users, are guilty by virtue of deviant social behaviors. To avoid such categorizing, Mark chose to conceal his diagnosis from others and maintained silence with Margaret about how he was exposed to the disease.

The narratives suggested that, especially for the heterosexual men in this study, the associations between AIDS and homosexuality or other forms of social "deviancy" were concerns that compelled secrecy with outsiders and silence between the caregiver and the ill person. An example of maintaining silence was provided by Norma, a woman who cared for her brother John, a heterosexual man who lived in a small rural community. Norma explained that silence about how John contracted AIDS was an assumed practice. As Norma stated, it was "just not one of the things we talked about."

> I have my suspicions about how he might have contacted it, but I never came

> out and asked him. I mean he could have been leading another life that I didn't know anything about, but I never, for his own self-respect and his dignity and everything, I just couldn't bring it up and I wouldn't ask him about it.

Talking with John about how he got AIDS was considered a disrespectful question and a threat to John's integrity. Norma's concerns about maintaining John's self-respect reflected her understanding of the constructed meanings of AIDS as a disease of moral taint and social deviancy. AIDS in the United States is a stigmatizing condition, not only because of its associations with stigmatized groups such as homosexuals or IV drug users, but also because of powerful metaphorical understandings of AIDS as plague, contagion, and death.

The AIDS Metaphors

Sontag (1979, 1989) and Ross (1988a, 1988b) examined metaphor as a vehicle that promotes shared meanings of disease in a culture. Used to explain something that is new or strange, a metaphor may be elaborated over time into a larger narrative that connects the known with the unknown. Though metaphor promotes understanding by highlighting similarities between two different things, a particular metaphor does not convey how many aspects of the phenomena are the same and how many are different. Thus, when used casually, metaphor distorts understanding about a new phenomenon. A dominant metaphor, such as the plague metaphor associated with AIDS, tends to overshadow or discount factual information about the actual epidemic (Ross, 1988a).

Plague is one of the principle metaphors by which the AIDS epidemic has been understood (Sontag, 1989). The narrative that expands the plague metaphor connects the AIDS epidemic with past cultural experiences and understandings about plagues. As with Bubonic plague or cholera, plagues have been understood to be contagious, deadly, catastrophic, of foreign origin, and typically brought upon a people as punishment from God (Sontag, 1989).

The notion of punishment is one of the oldest explanations of what causes disease. Throughout history, plagues have been understood as manifestations of God's judgment on a group of people who have sinned (Sontag, 1989). Those affected by the disease are regarded as deserving their illness because they are degraded, evil, or morally lax. In addition to AIDS as "plague" and as "punishment for sin," Ross (1988a) contended that the rhetorical style used in the American media shows AIDS to be part of several other social metaphors: AIDS as "death," "crime," "enemy," and "other."

AIDS as crime is understood in two ways. It is itself a kind of crime against humanity that must be solved by scientific researchers. And, secondly, people who have AIDS are potential "criminals," who may be viewed as carrying a deadly weapon. The metaphors of AIDS as "crime," "enemy," and "other" justify punitive responses and promote the notion that it is permissible to restrict civil rights of those categorized as criminals, enemies, or aliens.

The sense of "otherness" connected with the AIDS metaphors results in some of the most punishing consequences for people who have AIDS (Ross, 1989). The notion of being outside of the human community deprives persons and families affected by AIDS of respectful relationship, the very thing that defines human social being. The metaphor of otherness justifies treating the other less generously, fairly, or compassionately than we would otherwise treat our own.

Within the metaphors and narratives connected with disease lies the justification for cultural and personal responses to people who have the disease. All of the AIDS metaphors encourage denial of respect for persons--one of the dominant ethical concerns of caregivers in this study and one of the most important principles undergirding Western ethical understanding (Beauchamp & Childress, 1989; Ross, 1988a). Metaphors that characterize an ill person as guilty, sinful, apart and "as good as dead" encourage stigmatizing social responses.

Stigma

Goffman (1963) analyzed social stigma and the ways stigmatized persons manage a socially "spoiled identity." The Greek term stigma originally referred to a bodily sign that exposed something unusual or bad about the moral status of a person. Today, stigmatized persons include both those who bear some physical blemish and those who are disgraced through discrediting actions or behavior.

The central feature of a stigmatized person's situation is disqualification from full social acceptance or participation. Stigma has the effect of cutting the person off from society and from himself so that he or she is a discredited person facing an unaccepting world (Goffman, 1963).

Ways of managing stigma include trying to control social information and conceal the stigmatizing attribute, claiming that the stigmatizing condition is really a different condition, withdrawing from social contact, telling only a few trusted people, or trying to come together with others who are stigmatized in the same way (Goffman, 1963). All of these tactics were reflected in the narratives of caregivers in this study.

Caregivers indicated that the stigma attached to AIDS extended beyond the ill person to other members of the family. If children were present, they were viewed a especially vulnerable to stigmatizing social responses. Norma, a caregiver in this study, lived in a small rural community near her parents where she cared for her brother, John, and looked after his teenage daughter Patty as well as her own two children. Norma discussed her concerns about allowing John's AIDS diagnosis to be generally known in the community. She feared that disclosure of John's illness would be most harmful for John's daughter Patty and her own two sons.

> That was one of the hardest things. There were a lot of close friends of Patty's that I felt like she needed to talk to, but yet, if she had talked to them and told them that her dad had AIDS, they wouldn't have wanted anything to do with her whatsoever. And I didn't want it going around school. If one of the kids heard about it around school, it would go through like wild fire. And I didn't want that for her.

Norma feared Patty would be ostracized at school if children knew her father had AIDS. As Norma stated, "From experience, if they even hear the word AIDS or HIV, they're going to back off." Patty was told to conceal her father's illness from her friends. Only the school principal and counselor were informed about her father's illness. Norma, her children, and her parents formed the core of a tight inner circle of people who were told that John had AIDS.

> We didn't tell people because he didn't want people to know. Because the first thing is, well they're either gay or they're, you know, the stereotypes that they stick with AIDS. And he wasn't any of those, so he just didn't want people around to know.

To conceal John's identity as a person with AIDS, Norma told friends that he had cancer. This was a tactic used by several other caregivers, following Goffman's observation that the stigmatizing attribute may be passed off as a similar but less discreditable condition.

> P: First we told everybody...that he had cancer. And even with cancer there's a lot of questions. Like what kind of cancer? Where is it at? So we really didn't go into it....It was extremely hard for my dad to tell anybody.
>
> L: It was hard for him to have others know.
>
> P: Well, not so much that they knew. But he couldn't come right out and say it. He could not come out and say, "My son has AIDS." And, even to his closest friends, he never did tell em.

For John's elderly father, the disease carried such powerful negative connotations he could not give voice to the word "AIDS" or verbalize that "My son has AIDS." Talking about cancer was more acceptable, but elaborating a story to conceal AIDS proved stressful and demanded a constant type of self-monitoring. As Norma explained,

> P: You have to watch what you say. You know there's certain phrases that you acquire when you're taking care of an AIDS patient or when you're even studying AIDS, that don't go along with any other diseases.
>
> L: Do some of those come to mind?
>
> P: Well, like the T cell count. I never heard of T cell count until AIDS. The medications. There are just things like pneumocystis, the skin cancers and things like this, they just go with the virus itself....There's nothing else that it compares to. You can't say this is cancer and then start talking about the other things, because people are gonna go, "Now wait a minute...We never heard of cancer this way."
>
> L: So you had to watch what you'd say around certain people.
>
> P: Oh yeh, you have to.

Telling some family members and not others, avoiding the word AIDS, and pretending that AIDS was a different disease were tactics for managing John's "spoiled social identity." Norma also mentioned that she told a few special friends but asked them not to let John know they had been included in the inner circle. All of these tactics were ways to shield John from the stigmatizing effects of his illness.

Other caregivers described experiences of stigma and the effects of discrimination from health care professionals. Jeannette is a 52-year-old woman who took care of her son, Brian. She related an instance when Brian was embarrassed in front of a class of dental students by a teacher who claimed Brian could not receive dental services until he was tested for HIV.

> He went to the dentist at the school and they told him they couldn't work on him. It was a class, and they said that until he got tested for AIDS [they wouldn't work on him]. The dentist said that in front of the class and Brian was very humiliated....so Brian would never go back. He didn't want to go to the doctors. He didn't want to go see anybody about anything to have to do with it. And his teeth were getting bad....He had got terrible infections in his mouth and he suffered with that too.

Being embarrassed in front of a group of students and denied care set a course that Brian would follow in later times. Though assuming he was HIV-positive, Brian avoided testing and did not seek medical care for several years. The lesions in his mouth worsened. Like many others, Brian responded to stigma by avoiding people or situations that would draw attention to himself as a person who could be denied care or respect.

AIDS stigma is also related to bodily stigmata that the ill person may not be able to conceal. Dermatologic lesions, wasting syndrome, blindness, neurologic deficit, or paralysis are all possible complications of the illness which make AIDS a self-disclosing condition. Withdrawal from others is one tactic that can be used to manage physically stigmatizing conditions characteristic of AIDS.

Rachel, is a 39-year-old woman who cared for Clark, a gay man who had been her friend for over 20 years. Rachel explained that Clark was a man who was very concerned about appearance. Over the course of his illness, he developed molluscum contagiosum, a disfiguring viral skin condition that can cause tumors on the face and scalp. Rachel described Clark's reaction to this situation.

> God he hated that. He had those mollescums on his face and he went to a dermatologist and he would burn them off, and then they'd get red and crusty and they'd hurt. Then they'd sort of fall off. But they just kept coming back and he had a real collection of them around his mouth and he had them on his forehead and after awhile, really truly, I didn't see them anymore. Initially, I saw them, but then I didn't notice them. But he never failed to notice them. And so I sort of would tell him, I'd say, "Oh, I don't think people notice them that much." Even though I knew later on in the disease, when we walked down the street, people would stare at him. I don't know if he knew that or not. That people stared at him because of the way he looked at that point. I would just sort of brush it off. "Ah, you know, there's worse things. So you've got a few bumps on your face, it's nothing to worry about. It really isn't."

As Clark's caregiver, Rachel reached a point of seeing past the bodily stigmata of molluscum; yet she retained an awareness of people's stares and the possible effects that might have for Clark. She described herself as having a grasp of "the big picture," and that in relation to Clark's larger struggles with AIDS, molluscum was indeed a minor concern. In "brushing it off," Rachel tried to minimize the impact of Clark's condition, assuring him that she didn't notice and that others would not notice either. Rachel indicated, however, Clark was sensitive to the stigmatizing effects of a disfiguring disease. In addition to molluscum, he experienced hair loss and body wasting and responded to these disfiguring changes by keeping friends away. Clark's withdrawal and hesitancy to have friends visit had the effect of isolating Rachel as well. She discussed reasons why she had so few people available to her to help with Clark's care.

> I might have felt more comfortable bringing in somebody else to help me, but Clark didn't want someone else. It got to the point, unfortunately, that he didn't want anyone else in....People would want to come by and he didn't want them to come by. And I think he was a little embarrassed about his appearance. He had some weird thought about he didn't want people in his space, his living space...He didn't want anyone in his space. He would rather go out and meet them someplace else....He was a pretty private person, and he felt it was important to maintain dignity at almost all cost, at all cost.

Not wanting people in his space may have been one way for Clark to protect himself from his own "spoiled identity." The physical stigmata of facial tumors, hair loss, and weight loss were especially humiliating for a person who had prided himself on appearance. In Rachel's case, Clark's withdrawal from others created a situation of caregiving in isolation.

In contemporary times, AIDS has replaced cancer as the disease with the greatest capacity to stigmatize (Sontag, 1989). Having AIDS or caring for someone with AIDS continues to be an experience colored by a range of cultural meanings that encourage fear, exclusion, and discrimination. Internalized feelings of otherness, of being discredited, or of having one's identity spoiled are encouraged by the negative metaphors associated with AIDS. These personal responses add to the suffering of the ill person and their family and through social isolation complicate the context in which caregiving must be carried out. These observations support Powell-Cope and

Brown's (1992) findings related to the stigma associated with AIDS caregiving. As in their study, caregivers in this study were vulnerable to the personal consequences of stigma such as isolation, emotional turmoil, and shame (Powell-Cope & Brown, 1992).

Finding themselves in a cultural context of AIDS stigma, caregivers participated in practices aimed at "managing the spoiled identity" of the ill person. They acted by concealing the AIDS diagnosis, controlling information by telling only a small circle of trusted people, referring to the illness as cancer, or supporting the ill person's withdrawal from social contact.

At the same time, and somewhat paradoxically, caregivers referred to the positive effects of more progressive, socially organized responses to AIDS. I turn briefly to one example of a prosocial movement that has contributed to the context of care for some families.

Prosocial Responses

Perhaps not enough has been written about the prosocial responses that have occurred within the past decade of the AIDS epidemic. The emergence of community-based AIDS support organizations, in-patient AIDS hospices, legal protection against discrimination, and scientific advances in immunology, virology, and drug development have all occurred in response to the epidemic (Bayer & Kirp, 1994).

Hundreds of volunteer organizations have been established to assist persons with AIDS or HIV disease and their families (Kobasa, 1990). Such organizations are the result of grass roots efforts mainly by gay activists who were politicized early in the AIDS epidemic and whose mobilization to affect positive social responses to the AIDS epidemic cannot be underestimated (Shilts, 1987). Many of the socially organized efforts to prevent AIDS or support persons with HIV disease depend on large numbers of committed volunteers. Compared with the enormity of the epidemic, it can be argued that not enough is being done to prevent or treat the disease, but this argument should not overshadow the many examples of positive social responses that coexist with the social elements of stigma, discrimination, and fear. As Bayer and Kirp (1994) remarked, the United States has provided the very worst and the very best models of social response to AIDS.

The emergence of in-patient AIDS hospices is one example of socially organized efforts to support persons and families affected by HIV disease. In this study, three caregivers placed their family member in an in-patient AIDS hospice during the very late stage of illness. The hospice provided a context of safety and respite for two caregivers. In a third instance, it was the ill person who asked to be taken to a hospice to alleviate a growing burden on his family.

Chris, a gay man and caregiver, who first became involved with his friend Buddy through the volunteer AIDS peer support program. When Buddy became seriously ill, Chris made a commitment to be responsible for his care. He brought Buddy into his home, but was unable to provide 24-hour supervision. Affected by dementia, Buddy refused to stop smoking and one day set fire to the couch. Chris then arranged to have Buddy placed in an in-patient AIDS hospice. The hospice provided a safe physical context for Buddy's care, and Chris was able to visit Buddy two to three times a day. As Chris explained, the hospice was the safety net for providing humanitarian care for a man who was essentially alone in life.

> This man had no support system basically. He was estranged from his family for years. He didn't even know where to write them to let them know what was going on. He had no kind of spiritual community. His only friendships...were people that he would meet in bars...They didn't socialize outside of that. And then of course his partner...that relationship really was crumbling while this was going on. So outside of the people at the hospice, I really was his primary source of contact. And I think that was really, really important to him.

Within the context of the hospice, Buddy found a place where he could be socially accepted and supported through the terminal phase of his illness. Having no family and no significant or supportive friendships, the hospice became both family and friend. Chris helped Buddy adjust to the loss of his apartment and tried to create a home-like feeling in Buddy's room.

> One of the great things about the AIDS hospice is that they really encourage people to make their rooms their home. You can decorate however you want...I got about a dozen of his stuffed frogs and brought those so he would have something familiar around and I think that made him feel a little more like home... God was smiling on me over this one because I told you Buddy ...set my couch on fire smoking in bed and so I knew I needed to do something really, really quickly.

Though caring took place in the environment of the hospice, Chris described concerns common to all of the caregivers in this study. Paying attention to the caring space, providing emotional comfort, being aware of issues of dignity and control were made possible because of the support and availability of the hospice organization.

In this section, I have considered how the social meanings of disease can contribute to societal responses and contexts in which caregiving is worked out. The social contexts of care can be both positive and negative. In the next section, I look with greater detail at contexts created by local communities and specifically at ways in which the local communities shaped contexts of care for caregivers in this study.

Local Community as a Context for Care and Concern

MacIver (1970) referred to community as an "area of common life" where people develop in some kind or degree common characteristics, traditions, interests, modes of speech, and so on. Community is a question of the degree and intensity of the common life. Therefore, one may identify with a community depending on the degree or intensity with which one shares a common life with the community.

The narratives in this study suggested that local communities, though often difficult to define, served as contexts of care in multiple ways. In some situations, organized and committed care teams were made possible by a local community of involved gay friends and family. In other situations, especially in rural settings, a sense of community was more diffuse and difficult to identify in the caregiver's narrative. A collective sentiment of hostility towards gays or AIDS within a community affected caregiving by isolating the caregiver. Caregiving in this context was characterized by concealment.

I will comment first on the gay community as the context and source of the emergence of home care teams. In five situations in this study, care teams were made possible by a supportive community of gay friends and family. In one additional situation, the care team functioned more loosely, in part because the ill person had fewer complications and needed less assistance.

The context of highly organized and committed care teams will be contrasted to caregiving which took place in small, rural communities with few groups that were openly supportive of gays or persons affected by AIDS.

Gay Community

Goffman (1963) commented that members of a stigmatized group tend to come together into social groups, and that these groups are organized in varying degrees. Some contend that, as an already stigmatized group, the homosexual population experienced an increased sense of unity, organization, and activism as a result of the AIDS epidemic (Carter, 1989; Shilts, 1987).

Increasing unity within the gay community does not mean that potential members of the community choose to identify with or participate in the common concerns and practices of the community. One urban gay man in this study described himself and his partner as having few connections with a gay community; as a couple, they preferred to socialize with a heterosexual couple and looked to this husband and wife for support when one partner became ill. Another gay man lived in an isolated rural setting and described a limited network of friends, very few of whom were gay. Having a sparse friendship network, he opted to admit his ill partner to in-patient AIDS hospice when caregiving in isolation was no longer possible. One Lesbian caregiver described her participation in the gay leather community, a subculture which created for her a sense of commitment and responsibility to others in her group.

Several gay caregivers described themselves as well connected to a gay community. They had extensive gay friendship networks, well-established links with gay advocacy groups, and long-term involvements in AIDS service organizations. Caregiving in these situation tended to be characterized by highly organized care teams.

The complex and ambiguous sense of belonging to a "community" and specifically a "gay community" was described by Chris, a gay male caregiver, who had struggled to define community for himself.

> I've been having a lot of conversations with people trying to define it. What does it mean? I think I have several communities in my life. I have one that I live with...three men who all agreed that what we wanted to do was create an extended family. We're all estranged for a variety of reasons from our biological families, although we all have contact with them. We feel like we want to create something that feels like family. And so that's about having love and respect and emotional and spiritual and physical caring for each other. We consciously have made agreements, and some of them are very specific. "I will do this, if this happens." "I will be here for you in this way when I can." I mean, the three of us have talked about those things.
>
> I have an AIDS community that has people in it...who are working on this issue. And then there is a gay community for me. It is much more nebulous than I would have thought. I get referred to all the time as a mainstream gay man...I'm a member of the mainstream community. I don't buy it for a minute.... I'm in the minority. Most gay America is invisible, and they're quiet and they pay their taxes and they go to work and they want to be invisible.
>
> So I know I'm a part of that community somehow, somewhere. Except for my gender or my sexual orientation identity, I don't know how else, how I'm a part of that community....The caregiving community has a task and people from all walks of life come to that community. And in this epidemic, I think the caregiving community was initially grandmothers and mothers and gay men. That's who took care of people with AIDS. Hospitals didn't do it. The rest of the community didn't do it. Hospice workers wouldn't do it. Nursing homes wouldn't do it. It's really different now. There's all kinds of people who are giving now. They have a task. And their task is about, in different ways, about helping someone be comfortable and sort of live out whatever process they need to do for their life. And I think that's one of the things that's sort of different in caregiving from other communities, cause there's a job to do. It's not just how you dress or where you work or your orientation

> that defines the parameters of your community. It kind of cuts across all of that.

Chris expressed the understanding that, in fact, people have membership in many communities and communities serve common concerns in different ways. For Chris, community meant the chosen family--three men who had committed themselves to supporting one another in the traditional sense of family. It also meant the "AIDS community" made up of people who are actively working to curb the spread of the disease, find cures, and support those who have the disease. The gay community, for Chris, was a more nebulous entity, allowing his simultaneous awareness and confusion about where to find gay community and what it means. Additionally, community included a subgroup referred to as the "AIDS caregiving community"--made up initially of mothers, grandmothers and gay men who united around the job of caring for someone with AIDS.

Historically, in addition to grandmothers and mothers, people who were actively involved in gay organizations in major urban centers set into motion processes that would influence models of care for persons with AIDS. In the 1980's, community-based organizations that delivered direct services to persons dying with AIDS included the Gay Men's Health Crisis in New York City and the AIDS Foundation and the Shanti Project in San Francisco (Bayer & Kirp, 1994; Kobasa, 1990; Shilts, 1987).

The Shanti Project (Garfield & Spring, 1993) developed models of peer counselling and emotional support which were used to establish similar programs in Oregon. Shanti's philosophy of supporting the client's sense of control has served as a model for home care teams described in several narratives in this study.

Care Teams

Caregivers who had an established network of friends in the gay community were the ones most likely to organize home care teams. Terry, a gay activist and caregiver, was a key informant in this study in regards to the history, organization and functioning of home care teams. Terry drew upon his experiences in several care team situations and in gay activist organizations to describe the involvement of local gay communities in developing the concept and philosophy of home care teams.

> One of the things that has helped to propel care teams back into the imagination...is that they work....the gay community put them into effect. I think if the epidemic had occurred outside of an already marginalized group, we might not have seen the same effect....People would have drawn together around "death at this rate" in their natural group. And the natural group for a hugh number of homosexual people, the community with which they identify, is likely to be gay.
>
> What actually occurred in our case was that people all over the city began dying. Those of us who were in positions of leadership clearly understood this because of the number of associations that we tended to keep. I happened to be in one of the associations that had by far the largest number of volunteer hours involved....And we began having a couple of members, myself included, that sort of made it their interest to find out what in the hell is going on here.
>
> Some members formed the core of Cascade AIDS Project Services...which became a specific project called the PAL project...we were strictly into the Personal Active Listening project. Personal Active Listening project was peer counselling. Peer counselling rapidly came to include what we called practical support. And practical support evolved into teams.... A lot that was fundamental about Shanti and about Personal Active Listening has, I think, magnificently contributed to the concept of team around terminal illness....
>
> In this century we shipped people off to hospitals and I'm not saying that hospitals are bad, mind you, but I'm saying as human beings we became divorced from the death process and we hired people to take care of the burial and all that kind of stuff, and we just freak out about death as if it weren't a 100 percent certain part of life....Anyway I think what the Personal Active Listening, the Shanti part, really brought to us was returning control. The concept of returning control to the client at all times.

In this passage, Terry pointed to the influence of activist organizations such as The Shanti Project in reacquainting "the natural community" with caring for the dying and in fostering a philosophy of preserving control for persons with AIDS. Local gay activists groups adopted the concept of peer counselling with its emphasis on empowering the ill person. In some cases, peer counselling extended to practical support, which evolved further into the phenomenon of home care teams. Terry explained some of the fundamental values promoted by the people who formed care teams in the early days of the epidemic.

> We learned some very, very, very, very, very, very, very, very, very, very, very, very, very, very fundamental things. First of all, you cannot react to a human being like they're a patient and expect them to feel like you're being human with them. You're being medical with them...So there are some very basic concepts. Just the vocabulary alone of calling people clients, and really just kind of shuddering at the "patient" word all the time. It was all part of this returning control to the client. Returning control. Returning control. Striving to empower people, to be self-empowering...because they're engaged in a whole series of loss of controls. I mean the whole experience of AIDS is a grieving process....it's a long extended grieving process that is greatly aided by people who can in the course of their regular contract strive to empower this person in their life. That was actually the spin [put on it by the] family of choice not the family of origin....It had an effect on a person's health. It certainly has an effect on their well being. And the well being is what it's about. And the body's only part of the well being.

Terry suggested the community's concerns and efforts to deemphasize the medical approach to illness, humanize care, and promote individual empowerment and control. Issues of dignity, loss and control are apparent in the narratives of all of the caregivers in this study and are dealt with again in Chapter 6. Returning control was a practice suggested by all five of the caregivers who chose to organize care teams. Beyond the context of care teams, control, as discussed in Chapter 6, was a significant concern for all caregivers in this study. The strong emphasis on issues of control may relate to dominant Western cultural background meanings of the self. In contemporary American cultural, the adult self is understood as an autonomous, freely choosing, independent being. Extreme dependence is interpreted as extreme vulnerability and has the de-worlding effect, as stated by one caregiver, of "losing one's life before one dies."

The care team model typically involved the coordination of several team members to provide care around the clock; care team members enabled the ill person to remain in his own home and allowed the primary caregiver periods of needed respite. In this sample, the emergence of care teams typically occurred in the context of connection with the gay community. However, care teams did not emerge in all caring situations involving gay men in urban settings. Though connection with the gay community may be an essential factor in the emergence of care teams, it was not a sufficient one.

Other background circumstances were needed for care teams to become possible in particular caring situations. These included, first, willingness on the part of the person cared for to accept and adapt to a group care model, and second, care team members who had the shared values of commitment, responsibility, and respect for the ill person.

The ill person may initially be an active member of his own care team. In describing features of the care team for his friend Dewey, Terry talked about the role assumed by Dewey as a member of the team.

> Dewey participated in the whole thing right from the beginning. He participated, he understood the concept, he talked about the possibility. He

> wasn't like precommitted; he'd never done it. Dewey himself had never participated on a care team. He never took the PAL training. So it was a very personal choice that he made. He decided who would participate. He spoke to them in advance. He participated directly. He was present for most team meetings. Until he lost his speech, he explained to people how something got done. He was a wonderful human being to assist. He didn't like any more assistance than necessary. And he really appreciated the assistance that he was given.

Roy, another primary caregiver, described the involvement of his ill partner, Doug, in the selection of care team members.

> They were kind of hand picked. Doug had a lot to do with that. It was "Who are you comfortable with? Who do you want doing what?" By that time, I really learned, you give Doug as much control as he can handle. I wanted him to be able to feel he is calling as many of the shots as possible. And he agreed that I'd be the chief, I'd kind of control it. But he could designate who we want. And we tried a few people out and then he'd tell me after that fact, "You know, I just don't care for this person or that person or whatever." So we kind of had to keep juggling that and feeling it out and talking about it constantly.

Here Roy pointed out that Doug was at the center of decisions to select care team members. Though care team members may already have been in a preexisting network of friends and relatives, not every person was seen as suitable for the role. Roy also explained that some members of the team were there for personal caregiving, while others were there for emotional support. Care team members were described by primary caregivers as people who have "care" and "willingness" as their first concerns. They shared values of commitment and responsibility. Their caring practices were informed by an underlying philosophy that respected the particularity of the ill person and that aimed at preserving control and dignity for the person with AIDS.

Care team members were not restricted to gay friends or the family of choice, but included other friends and biological family members. In situations described by caregivers in this study, care team members included sisters, mothers, fathers, and nieces as fully functioning care team members. In this sample, five situations were characterized by involved, highly committed and well-organized care teams. In some situations, the care team resembled a highly organized, well-functioning health care organization with an appointed administrator, variously skilled workers, schedules, records for documenting treatments and responses, between-shift reports, department meetings and inservices.

Having participated in several care teams, Terry was able to describe in detail the elements needed to make a care team successful. Roles and strategies identified included the administrator, the client, the team member, team meetings, outside support groups, the use of journals and logs, and other communication techniques such as debriefings, a communication board or keeping in touch by phone.

A product of the present study is insight into the contextual factors affecting caring practices and knowledge about exemplary ways of human caring embedded in overlooked communities of care and concern. There is a call here for serious social consideration of the caring practices emerging within gay communities that are coping with the human suffering brought on by AIDS. The phenomenon of home care teams is a most dramatic and powerful example of human caring occurring within this community. It is a potent corrective to the prejudiced view of persons with AIDS, particularly gay men, as either helpless victims or hated pariahs. The practical knowledge contained within the community has the potential to provide a model of care for a diverse range of human conditions.

Rural Communities

Four caregiving situations in this study took place in rural settings. These situations were notable for caregiver's general lack of a sense of community in caring for the person with AIDS. In contrast to the urban gay men who looked to the gay community, AIDS service organizations, or care teams for help, rural caregivers in this study reflected to varying degrees the experience of caregiving in isolation. Three of these caregivers were women; one was a gay man who described a life pattern of being a "loner."

In one rural setting, an in-patient AIDS hospice had been established and was used by one caregiver in this study to manage his partner's terminal care. In this rural community, gays and others affected by HIV formed an "underground" network that operated quietly but not openly to support families and persons with AIDS.

Theresa, a woman who cared for JR, a gay man, described a similar situation in her own rural community:

> We have a contact at the hospital and whenever there's a new guy, or a girl, or whatever, a new patient that is admitted to the medical floor, she gets on the wires and says "Hey, we've got a new one, we need some support." When she says "we've got a new one" she's says "our community." She's referring to our community which is all of the staff, volunteers, friends, clients and family of the AIDS care home. We classify us all as a community....And when she calls us and lets us know, she says "We've got a new one." She's saying "all of us." It's all of our responsibility to make sure that person knows that they are loved, they are not alone and that we are there for them....Because in turn, they will be there for us. It's a very, very important issue and policy that needs to be kept up because of the type of disease that this is. This is a very lonely disease. It is the loneliest thing that I've ever ran across in my life and I'm very grateful for our community.

Through the anonymous contact at the hospital, Theresa and JR were put in touch with the local underground network of AIDS supporters. The network provided a used refrigerator for JR's house, and from time to time they brought food to the home. Theresa found one close support through the network; however, her story was largely one of an isolated caregiver. She cared for a difficult person who was affected by dementia and who was alienated from most of his family and friends.

For caregivers in other rural settings, nondisclosure and concealment of the caregiving situation was a major concern. Norma's story, related earlier in this chapter, attested to the isolation brought on by concealing the disease. Effort was expended in guarding the family secret, and many hours were spent driving to an urban center for doctor visits or hospital care. Though communities of care may exist in rural settings, they are more difficult to access and generally provide fewer resources for caregivers.

Summary

In this chapter, I have looked at aspects of the cultural contexts of caring for a person with AIDS. Narrative data were used to support the thesis that caregivers are situated in both local communities and larger cultural contexts that bring meaning to the caregiving situation and that create or limit possibilities of care. In some cases, the negative social metaphors of AIDS brought meanings of shame, taint, and deviancy to the family's effort to care for a member with AIDS. Within this same cultural milieu, smaller communities of care expressed prosocial responses such as the organization of AIDS support groups and AIDS hospices, which provide possibilities of safety and respite for caregivers and ill persons. Local gay communities have developed practical knowledge and created powerful models of care in practices connected with home care teams. In other instances, most notably in the rural settings referred to in this sample, communities have largely failed to create supportive contexts of care. In the next chapter, I turn to the family--a more private realm of caregiving, which was both context and concern for caregivers in this study.

CHAPTER 5

FAMILY AS CONTEXT AND CONCERN

In this chapter, family is described as both a context of care and a dominant concern of primary caregivers. Narrative data and interpretive commentary are used to support the claim that caring practices are affected by and carried out within a complex family context. Family as context means that caring is worked out within the traditions, relationships, and everyday practices of a particular family. Family as a concern implies that family is a focus of concern for many primary caregivers. Illness and caregiving affect ways in which families function, altering established relationships and everyday ways of living.

Family is defined broadly to include members of the family of origin, married couples and children in the family of procreation, and partners and friends in the family of choice. The sample included caregiving situations from all of these types of family structures. I interviewed sisters, a mother, wives, gay men who cared for their partners, and both men and women who cared for a friend with AIDS. In most situations, the ill person was cared for by a partner or friend from the family of choice. In five situations, the caregiver was from the family of origin.

In the following sections, I consider caregivers' concerns related to interactions between the family of choice and the family of origin. Some caregiving situations involved care teams with members from both the family of choice and the family of origin. The care teams in this sample were described as functioning well, with ongoing practical support and emotional exchange between the primary caregiver and other family members.

Concerns about conflict within families were described by many but not all of the caregivers in this study. Conflicts between siblings or intergenerational conflicts between wives and mothers were evident in some situations. Several caregivers experienced anger in relation to family conflict; and, in some cases, anger was directed at the ill person. Other caregivers described concerns about the ill person's emotional distancing from the family of origin. Caregivers also expressed concerns relating to the effects of AIDS caregiving on children in the family. In addition to concerns about conflict, emotional cut off, or the effects on children, I will include here a brief consideration of caregivers who could be considered "disenfranchised." These caregivers were friends to the person with AIDS and did not fit traditional definitions of "family." Being neither committed partners nor married spouses, they had needs that were not socially legitimized, and they tended to carry out the work of caregiving in relative isolation.

Families of Choice and Families of Origin

Analysis of the narratives in this study revealed at least five characteristic ways in which family could be seen as both a context of care and a concern for primary caregivers. Both the families of choice and the families of origin were involved in these patterns of context and concern.

In all but three situations, the person with AIDS was a gay man; most were survived by parents and siblings who wanted to become involved in their care. Sharing the role and responsibilities of caregiving with a mother, sister, or father-in-law was a concern for some primary caregivers. In some situations, parents became emotionally closer to a gay son who was ill, while in other families parents remained emotionally and geographically distant, continuing an established pattern of silence and alienation.

The characteristic ways in which family emerged as context or as concern are described and labeled here as: 1) involved families, 2) estranged families, 3) the reconciled family, 4) families in conflict and 5) families with young children. Concerns of caregivers who described highly involved, well-functioning families will be considered first.

Involved Families

In this sample, involved families were characterized by strong bonds and good communication, an acceptance of homosexuality, avoidance of competition among family members for privileges related to caregiving, and an understanding of one another's needs. Fred, a participant who cared for his partner Paul, told a story of close involvement between the family of origin and the family of choice. Fred described several factors characterizing the involvement of both families.

Paul had been one of six children growing up in a family that moved frequently each time their father, a minister, was transferred to a new church. Their frequent relocations made the family a close-knit group. After the children were grown, Paul's father came out as a gay man, establishing a family precedent and history for dealing openly with issues of homosexuality. Paul maintained a close relationship with his parents, particularly with his mother, and his other siblings.

Paul and Fred met in 1979. They communicated well, made a commitment to one another, and maintained a long-term relationship of 14 years. During that time, Fred was accepted into Paul's family and regarded as another son.

In their own community, Paul and Fred were outgoing and actively built a large network of friends. When Paul became ill, these friends readily contributed to his care. As illness progressed, Paul and Fred organized a care team which involved friends from the gay community and member's of Paul's biological family. Fred explained the involvement of these family members in the following excerpt.

> At one point Paul had to make a decision about whether he wanted to die here or whether or not he wanted to die back there [with his family]. His mother wrote this incredibly beautiful letter...saying we really want you to come back here to die. Initially he decided to do that, but then he decided to stay here. All of them came out at various times. When he died his two sisters were both here. And his three brothers had visited probably 6 weeks before he died. So that was a really hard decision for everyone involved.
>
> I think I was really lucky and I think Paul was really lucky too. I think a lot of people I know, especially gay men or lesbians, deal with the family here and the family of origin getting into competition. It was really important to me that that did not happen, and it was also very important to his family. I've felt like a son in their family and they've been very welcoming to me.

The cooperation and involvement Fred described was made possible by the shared value of making sure that the chosen family and the family of origin did not get into competition with one another. Fred understood the importance of this stance from his exposure to others in the gay community who experienced the conflicting and competing interests of the family of choice and the family or origin. After Paul made the choice to stay in his community rather than go home to die, his sister Judy moved nearby to participate in his care. This presented challenges to both Fred and Paul and they dealt with competing feelings of wanting their privacy yet needing family support.

> Judy...really wanted to come down but...We were really struggling, as Paul was getting sicker, with losing control of our privacy. Just losing control left and right.
>
> Judy became sort of a touch point for me and I think even more so for Paul. [This was] just another symbol of our lives being upset. "Now Judy is going tc come in and just take over." I love Judy...You can talk to Judy which I really like, because what I learned to do was to be <u>very</u> up front about what I needed. When something upset me I learned to be very clear. "Hey, Fred, you gotta deal with it. You can't let this stuff fester. You can't cover something up. You need to put it out. You don't need to blame somebody, but you do need to deal with it." Once I accepted that Judy was going to be with us, I just said, "OK if you're going to be with us, this is what we need." And Paul also did that.
>
> We actually had a sort of real knock down, drag out fight in June which was wonderful because it just cleared the board....The other thing we got clear about was that we got clear about Judy--what Judy needed. Judy needed to feel like she was helpful. She needed to have a connection with her brother. She needed to deal with the whole powerlessness she felt. And there's a whole another dynamic that I only began to realize after Paul had died. That is, what it's like to have a relative die across the country....People tell me that you just feel totally helpless. I mean there's such strong social expectations of what families are supposed to do for someone in their family. People make comments like "What are you doing here? Why aren't you there helping?"
>
> Judy...represented everybody in the family being here. She actually moved here. She got an apartment here....She was here three days a week and she gave me a break. Basically like Tuesday and Wednesday, and I took those days and just got out of here. And I needed that. I really needed that.

In this narrative, Fred draws a picture of a family that had created strong bonds. There was a history of familiarity with and acceptance of homosexuality. Fred was regarded as a son in Paul's family. As Paul became ill, members of the family of origin were affected by their sense of helplessness and by the cultural imperative that expects family members to care for one another. Despite the geographical distancing that affects many, if not most families, family members are supposed to be present and give care to one another in times of need. Judy helped to fulfill this cultural demand by "representing everybody" with her presence and participation in caregiving.

Involvement in this paradigm case was characterized by the family members' skilled ability to communicate about their respective situations. Though conflict occurred, even in the form of "a real knock-down, drag-out fight," it occurred in a way that opened up communication and brought members into closer contact. Judy was a person "you can talk to" and both Fred and Paul placed a value on dealing with issues, "being up front," "not covering up," and "not letting things fester." Conflict was allowed to serve the useful purpose of "clearing the board." Thus, conflict was not missing but rather was dealt with skillfully.

Family members reached an understanding and acceptance that there are needs on all sides. Fred and Paul learned to express their own needs, but they also gained awareness and accepted Judy's need to have connection, to be with Paul and to deal in a representative way with the family's sense of helplessness.

In summary, Fred's narrative presented a paradigm case of care in the context of an involved family. The family was characterized by a history of close bonds, familiarity and comfort with issues of homosexuality, open and direct communication, and awareness and acceptance of each other's needs. Cooperation and positive emotional exchange were familiar practices. In contrast to this picture, the following section presents a situation in which the family of choice and the family of origin did not find ways to overcome a history of distancing and emotional cutoff.

Estranged Families

Estranged families were characterized by the absence of meaningful connection among family members. Typically, in the family of origin, there was a history of intolerance to homosexuality. Jared's story illustrates a family context in which the family of origin had maintained a long history of emotional separation from their gay son Dennis. Jared was the caregiver for Dennis, his partner of 11 and a half years. In the following text, Jared described the dynamics of a family visit which turned into a devastating experience for Dennis two weeks before he died.

> Dennis, because of his estrangement with his family,...had not agenda about their coming. [He had] not really been terribly close and communication had always been difficult and his folks [were] very awkward in their communication and emotional skills...And I did not have the type of relationship and it was not my agenda to see that they came. I sort of knew that we would be doing a certain amount of taking care of them; they were not going to jump in and be aiding to us.
>
> They came the first weekend of December. We had snow in the passes. It was a cold time...His parents, at that time, were just passing their mid '70's. They will not fly; they will not take a train; they will not use public accommodations for the most part. So his sister flew out and drove up with his folks; it's a 2,000 mile drive. They were planning to get here on a Friday and stay through that weekend, but because of the storm his folks were very concerned about being able to get back over the passes.
>
> When we would ask Dennis, we would ask, "Do you want your folks to come?" He had no need for them to come. He felt he had closure. He felt that there was nothing that he needed to say to them. So the decision to have his folks come was not driven by his need. It was really...for their benefit.... By the time they came to visit, his communication had deteriorated; his speaking was very restricted at that point. His folks came. We did a family dinner and I felt very good about that.
>
> We thought they were going to be there through the weekend. But the next morning his folks arrived to say that they were there to say their final

> farewells. They were leaving because they were worried about snow in the passes.... That was devastating; his folks being there was really a devastating event, because it was a validation and complete demonstration of how dysfunctional they were and how much they couldn't cope with it.
>
> And he let go immediately thereafter. It was much more emotionally painful for him than he realized or I think we realized.... These folks [weren't] there for him. And I would say that onset preceded the next two weeks of his just shutting down and letting go.
>
> We were sort of shell shocked...by the experience because we couldn't fathom that worrying about getting over the mountain passes was more important than their son is dying and you're never going to see him again. It was very clear that it was just emotionally took a significant toll and I think we both just saw an emotional shutting down. I would say that preceded a very rapid deterioration.

We see this situation through Jared's eyes and therefore with the meaning the situation held for him. Jared described a context where the family of choice and the family of origin had established long-term patterns of distance, awkward communication, and avoidance. Neither Jared nor Dennis felt a need to have the parents visit before Dennis died; but they supported the idea for the parents' benefit.

Here, there is a suggestion of responding to another culturally embedded imperative to "set things right" or "take care of unfinished business" before death. Jared recognized a possibility that the parents might need "to have closure" with their son. Though realizing the visit would mean a certain amount of taking care of the parents, Jared was willing to accept added work to allow the family time and space to have closure.

The visit, however, came as a painful reminder of a long history of emotional cutoff and alienation between this son and his parents. For Jared, cutting the visit short confirmed his understanding of a background of a family where parents had cut a son out of their lives. The act of placing concern for travel over concerns for a son who was dying was confirmation of Dennis' long-term experience of repudiation. Unlike so many other family stories of concern about "being present," "being there," or "being with," this was a story of turning away, a story that conveyed and confirmed the long-felt sense of being forsaken. As recounted by Jared, it is a story of lost care and concern. In this case, closing the geographical distance between parents and their son could not close the emotional one.

Jared perceived Dennis as understanding the meanings of this visit as "validating how dysfunctional they were and how they couldn't cope with it."

For Jared, as well as for Dennis, the visit was an experience bereft of connection, comfort, or care, a devastating event that had a wounding effect for everyone, but especially for Dennis. According to Jared, Dennis began to shut down and withdraw after the visit. I asked Jared if he had regrets about this incident.

> No. No. It was very important for their closure. I mean I think that was important. I think we were just dumbfounded by the events. Do I regret it? No. Would he have been better off without it? Probably not. I still think you know, even though it was painful, it allowed a closure with family that...would not have happened.

Though painful, providing a time and space for the parents to have closure with their son was for Jared a correct action which he did not regret, despite the emotional withdrawal that it appeared to cause for Dennis.

Here, then, family is both a context of care, an object of care and an arena of concern for caregivers.

A second story of alienation between a son and his parents was related by Seth and Matt, two gay men who took care of Jerry, their 31-year-old friend. Seth, Matt, and Jerry had been friends for many years and had participated in the care of Jerry's partner, Frank, who died from AIDS. At the time of Frank's death, Seth and Matt made a promise to look after Jerry. Both Seth and Matt spoke about their frustrations in dealing with Jerry's parents during caregiving. The following is a summary of their conversation.

> His parents were within forty-five minutes and they never came to see him...never once. They were supposed to come to say goodbye before we were leaving to come up here. They made excuses for two days in a row. We brought a big trailer down to help him move his stuff. And he was real anxious for us to meet his parents. But they just called up and said we'd better take care of him. His mother said, "We have a lot of animals and we have to take care of the animals today." Things like that. Then after he died she was the first on the phone wondering if there was any money or things for her...He said we were his chosen family and that was more important than his real family. We were shocked. Disgusted. I think they're despicable. We had a few words afterwards, but it ended up amiably because it was kind of pointless not to. For Jerry's sake; it wasn't worth it. They got kind of demanding about what possessions Jerry may have brought up here that they could have and that sort of thing. There wasn't anything to begin with. And the fact that they spent more energy wondering about his television set than they did about him. That's just the way they were and they're going to have to live with that. You realize they are who and what they are and that's the way they're going to be. I just felt bad for Jerry. Just to see him so disappointed. He was really disappointed that they didn't come and visit him.

Seth and Matt told another story of a son cast out of his parents' concern. As the family of choice, Seth and Matt witnessed Jerry's disappointment when his parents refused to see him. Yet they did not cut off communication with the family entirely; they made a tentative peace with Jerry's mother because open conflict "wasn't worth it." Emotional cut off and hurt related to the family of origin became a caregiving concern that Seth and Matt could do little to change. Like Jared in the previous example, they were only able to keep open some minimal means of contact between parents and son.

The meanings of the chosen family in the context of gay community was explained somewhat by Seth during the interview. As Seth maintained, family does not necessarily mean involvement with parents or siblings. A sense of family is built from a community of people who extend concern to one another and who show through caring practices that members of the family matter. As Seth explained:

> Jerry was part of our extended family...Family is a group of people who satisfy each other's needs to whatever definition they particularly want to bestow on it. [It is] as extended as they perhaps want to extend it. Even with blood relatives, your family and your extended family isn't that concrete. It isn't always your mother, your parents, your brother, your sister. There are some people who are much closer to their cousins or their uncles. So there's really no definition as to when it becomes direct [family] or when it becomes extended or whatever. But it's basically, especially in the gay community, it's that group of people who find a cohesiveness to satisfy what ever needs [there are]. Not only sexual needs but social needs, emotional needs. And it can be whatever gender, whatever age, whatever amount of people are necessary. It's communal.

In situations of estrangement, when needs for care and concern are unmet, one may cope with loss of connection by reconstructing family. Family is reconstructed by people who come together to satisfy one another's most basic needs.

In this study, estrangement between the family of origin and the family of choice was characterized by communication that was awkward or closed down, by rejection of homosexuality, and by the shutting down of concern. The cultural imperatives for families to sustain care and concern were broken down in these situations and caregivers had few possibilities to change long-standing patterns of disconnection. The stories of estrangement in families were disheartening because they were marked by a lack of concern--a void or sense of absence that in many cases could not be overcome.

In some cases, there are opportunities for reconciliation as revealed in the narratives that follow. Estranged families can sometimes be healed by AIDS in the sense that life-threatening illness forces members of the family to overcome their past histories.

The Reconciled Family

The following section presents a story of reconciliation between a mother and son. Estrangement and the practice of avoiding difficult family issues were overcome.

Jeff is a 42-year-old gay man who cared for Chip, his partner of 5 years. Chip was the son of an American father and Russion emigrant mother who had never acknowledge that their son was gay. Jeff described Chip as a man who characteristically coped with stress through emotional withdrawal--often withdrawing in a literal sense by shutting himself in his room for long periods of time. Though he had developed Kaposi's sarcoma lesions on his legs, Chip resisted medical care or HIV antibody testing for several years. When these issues could no longer be hidden or avoided, he finally confronted the dual ordeals of telling his parents that he was gay and that he had AIDS. As Jeff stated, Chip's response was one of worry and fear: "What happens if I get sick? My parents don't even know. I've never even told them forthright that I'm gay. How are they gonna react?"

Unlike Chip, Jeff was orphaned at an early age and was raised in foster homes. He had never known his biological parents. His narrative suggests the special meaning that family holds for him and the efforts he made to reconcile Chip with his parents.

> Chip's mother was a Russian immigrant. She came over from Russia when she was 14. Basic family religious background. She was very structured and Chip was not. So he broke her mold I guess. And it was never spoken of that their son was gay. I had been playing social worker for several years there. Chip was pretty estranged from his mother for quite a long time. His father and he had a great relationship. Early on he lamented the fact that he'd kinda wanted to be closer to his parents but didn't know how. So I kind of initiated it saying "You don't know how fortunate you are that you have a family. I have none. I was raised in orphanages." ...So I would read him my riot acts and he'd say, "Well, well I've tried." So, "Well, let's try different things."

Jeff was accepted and well liked by Chip's parents and, despite a difficult relationship between Chip and his mother, Jeff encouraged Chip to keep communication open with his family. Jeff described how caring for Chip extended to caring about Chip's family.

> It took a lot of work by me on the phone. I was on the phone with his mom and dad, back and forth. And we finally got Lyla, Chip's mom, over the fact, because she would to go into this "sin of homosexuality" thing. And I said, "Lyla, it doesn't matter. You have a sick son. That has to be the issue now. It's time you two did get together and talk." Because, while they both wanted to get together and talk, they were both out here somewhere (spreading his arms apart) going through all of the wrong motions to get to the center. ...She refused to come to the hospital for about 4 days. So during that four day period I was doing the back and forth stuff. The intervention stuff. The family counselling.

Jeff's story is one of working to change a past history of estrangement between Chip and his mother. Part of his caregiving was to open up the relational system in the family through doing "the family counselling." Chip's parents, who were in their 70's, responded to these efforts, turned toward their son, and eventually became actively involved with Chip's care team. As Jeff stated, "It evolved and the four of us became really, really close."

Jeff's story of reconciliation was unique in these narratives, though other caregivers commented that AIDS "brought the family closer together." Reconciliation was made possible by talking openly, putting the issues of homosexuality on the back burner, accepting a gay partner, and working to sort through the overriding and cementing values of care and concern for an ill member.

Families in Conflict

Conflict in families is inevitable. Examples of conflict were evident in all of the stories of family care. However, conflict was deeper and more divisive for some families than it was for others. This latter type of conflict was associated with several factors. In some families, caregiving was preceded by a past history of rivalry among family members--for example, rivalry among siblings or competition between in-laws. Additionally, patterns of family communication may have been marked by certain prohibitions. It may have been taboo, for example, to express anger, to address differences or air disagreements within the family. Secret keeping was not uncommon. There were also different levels of understanding about AIDS or different conceptions about good caregiving. Limited physical space often exacerbated conflict. During caregiving, old conflicts may resurface taking on different forms in the arena of caregiving or new conflicts may arise, especially when the dying person can no longer participate in their own care (Sankar, 1991)

Conflict can be precipitated when family roles shift as occurs with the progressive deterioration of the ill person. Caregiving can create a new intimacy and a sense of exclusivity in the relationship between the caregiver and the ill person, leaving other family members on the outside (Sankar, 1993).

Jeannette, a 52-year-old mother who cared for her youngest son Brian, provided a paradigm case of caregiving in the midst of family conflict. Jeannette's large family included four boys and an adopted step-daughter. Jeannette was a single parent during much of Brian's youth, which helped create a special bond between them. With her older children gone from home, Jeannette regarded Brian as her roommate and best friend. At age 15, Brian came out to his mother as gay. He went through a tumultuous adolescence, eventually dropping out of high school and running away from home. He went to the big city "to meet gay people" and hang out at bars. While Brian's mother was an accepting and steady presence in his life, two of his brothers rejected Brian's life style and tormented him for being gay.

Suspecting that he was infected with HIV from the early years of the epidemic, Brian developed suspicious "bruises" on his legs but refused testing and delayed medical attention for several years. He experienced bouts with thrush, shingles, diarrhea and weight loss during the intervening years. When Brian commences on a final downhill course, he was dependent upon his mother for care.

Jeannette's care for her son progressed from emotional support during the early phases of disease to intense involvement with day-to-day technical and intimate care during the terminal stage of illness. Brian progressed from numbness and weakness in his extremities to near total paralysis. Expressing the need to be as close as possible to her son during the terminal phase of his illness, Jeannette eventually moved into his room and slept on the floor near Brian's bed.

The conflict in Jeannette's story pertained mainly to dissention between Jeannette and Brian's oldest brother, Eric. Jeannette described a past history of conflict between the two brothers, which typically centered on the issue of Brian's homosexual lifestyle. As caregiving became more demanding on Jeannette, the brothers became involved with Brian's care. Though Eric chose to participate in Brian's care, Jeannette grew concerned about the older brother's insensitivity to Brian's needs. In the following passage, Jeannette describes a trip to the hospital. Eric is presented as the brother who just "didn't have it in him to be a caregiver."

> Eric went with us to the hospital....We were very gentle with Brian. We would let him do as much as he wanted to do at that point. When we would get him into the wheelchair, [we would] at least give him half-way pretense [of being able to move himself]. I mean, let him have some dignity that he was getting into the wheelchair by holding on to us....I couldn't get him to the doctor by myself, it was getting so bad so fast. Eric picked him up and twirled him around and put him in the wheelchair like he's a big macho guy. Kevin and I didn't say anything, but when Eric did that, twirled him around like he was dancing with him and puts him in the wheelchair, Kevin and I are like "Oh my god." It's just like Eric really didn't know what to do. He doesn't have it in him to be a caregiver.

Eric's failure to respond to Brian's vulnerability and need for dignity was repeated many times over the course of Brian's illness. Jeannette described instances when Eric was abrasive, talked loudly and inappropriately, practicing karate kicks and maneuvers in Brian's room, bumping the bed and generally ignoring Brian's need for a peaceful space. Physical space for caregiving, in this family, as in others was at a premium. Eric also demonstrated his discomfort when touching someone with AIDS.

> Eric was afraid to touch Brian. He was afraid of getting AIDS. When Brian vomited, Eric was afraid there was blood in it, and he touched some of the

> vomit and he's probably to this day worried that he has AIDS because of that. When we were turning Brian, he stayed really far away. Then once Brian asked for something to drink when we were at the hospital making arrangements for the surgery. Eric went in and opened up the 7-up and he held it for Brian and kind of steadied it while Brian was drinking....Eric went like this to Brian's lip (brushes lip lightly) and he went over to the sink and scrubbed his hands. Brian and I were watching him do that. It just crushed me. I was thinking, "Oh, poor Brian."

AIDS introduced issues of threat, infectivity, and the element of the unknown into the family dynamic. Family members, like Eric, may be uncomfortable touching a person with AIDS because of fear that not all is known about how the disease is transmitted. These family members may need information or may need an acceptable way of expressing their fears or hesitancy. Jeannette was dismayed by Eric's self-protective behaviors. Yet Eric appeared to have no avenue in the family for voicing his discomfort or working through his fears. Communication about conflict was never open. Jeannette saw herself as the person in the middle and largely suppressed her feelings of anger toward Eric in the interests of trying to make everybody happy; in Jeannette's perception, however, Eric continued to make a traumatic experience even worse.

Jeannette's story suggested a background of family relationships that may have set the stage for more overt forms of conflict during the stress of intense caregiving. Over the years, Jeannette and Brian had developed a special bond fostered by several circumstances. Brian was the youngest child, the only child who lived with his mother after his parents divorces, the child who was taunted by his older siblings, and the child who was HIV positive and progressively ill. Brian and his mother became best friends and travelling companions who took camping trips and cross country journeys together. They kept secrets from other family members. Jeannette kept secrets about Brian's lovers and later kept the secret that he was HIV positive. Over time, these dynamics may have continued as patterns of unresolved rivalry or sibling competition which was exacerbated by Brian's terminal illness. Brian himself anticipated that their closeness would result in jealousy and would cause a separation between Jeannette and her other children.

Conflict in the family has consequences for all family members and particularly for caregivers and for persons who are ill. Like Brian, the ill person may have concerns about "what was going to happen with his family" after he dies. Letting go may be more difficult (Sankar, 1991). Anger, hostility and resentment drain energy from the primary caregiver, who is already physically and emotionally stressed by caregiving. Feelings of frustration and suppressed anger divert attention from caregiving goals, and conflicted relationships may make it difficult for the primary caregiver to obtain help in giving care. When conflict and tension persist, maintaining a calm and peaceful caring space is no longer possible. Unresolved conflict may extend into the bereavement period and lead to the eventual estrangement of family members. In this situation, Jeannette stated that Eric eventually "alienated himself" from the rest of the family. Loss of contact may have made bereavement for this family more difficult.

Sankar (1991) remarked that in caring for the dying person some of the most divisive conflicts are disagreements among family members over the way care is provided. Conflict may cause emotional or even physical problems for the dying person. A calm environment, both in the physical and psychological sense, "helps the dying person tolerate pain and gives him or her the satisfaction of leaving a family at peace rather than in conflict" (Sankar, 1991).

When the ill person is cared for at home, families may find no neutral spaces or impartial structures for imposing a system for dealing with conflict (Sankar, 1991). Family members, for example, may have tacit territorial claims on living space that are disturbed by caregiving and by having members of the extended family in the home. Everyday practices may easily collide when family members move together to care for a person with AIDS. A special closeness can develop between a caregiver and an ill person that can set up conflicts with others who may feel they have been excluded or usurped.

These elements were present in another story of conflict told by Laurie, who cared for her husband Kiko with the help of her mother-in-law, Antonia. Kiko, who was born in Mexico, brought his mother and father to the United States to live with his family during the last six months of his life. Laurie, Kiko, their three children, Antonia, and Mario, the father, lived together in the household while caring for Kiko during his last six months. Laurie described conflict with Kiko's parents as the most difficult part of her experience.

> I would say the hardest part was dealing with having his folks here on top of this hellish winter we'd had....We had often wanted to have them come up, or he wanted his mom to be able to come up here. I think he saw it as a last chance to do something special for his folks. To get them to the United States. And I think he wanted them here in case he did die. Wanted them here in the last days. He also wanted her here because he said, "Laurie, you're gonna get tired, and then what?" You know, "You're gonna get tired of looking after me."

Having Antonia and Mario in the home was stressful for Laurie, who like Jared, experienced the presence of the parents as added work. Antonia and Mario were like "fish out of water," in a foreign land, unfamiliar with an American household, and separated from their large family in Mexico. As Laurie stated, "It was like taking them under your wing and teaching them everything. And taking them everywhere."

Laurie's narrative suggested an undercurrent of suspicion and mistrust between family members. During the summer months, Kiko began to improve. Laurie guessed that Kiko's parents silently took credit for his turn toward the better and suspected that she was doing something "to make him get sick." Issues of mistrust were fueled by cultural differences in understanding disease and in responding to illness. Laurie, for example, had little patience with Antonia's responses to Kiko's minor complaints.

> P: He would be pretty perky in the morning and then he might get a head ache. And she'd be bustling over him. I refused to go into crisis mode for something like that, after what I'd been through, that was nothing. She would be worried and giving him massages and saying, "Oh I gotta do this for you, and I gotta get this herb for you, you need this tea and you need that." And squashing his head. This is something they did all the time. In fact, Frankie saw it so much this summer that now...if he bonks his head or if he gets scared, he asks me "Momma, squish my head." ...They figure that when you get scared, or if you...have a big, bad headache, then it's because the sutures in your skull have kind of separated. So you have to have them re-squashed together....I'm not sure, exactly, the whole reason for this, but I have a feeling it has something to do with evil spirits getting in there and messing up your brain and whatever.
>
> L: So that's susto?
>
> P: Susto. Right. Esta estustado....And just that kind of buss-i-ly boob-i-tee, cooking him everything under the sun.

Though living in the same household, Laurie and Antonia were "world's apart" in their experiences, their understanding of AIDS, and their responses to Kiko's illness. Laurie quickly soured on Antonia's frantic attentions to Kiko and soon felt "invaded" and "cabin feverish," as if her house were no longer her own. Antonia, finding a territory that she could lay claim to, took over the duties of the kitchen and attended to Kiko's meals.

> He couldn't handle certain foods...What his mind could tolerate as being tasty was narrowing and narrowing and narrowing so much. He just couldn't handle a lot of things....I kind a just let it go. I let her take over [the food] part. That was something that she felt comfortable with, that was important to her to be always be feeding and feeding him. That was her way of dealing with her stress and her idea of curing him was the food. And that was fine with me. I was sick of dealing with it....It was a relief for awhile. And then it was like, "OK I'll tolerate it. At least she's doing that, and I don't have to do it for him." But it wasn't a situation that I was grateful for, because after a while, he didn't want to eat, and yet she was forcing him to.

Here, the conflicts between wife and mother-in-law center on the caregiving concerns of finding the right food, getting the ill person to eat, and allowing the ill person their own autonomy in the matter. Though she "tolerated it," Laurie perceived Antonia as forcing her way and Kiko as acquiescing in order to please his mother.

> He would eat because he wanted to please her. He wanted to let her feel satisfied and fulfilled in that she could get that down him. Cause I talked to him when she wasn't around and I'd say, "Kiko, if you don't want to eat it, you don't have to eat it. Why do you let her do this to you?" And he said,"I don't want to eat it but she needs me too and I want to do it for her."...I think too he was starting to regress like a little child and he would fall into that obedience thing. "OK, Mama. OK, Mama." Especially near the end.

Laurie is usurped from her position in the kitchen and to some extent from her position as wife and primary caregiver. Under the sway of the mother's will, Laurie perceives that Kiko was regressing toward more childlike ways. In contrast, Laurie valued keeping Kiko in control of his life as much as possible; this meant Kiko should eat only when and what he wanted to eat. But this value was not shared by Antonia, and as Kiko weakened he was no longer in charge. Antonia forced him to eat when he didn't want to. Though confrontation was not a family style, the issue of food eventually resulted in an argument with Laurie telling her mother-in-law to "back off."

> The Sunday before he died, he was sitting up there and he was most obviously spacing out. We'd been spoon feeding him for quite a while, like around two weeks or so....She was trying to get him to eat once again, like a hard roll soaked in avena, and he didn't want it and he voiced that. And he voiced it again, and he voiced it again. I hadn't gotten any sleep these last weeks either. So I just told her "Leave him alone!" I wasn't gonna be diplomatic or anything. I said, "Leave him alone! Let him make his own decisions." She just kind of muttered to herself and kind of gave up after awhile....She backed off because I told her to back off.

As Kiko grew sicker, conflict between Laurie and her mother-in-law escalated. Antonia stated that she wanted to take Kiko back to Mexico where she could care for him, implying as Laurie stated, that he would be better off under his mother's care.

> She was voicing what I realized and knew in my heart that she was thinking all along. That I couldn't take care of him and that she could do so much better. She wasn't to the point where she could appreciate what I had been doing, cause she hadn't lived through it. And now he was slipping away and she couldn't understand it and she didn't want to understand it....I remember going into my room and going, "Please God, please do not let me annihilate this woman. Don't let me annihilate her."

In this situation, conflict took the form of competition between caregivers--a mother believing that she could do better than the wife and vying to be in control of caregiving. Antonia had great difficulty accepting the reality that Kiko might die and that she ultimately couldn't make him better. Another hard reality for her was Kiko's decision in the United States instead of having his body returned to Mexico. Though Laurie's anger mounted, she nevertheless understood that Antonia had her own difficulties--being in a foreign country disconnected from everything familiar in one's culture and facing the loss of another child were struggles for Antonia as well.

> It was hard. I can't imagine how it must be really. I mean as your son, and having lost so many. And he was probably the one who they counted on for their retirement. He [was] the lucky one.... you can probably note a little anger....Yeh, there's anger....I was angry. I mean there was always that undercurrent.

For Laurie, the emotional tone of caregiving was often described as one of feeling angry, tense and trapped. Her attempts to break through deadlocked communication with Antonia did not work. Moreover, she had no private space and little time to herself. Antonia became distant, despondent, suspicious and jealous, and at one point accused Laurie of having an affair with Kiko's father Mario. Though concerned, Kiko could not deal directly or effectively with the tension in the household and mostly avoided the situation. Because Kiko believed that he needed his parents' help, sending them back to Mexico was "out of the question." Eventually, the undercurrent of anger and resentment surfaced in an argument between Laurie and Kiko.

> That's part of my anger. I think...I'm angry that I was angry. I was starting to get ticked off at him. Of what he was putting us through....One day finally, his mom had left [the house], and he asked me for something. He said, "It's your obligation." And I said, "Obligation? Obligation! Hmmm. That's a funny word. Tell you what. I'm am sick to death of your obligations." And I just really unloaded on him. I said, "I don't mind looking after you and your illness. I've proven that. I've been up in the hospital with you. I've done what it's taken to take care of you and the kids. Farming them out if needs be, and coordinating everything. That pales in comparison to what this is." I says, "It's not enough that you've been sick for the last two years? two and a half years? It's not enough? That we've all been in danger of having this? And carried this emotional load? That's not enough? It's not enough that you're

> gonna die. And I know that? It's not enough?" I mean I was just dumping on him. It's awful for me to do that. And I don't know if I'll ever let myself forgive myself. I said, "It's not enough to have your in-laws in my face for 5 months? That's not enough? I couldn't stand to have my sister in my face, who is my best friend practically. I couldn't handle having her in as close of contact for as long as I've had your parents." I said, "Could you handle having your in laws stay with you all the time? And then, your mother calls me a whore in my own house? That's seems like very little? And then you expect me to get excited about our business? And do that too? And then go and pull everybody out of school for the winter and go down to Mexico? And like I really want to see them! I really want to spend time with them!" And he for the first time in his life, he did not have a come back. He couldn't say anything. And he was not that mentally gone. He knew what I was saying. He never got on the defensive about it because he knew that everything I was telling him was true. He says, "You know, you're right. It is hard."

After Kiko's death, Laurie and Antonia reached a truce. The conflict and anger of the caregiving situation lost its center and much of its force. Laurie struggled with issues of forgiving herself for her angry outburst at Kiko, feeling "angry that she was angry" and experiencing guilt over her part in causing Kiko harm.

Though conflict is played out within the special circumstances of each family, some similarities across caregiving situations were suggested in this study. Conflict may become a context of family caregiving when there are unresolved past rivalries among family members; when communication is characterized by avoidance, silence, or secret keeping; when there is unexpressed fear, misunderstanding or lack of familiarity with AIDS as a disease process; when there is discomfort with homosexuality; when there are differing values regarding the nature of caregiving; or when there is very little personal space or time for caregivers during episodes of intense physical care.

Families in conflict, unlike estranged families, may display high levels of care and concern. Conflict may be driven by differences over the issues presented by caregiving. For example, conflict may be centered on how to comport oneself in relation to the ill person; who has greater access to the ill person; who has the final decision-making authority about issues of care such as what modes of care to continue or stop. By and large, in this study, conflict was characterized by concern, and not by its absence.

Families with Children

In four situations in this study, minor children were present in the home during part or all of the caregiving for the person with AIDS. Laurie and Kiko had three children--Frankie, two, Tina, five, and Marta, nine. Joe's teenaged daughter Patty lived with her father until two weeks before he died. Joe's nephew, 11-year-old Richard, helped with his care. JR's son, 14-year old Danny, lived in the home with his father until AIDS dementia led to JR's erratic and unsafe behavior. Dewey's 11-year-old niece participated on her uncle's care team and eventually created the design for Dewey's memorial quilt. In two other situations, teenagers were present in the home for part of the caregiving experience.

Caregivers had multiple concerns about the effects of caregiving on their young children. Most were concerned about disclosure, believing that the children would be stigmatized if AIDS in the family were generally known. Mothers with young children, like Norma and Laurie, were extremely stressed by the multiple demands of care, both from the children and the ill person. Laurie recalled exhaustion and the feeling of being totally consumed during periods when the children needed her attention and Kiko was acutely ill.

> The kids would be sick, I wouldn't get much sleep, it would be interrupted constantly by either the kids or him. A lot of times I didn't have anybody else coming in. It was just, I don't know totally consuming. I mean there was something my whole day. Just no sleep, no this, no that. Tending to him, tending to the kids, trying to keep them quiet....I was getting up at 5 or 6 to change his IV's and...then I'd have to cook him something special to eat....And then get the kids up and get the kids off to school, and then have Frankie and Tina to deal with here. And then just taking care of him, having to move him with his IV pole to get him to the bathroom and things like that, wrapping him up to maybe bathe him.

Laurie described periods of extreme exhaustion, pulled between caring for Kiko and carrying on the major responsibilities of care for three children. Other concerns centered around issues of infectivity. Caregivers questioned whether children could be exposed to the virus and had concerns about their safety in relation to caregiving activities. Laurie explained her awareness of sharps being present in the house and the need to explain carefully to the children rules about needles or syringes.

> The IV stuff was in the boxes that the home care brought them in. I would keep them all in the same corner in the room there. The hazardous waste disposal, that was on top of our dresser and so was the rubbermaid case of medicines. Everything was out of reach of the kids....It was no big deal but we had to keep it out of Frankie's reach. There was some concern about that a little bit. You know, kids getting in. Tina liked to play with the syringes, the syringe without the needles....You kind a wonder what you should do about that. She liked to have her own little kit and one of these nurses who was so great with her would give her some of the copies of her paperwork, and Tina would write down and be the nurse too. And she'd let her have some of the syringes without the needles. Some of the empty bottles to have her own little medical kit. It was kind a hard to know where to call it....In this day and age, you don't want to have kids so familiar with that kind of stuff that they would pick it up and what if it does have a needle on it?

Tina, aged five, became interested in her father's care. She played nurse and tried to help him by "taking the blood pressure" and giving her dad advice. In regards to

Tina, Laurie said,

> She was always right in there. She wanted to know how. She would copy. She would mimic what the nurse was doing and it was hilarious. And the nurses usually got a kick out of it. Like I said, some of them didn't have much patience for it, but most of the time they were really good about it, and she like to blow up the blood pressure cuff, cause that had to be done every 15 minutes during those infusions. They had to be real careful. They'd unscrew the thing so that when she did puff it, it didn't blow up (laughing).

Through play, Tina participated in her father's care, mimicking the nurse and helping him to get well. Marta the oldest child had to find her own place in the caregiving configuration.

> More often Marta would assume the role, or I would put it upon her, to just take care of Frankie. Get him out of the way. And keep him occupied, so she was more of a support person in that realm than she was involved with daddy's care. Plus, I think, she doesn't like to compete with Tina. So, when Tina would be doing something, she'll kind a back off and find something different to do, because she really doesn't want to compete.

At age 9, Marta became a support person in the family, taking care of baby Frankie, freeing her mother for the duties of caring for Kiko and the home, and following a policy of noninterference with Tina.

In another caregiving situation, Norma described 11-year-old Richard's part in caring for his uncle Joe. Joe and Norma were brother and sister from a tight-knit family including their elderly parents, Norma's two sons, and Joe's teenage daughter Patty. The three households were situated on the same parcel of land in a rural setting. Richard, Norma's older boy, frequently relieved his other family members by spending the night with his uncle and being available if Joe should need help. On one occasion, Joe fell after getting out of bed, and Richard was too small to help him off the floor. Norma described her concerns about young children carrying too much of the concern and burden of caregiving.

> We let the kids spend the night over there. But he would fall and he didn't want to call anybody to help him....It was really hard. Richard was trying to help and tried to get him up and everything and tried to do everything that Joe wanted him to do and Joe would try to tell him how to do it and everything, but you know Richard was only 11 years old. We did depend on Richard a lot. He was the one that could get up between us and help. Richard really cried the next day because he said, "Mom, I couldn't even move him." He said, "He fell out of bed." Richard was sleeping on a cot right there in the living room and he said, "I heard him fall. He said he was getting up to go to the bathroom. I tried and he wouldn't let me call anybody." Richard said, "Wait I'll go get mom." And Joe said "No, just give me a blanket and let me rest for a minute and then I can get back in bed." Richard must have worked with him probably for about an hour or hour and a half before Joe said, "Just leave me here, give me another blanket and I'll stay here on the floor before grandma and them get up in the morning."

The next morning, Norma found Joe covered with a blanket on the floor where he had spent the night. Richard cried hard about the incident and his inability to help lift his uncle off the floor. Reflecting on Richard's reaction, Norma explained:

> My feeling was that my baby going through that. He's just a baby. We're putting too much on the kids and that's when we decided that we gotta go back to make sure that either mom or I was there at night, not depending on the kids to do it. They didn't need that put on them on top of everything else.

Richard's reaction to his uncle's fall brought to Norma the realization that the adults had depended too much on help from the children. Though Richard continued to participate in Joe's care, Norma and her mother changed their own practices, focusing on the needs of the children, allowing the children to help, but also trying to find for the children the right balance between caring and being cared for.

In years to come, AIDS in families can be expected to affect more and more young children, like Tina, Marta, and Richard who will contribute to the care of the ill person and to the support of the entire family. Adults may have concerns regarding the role of children in caregiving, the stigma associated with having a parent or relative with AIDS, the risks of infectivity, the potential of accidents involving medical equipment in the home, or their adjustment to the experience of witnessing the serious illness, decline and death of a loved one.

Disenfranchised Caregivers

To be disenfranchised means to be deprived of a right or a privilege ordinarily afforded to the members of a community. The privileges assigned to family caregivers in our culture include understanding, concern, and help from neighbors, community, friends, or members of the extended family system. In this study, disenfranchised caregivers were those who did not fit the commonly understood meanings of family. These caregivers were mostly women who were friends to the ill person. They cared for gay men and were not related by blood ties or by marriage. Three women told stories of isolated caregiving, distant from the ill person's family and, in two cases, disconnected from a larger gay community. They described concerns about their interactions with health care professionals, difficulties communicating with social welfare agencies, concerns about relating to the ill person's biological family, and concerns about asking for time off from work to care for the ill person.

Rachel, a 39-year-old woman who cared for Clark, her friend of 20 years, stated that friends found it hard to understand why she would take on the role of caregiver.

> People...can't, don't understand why I would do it. Why I did it or why I wasn't more grossed out. How could you do it? Care for someone you loved

so much? How could you let go of him?

Rachel's story was one of caring for Clark in relative isolation. She continued working during Clark's terminal illness, taking vacation days from work in order to be with Clark as much as possible. She hesitated to disclose her caregiving role with colleagues at work, telling only one close friend, a gay man named Bob. Lacking a legitimate caregiving role such as sister, mother, wife, or lover, Rachel felt others could not understand or support her involvement as caregiver for Clark. She told her story to few people and described a caregiving experience of intense involvement with Clark. Though she recognized a need for support, she believed that seeking outside help would demand more time and energy than she had to give.

Clark had a distant relationship with his parents, who rejected homosexuality. Rachel remarked that Clark wanted to spare his family because he had "caused his parents enough grief already." During his illness, Rachel maintained contact but was not close with or emotionally supported by Clark's family.

Rachel described her "disenfranchised" position in the following conversation.

> Clark died between Monday and Tuesday. Tuesday was just a blur. I suddenly felt like there was nothing to do. Clark was gone and my whole life had been wrapped up in Clark for 5 or 6 months. I mean in an intense kind of way...My friend Bob came over Wednesday and then I went back to work Thursday. I would have taken more time but, you know, Clark wasn't my husband, and he wasn't a relative. I mean, it was sort of an undefined relationship to many people and in some ways to, I suppose to some people, it doesn't warrant sort of what is due a wife or a relative or in terms of grieving and taking time. I probably went back to work a little bit soon. He died on Tuesday. I went back to work on Thursday. And you know for someone I had known for 20 years, I probably would have. But I was out of time anyway. I didn't have any time left. Many people were very kind. I got some nice cards, and some nice flowers.

Here, Rachel described the disenfranchised position of being in an "undefined relationship" of care. She was unable to take time or lay claim to a legitimate reason to grieve. Caregiving in our culture remains within the confines of the family and is overlooked, undervalued, and misunderstood if it is not so circumscribed. When caring occurs outside of the commonly understood bonds of family, it is not recognized as a legitimate enterprise. AIDS has already challenged cultural understandings about family and will continue to do so. AIDS caregiving may extend our notions about care and about where caring can legitimate occur.

Summary

In this chapter I have considered family as both a context of care and a significant concern of most caregivers. The narratives provided examples of interactions between the families of origin and the chosen families of the ill person. Involved families, estranged families, families in conflict, and families with children provide contexts for care and present concerns toward which caregivers turn their attention. Disenfranchised caregivers were viewed as friends who did not fit common cultural meanings of family and whose work was neither socially expected nor socially sanctioned in a way that afforded understanding and support.

CHAPTER 6

MORAL CONCERNS AND MEANINGS OF AIDS FAMILY CAREGIVERS

Chapters 4 and 5 set forth the first part of the overall interpretive account--that caring practices are shaped by broad cultural contexts, local communities, and family contexts of care. In this chapter, I present the second part of the interpretive account--that the moral meanings and concerns of caregivers are fundamental to caring practices and can be studied and understood in the everyday language of the participants.

As distinct from other concerns, moral concerns are characterized by relationality and by attention to what is good or bad in the situation for the self or others. Moral concerns typically direct us beyond the self or direct us to sustain the self in relation to the good of others. Though I dwell in my world in a concernful way, not all of my concerns count as moral concerns. For example, my concern to check the oil in my car usually does not fall within the domain of moral concerns. But moral concerns and actions are only understood within meaning-filled contexts and situations. I may have a concern about keeping my car in good running order because I have an ill father at home and I think that at a moment's notice, he may need to be rushed to the hospital. If such were the case, my moral concern shows up in my "being prepared" to respond to his needs in a way that protects his well-being.

Stories of moral relevance are those that relate to what is right or wrong in human action and what is either good or bad for others or for the self in particular situations. In relation to AIDS caregiving, moral concerns were reflected in caregivers' stories about what was good or bad for the ill person and about what was the right or wrong thing to do in relation to giving care. Because moral concerns undergird and motivat practical activities of care, this chapter is primary in understanding the caring practices that are explicated throughout this interpretive account.

Meaning, Concern, and Caring Practices in the Moral Domain

Heidegger claimed that, for the most part, acting in the world occurs in a seamless, smoothly functioning way. We grasp meaning, formulate concerns and respond with the skilled body in prereflective, holistic modes of being that we can never fully understand. Thus, reflective analysis of meanings, concerns, practices, and practical knowledge is necessarily somewhat artificial and tends to bolster the incorrect notion that our own smooth functioning can be fully explicated. Nonetheless, it may be useful to lay out--insofar as it is possible--some of distinctions among moral concerns and meanings and the subsequent caring practices they engender, acknowledging that any such account will necessarily be incomplete. This is undertaken to promote a common ground for understanding the interpretive approach taken in this chapter.

An example from a common caregiving situation in this study is used to illustrate how meanings, concerns, and practices may be distinguished, yet seen to flow smoothly together as one moves through the world. Many caregivers in this sample talked about issues involved with loss of bowel control and the need to introduce diapers in the caregiving situation. Typically, this was a situation fraught with multiple meanings and concerns for caregivers and for the persons cared for.

In the following text, Rachel explained her responses to Clark's loss of bowel control and her decision to persuade him to accept diapers. She had returned home one day to discover that Clark had soiled himself as well as the bed and carpet in a desperate attempt to make it to the bathroom.

> He was disgusted with himself and in tears and said he couldn't make it. He woke up and he realized he was having a bowel movement and tried to get to the bathroom but he couldn't. It was just such a hugh mess. And after I'd cleaned that all up, I had to get him into the bathroom and wash him up and get his bed sheets changed. He had to be washed. I had to Lysol, take bleach water and do the whole bathroom and I had to be gloved up. It was a mess. I decided that I was going to have to gently urge him into Depends, cause I could not do this again. So once the initial shock was over, and he had slept and was cleaned up, we had a little talk. I said, "It's not that big a deal. It just would be a safeguard." It's just like, I tried to couch it in a way that I didn't think he would really need them but it would help. He could just take them off and throw them away and they could be clean and that'd be great. You know, "It wasn't going to be a problem." It wasn't like he had become an infant again and his diapers were going to have to be changed. This was just a backup system. A sort of little something in place. That's how I presented it. I felt badly for him cause he was totally humiliated and he realized he didn't have the strength to get it cleaned up himself and he just got back into bed and fell asleep.

Moral Meanings

Getting clear on all of the meanings in this situation may not be entirely possible; however, we can understand some of them. In our culture, incontinence in an adult relays meanings of being infantile, dependent, and out of control. Being "soiled" and having to "be changed" by another person threatens one's dignity and conveys meanings of being dirty and disgusting. Deep embarrassment about being the cause of the "hugh mess" or the source of unpleasant smells or bodily sounds may be accompanied by extended meanings such as losing the ability to trust the body, feeling the need to distance oneself from other people or wanting to avoid public places. The loss of bowel control means that the ill person can no longer depend on the taken-for-granted, habitual body; it implies a loss of being at ease with one's body. Incontinence and being too weak to clean oneself convey symbolic meanings of a regressed, vulnerable, disgusting and dependent self. Further, having to "be changed" by another person holds meanings for one's closest interpersonal relationships--one is called upon to accept a new level of trust and protective care from others.

Particular individuals extend meanings to the life world in distinctive ways (Kleinman, 1988). As Kleinman (1988) contends, the meanings associated with illness and its symptoms are partly derived from meanings in the culture and partly derived from how the individual interprets his particular situation. Meanings such as being vulnerable, dependent, disgusting, and uncomfortable in one's social world take on moral significance because of they damage one's dignity and add to the suffering already created by the disease.

Moral Concerns

In a culture that values independence, self-control, self-care and cleanliness, this situation brings up concerns about the impact of soiling oneself and having to be diapered. Concerns direct our attention and undergird our practical activities in the life world. Rachel's concern was concerned that Clark would be deeply shamed and humiliated by the meanings of his situation. Concerns about the impact of humiliation, shame, and the indignity of being diapered, as well as concerns about the associated loss of a life world, are moral concerns because they focus on some of the most deeply valued goods inherent to the self. Moral concerns shaped the way Rachel responded in the situation, defining the morally relevant aspects of her care.

Caring Practices

Moral concerns undergird many of the caring practices articulated in this interpretive account. In Rachel's narrative, moral concerns about the humiliation and indignity of being diapered undergird practices aimed at minimizing harm. In the continuing narrative, Rachel described specific caring practices aimed at protecting Clark from humiliation and shame.

> I brought the Depends home and he was just mortified that we were going to do this. I just presented it as "an option for nighttime wear." So he got in the Depends. And he started wearing them. He really did lose control and he really did have to be changed. That was really hard for him; it would be hard for me.... So instead of changing him like a baby laying down on his back, he would stand up for it. Hold on to his walker. [He would] let me take the Depends off, then wash him up, and put a clean one on and put clean pajamas. He didn't want me to do it in his bed and I thought, just for hygiene reasons, it was better not to change him in bed too. He wanted to be standing up while this was happening and that was fine. In some ways that made it easier, like this is pretty routine stuff, like I was just scrubbing his back or something, which obviously I wasn't. That was a real tough thing because that was sort of the final indignity I think for him.

As suggested by Bowers' (1987) theory of protective care, Rachel protected Clark from the humiliating meanings of having to wear diapers. As part of her care, Rachel acted to minimize the cultural meanings of being diapered by explaining to Clark that it was "not a big deal." She presented the diaper as "a little something in place," "a back-up system," "an option for nighttime wear"--a safeguard that probably wouldn't be needed. She timed herself, waiting until Clark was "over the initial shock," was clean, and had slept. Additionally, the meanings implicit in lying down "like a baby" were avoided by letting Clark stand up by his walker, as one would do when changing pants or pajamas. Rachel acted with nonchalance, handling the situation as "pretty routine stuff" rather than showing her concern in a way that might add to Clark's experience of "the final indignity." Rachel also explained that she set up a discrete system for storing the diapers, out of the view of visitors and Clark himself.

This example is given to illustrate how moral meanings, moral concerns, and caring practices are interwoven in situations of care. These aspects of care flow smoothly together, not lending themselves entirely to crisp distinctions or definitions. Soliciting stories in which the moral meanings and concerns of caregivers could be revealed was a planned part of the research and will be discussed next.

Soliciting Stories of Moral Relevance

In an attempt to stay close to the natural language of participants, I did not use the term moral concern during interviews or directly ask participants to describe moral dilemmas or situations. In many cases, however, participants spontaneously described morally relevant issues of care. I also asked indirect questions intended to elicit descriptions of moral concern. For example, I asked participants to relate what was most important in their care or what they would have changed about their care if they could do it over again. (See Interview Guide in Appendix B.) Questions about what was most important in care were intended to capture participants' notions of right actions or what they perceived as good for the ill person. Asking participants what they would have changed about their care was designed to elicit notions about what was harmful for the ill person as well as what was right or wrong action in relation to caregiving.

Asking participants what they might have changed elicited from some caregivers stories of regret about causing harm. In hind sight, outcomes were known and decisions about caregiving were evaluated differently. Some situations were associated with guilt and may have been painful for caregivers to recall and describe. Stories about regrets in caregiving brought to the fore the moral ambiguity that caregivers experienced in concrete situations. Dwelling in uncertainty, caregivers were unable to determine the effects of particular acts and often could not decide if a particular act was the right thing to do or would ultimately lead to greater harm. In complex caregiving situations, the boundaries between doing good and causing harm can be vague and may be associated with moral uncertainty for the caregiver.

The narratives in this study provided a view of the moral understandings that motivated participants in their actions as caregivers. Narrative text will be presented here to preserve the contextual richness in which caregivers made decisions or responded morally in specific caring situations. The attempt here is to stay close to the everyday language of the informants rather than adopt the language of moral philosophy.

Loss as a Context for Moral Concern

In this study, loss associated with AIDS created the context for many of the moral concerns described by caregivers. Kleinman (1988) viewed loss as a central meaning in the experience of chronic illness. In the life world of the ill person, losses are intertwined and multidimensional in their effects. Additionally, as Kleinman asserted, losses are interpreted; in other words, loss is given significance in the life world of the family and the ill person.

In relation to AIDS, the experiences and meanings of loss radically alter customary ways of being in the world, profoundly affecting both the ill person and th caregiver. In this section, I will discuss the kinds of losses facing caregivers and persons living with HIV disease and offer interpretations of the related meanings of loss disclosed in participants' stories of care. Since loss interrupts the ways a person has learned to think, act, and be in the life world, it creates the conditions or context for commonly held moral concerns.

Kinds of Loss in the Experience of Living with AIDS

A central concern expressed by all of the caregivers in this study was their deep awareness of the unrelenting losses experienced by the person with AIDS. The losses were multiple and uncompromising and presented in unpredictable patterns and permutations in the lives of the persons with AIDS. Kinds of loss included losses of the body, social and relational loss, material loss, and in some cases, loss of mental capacity.

Losses of the body may have included loss of sight, hearing, physical energy, balance or mobility; the loss of bowel and bladder control; or loss of the ability to swallow or tolerate food. These bodily losses as well as body wasting, painful or the disfiguring conditions of the skin or soft tissue; or painful oral lesions led to the loss of the "habitual body"--the everyday way of dwelling and being at home with one's own body.

Social losses included the loss of usual roles in everyday life such as the loss of one's job or not being able to fulfill the roles of father, partner, friend, volunteer, or community activist. Having to quit a job, give up travel, curtail outings, or give up driving restricted both the social and the physical world. For the gay men in this study, social loss also included multiple losses of friends or family members who had died from AIDS.

As end-stage disease ensued, the ill person may have lost the ability to relate in customary ways as a partner, husband, father, or friend. Disengagement in response to terminal illness was common. These kinds of losses may be categorized as relational losses. The loss of customary ways of relating was a shared loss affecting both the ill person and the caregiver. Frequently, but not always, relational losses involved AIDS dementia. More than any other loss, the onset of dementia, involving forgetfulness, confusion, erratic or belligerent behavior, signified the irrevocable loss of personhood. Losing a job, becoming disabled, or living on social welfare may have led to material losses which made it impossible to sustain a former lifestyle.

The combinations of loss described in these narratives set up the conditions for many moral concerns uncovered in the narratives. As illness progressed, caregivers stood alongside the ill person attentive to the significance of loss in the ill person's life. Multiple, cumulative losses were seen as a relentless "chipping away" of one's dignity, identity, or sense of self. Working out ways to respond to loss became a morally relevant aspect of care.

The Related Meanings of Loss

All caregivers in this study related stories which included the significance of loss in the life of the ill person. Loss conveyed several interrelated meanings including the gradual loss of the habitual body, the loss of familiar things and people in the life world, the loss of customary ways of relating to others, and the loss of control over one's usual way of being in the world, and ultimately the loss of life. All of these meanings of loss will be discussed and illustrated in the following sections.

Loss of a life world. Loss related to AIDS includes the ultimate realization that AIDS is a fatal disease. With the exception of a few long-term survivors known to have remained healthy for 15 or more years, most infected persons progress to terminal disease. Given the current state of medical knowledge and technical control, most people with AIDS die a premature death.

It is beyond our grasp to articulate the full significance of loss for a person facing terminal illness and untimely death, and this kind of suffering is certainly not limited to those affected by AIDS. However, it can be said that somewhere in the progression toward end-stage disease, the life world of the person with AIDS is up ended. As one caregiver stated, "the world fell apart."

Theresa's narrative reflected the profound sense of the loss of world experienced by JR, a gay man affected by AIDS dementia whose behavior over time had become erratic and increasingly aggressive. In the following excerpt, Theresa reflected on JR's loss of world.

> Before their body dies, they lose their life. He lost his pride and joy, his car. Then he lost his son because he was no longer stable. Basically, he'd see his

> son once in awhile, but not very often. And he lost his ability to walk. He lost control of his money. The only thing he had left was his cigarettes. And I hated having to take those away. Because that's the only part of his control of his life he had left.

In this situation, Theresa took control of JR's cigarettes fearing that he would unwittingly start a fire if allowed to smoke unsupervised. It was an action she regretted because taking away JR's cigarettes was taking away one of the few things left in his extremely diminished world. JR "lost his life before his body died" in that he had lost a life world. JR formerly enjoyed travelling, partying, driving an expensive car, being with his son, and doing more or less as he wished. AIDS dementia, progressive paralysis, and multiple illnesses eroded JR's world before taking his physical body.

Loss of relationship. The multiple losses associated with AIDS impact caregivers who share many of the experiences of the ill person. Shared losses included the loss of practiced ways of relating to a partner or spouse. These losses were painful for caregivers to witness and to experience. Laurie, for example, described painful transitions when she realized Kiko was "slipping away," no longer available to her as the husband he had been in the past. She described Kiko as a man who held on to his roles as husband, father and leader of the family as long as possible. He had worked hard at two jobs and his own business, supporting his parents and his own family of five. In the following passage Laurie suggested the embodied ways in which loss can be experienced and understood.

> I told him I had a headache and...he wanted to give me a massage. He was laying down in the bed and he wanted to reach up and he tried to give me a massage. But I told him, "No it's OK, honey, it's OK." I said, "It's all right

> honey. You don't have very much energy, I'd rather you spent it doing something else." I was very cold. I was distant. But it was a protective factor because I didn't want to break down right there. It was a situation where it hurt worse to just be touched lightly because he didn't have the strength. It hurt me, my feelings, or it just bothered me more. Sure I was in pain, but it hurt me more to have just the light touch than to have nothing at all. Because it represented him slipping away I guess.

Most caregivers, like Laurie, described the painfulness of watching the ill person "slip away." Caregivers viewed this kind of experience as the hardest part of caregiving. In addition to this concern, Laurie elucidated the embodied ways in which loss can be communicated and understood. Here, Laurie experienced loss through a changed and unfamiliar touch. Kiko's light touch communicated in an embodied way the deep loss that Laurie and Kiko were facing as a couple. Experiencing the painfulness of her situation, Laurie's response was both self-protective and protective of Kiko. Not wanting "to break down" in front of Kiko--an action that could bring harm--Laurie maintained a distance, backed away and urged Kiko to conserve his energy. Being "cold" and "distant" was preferable to breakdown because it protected Kiko from the meanings of loss--not only the loss of physical strength but the loss of his usual capacity as a husband to comfort his wife or ease her pain.

As physical weakness and dementia progressed, Kiko and Laurie experienced the further relational losses of his illness.

> He never gave up his leadership of the family until maybe the last month of his life. And not really totally until maybe the last week of his life. He was still my husband, comforting me, until the last couple or three weeks probably. Then I noticed that he didn't seem to be capable of noticing that I needed to have a hug. I remember one time I was in the kitchen. He knew that I was upset. He knew I was tired. Or he should have known, but it wasn't entering.

> Normally, he would have just come over and given me a hug. But he wasn't doing that any more. I remember thinking, "He's beyond now. He can't comfort me." It was kind of like somewhere in there, he's not even fathoming that I need it.

Here Laurie described losing the normal husband-wife relationship she and Kiko had known in the past. Kiko was no longer capable of fathoming or even noticing his wife's needs. The practical understanding and responding that comes from years of close relationship were no longer available to him or to Laurie. As Laurie stated, in a most poignant way, the Kiko she had known was now somewhere "beyond."

Loss of future time. Brown and Powell-Cope (1993) noted that AIDS caregivers experienced a phenomenon of transformed time, where perceptions of time were changed. One aspect of transformed time was diminished attention or ability to contemplate the future. Caregivers avoided specific mental images of the future. Similar findings were uncovered in the present study. Roy, an HIV positive caregiver, who took care of his partner Doug, reflected upon his own limited way of attending to the future.

> I try very hard not to predict what my future's going to be because I could get really obsessive. That's one of the things I noticed with Doug, when his friend died a year before him. Sometime's I'd see Doug projecting his friend's sickness onto himself and then, if it would become a reality, it would become this self-fulfilling prophesy kind of thing. I think we need to kind of guard ourselves against it. Because no two people's paths are the same. And we don't want to create a self-fulfilling prophesy for God's sake. So I try not to project Doug's life and many of the other people I've watched die or been with when they died, and all the various things that happened. I try not to project them onto my own life. Because if I do, it makes me more or less stop living.

From a phenomenological perspective, the person is projected or "thrown" into the future (Benner & Wrubel, 1989; Dreyfus, 1991); however, HIV disease brings with it an altered self-understanding that foreshortens future time and constricts one's future horizons and possibilities. Roy, for example, described how he stays in the present and avoids focusing on the future "ugly prospects of the disease." Roy's caution in thinking about his "prospects" suggested the loss of a young person's customary way of projecting the self into future time. This loss of future may be considered a more abstract form of loss, but a no less powerful threat to a coherent understanding of the self.

Loss of the controlling self. A dominant understanding for the participants in this study was that multiple losses signify loss of control over one's life. This meaning may have special salience in our own culture where a conception of the self as a radically free, self-determining agent is highly valued. The controlling self represents a common way of being in our world. Additionally, issues of personal dominance and control may have special salience for males in our culture. All of the persons cared for in this study were male; concerns about control may or may not have equal weight when the persons cared for are women.

Roy's narrative provided an example of how specific losses conveyed meanings of "losing control over one's life." Roy articulated the connection between actual forms of loss and the interpreted experience of losing control over one's life. In the following text, he described Doug's experience of losing eyesight and his subsequent need to give up driving.

> His sight had finally reached the point where it was really dangerous for him to be behind the wheel. In fact he came home one day and walked in that door and he was shaking like a leaf, and...said, "Well I just about killed somebody in the car...I'm not driving the car. Here's the keys. Take them away from

> me...Tell my office to come and pick up the car and to use it for the business. I'm not driving it." So that was a major day....I took the keys and I said, "I think you're making the right decision. You're making the decision and I think you've reached the point where you've realized what's right and I concur. I support you. If you need to get around, I'll get you around."
>
> Well, I think that started about a 24-hour stewing session for Doug. Because there was the reality of "I can't drive anymore and I'm not going to be able to get around." ...Then he began to resent the situation, though actually had made the decision himself. So, he'd complain about the way I was driving, or it just surfaced in a number of different ways. Finally it came out. We had a discussion about it, and he finally said, "It's the control issue" once again.

Doug's loss of eyesight had multiple implications in his life. Among these were the loss of his car, the loss of his ability to come and go at will, and consequently, the loss of his formerly taken-for-granted identity in the life world. These losses constricted both the physical and social world, signifying for Doug the loss of his customary way of being and acting as an agent of control. Though he had made the decision himself, Doug resented his new reliance on Roy. Roy described Doug's insight into the meanings of loss and control in his life.

> One thing I remember him communicating to me was his feeling about the issue of control. He made it very clear one day that as you become disabled from this disease, you start to lose control over things that you once had control over in life. That may affect different people differently. Doug was a very controlling kind of person. He controlled his business. He controlled his life. He controlled every move that he made. That's what made him as successful as he was. He controlled other people's lives. He was just a real doer. A real proactive person, a proactive thinker. And so as he would become more disabled and not be able to do something for himself, I would step in and do that. And I happen to be a very controlling person too. I wouldn't let anything slip. Nothing slipped through the cracks and there were times when I was controlling too much. And those were the times when Doug would speak out and communicate and make it really clear. He says "I just want you to be aware of the fact that my control is going and I resent that." He said, "I resent not being able to do the things that I used to do for myself."

For Doug, diminished eyesight and the consequent loss of his car were significant life-altering transitions. Being a person who controlled his business and "every move he made," being "a real doer," a "proactive person and thinker," always being able "to do for himself" were person-defining aspects of Doug's former self. Sankar (1991) stated that the aspect of exercising control is most closely tied to adult identity our culture. Giving up control over how one acts or moves through the world is equivalent to losing an adult identity.

Loss of control was both a meaning and a concern for almost all of the caregivers in this study, including female caregivers who cared for men with AIDS. In subsequent sections, the meanings of loss and control will be linked to a common response of "returning control" to the ill person.

Summary. As with other progressively worsening chronic illnesses (Kleinman, 1988), loss was a dominant aspect of the AIDS experience in these narratives. Losses were intertwined and included loss of bodily functions, social and relational loss, material loss, and in some cases loss of mental capacity. Caregivers in this study were attentive to the multiple meanings of losses associated with illness and frequently tried to soften the impact of loss on the ill person. The related meanings of loss included loss of a life world, loss of customary ways of being in relationship, loss of future time, and loss of self-understandings, such as the understanding of self as a controlling agent in the world.

Cumulative losses presented profound threats to personhood and eventually to the very life of the ill person. In this sense, multiple losses were understood as harm; accumulating loss damaged the integrity and personhood of the person cared for.

Because such losses loss signified harm, experiences of loss created the context for moral concerns that motivated morally relevant acts of care. Caregivers told stories about minimizing the effects of loss when possible. Many of their caring responses centered around efforts to protect dignity and preserve a sense of self. The next section deals with specific responses that were aimed at protecting the dignity and preserving the sense of self of the person with AIDS.

Moral Concerns and Caring Practices Related to Dignity and a Sense of Self

Gadow (1985) viewed caring as a moral endeavor which entails a commitment to protecting and enhancing the dignity of persons cared for. In Gadow's view, "a being has dignity when it gives to itself its meaning and so creates for itself integrity." Cultural meanings, such as the negative metaphors associated with AIDS, have the potential to diminish dignity by imposing negative meanings from outside the individual. Gadow viewed the disruption of integrity as an indignity which can be brought on--not only by conditions of illness--but also by the objectification of persons which may occur when they are treated or cared for. For Gadow, caring as a moral ideal involves protecting the dignity of the person by protecting the person from being reduced to "the moral status of an object." Stated differently, commitment to dignity and attention to the integrity and personhood of the ill person constitutes moral caring.

Sankar (1991) linked dignity with protecting the person's modesty. Swanson (1991) connected concerns for dignity with the caring process of doing for, stating that when an ill person requires another to do for them, it can cause embarrassment and requires the caregiver to consciously act to preserve the dignity of the other.

Caregivers frequently used the word dignity in connection with concerns about bodily shame and embarrassment. The word respect was also used to denote concerns about respecting personhood or a sense of self. The terms dignity, personhood, and sense of self are used in interchangeable ways in this interpretive account to signify a sphere of moral concern that directed caring practices. These included practices aimed at protecting the ill person from humiliation and shame, keeping the ill person in control, respecting decisions, keeping things the same, and respecting the spiritual self.

Protecting from Humiliation and Shame

Preserving dignity in the form of protecting from humiliation and shame was a concern shared by several caregivers. Humiliation and shame were meanings typically associated with the ill person's need for intimate bodily care--such as needing to have a diaper changed or needing assistance when vomiting. The exemplar given earlier involving Rachel and Clark provided a view of care aimed at protecting the ill person from humiliation and shame. Rachel's approach to intimate care and her sensitivity to the indignity of being diapered were noteworthy in these narratives.

Jeannette, a mother who cared for her son Brian also alluded to disguising the meanings connected with diapering. For example, she never used the word diaper, but consistently referred to diapers as "pads" in order to make a humiliating situation more acceptable to her adult son.

Terry referred to diapering as the ultimate indignity and loss of control for the ill person. He cited "humiliation control" as one of the primary aims of caregiving. He described an incident when Dewey's entire family gathered around him to protect him from the humiliating experience of having uncontrollable diarrhea in a public place. Roy also recounted a humiliating incident that occurred when Doug had uncontrollable diarrhea in a department store.

> I chased him through the store and we got into the restroom. It was a mess. And there were people around. There were people around in there and we were trying to communicate through the stall and give one another sign language without embarrassing one another. Finally I went to the clothes department, and I bought a great pair of slacks and a whole set of underwear and bought it and stuck it in the bag and took it into the men's room and discretely passed it under the counter and he took care of things in there and changed his clothes and so on and so forth. And we got home and of course that was a devastating event.

For Doug, uncontrollable diarrhea in a public place brought deep feelings of shame and embarrassment. Roy's immediate actions were concerned with protecting Doug, as discretely as possible, from his humiliation. To protect Doug from similar experiences, public outings were carefully planned and prepared for and eventually excursions were severely curtailed.

> We got to the point where we just didn't travel to places where we couldn't be very, very near a toilet. We just monitored our outings. All these restrictions that kept walling in on that quality of life, just narrowing that, the things that you would have done if you could have done them. But you can't.

The public experiences of losing control over one's most intimate bodily functions were particularly devastating for ill persons and for caregivers. Having personal mastery, independence, freedom, and control were no longer available ways to understand the self.

Keeping the Ill Person in Control

Maximizing the control of the ill person was a common theme in the narratives. Caregivers acted so as not to add to the ill person's loss and, in so doing, they attempted to preserve a former sense of self. Many caregivers expressed concerns about finding the right balance between taking control and returning control. Several caregivers described regrets about depriving the ill person of control over a decision or situation. Others, like Roy, let the ill person "lead the parade" as much as possible, and for as long as possible, while remaining watchful in relation to how things were working out. As Roy stated,

> I usually would let Doug lead the parade. Unless it seemed like the parade wasn't going in a very sensible direction. When he might just have been in a bad mood or he might just have been angry about something, and just wasn't wanting to be clear or reasonable. In which case then we'd kind of have to work through that and make some decisions and get him to finally agree on something that maybe made more sense.

Terry, a caregiver who cared for his ex-partner Dewey, suggested the importance of returning control and referred to it as re-empowering the ill person. He described the practice of returning control as stemming from the philosophy of empowerment that guides the Personal Active Listening training conducted by an community-based AIDS support agency. In the exemplar that follows, Terry referred to this training and explicated the notion of returning control.

> Fundamental to that training is re-empowering a patient. Re-empowering a client. Re-empowering a person. What it means to be of true service is at all times to try and return control. Because the individual is going through just an endless series of losses, and grieving connected with each of those losses. It might be their ability to eat certain kinds of food, or their ability to eat

> whatever they want when they want to, or their ability to sleep when they wan to, or their ability to sleep without soaking the sheets or their ability to keep food down or their ability to not lose weight or all these things. Then they can't have a bird, then they can't have a cat, then they can't have this, then they can't have that, then they can't get out of bed, then they can't feed themselves. It's just this endless series of letting go. So re-empowering the person by giving them choices. "Do you want red Jello, green Jello, yellow Jello, or pink Jello?" Asking them what they want. Matching your breathing pattern with them. Trying to be sensitive to where they are. Allowing them to be okay. Not having to fill the space with sound. All that "technique-y" stuff really is about staying focused on the individual and empowering them. It's really staying centered on the individual and not bringing our own stuff into the picture because we're uncomfortable with what they are doing.

In this passage, Terry detailed his understanding of the endless stream of losses experienced by the person with AIDS. Loss of control is connected with loss of the habitual body and loss of the life world, and understood ultimately as the loss of self. Terry viewed the essence of returning control as staying focused on the ill person. Though Terry learned about returning control during his volunteer training, the underlying moral concerns described by Terry had greater depth of meaning and purpose then the "techniques" he learned in training. In the context of caring, returning control is a moral endeavor because it entails a move away from the self in order to focus on respecting the integrity of the other. Returning control may involve giving choices, which is an act that affirms possibilities in a world shut down by loss. Essentially, returning control depends on "staying centered on the individual" and "being sensitive to where they are." Giving choices, asking what they want, and matching patterns of breathing are ways to stay focused on the ill person. Focusing on the other, "not bringing our own stuff into the picture," is the empowering feature of returning control--a response that avoids adding to the loss and vulnerability of the ill person.

Balancing control between caregiver and the ill person was sometimes difficult. For example, when Doug lost eye sight, Roy's first response was to quickly step in and do whatever Doug was having difficulty doing for himself. But this approach risked taking over too much. Eventually, Roy tried to find the right balance between taking over and stepping back.

Awareness of the differences between taking control and returning control was reflected in the narrative of several other caregivers in the study and suggested Heidegger's distinction between two ways of caring for others. In the first way, the one caring "leaps in" and "takes over for the other"--a practice that can foster dependency or domination. In the second way, the one caring "leaps ahead" of the other in order to give care back "authentically"--a practice that helps the other to care for his own being. In several situations caregivers in this study described occasions when they weighed the alternative of "leaping in" and "leaping ahead" of the person cared for (Dreyfus, 1991).

Fred is a caregiver who echoed these thoughts when he described regrets about persuading his ill partner Paul to quit his job. As illness progressed, Paul experienced increasing stress and fatigue and had episodes of forgetfulness. Fearing that Paul might be developing dementia, Fred described himself as leaping in and taking over, convincing Paul that the best thing to do was to quit his job. Fred described his regrets in the following passage.

> When this stuff started happening I said "I can't take this anymore" and I really sort of very heavily handedly said, "You've got to quit" and I regretted

> that a lot. The regret was that I blew out a lot of confidence in his own decision making by doing that. I started out saying, "I'm really concerned about you I think you ought to look at quitting." I started out with that process, and I obviously had the objective that I wanted him to quit.
>
> What I didn't realize was that he needed to [work]. It's a tradeoff between physical health and an emotional thing. I always grew up with the thing that you always go for physical health. And some how or other I learned over the past year and a half that it's not the only thing to consider. You know, work was incredibly important to him.

Soliciting stories of caregivers' regrets in concrete caring situations was one approach to uncovering knowledge about the moral concerns of care. Here Fred described his regret about taking away control, adding to emotional loss, and thereby deepening the suffering of the ill person. Regret revealed to Fred the possibility of another stance--that of staying focused on Paul's needs even though physical health may be threatened and placing his own agenda second to that of the ill person.

> One of the things I got very clear on after Paul quit was I just saw how quickly he emotionally fell apart because I almost pushed him out by saying "you have to quit." So for the rest of his life, I was very attuned to realizing what was my agenda versus what he really wanted to do. And really it was more important for me to take the time to figure out what he wanted to do ...and that's just something I learned around that whole thing about him quitting.

Concerns about loss of control can occur at any point in the disease trajectory. Jared, a caregiver who cared for his partner Dennis, talked about concerns relating to loss and control in the very late stage of terminal illness. Dennis had experienced progressive loss of movement and speech related to progressive multifocal leukoencephalopathy. Despite near-total paralysis and the inability to speak, Jared was concerned about keeping Dennis involved and in control as much as possible.

> It started being slurred speech. And then just losing the ability to form

> sentences. He moved towards single word speech. By the very end, I would say the last few days prior to the active dying process, I got to the point where I had a very hard time distinguishing a "yes" from a "no." And because of the loss of motor skills, giving a head shake or something else got difficult. I would try and do as much as I could to not make assumptions about what he wanted. I would try and check in. "Is this okay? Is this what you want?" And get validation that would keep him as much in control.

The devastating nature of Dennis' loss may have in fact heightened Jared's resolve to find ways to confer control and preserve personhood. Because of paralysis, communication was nearly impossible; nevertheless Jared strived to preserve control by asking permission, interpreting answers, making no assumptions, and conforming to Dennis' needs.

The moral meanings of loss and responses that keep the ill person in control were also expressed by female caregivers in the study. Theresa, for example, described her regret about adding to JR's loss by taking away his cigarettes. Rachel, another female caregiver, promoted Clark's sense of independence and control for as long as possible. In the following text segment, Rachel explained that she gained some of her understanding about issues of dignity and control through caring for her dying father.

> I remembered from my dad making them do everything they can. The pull is, "It would be much easier if I did this myself." But for their own dignity, give them the opportunity, let them do as much as they can, because at some point he won't be able to do it for himself. So there's that tug. "I can get it done much faster." But if Clark insists on doing that, he should do it. Just let him do it, even though it's just like letting a kid do it. You knew there was going to be spilled milk everywhere and it was going to be a mess but you should let the kid experience it. The same thing with Clark. If he thinks he can take this shower by himself, he will.

An essential aspect of keeping the ill person in control is resisting the urge to "leap in" and take over. Returning or preserving control, in even the smallest ways, are acts intended to protect the dignity and personhood of the ill person. Rachel pointed out that dignity can be protected by not doing for the other--the opposite of Swanson's "doing for." Protecting dignity can occur by giving opportunities and making time for the ill person to do things more slowly and less perfectly than one might otherwise be able to do oneself.

Respecting Decisions

Linked to the practice of keeping the ill person in control were caregivers' efforts to respect the decisions of the ones cared for. Jeannette described her central concern of assuring her son Brian that he would retain control in making decisions about his own care. Though Jeannette occasionally tried to influence a course of action, Brian was ultimately in charge of making his own decisions. Jeannette cited this as one of the most important aspects of her care.

> I let him make the decisions...Because it was his life, his death. And if I had tried to manipulate him or get him to do anything other than what he wanted to do, it would have taken away all of his pride. It would have destroyed him. He was not the kind of person. He had to be able to be his own person.

Earlier in the course of Brian's illness, Jeannette learned that a commitment to letting Brian make his own decisions would not be an easy or clearcut goal of caring. From Jeannette's perspective, Brian sometimes made decisions that were not in his own best interest.

> I think he thought I was gonna try to tell him what to do, tell him what medicine to take. And I wanted him to know that wasn't the way it was. You know, that whatever he wanted to do, I would respect that. And at times that was very hard....because I knew sometimes his decisions were probably not in his own best interest and that he wasn't taking good enough care of himself....there is a fine line sometimes between making Brian do what he needs to do and taking care of him and letting him make his decisions.

There were times when Jeannette, like other caregivers, had to deal with conflicting moral concerns such as the conflict alluded to here. Supporting Brian's decisions was an action that shored up his sense of self but which conflicted with concerns about harmful alternatives such as not caring for the physical self.

> Way back there when I wanted him to go to the doctor and he was on alpha-interferon and I wanted to tell him I thought it would be best for him to quit because I noticed he was sicker when he was on that than when he wasn't. It wasn't helping. But all I could do was just make a suggestion....That's just another example where I had to be.

The moral concerns of protecting a sense of self and preventing harm to the sick body came into conflict in situations such as this. Even though there was a clearcut understanding about which value should take precedence, Jeannette still experienced the discomfort of watching Brian chose an action which seemed to make the body sicker. Like Jeannette, Fred described his difficulty with supporting Paul's decision to undergo chemotherapy. Fred ultimately decided that "it was Paul's life"; and he supported Paul's decisions to pursue chemotherapy.

Keeping Things the Same

In some situations, preserving a sense of self involved efforts by the caregiver and the ill person to keep everyday life the same. Striving to maintain the familiar rhythm and structure of the everyday world was a response to threats of illness and loss. Dale is a gay man who cared for his partner Ted. Dale expressed his commitment to caring for Ted in terms of "not wanting to change a thing."

> I always knew after the second testing that he was going to be gone in a matter of years. So I told myself, "Well, I'm just going to make the best of it for him and for me and see it through." I said, "I'm going to see it through and be there for him, be his companion, and not change a thing." So I didn't

> change a thing. We just went about our business. I was living my life. He was living his life. It wasn't like ignored or denied at that point, but like any other couple out there, we just went about our lives as best as we could.

Dale qualified this statement by saying that after Ted's second positive HIV antibody result, they spent more time together as a couple. They enjoyed the ordinary, small pleasure of daily living.

> We did more things together....Go for walks at night, down at the waterfront. Go all the way down by the bridge. We'd go for long walks, and we were doing our collecting hobby together, going out to see movies, having company over, stuff like that.

Similarly, Art, a caregiver, described keeping things the same as a dominant concern for his partner Stan. Art described his life with Stan as "a little fantasy world" that they didn't want to change. Stan and Art, together with their friend Brenda enjoyed going to the bars--a part of life Stan did not want to give up even when he became quite ill.

> Even as Stan was getting sick, he didn't want our life style to change. It was funny, cause he'd call Brenda at work and say "Well, Art wants to go out." And she'd say "Well, if you're up to it." And then he'd call me at work and say, "Brenda wanted to go out." And then we'd go out. So that was his thing. We'd go out and have a couple of cocktails, the three of us. Stan would go and take his cushion cause he was losing so much weight, he had a bony butt. We'd go out and he'd have a 7-Up. He got up every morning. The only morning he didn't get up is the day he died. He always made sure he was up when I went to work. I don't know, it's like, he really didn't want things to change that much. And I think in his way he was working at it--to be as close to as normal as it could be.

Both Art and Stan worked to minimize disruptions and keep their lives as normal as possible. When Stan grew weaker and could no longer help at home, Art tried to maintain the house in the same way. He cleaned house, kept cut flowers on the tables and put potted plants down the porch stairs as Stan had always done in the past.

Keeping things the same figured in the stories of several caregivers to different degrees. For Stan and Art, keeping things normal was a dominant tone of their lives together during illness. For Laurie and Kiko, keeping things the same largely involved trying to keep things normal for their children. It was an approach that characterized the responses of couples who had established long-term relationships.

For caregivers who did not share established daily routines with the person cared for, keeping things the same took the form of acting to preserve a familiar lifeworld for the ill person. This was the case for Jeannette who cared for her son; for Darlene who cared for her brother; and for others who cared for friends. These caregivers encouraged former friends to keep contact with the ill person and attended to the physical aspects of a caring space, including in that space familiar things from a past life.

Shielding the ill person from humiliation and shame, keeping the ill person in control, supporting the ill person's decisions, and keeping things the same were ways that caregivers in this study found to protect dignity and preserve a sense of self for the ill person. One further action in this domain of concern involved respecting the spirituality of the ill person, referred to in the next section as respecting the spiritual self.

Respecting the Spiritual Self

Terry, a participant who cared for Dewey, his long-time friend and ex-partner, talked at length about the meaning of showing respect for the essence of "who the ill person really is." This conversation was unique among the narratives but was a powerful exemplar of the notion of respecting the spiritual self as a caring response that addressed existential hope and the integrity of the self. Terry viewed the ill person as a transcendent being who was more than the ill body. The following passage paraphrases Terry's descriptions of respect for "who Dewey really was."

> In the spiritual realm, anything that was of any significance whatsoever, Dewey got to do. All I could do was respect where he was at and to share with him to the extent that he wished it....My way of relating to Dewey spiritually, which was a very new thought approach, was to relate to him as a Holy Child of God. To relate to him as the living Christ--heir and brother to the historical Jesus, virtually. That's an aspect of respect.
>
> I would use the word <u>respect</u> as different from <u>care</u>. I could use the word <u>care</u> around physical stuff....changing their diaper or feeding them or anything like that would be <u>care</u>...creating space for the person to be in, holding them when they needed to be held, having their tears or their anger or their frustration, their depression be okay, being able to have them feel safe...I could call that stuff <u>care</u>.
>
> But at the spiritual level, it's like, "I know who you really are, you can't fool me, I know who you really are. You are someone that is awesomely wise and caring and passionate and loving." That approach tends to call that forth in people. If I say to Dewey, "You are whole, you are a whole and perfect person just waking up to who you've been and not this vermin struggling to be something," he is perfect, whole and free and is just figuring out what that means....at a spiritual level, there's not like really anything there for me to do except to support Dewey and understanding more fully who he really was.

In Terry's narrative, we find the dualism inherent in the language of many caregivers in this study. Suggested here is Kleinman's (1988) notion of the body-self, whereby the ill person is both a body and something other than body. As body, Dewey could be cared for--held, diapered and fed. A space could be made for him; his feelings could be acknowledged and accepted; he could be helped to feel safe. As other-than-body, Dewey could only be respected, but not "cared for" in the same sense as caring for the body. Terry respected Dewey's "real self" as "a holy child of

God"--a transcendent being who was already whole, perfect and free. Standing on this Christian interpretation and tradition, Terry did not see loss as the only consequence of the "hideousness" of the illness. He also saw transcendence and took up the practice of trying to understand more fully who Dewey "really was."

Summary

Concerns about dignity, integrity, personhood, and sense of self were presented here as a dominant sphere of moral concern for AIDS caregivers in this study. The interpretation offered here is in concert with Gadow's thesis that caring is a moral endeavor involving a commitment to the protection and enhancement of human dignity and integrity. The cumulative losses associated with AIDS were seen as creating the context for moral concerns and caring practices. Practices aimed at protecting dignity and preserving a sense of self included protecting the ill person from humiliation and shame; keeping the ill person in control; respecting decisions; keeping things the same; and respecting the spiritual self. In the following section, a separate moral concern is presented. A paradigm case is used to illustrate the concerns and consequences of keeping secrets and living with lies.

Keeping Secrets and Living with Lies

As suggested in Chapter 4, secrecy surrounding AIDS is often compelled by social stigma and fear of the negative consequences of disclosure. Though degrees of secrecy vary, having to make decisions about "who to tell" is a universal experience for persons with AIDS and for their families (Brown & Powell-Cope, 1991). Reasons for secrecy may include the desire to protect others from worry; the need to protect oneself from disgrace, undue attention, questioning or pity; the need to protect one's job, medical insurance, or social standing; or the need to protect one's family members from shame, discrimination or ostracism.

In this study, some families chose selective disclosure, which might involve, for example, telling family members and selected friends but withholding information from colleagues at work. A few were concerned about guarding the secret closely, telling only a few persons in a very tight circle of "insiders." Others were completely open about the HIV status of the ill person.

Disclosure of an AIDS diagnosis has unforeseen consequences that may bring significant harm to those affected by AIDS. For this reason, decisions about disclosure are morally relevant decisions that have implications for the person with AIDS and for the family. For those who were not free to disclose, keeping secrets and telling lies became a moral concern confronted repeatedly in day to day interactions with others.

Urban gay men in this study were generally less concerned about secrecy than were wives or caregivers in rural areas. In some situations, gay men were open with friends in their social network but kept secrets from members of the biological family. Three women caregivers described sustained efforts to keep AIDS a secret. Margaret, a wife who cared for her husband Mark; Norma, a sister who cared for her brother Joe; and Laurie, a wife who cared for her husband Kiko, were caregivers who had significant concerns about nondisclosure. Margaret's story presented a paradigm case of conflicting moral concerns that converged on the central issues of keeping secrets and living with lies. In Margaret's long narrative, the overlapping moral concerns of personhood, dignity, control, privacy, keeping promises, causing harm and suicide were interconnecting themes. This paradigm case will be used as a mechanism for exploring the intersecting issues of keeping secrets and living with lies.

Margaret and Mark, a paradigm case. As introduced in Chapter 4, Margaret was a caregiver for her husband Mark during their three years of marriage. Mark feared disclosure of his AIDS diagnosis and insisted that he had a right to keep the cause of his illness a strict secret and that Margaret had a duty to comply with his wish for privacy. He exacted from Margaret a promise not to disclose the nature of his disease to friends or to her closest family members including her mother and three grown children. As Margaret related:

> He went to his death not having told a soul. I was denied the opportunity to get support and got caught up in this horrible web of lies that really persisted until three months before he died....He didn't tell his mother he had AIDS, he didn't tell any of my three children with whom he was very close with, two out of the three. His best friend, his best male, he didn't tell. He didn't tell anyone.

As discussed in Chapter 4, Mark feared the effects of stigma and connotations of AIDS as a gay disease signifying social deviancy. Margaret saw in Mark a fundamental lack of self-esteem which led to his inability to accept AIDS as part of his own self-identity. She explained that during his childhood Mark had experienced himself as the outsider, as someone who was different from everyone else in his family. Mark was an illegitimate child who spent his first two years in an orphanage and was later reunited with his mother and new step-father. His illegitimacy and later adoption were family secrets never shared with Mark, until he accidentally discovered a copy of his birth certificate. This history revealed that secrecy and nondisclosure had played a part in Mark's early family life and identity. As Margaret stated:

> He spent his whole life believing there was something inherently flawed about him. He wrote in the journal "I came into this world in shame, unloved and unwanted" and he was terrified that he would go out the same way. The friends that I talked to afterwards about what was really going on...were just heart sick and angry that he hadn't trusted in their relationship enough and I would tell them it's nothing to do with the quality of the relationship with you that he had. It had everything to do with his personal lack of self-esteem and since he couldn't forgive himself for having contracted this disease, and since he judged himself, and since he couldn't even count on his own mother's love, how could he trust that other people really cared for him. That's truly the tragedy of his life

Mark's underlying lack of self-acceptance extended to his illness. He could not accept or forgive himself for being a person with AIDS. Margaret understood AIDS as a condition that threatened Mark's self-identity and self-respect. Thus, for Margaret, keeping the secret of AIDS was a practice that protected personhood and decreased Mark's vulnerability.

Secrecy forced Mark and Margaret to alter ordinary ways of relating with friends. Due to the uncertainty of AIDS, setting a future social engagement with friends was difficult, yet impossible to explain why. Making up stories, side-stepping issues, and creating false impressions became a practiced way of relating. In order to keep the "awful secret," Margaret and Mark devised ways to dissemble about his illness. Margaret learned how to "cover" for Mark in order to divert attention from his disabilities. In the following text, Margaret described how she covered for Mark on a cross-country trip to visit friends.

> Some friends in Texas gave a dinner party for us when we arrived. He had one of his bouts of horrible vomiting and diarrhea so there's this house full of guests who came to meet my new husband. I lived in Texas for 8 years and everybody's there to meet him. He's up in the bathroom and in bed and doesn't get to meet people. And so the issue is food poisoning. So we do some lying around that.... he was too weak to carry his own suitcase much less mine. And so trying to figure out how to get him involved in conversation and for me to slip out and get the suit cases in because he couldn't walk up a flight of stairs without being short of breath without... I mean like my job was to cover for his progressive physical infirmity in a way that didn't call ... you know ... in a way that didn't call attention to him. And I got good at that.

Margaret worked to disguise the real nature of Mark's situation. As suggested by Goffman (1963), calling the illness by another name, in this case "food poisoning," was a tactic used to deflect questions and avoid stigma. Diverting attention and creating false appearances were further ways to protect Mark's dignity. Through Margaret's actions, Mark was relieved of the socially expected male behavior of carrying the suitcases; being provided with a way out, Mark was able to preserve and project a socially acceptable self-image.

Margaret and Mark remained active and involved with friends and work for many months, and deception became part of daily life. Avoiding, misleading, and maintaining an image were part of their lives together, but not the only part. Margaret referred to their cross-country travel as a "wonderful, wonderful trip," and described many instances of enjoying time together.

Mark's business and professional work decreased but remained an important part of the couple's social world. Work was a way to keep up both a public and privately held image of the self. Mark reported to his office sporadically and made business contacts when possible. Meanwhile, Margaret took over the bulk of the work and continued to act as Mark's cover.

> I remember our office was downtown and we had a couple of rooms and a secretary and our offices were on the second floor so it was a long stairs from the first to second floor. And for a year and a half, when we got to the stairs, he'd say "You go on ahead" and it would take him the longest time to get to the top of the stairs and then he would have to catch his breath. We went to see clients again trying to do this. He was too weak to carry his own brief case from the parking lot in to see the clients. I carried his briefcase till we got just to the door. We'd have to leave early so he could catch his breath before we would go in to a meeting.

Margaret helped Mark maintain his public image and in this way she softened the losses that Mark was experiencing. Travelling, being together, having a social life were aspects that worked very well in their marriage. But these pleasurable parts of life were made possible because Margaret found ways to cover up Mark's "spoiled identity," to preserve personhood, protect dignity, and make possible for him a continued social world.

As illness progressed, the pressure of living with lies increased and the issues of disclosure caused frequent arguments. Though disagreeing about their respective rights and needs, Margaret ultimately subordinated her own needs to Mark's need to preserve privacy and his own sense of identity. She described Mark's insistence on confidentiality.

> The core of our disagreement came down to his firmly held belief that the information about his medical diagnosis was his, and his alone, and that the only persons who were entitled to that medical information about his body were persons that he chose to share that with. He denied to the very end that as his wife I was affected by his illness and that I had rights and I had needs. [He denied] because of our life that is was my information as well, in terms as how it was...affecting me. He never would accept that.

Here it is suggested that Mark interpreted himself as an individual whose meanings, issues, and concerns could be radically removed from those of family, friends or community. Privacy was seen as a nonnegotiable, absolute right, a personal possession disconnected from the interests of others. Mark reduced the intersecting moral issues of disclosure, secrecy, and Margaret's growing isolation to a matter of one's right to possess and control information about the body. Mark was unable or unwilling to connect the issues of personal rights of privacy with the damaging effects of extreme secrecy.

To reinforce his position and to ensure Margaret's allegiance, Mark raised the threat of harming himself. Mark vowed to commit suicide, if AIDS were to become public knowledge. Margaret described this as the "club" that Mark held over her head.

> The club that he held over my head and it worked very effectively for a long, long time was to...threaten me that if I told another living soul what was wrong with him he would kill himself. He would not live if he ever believed that it was common knowledge and that it was up to me whether he committed suicide or not, by whether I would keep his awful secret. It was a horrible threat because he meant it.

Margaret acceded to Mark's wishes but at a considerable cost to herself. She began to experience the breakdown and damage brought on by living with lies.

> The hardest part in our marriage was living a constant lie...to my mother, to my children, to all of our friends...it was the biggest tension between us....He knew it was hurting me, but he own fears were so large that he couldn't release me to talk about it....Psychologically his need for secrecy to the end, that was the biggest conflict in our marriage and in our life and it created, it truly intensified, the struggle to be a caregiver as well, because in that climate of not telling people what was wrong, it also limited the people who could assist me in any way. Because if people couldn't know the diagnosis, then they couldn't be told what they needed to do to protect themselves in giving him physical care. So it absolutely restricted caregivers.

For Margaret, the consequences of secrecy included emotional isolation and the physical exhaustion of being a solitary caregiver unable to seek practical support from family or friends. Secrecy created a distance between Margaret and her children, damaging communication and disrupting former connections within the family. One painful consequence was alienation from her daughter, Danielle. Avoiding questions and lying to her daughter created a serious moral concern for Margaret. She talked about these concerns in a caregiver support group.

> What I used to talk about in the support group a lot was this dilemma. How do I stay in integrity with my children when there are all these lies and then trying to keep the lies straight about why this, why that. It was just, everything. I guess the most common lies were people would look at him, like the kids would look at him and say, "Mom what's wrong with him?" "What's wrong with Mark?" "What's going on?" "Why's he taking all this medicine?" We used the diabetes and diabetic neuropathy stuff to the hilt....
>
> I remember when we got married, my daughter was in high school and she and I had been living alone because the other kids were gone for three years. She was then my best friend, and she had mom all to herself, and I'd raised her alone since she was two. And all of a sudden this man comes into our house in our life and it's somebody that she adored and with whom she had a far more affectionate and real relationship than her biological father and all of a sudden she's cut out. She lost her place in the household. She'd come into the room when he was first home from the hospital and of course, we were consumed with talking about what all this meant in our lives. Probably 90 percent of the conversations within the first 60 days were related to his illness...how long he was going to live and what it meant, and if he'd ever be able to go back. Any time she'd come into the room, we were quiet. She processed that as total rejection and then did this acting out thing. So by the spring she left not speaking to either one of us.... She moved out, and they were never reconciled the two of them.

The intent and end results of secrecy are to control information, protect the self and exclude others. In this situation, Danielle experienced the sense of exclusion created by secrecy. The relationship between Mark and Danielle was "poisoned" by these effects.

Though Margaret learned to monitor herself and became practiced at being indirect or keeping silent, AIDS is a disease that eventually becomes hard to disguise. Danielle eventually suspected that Mark had AIDS and confronted her mother, demanding to know the truth. Though eventually reconciled with her daughter, Margaret described an evolving situation of growing dilemmas in relating with Mark. Having failed in her promise of sworn secrecy, she now had to contemplate how truthful to be with her husband. How much should he know about her disclosure to Danielle? Truth telling and "being in integrity" with Mark was seen by Margaret as a moral imperative. She described Mark's strong reaction when he learned that Danielle had been told the secret.

> He just went insane....He went out of here...and I didn't know where he had gone. I expected when I came home that I might find him dead. That he might have done that. I remember that day being in just agony wondering "Do I call the police? Do I call his doctors? What do I do?" I really thought he might be taking his own life and at that moment he was crazy with fear, crazy with rage, crazy. I remember calling my own counsellor and saying, "I've got to see you within hours." Morally I was caught in this terrible dilemma.....The dilemma was: might he do something to try to end his life and who do I? Do I need to talk to his doctors about this? He hadn't talked to them about this suicide plan and what all he was gonna do. What was he going to do? Is he going to do something rash out of this terrible, painful place that he had gotten himself into because of my behavior? And because of the emotional volatility of where he was and his anguish? He was crazy and...I felt like he needed to be restrained from doing that. I was just terrified. So I ended up being relieved when I came home and he was alive. I didn't know whether I would find him dead or not.

Here Margaret described the experience of being caught between conflicting moral concerns and the emotions connected with not knowing the right thing to do. Mark's "insane" behavior and threats of self-destruction were terrifying and connected in

Margaret's thinking with her own behaviors of breaking a promise and betraying his confidence.

Individual rights, from Mark's position, were paramount, and in previous conversations Mark had reserved for himself the right to end his life. For Margaret, the situation presented multiple sources of moral confusion. She struggled with questions about how to locate the right action under the particular circumstances. Was suicide Mark's right? If so, was suicide a right only under certain circumstances and not others? If this situation represented a "rash" gesture on Mark's part, rather than a carefully considered one, what should she do? What were the implications of trying to restrain him? If she were to stop him, would there be further damage to his dignity and the integrity of their relationship?

Margaret contemplated the limits of secrecy. Where were the boundaries between causing harm and doing good in this situation? She had overstepped one boundary by disclosing Mark's diagnosis to Danielle. Should she now overstep further boundaries and disclose Mark's suicidal ideation to his doctors? To the police? Though terrified, Margaret decided not to act in this situation. She returned home and was relieved to find Mark alive.

The damaging effects of secrecy and Margaret's emotional isolation culminated in depression. Margaret was drained by the mental and emotional tensions of living with lies.

> I wanted to be able to tell my children and our most intimate friends that he was dying and that he had AIDS. It wasn't so much that he was dying. Because it was the frustration for me of living in the absence of this integrity. Every time I told a lie, it created such mental and emotional tension for me, at

> a time when my energies were already so sapped by the physical demands of caregiving and the emotional horror of watching this person I adored die. [I had] the uncertainty of knowing whether I was going to have him for a week, a month, or another year, and then to have this addition crap in terms of my inability to be truthful to people who really mattered and also my inability to get any sort of emotional support from people.

At one point, Margaret became deeply depressed. She described having thoughts about devising ways to share Mark's disease.

> I got very, I got clinically depressed at a point, about a year into his illness and our marriage. What was the alarm bell for me was, I knew I was sad, I knew I was depressed, but I got into this whirlpool of pessimism. That I just felt like everyday I was sinking further and further into this place I'd never been before. I was seeing a counsellor almost weekly in addition to the support group, and that was helpful and she knew everything, but the it wasn't enough. When I knew I had to get some medical help was when I was drawn for quite some time to his dirty needles. I desperately wanted to die. I desperately wanted to die after he did. I wanted to share his illness. I didn't want him to leave me. I wanted to have AIDS too....and so it was true suicide and the means were right at my disposal and those needles were still, just were calling to me and so I got on antidepressants.

Margaret sought help, was placed on medication, and survived her depression. After a year of counselling, she stopped taking antidepressant medication. She also sought ways to resolve the situation of being caught in the middle of concerns and responsibilities for her husband, her children and herself. She joined a support group in a distant city where she and her husband were not known. She decided that she would not voluntarily disclose Mark's status to her children, but she would tell the truth if she were directly asked. She stated that eventually, "the lies were so obviously lies that people quit asking."

Though in one sense it was easier for Margaret when "people quit asking," it was also more isolating. Throughout the experience, Margaret was aware of the costs of secrecy. She carried a physical, psychological and emotional burden that was exacerbated by the self-isolating effects of the secret. She had few people to call upon for practical help. Though she was not physically or geographically distant from family or friends, she was emotionally cut off. She was deprived of needed emotional release and was in conflict with her own values of "being in integrity" with those that mattered most to her. In this latter sense, she experienced a kind of crisis of the self; "living in the absence of integrity" was an existential problem that Margaret could not resolve until the last days of Mark's life, when she began to disclose the cause of Mark's illness to their friends and family members.

These issues were cast against the positive and person-preserving effects of keeping the secret. Mark's life was made bearable by Margaret's protection of his sense of dignity, preservation of his self-identity, and his social world.

The effects of secrecy. Secrecy has both positive and negative effects in the lives of families affected by AIDS. Though secrecy can protect a family from unwanted intrusions and discrimination, it can also encourage conflicts over control of information and power relationships within a family. Connections within the family can be disrupted and reordered by the secret, which pits insiders and outsiders against one another.

It is possible to understand Margaret's position as one of being caught in the middle of a dilemma with no acceptable alternatives. For Mark, fear of disclosure deformed the experience of being ill and added to his physical and emotional suffering. Secrecy was needed to protect Mark's sense of being a person in the world, yet it was the root cause of breakdown for Margaret and damaged her lines of connections with the people who mattered in her life.

In Secrets, Bok (1983) presented an analysis that has relevance for understanding the moral concerns and experiences of concealment in the lives of persons affected by AIDS. Bok stated there can be no moral presumption either for or against secrecy. Keeping secrets is a human practice that has both positive and negative effects. A degree of concealment accompanies all that human beings do or say, and it is by examining particular practices of secrecy that we determine which practices are discreditable and which are not. Secrets impose burdens but also confer power to those who conceal information. Insofar as concealment creates separations and serves to distance people, secrecy has the potential to isolate and to thwart moral perception and choice. Conflicts over secrecy--either between the society and the individual or between individuals--are conflicts over power. Holding back information about oneself influences how one is seen by others. To have no capacity for secrecy is to be powerless and out of control over how one is seen and responded to. Control over the balance of secrecy and openness in one's life preserves central aspects of identity, allowing people to guard their autonomy and ultimately their mental well-being.

Both the positive and negative aspects of secrecy are demonstrated in Margaret's story. Though the extent of Mark's concealment seems extreme, keeping AIDS a secret is a gesture that protects and preserves central aspects of Mark's identity and well-being. Margaret put Mark's well-being foremost in her thinking and action. Thus, covering up and telling lies were aspects of a protective concern.

Like other exercises of power, secrecy can spread and become obsessive. In this situation, threats to Mark's self-identity seemed to diminish his capacity to comprehend any other moral perspective; and his consequent exercise of power and control seemed out of proportion to Margaret's suffering. Extreme secrecy can distort perception (Bok, 1983). Fear and the need for extreme secrecy distorted Mark's experience of illness, added to suffering, and at times led to his "insane" behavior. Margaret's choice was to "remain in integrity with her husband," a man whom she loved and with whom she shared an otherwise very rich life.

Secrecy was an aspect of the experience of other caregivers in this study, although not to the extreme degree described by Margaret. Norma, a caregiver living in a rural community, also felt the isolating effects of living with secrets. Laurie and Kiko carefully guarded the secret of AIDS out of fear that their young children would be the targets of negative repercussions. They eventually identified a group of supportive friends and family members who were told. Their decision for partial disclosure was more typical of families in the study.

Being There

During interviews, caregivers in this study were asked what was most important about their care. Following MacIntyre (1984), the intent of this question was to solicit narrative that would promote an understanding of the notion of the good embedded in caring practices. With few exceptions, caregivers' common response was stated unhesitatingly as "being there" for the ill person.

Several caregivers used the terms <u>being there</u> or <u>being present</u> to articulate what was most important in their care. Roy described more fully his understanding of this moral concern in the following passages.

> When we were at home, we were constantly dealing with needles and what if he had another convulsion and what if he had a seizure because he was having seizures rather regularly. And that wasn't giving care at all. That was just being in panic mode all the time. And being in the hospital and knowing if he had another convulsion, another seizure, all you had to do was push a button and a real technical person would be there to aid you and...you could do the kind of caregiving of holding a hand, and being there, and supporting. Being there for that person, being there emotionally.
>
> And that was important. I just couldn't give any more technical care. But even during that period in the hospital, I was there every time the nurses changed him. I was there to help roll, and change, and move the sheets. I never gave up the technical care, but I was sure thankful for that extra technical support so I could give the other kind of emotional care. Which was paramount and absolutely the most important type of care that you wanted him to get.

For Roy, being there had the meanings of being there in the physical sense to help roll, change, and move sheets, but more importantly being there in the emotional sense--to support by being present and responsive to Doug's feelings.

During a second interview with Roy, I asked more directly what he viewed as the most important part of his care. Roy confirmed and validated his earlier statements.

> L: If you had to say the one part of your care that was most worthwhile, what would that be?
>
> P: It was emotional support. Yeh, that was the most important. I mean you can have all of the incredible technical care in the world, but if you don't have the emotional care to back it up, it doesn't mean much.
>
> L: What goes into emotional care?
>
> P: Being willing to communicate, and to listen, and to talk, to be able to talk and express how you feel and to be able to be calm enough and quiet enough and open enough to listen to what the other person is trying to communicate....just trying to be there and physically present, and emotionally present for Doug. That if he should wake up or he should come to

> consciousness and be at all concerned about where he was or what was going on that there would be someone there to hold his hand, a familiar voice, to say "It's OK." "What do you need?" "What do you want?" "Everything's under control."

Again Roy relayed that what was most important in care was the double sense of being present to the ill person both physically and emotionally. Being there in the emotional sense included listening, being available to talk, sharing his own feelings, being open enough to Doug to really hear what he was trying to communicate. Being there in the physical sense meant being there to hold a hand, being calm, being quiet.

Roy's spontaneous description of what mattered most in his care suggested Swanson's (1991) definition of "being with." In her middle-range theory of caring, Swanson described the caring process of "being with" as "being emotionally present to the other."

> It involves simply "being there," conveying ongoing availability, and sharing feelings, whether joyful or painful. Yet, the presence and sharing are responsibly monitored so that the one caring does not ultimately burden the one cared for. Being with...is more then understanding another's plight; it is becoming emotionally open to the other's reality. The message conveyed through being with is that the other's experience matters to the one caring (Swanson, 1991).

Al, a caregiver for his partner Don, responded much like Roy when asked what was the most worthwhile part of his care.

> L: What seemed to be the most worthwhile part of your caring?
>
> P: Being there to help somebody out when they need it. Just there to listen to them. Help them out. Do what you can. Make them comfortable.

Some caregivers, like Dale, emphasized the physical sense of being there for the ill person.

> I wouldn't let myself get away from it. The only times I got away from it was when I had to go and pick up meds. Like morphine or something at a pharmacy. There was one time I had to go pick morphine up; so I got away from it for about an hour. That was when the relatives were here. That was it. But I didn't want to get away from it. He needed me there, you know, that man was dying and the thing that meant the most to him during those last few weeks of his life were the fact that I was there by his side.

Summary

Caring practices can never be reduced to a formula or a list of tasks because they are guided not only by the contexts in which care occurs but also by the moral concerns that are held by caregivers and the people they care for. In this chapter, moral meanings and concerns of AIDS caregivers were considered. Moral concerns were seen as fundamental to caring practices, shaping responses and guiding what caregivers attend to in any particular situation.

In this account, the multiple meanings and kinds of losses experienced by people with AIDS were seen as creating conditions for caregivers' concerns about dignity and a sense of self. Practices aimed at protecting dignity and a sense of self were explicated. These included protecting the ill person from humiliating and shame, keeping the ill person in control, respecting decisions, keeping things the same, and respecting the spiritual self. It may be that the moral concern of protecting dignity is a near universal concern linked with human caring; however, the practices that emerge from this concern may be quite varied. Issues of "returning control," for example, may or may not be a central practice among those who care for women or for persons from diverse ethnic groups.

Several caregivers expressed concerns about the needs for concealment, keeping secrets, and living with lies. These concerns were introduced in Chapter 4 as an outcome of the extreme stigma that society attaches to AIDS. In this chapter, a paradigm case was presented to illustrate how secrecy and living with lies can become a moral concern intertwined with issues of power, identity, and control. Being there was presented as an aspect of the notion of the good integral to the caring practices of participants of this study. For caregivers, being there conveyed both a physical and emotional sense of being present and available to the ill person.

In the following chapter, I will turn to the third part of the overall thesis used to organize this interpretive account--that the progression of the disease shapes a general continuum of care that can be traced through the narratives.

CHAPTER 7

CONCERNS AND PRACTICES ACROSS THE CONTINUUM OF CARE

The moral issues discussed in the preceding chapter form threads of concern that run through many, if not most, of the caring practices identified in this account. In this chapter, concerns about dignity and a sense of self, as well as questions about doing good or causing harm, are evident in the examples of care. Here, however, I wish to emphasize a third aspect of the overall interpretive account--that caregivers' meanings, concerns, and caring practices are shaped by the specific course of disease in the ill person.

Although AIDS conforms to a generally predictable course of immunological demise, there is tremendous variation in the combination of opportunistic infections, cancers, or AIDS-related syndromes experienced by specific individuals. Thus, specific concerns and caring practices may look quite different from case to case. However, the overall progression of disease presents enough similarity that a general continuum of care can be discerned. This continuum is characterized by changing concerns and caring practices which may be traced along a common path.

The two concepts of trajectory and transition were helpful in laying out an account of disease progression and a continuum of care.

The Trajectory of Illness

Strauss et al. (1984) introduced the concept of trajectory and its associated work (trajectory work) as a central notion for explaining the experiences and problems of the chronically ill. Strauss distinguished between a <u>course of illness</u>, which has more or less characteristic symptomatic phases known to medical science, and an illness trajectory, which refers to the total organization, meaning, and impact of the work done by ill persons and their families to handle contingencies of illness as best they can. Many of the aspects of trajectory work as proposed by Strauss and his colleagues fit the experiences of persons with AIDS and their primary caregivers.

AIDS is a disease with an uncertain course and trajectory. For any given individual, it is uncertain which related cancer or opportunistic infection will arise; what combination of disabilities might develop; or when disabling or disfiguring conditions will appear. As observed by Strauss et al. (1984) and documented by Brown and Powell-Cope (1991), uncertainty both in the course of illness and in the associated trajectory of work needed to managed the illness tends to maximize hardship for persons with AIDS and their family caregivers. In relation to uncertainty, the ill person or caregiver may seek cues or carefully watch for signs indicating a move to a worsening phase of illness. As phases of illness advance, a person's view of his or her trajectory can profoundly affect the sense of self or personal identity (Strauss et al., 1984). Additionally, chronic disease and its management alter social interaction, often leading to loss of contact and social isolation. Uncertainty, threats to self, and social isolation are aspects of the chronic illness trajectory noted by Strauss et al. (1984) and are also aspects of the AIDS caregiver experience documented by Brown and Powell-Cope (1991) and pointed out in the previous chapters of the present account.

Transitions

Transition has been conceptualized as a process occurring over time involving movement or flow from one state to another and containing stages or phases (Schumacher & Meleis, 1994). Transitions in individuals and families include changes in identities, roles, relationships, abilities and patterns of behavior. Meleis (1991) defined transition as:

> Change in health status, in role relations, in expectations, or in abilities. It denotes changes in needs of all human systems. Transition requires the person to incorporate new knowledge, to alter behavior, and therefore to change the definition of self in social context, of a healthy or ill self, or of internal and external needs, which affects the health status.

Brown and Powell-Cope (1991) identified "transitions through uncertainty" as the core category of their theory on AIDS family caregiving. Transitions in their work and in the present account can be understood in at least two ways. In one sense, transition refers to the entire caregiving experience as a life stage that may last for a few months or extend over several years. Brown & Powell-Cope (1991) viewed the caregiving transition as "a period of major change in life circumstances accompanied by uncertainty, questioning one's basic assumptions, and reexamining plans for living in the world."

Data from the present study support the notion of the caring experience as a significant and transitional life phase. Theresa, for example, stated that "It's changed my life. I'm now a care provider. It's been a growing experience for me." In regards to her caregiving experience, Norma stated:

> Your whole life changes. You cherish life a lot more. You don't put an emphasis on the things that are not important.

Transition, in the second sense, can be understood as changes in caregivers' concerns and practices occurring during the illness and in response to the progression of the disease. The focus of this chapter is on this second sense of transition and change.

In this chapter, I will discuss how particular caring concerns and activities emerged and then changed during the progression of HIV disease. Though specific caring practices were seen to change with the progression of the disease, the moral stance of caregivers appeared to be characterized by fairly stable moral concerns. Concerns about dignity, for example, were reflected throughout the continuum of care, though specific caring acts played out differently as the ill person moved from early to mid to late stages of disease.

The Continuum of Care

Understanding transitions in concerns and caring practices demands some insight into the sources of change for caregivers and the person with AIDS. Events in the natural progression of HIV disease and responses to those events were the root sources of change in the caregiving experience.

Though manifestations of HIV disease vary widely from person to person, the progression of disease can be predicted in a generalized way (Pantaleo, Graziosi, & Fauci, 1993). latency can extend for several years before constitutional symptoms such as weight loss, fevers, or fatigue. Constitutional symptoms mark the middle stage of disease which begins the highly unpredictable course of events that contributes to the experience of uncertainty. After a critical level of immune dysfunction is reached, AIDS-defining opportunistic infections and/or cancers develop, marking the onset of advanced-stage disease.

During the latency period, the HIV infected person is typically well, may or may not be aware of their HIV-positive status, and may require no special assistance. Emotional and psychological issues, however, may be prominent for those who know they are HIV positive. In later stages, as opportunistic infections and AIDS-related syndromes take hold, needs for physical care and emotional support intensify. Duffy (1994) described 14 crisis points in the progression of HIV disease which may lead to crises for persons who are HIV positive. Duffy listed these as: making the decision to be tested, receiving the result, obtaining medical care, noticing physical changes, experiencing HIV-related symptoms, disclosing to family and friends, being hospitalized for the first time, receiving an AIDS diagnosis, changing life styles, making decisions about terminal care and preparing for death. Some of these events may also precipitate changes in caregivers' concerns and practices.

For this study, understanding the general outlines of disease progression in any one situation was useful for gaining insight into caring practices. During interviews, I asked caregivers to sketch out the course of the disease and the associated trajectory of illness events experienced by the person with AIDS. I asked for specific dates of new diagnoses, hospitalization, or the emergence of new symptoms in order to get a sense of the nature, pace and magnitude of changes that were occurring. I used this overview to prompt caregivers to discuss caring practices associated with events in the trajectory of illness.

As illness events or crises became more frequent, many caregivers described a period of "getting settled" for caregiving. This period of time may have involved moving to a new house, relocating to a different city, or moving in with a relative. The emergence of new symptoms or diagnoses may have created the need to seek medical care from a new specialist, adjust to a new clinic or caregiving regime, acquire new skills, or gain knowledge about foods, medications, equipment, or treatments. Disability might have resulted in significant changes in financial resources and lifestyle. In other words, the progression toward AIDS, disability and ultimately death set up a changing life world where concerns, skills, practices and abilities were also in flux.

Since the course of disease varies markedly in HIV infection, specific concerns and caring practices looked different from one situation to another. Taken together, however, the narratives reflected common patterns. Many caregivers, for example, referred to turning points or shifts in their awareness when concerns and caring practices took on a different character or intensity. During these shifts, new caring practices might be called forth or earlier practices dropped.

Some practices such as being there for the ill person might be initiated early in the chronology of care and intensify throughout the caregiving experience. Other caring practices, such as attending to the caring space, mastering technical skills needed during "high gear" technical caregiving or coordinating complex care such as care teams might be worked out by caregivers only in the very late stages of illness. Other practices, such as concerns and actions related to providing food might eventually be dropped. Concerns such as addressing issues of faith and spirituality or talking about death may not take place at all, depending on how the ill person chose to cope with having AIDS or whether the ill person was affected by AIDS dementia. In the following sections, I wish to highlight events in the trajectory of illness and describe changes in concerns and caring practices.

Adjusting to the Diagnosis

As documented elsewhere (Pohl, Kay, & Toft, 1990), learning about one's HIV status is typically a catastrophic event that affects not only the individual who is HIV positive, but the individual's entire family and system of friends. Typically, reactions to learning about one's HIV status include feelings of shock, anger, fear, denial, withdrawal, sadness or shame (Pohl, Kay, & Toft, 1990). Caregivers in this study typically experienced these same emotions; a period of adjustment was needed before they could envision what kind of action to take or how to move forward.

Denial and avoidance. Several narratives suggested the effects of the interconnected meanings of denial, avoidance and maintaining hope in the face of HIV disease. Narratives suggested that as adjustment to the diagnosis occurred, responses to the diagnosis may have shifted from an initial denial to an awareness of using avoidance to maintain hope.

Some caregivers, especially those who were not connected with the gay community, went through a period of profound shock, disbelief, and denial when learning about the HIV status of the person cared for. Denial was a word used frequently by caregivers in relation to learning about the diagnosis and in relation to accepting the ominous meanings of signs of advancing disease. Jeff referred to Chip's "classic denial" about being HIV positive.

> He was pretty depressed for awhile And it was hard to get him to talk about it. It was hard to get him to talk about any HIV/AIDS issues at all. When something came on the television, it would be turned off or switched channels. He was in classic denial.

Denial may be an initial protective mechanism which allows time for adjustment. When it delays or prevents getting help, it may have negative effects for the ill person and for the caregiver. As Jeff remarked:

> It was infuriating to me because he wouldn't talk about it. And by not talking, he wouldn't do anything about it. And you can't force a person. You can't tie them down. And I would try different things. I would try, "Look we're together, we love each other, but if you're not gonna take care of yourself, it's kind of a slap in the face to me."

In this study, there were several stories of initially delaying or avoiding medical care as in the above case. Laurie's narrative described responding to a positive HIV test with disbelief, denial and avoidance.

Laurie is a 31-year-old wife who cared for her husband Kiko during two and a half years of illness. Before his AIDS diagnosis was known, Kiko, a 33-year-old Mexican national, became acutely ill and nearly died due to extrapulmonary tuberculosis. After recovering, Kiko applied for life insurance but was denied because of a positive HIV antibody test. At the time of the insurance denial, Laurie was pregnant and planning to deliver their third child. She consulted her obstetrician about Kiko's positive HIV result and learned that Kiko had probably already progressed to AIDS. Neither Kiko nor Laurie were knowledgeable about the issues presented by AIDS. The news of HIV disease was experienced as a profound world-altering shock. As Laurie described their reaction:

> It was just horrid. I wasn't so worried about myself, I was worried about this baby. I was so scared. What about this poor little baby? What if he's born with it? What if Tina has it? It was just horrible.... I remember one time he broke down and said, "Oh, Laurie, if I've given this to you, I just hope you can forgive me." And he was just bawling. And I said, "Hey, it could be me giving it to you. Who knows? I could have given it to you for all [I know]." We were really distraught. We spent a long time; we'd put a movie on for the girls and go out and talk under the tree or in the truck or something or over by the hammock. It was like just this big cloud had descended over us.

Laurie and Kiko responded with shock, disbelief and dread that the virus could have already passed between them or to the children. The notion of asking forgiveness suggested Kiko's feelings of blameworthiness and guilt associated with culturally embedded meanings of AIDS as retribution for sin. In their distraught state, Laurie and Kiko waited one week for Laurie's test result, which was negative. She recalled at that point their urge to put Kiko's situation "out of their mind."

> I said, "Oh that makes me feel better because maybe it's not true. Maybe Kiko's isn't true." How can it be possible that I'm negative after all these years. How can it be that way? ...When I told him it was negative, he was just so happy. He hugged me and he was dancing me around, but I couldn't get that happy until I knew that he was negative too. I thought "How can you be so happy Kiko?" If what they say about you is true, how can you be so happy for me? But he said, "No, no...If you're great, I'm happy."...So we just kind of put it out of our mind for awhile.

Laurie and Kiko were preoccupied with a new baby and tried to put HIV "our of mind." They continued to build their private business and kept Kiko's test result a secret.

During the following months, Kiko tested two more times-- each time looking for a negative result; yet each test confirming that he was, indeed, HIV positive. After the test site nurse urged them to seek medical care, Laurie and Kiko decided it was time to move forward and seek help. As Laurie recalls,

> We were just so scared. We didn't know anything about it. I mean other thar a few press things that we'd read. When we were told to get ahold of this doctor, I didn't want to....It was such an ominous thing to us. We thought, "We're going to be stigmatized and people are not going to want to have anything to do with us." ...If I make that phone call to this doctor, that's just going to make it real....See we really didn't know anything. And we didn't want to know in a way.
>
> So we were doing our business. We would go to the test site and get this bad news and then we'd go and work on the business together. It was his way of dealing with stuff. If it's a negative, he kind of just put it on a shelf and didn't want to always talk about it. When I got kind of talking too much about it, he'd say, "OK that's enough. I can't handle any more. It's making me sick."

Learning about Kiko's HIV status was a major life crisis, a profound shock, and a turning point for the family that was followed by a period of denial, fear and avoidance. The social context of stigma and the meanings of being ostracized by other promoted avoidance and contributed to fear, denial, and delayed care.

Within six months of the initial test result, Kiko suffered a second crisis and was hospitalized again in critical condition. After this event, Kiko learned that he was "in stage 6 HIV disease." These events marked another transition for Kiko and Laurie, who had now been forced to confront a new reality and take up questions about what to do next.

For Kiko and Laurie, learning about the AIDS diagnosis was the first step in confronting a progressive series of life-altering changes. After a period of avoidance and adjustment, Laurie stated that they had to "normalize the crisis." They faced the fear of AIDS and sought medical help.

Maintaining hope. The narratives suggested that over the course of illness, denial sometimes took on a form which involved viewing life with hope, perspective, detachment, or even humor. This is a form of response described by Pohl et al. (1990) as "positive denial." While fully admitting that AIDS had entered their lives, Kiko and Laurie, like other families, did choose to pursue their interests, to continue building their business, and to find humor in many of their situations. Even during the most frustrating moments, Laurie commented that "we were able to maintain our humor. That's the only way we could survive it."

Near the end of Kiko's life, Laurie supported her husband's hopes for getting better in the warmer climates of Mexico. Knowing that Kiko was far too ill to make the trip, Laurie nonetheless made efforts to prepare for his return to Mexico, supporting a kind of "positive denial" and in so doing maintaining Kiko's hope. As Laurie explained:

> In his mind, he was still gonna get better. And he was still gonna be able to get even better down there. He would be able to get around on the bus system and he could go to Guadalajara and visit all his friends and his family. His idea was to get down there. He wanted to go home and he wanted to see his brothers and sister. He knew that he needed a goal. He always had a new goal to look forward to and he knew that was his new goal. He always had to be planning ahead. I mean that was what kept him alive as long as it did. That was his way. You have to have something to look forward to.

For Laurie, maintaining hope involved recognizing and supporting the importance of "new goals to look forward to." Laurie attempted to sustain the everyday experience of projecting the self forward into the future. Holding on to the goal of going home to Mexico was Kiko's way of projecting the self forward and maintaining hope in the face of life-threatening illness.

This notion of maintaining hope is similar to Swanson's (1991) category of caring called "maintaining belief," where "the one caring maintains a hope-filled, as opposed to hopeless, attitude" and offers optimism. Throughout caregiving, primary caregivers may tread a fine line between expressing a positive denial that supports hope and a more negative denial that avoids reality and therefore prevents getting help.

The interconnected and changing patterns of denial, avoidance, and hope can also be seen in the contrasting situation of Jared and Dennis. Jared is an HIV-positive gay man who cared for Dennis, his partner of 11 and a half years.

Gay men, especially those who had high risk behaviors in the past, may have lived with a paradoxical sense of "hoping that they had escaped HIV," while quietly assuming that the disease was already part of their lives. For Jared and Dennis, learning about one's HIV antibody status and level of immune dysfunction were definite calls to shift concerns from avoidance and hope to facing the fear of AIDS.

In the following text, Jared explained how he and Dennis viewed the issue of being tested for the AIDS virus during the mid-1980's.

> Dennis was a promiscuous gay man in New York for nine years. And by that, he was going to bath houses and being in sexual situations where he would clearly had been at risk for exposure to the HIV virus....I think we knew that he had been in a place that it was <u>very</u> likely he should have been exposed. All we could do at that point, because there was nothing anybody knew what to do, was you crossed your fingers and just sort of hoped for the best and hoped that somehow you had not been exposed.
>
> The assumption was that I would have been exposed through my contact with him. We always assumed from very early in the relationship that we both were vulnerable. I don't know when testing for AIDS began to show up, maybe about '85, '86....There were a lot of issues early on about confidentiality and what happens with insurance, what happens if you have this, so it was fairly controversial when it first came out. We were pretty

> attuned to that dialogue in the gay media.
>
> I think we made a decision...from '86 through winter of the early part of '89, the reality was there was nothing available to do about AIDS. So you can go and do a test for antibodies and you can learn you have this disease and then there's nothing more to do about it except wait. And there was not anybody I knew who could testify that they were happier or better off for having that knowledge. So it was a very conscious decision that we're probably infected and you don't know when that's going to become active, but we'll still keep our fingers crossed and the longer the time goes, then maybe, just maybe, we'll have been lucky enough to avert exposure.

In this passage, denial is tempered and hope is measured; yet these issues can be seen as intersecting concerns. Avoiding knowledge about HIV disease was seen as having a direct impact on one's happiness. Before AZT, the blunt reality was that no medical treatments were available for HIV positive persons who were well. Being unable to identify any positive benefits of knowing one's HIV status, Jared and Dennis decided to avoid testing. They hung onto a quiet hope that they might have escaped exposure. As Jared remarked:

> I did not want to bring that unhappiness into our lives when there was nothing to do about it. In winter of 1989, the rules changed, AZT became available in a general way, and AZT clearly seemed to be having an impact on people's survivability. And it became the first time that the argument said, "Go get tested; get early intervention." It now makes sense to have that information; there's something you can do about it, that it's not going to cure you, but it might impact your ability to stay healthier longer.
>
> And with that we made the switch saying "Okay, the time has come." And so we went in and we did anonymous testing.

For Jared and Dennis, AZT triggered the transition from living with avoidance to living with a more secure sense of what they now had to face. The test made their situation real. As Jared remarked, "It put the ghost to rest."

> Dennis used to talk about a metaphor that you know, "Run from a ghost and it

> will change you; turn and face it and it will go away." I think that was really true for him.

The issues of denial, avoidance and maintaining hope are introduced early in the progression of HIV disease. Initial reactions to a positive HIV antibody test may include the mixed responses of denying, avoiding, and hoping. Of course, learning about one's HIV status may come at different points in the progression of disease. A with Laurie and Kiko, illness of crisis proportions may be the first indication of underlying HIV infection. In other situations, antibody testing may occur during the latency period and be followed by long periods of wellness. Initial reactions of denial and avoidance may change character as the disease progresses, taking the form of "positive denial" in which caregivers maintain hope and promote a positive outlook on "living life." When initial shock, fear or denial are overcome, HIV may become the stimulus for making changes and "living life to the fullest."

Care During Wellness

In the natural course of HIV disease, the period of clinical latency may last for several years. Jared, for example, has been HIV positive for 10 to 11 years and has maintained wellness throughout this period of time. Even when CD4 cell counts drop markedly, the person with AIDS may enjoy extended periods of wellness and independent functioning. Stories of caring during periods of wellness were not prominent in the data. Most of the participants did not identify themselves as "caregivers" during long periods of wellness and may have skipped over stories of caring activities. More data using a longitudinal design to follow caregivers would be needed to uncover more detailed stories of concern and care during periods of wellness. There were suggestions in this data base, however, that during wellness, caregivers' concerns and practices clustered around two patterns: maintaining an atmosphere of balance and normalcy in daily life and making the most of present time.

Maintaining balance and normalcy in daily life. Pohl, Kay and Toft (1990) provided some insights into the activities of care during quiescent periods of HIV disease. They described four stages in the AIDS caregiving experience, which they labelled discovering, adapting, coasting and colliding. They suggested that these stages are "artificial" but useful guideposts for caregivers. All caregivers may not experience all four stages; they may experience the stages in a unique order, or may cycle through stages again and again.

The notions of "adapting" and "coasting" were useful for describing caring during periods of wellness. Adapting was described as what caregivers do to try to get on with life or make life regular again. This period may involve revising life plans or taking action to change one's circumstances in an effort to make things either "normal" or somehow "right" (Pohl, Kay, & Toft, 1990). Jared, an HIV positive caregiver, described his own experiences as an HIV positive person to get the right balance in his life. He began to examine major life decisions and decided to change jobs.

> I was under a lot of stress at the job that I worked at. I was not happy in the office that I was working at and for me, it was just very clear, that if HIV is really now confirmed, then what are the important decisions in life? I was very clear I wanted out of the work situation I was in. I switched jobs within probably a month of that.

Caregivers, especially those how are themselves HIV positive, may help with such "adapting" strategies during early periods of wellness, although as stated these stories tend to be overshadowed in the present study.

Pohl, Kay and Toft (1990) described "coasting" as achieving balance, getting used to a changed lifestyle, and changing relationships with friends. For some caregivers in this study, especially for the gay men, wellness was a time of getting involved in community and setting up systems of support. Rachel described these responses in the following passage about Clark.

> Clark went to a support group. And it was good for him. And I was just as pleased as anything he found a support group to go to. The first one he went to he didn't like. He thought the facilitator stunk and it was sort of that stereotype of the worst support group. Some facilitator who was not HIV positive and wasn't gay who said, "I see that Tim is angry tonight. Tim would you like to tell us about it?" And this just sent Clark through the ceiling. But he met another man there, Barry, who has since died. They sort of became pals. They became sort of telephone pals and would eat breakfast together. So then they decided to advertise in the gay paper for a social group. They were sick about talking about their disease. They just wanted to meet other people in their same situation and look to the positive.
>
> So they had these Friday night gatherings, every other Friday night. People brought food and it was just to meet other people and socialize. That was perfect, I loved it. All I had to do was drive him there and drop him off. It was really nice. And I was excited that he found support and I felt that was a great deal.

During periods of relative wellness, it was important for Clark to set up a system of support that felt right and that didn't emphasize illness. Rachel facilitated these interests but largely stayed in the background while Clark negotiated the "coasting" phase of coping with illness.

Making the most of present time. Living with HIV or AIDS forces the recognition of a limited future. In response to this meaning, caregivers described efforts to improve the quality of time left for the person cared for. Roy, for example stated: "The thing that was most important to me was to be here for him. To make sure that the quality of his life stayed as high as he could possibly get it." Referring to the presence of AIDS in their lives, Roy remarked:

> I think what it did was that it increased our dedication to have the best quality of life possible. It's like, "OK there may not be a tomorrow, then we're gonna make pretty damn well sure that today is quality-plus. A-plus to the nth degree."

Having the material resources to optimize their present time, Roy and Doug ate at the best restaurants, travelled to Hawaii, and spent five weeks exploring Europe, a trip Roy described as "second to none."

Travel was a common enjoyment described and used by caregivers to optimize present time. Trips were often a form of making pleasurable memories. Even during advanced-stage disease, travel was a way to optimize the present. Rachel, for example, worked to optimize present time for Clark even after long periods of wellness were no longer in his future. Rachel took Clark on several trips, packing up supplies, unpacking, and setting up ganciclovir infusions in their motel room. As Rachel stated:

> We'd go in the motel room and figure out how we were going to hang the bag higher than his heart and how I could hook it up. I'd take picture frames up. We rigged up stuff all over the place to make it happen. And we had to keep things cold and...counting out the number and take a small sharp's bucket and how many alcohol swabs do we need and how many syringes do we need and how much saline and how much heparin and we packed this all up every time. And then we'd make a list of his pills....We packed up all the pills and the bactrim and...make a list and it was worth it. I mean, it gave him such pleasure to get away and feel like he still had some independence and he

> wasn't tied to this disease. He was very determined to make sure the disease didn't rule him. And that was something I would [promote]...he wasn't going to let this disease overtake him.

Travel as a way to optimize present time counteracted the constant intrusions of disease. Other caregivers talked about travelling to Hawaii, Europe, or the Caribbean with their partners, or taking sight seeing trips across the United States. Kiko took his family to Mexico. There were efforts by some to make holidays memorable. Jeff and Al, for example, talked about making Christmas a special time.

Caring practices during wellness were not especially vivid in these narratives and not all of the participants identified themselves as "caregivers" during these times. Their stories did convey a shared sense of getting on with life, staying balanced, maintaining a sense of normalcy, and making the most of present time.

Making the Shift to Persistent Illness

With increasing breakdown of the immune system, AIDS-related illnesses appear, eventually becoming more and more debilitating. Periods of wellness grow shorter and more tenuous. The intrusions of the illness and the medical treatments intended to relieve them become ever present in the world of the ill person. Fred, a caregiver, described the unfolding of this situation for his partner Paul.

> In September, basically the world fell apart. He got diagnosed with KS and he also got diagnosed with CVM and got a third thing too. It basically was a diagnosis a week and there were a lot of doctor visits. Really, that's when the doctor stuff really started increasing. Over that summer he was just deteriorating; he was losing weight; and all he did was work. We were really fighting a lot because I was really angry at him because I felt like the only part of life he was willing to do was work and come home and go straight to bed.

As related in Chapter 6, Fred convinced his partner Paul to quit work--an action he later regretted because the loss of work diminished Paul's confidence and threatened his sense of worth.

Reflecting on this turn, Fred stated:

> I think it was good that he quit but it's such a painful decision for someone to quit their job and what it says about your viability and how long I'm going to live. There's this whole process of being labelled as disabled. It's just another label; first it's an AIDS label; then he's getting disabled; he's not gonna work. So what's his value? What am I to do to live out my life here? Very depressed. Very scared. I was very scared. It took about two months to get emotionally stable in that situation.

Here, Fred identifies some of the markers of the shift to persistent illness--going through the labeling process of disability; not being able to hold down fulltime work; feeling depressed and scared. For Paul, Kaposi's sarcoma caused an obstructing lesion in the throat. It was inoperable but responsive to chemotherapy. Though Fred was ambivalent about supporting the decision, Paul decided to pursue chemotherapy.

> The other battle that he had was around his chemotherapy. It's something that we dealt with until the day he died and Paul and I had differing opinions about how to deal with stuff. I'm much more skeptical of the medical model than he was. I'm much more into acupuncture and vitamins and Chinese herbs. Again a lot of the drugs involved in treating AIDS are just toxic. Powerfully toxic drugs. But it was his decision. It wasn't my decision.

Persistent illness brings not only the negative effects of disease but the punishing and toxic side effects of the medical treatments. Some caregivers, like Fred, disagreed with or were ambivalent about the course of treatment but deferred to the decisions of the ill person. Respecting decisions was a viewed as a commonly shared moral aspect of care in the preceding chapter. Though chemotherapy reduced the lesion in Paul's throat, the side effects were debilitating. Fred described Paul's ultimate predicament of never being able to get well again and having to chose one's sickness.

> I can remember Paul saying, "Do I want to be sick from chemotherapy or do I want to be sick because the lesions are growing? Or do I want to be sick because I'm anemic?" I mean the chemotherapy side effects started really kicking in with the anemia so it no longer became a thing of "I can select a course of treatment and be better." It's like, "I can select a course of treatment but I have to choose my symptoms." I have to choose which sickness I'm going to be and so there was really a point when he said, "I'm always going to be sick. I can pick what kind of sick I'm gonna be, but I'm really depressed because I realize that I'm not going to be healthy. I'm not getting better."

Fred's narrative captures the stage of persistent illness, marked by the combination of cancers, infections, and toxic side effects of treatments such as chemotherapy. Sometimes referred to as the "cascade of illnesses" (McCusick, 1992), moving to this stage is a depressing and frightening time for the ill person and the family. Caregivers' concerns intensify and practices change, bringing on a new level or watchfulness and urgency about symptoms and closer contact with the medical care providers.

Getting Settled for Caregiving

Persistent illness means that an AIDS diagnosis has been established and that cancers or opportunistic infections have taken hold. Periods of acute illness may be interspersed with times of remission, but remissions generally become shorter and shorter and the ill person begins to experience continuing decline. As the period of extended wellness fades into the past, primary caregivers typically begin to adopt a view of themselves as caregivers. During this shift, many participants described a period of "getting settled" for caregiving.

Caregivers suggested that getting settled was a transitional time that involved making a move to a new home or returning to a place that was closer to family or friends. Getting settled may show up later as "working out systems" in the home to accommodate technical care or "creating a caring space" when the person with AIDS becomes increasingly confined.

For Fred and Paul, part of the issue of getting settled centered around whether or not Paul should move back East to be with his family when he died.

> He just said one day, "I want to go back to Boston to die."...So we had a conversation about that and I was feeling a lot of panic at the time and not sharing that. I just let it sit and he sensed that I was upset about it and he said, "Well what do you want to do?" and I said, "Well I don't feel like I have a right to tell or say." And he said,"Well I want to know what you feel about this. It doesn't mean that you get to decide but I do want to know what you feel." So I said "Well I feel really nervous about it" and I shared that it would be hard for me. "I will go wherever you want." So then I also shared that honestly my support system is here. I like his family a lot but I don't know his family on a day to day kind of basis. That's really what it was all about. Day to day support.
>
> I think, it would have worked out fine if we would have done that too. But when he thought about it on a day to day, he didn't really know his family that well on a day to day basis, on a sort of a living basis. And he knew a lot of people here, so there would have been a lot of working out and communication and struggling and defining around how that would work.

Here, the issues of getting settled involved concerns about family, continuity with a community of friends, and day to day support for the caregiver as well as the ill person. Support for Fred, the caregiver, was an important aspect of making the decision to stay among friends rather than move back to be with Paul's biological family. Fred and Paul decided to sell their suburban house and move into a neighborhood in the city to be closer to services and their community.

The process of getting settled happened abruptly for some caregivers, such as

Darlene, who unexpectedly decided to care for her brother Steven. Darlene moved Steven into her home when he was steadily declining and no longer able to manage on his own in a distant state. For Darlene, getting settled involved a time-pressured one-month process of locating services, educating herself, and creating a space both physically and emotionally for Steven in her home.

> He made the decision to come here. We got busy starting to arrange for him to come here...we had a lot of things to do. Just cleaning out a room for one thing, getting his phone, or getting his cable in there, or getting the doctor lined up. I talked to the AIDS people. I lined up the visit with the nurse at the AIDS organization...we didn't have the info from around here. We had an appointment already made when he came. Physically making arrangements. Cleaning the room because he wanted to bring his stuff...just so he'd feel like it was at least his bedroom if nothing else. Having his own furniture in there, getting ours out...It was scary. I remember the first week he was here, lying in bed crying. Scared, just plain scared, of him, of his disease. I mean just thinking "Oh my god"....Thinking "How am I going to deal with it and actually be in the house? I haven't done this before. I don't know much about it." And thinking actually it would have been easier if he had died in Phoenix and just to be notified of the death and do your grieving from a distance. But no...that thinking didn't last very long.

For Darlene, making a space for her brother Steven and getting mentally and emotionally prepared to give care was compressed into a short period of time. It involved confronting her own fears about AIDS, about hands-on care and knowing that her brother was coming home to die.

Getting settled for caregiving can involve working out systems in the home to make caregiving go more smoothly or can involve thoughtful ways to make a space more suitable for care. Jeff, for example, described setting up monitors throughout the house, moving out of the bedroom he shared with Chip, moving in a series of hospital beds until they found the right one, setting up a medication station outside

Chip's room, and arranging the bathroom.

> I set the bathroom up. During the time when he was still mobile enough to use the bathroom, I put hoses on the bathtub because I didn't want him standing in the shower. Pads in the bathtub when he wanted to take a bath. Pads, air mattress type things, that you plug into the bathtub. Grips on the commode itself so he could raise and lower himself without putting too much exertion on his legs. I tried to take off everything in the house that I could think of that would give way should he fall on it or grab hold of...in the bathroom, towels racks. Especially towel racks that are in plaster board. A seat for the bathtub. It was pretty much a mobility thing. Light switches. I changed all of the light switches. Got rid of most of the dimmers, except in the living room. I didn't want him to be turning dimmers because you push them in and if you didn't click them right, they wouldn't turn on. I wanted the light on so what I did was replace them with light switches. There's a thing you hit and it has a night light on it. It flicks off and on. All you did was hit the wall essentially. I put up a small refrigerator in the room, one of those little guys, so there would always be juices, Gator Aides for him to drink as opposed to water.

Jeff described a striking example of a caregivers' forethought about making the home safe and getting things set in order to take care of Chip.

In the above examples, getting settled involved a range of considerations about settling in for the long haul of caregiving. It included considerations of place--for example, moving "back home" versus staying with one's chosen community of friends; getting emotionally and physically prepared to stay the course of caregiving; and taking concrete actions to prepare a caring space for the ill person.

Moving into High Gear

High gear was a term used by one of the caregivers in this study. It captured the sense of the complex, emotionally and physically exhausting care carried out by some, but not all, of the caregivers during later stages of advanced illness. High gear was characterized by technical care; caregivers learned the skills of managing medication pumps and IV lines and solutions; they changed dressings; flushed catheters; coordinated complicated medication schedules; treated fevers, diarrhea, and nausea; and managed different kinds of pain. Intimate care, such as helping the ill person with diarrhea or vomiting, was part of this period of care. This phase was particularly stressing because caregivers also had to run a household, manage finances, keep up with an outside job, and in some case attend to small children.

Going it alone. Laurie was the caregiver who used the term high gear to describe this period of intense caregiving. Though surrounded by children and assisted by a team of in-home IV therapists, Laurie's story suggested an experience of "going it alone" during this phase of care.

> P: It was all me. There was no hospital even. I was trying to help him make the judgment calls. In January I said, "Kiko, I can't deal with this. Please let me take you in to the doctor at least. And if it's something that can be treated at home then we'll find out and we'll do it at home"...So IV care started coming out....It seemed like every time he got sick the kids got sick too. I mean it was just one big raucous mess, usually. Just the little day to day things. He would have problems vomiting and this and that through that whole winter. It wasn't like it was an acute thing and it was over with in a couple of weeks or three weeks, or something. It was acute and then it was high power. I remember at the end of January, he was starting to come out of this. The treatment was working and it was almost like, I could get out of the high gear and shift to a little lower gear, and when I had a chance to do that, I just about collapsed.
>
> L: Tell me what high gear was like for you.
>
> P: High gear? Well, the kids would be sick, I wouldn't get much sleep. It would be interrupted constantly either the kids or him. A lot of times I didn't have anybody else coming in. It was just totally consuming. I mean there was something my whole day. No sleep, no this, no that. Tending to him, tending to the kids, trying to keep them quiet. I think I was getting up at 5 or 6 to change his IV's and he was eating, so I'd have to cook him something special to eat. And then get the kids off to school, and then have Frankie and Tina to deal with here. And then just taking care of it, having to move him

> with his IV pole to get him to the bathroom and things like that, wrapping him up to bathe him. He was having continuous infusion for a while and then it was dropped down to twice, two bags a day instead of three. I had to coordinate his IV's you know, as far as getting everything. I'd have to speed it up a little bit if they were going to be coming out at noon instead of 3 like originally planned. I'd have to speed it up and kind of push the liquids into him before hand because they wanted his kidneys full before hand. Just the scheduling of everything. That was the routine, it was just a full, full time.

As Laurie's narrative attests, during times of "high gear," technical and intimate care expanded to fill all available time. Caregivers had an intense focus on the demands of the present with little leeway for themselves or others. The caring regimen was highly technical, oppressively controlled by the clock, dominated by lines and solutions and the coming and going of heath care professionals. The trade off was the hope of buying time for the ill person.

Rachel suggested the sense of this high gear phase of care in her own experience with Clark. Referring to maintaining a technological regimen for Clark, Rachel stated:

> When he got home from the hospital we made a stab at it. I would start IVs at 6:30 in the morning and would not finish till 10:00 at night. And it was constant, between medicines and saline, of stuff going through. He was taking an anti-nausea something; he was taking gancyclovir; he was taking saline; he was taking something with magnesium and vitamins in it. After two or three days of this, I couldn't even see straight anymore. He said, "This is ridiculous. I can't live like this." And he had talked to his doctor on the phone and she said, "Well, if you go on hospice, you know, part of it is giving up all of your medicines that are supposedly extending your life in some way." And he said, "I don't care."

For Rachel and Clark the period of technological care lasted only a few days. Clark opted to forego the medical regimen, give up technical care and the complex schedule of medications and hydration, and pursue palliative care. As pointed out in the following section, palliative care demanded no less concern from Rachel as a caregiver, but the nature of care shifted from the frantic pace of the technical clock to a pace more in tune with the slowing of the dying body. Palliative care involved following rhythms and patterns of care that would ease suffering and pain.

Organizing care teams. In Chapter 4, care teams were discussed in relation to the social context of caring for a person with AIDS and were linked primarily with the family's connection to a gay community. Here, I will discuss how care teams functioned during periods of high gear technical care, and indeed, made that kind of care possible. Care teams did not function solely for the purpose of making technical care work in the home, but members of the care teams frequently participated in this phase of care in a number of ways, from learning technical skills to taking over the more mundane chores of running the household. Teams typically were not fully organized until 24-hour care was needed. In some situations, the focus of the care team from the out set was palliative care, rather than "high gear" technical care.

Roy's experience provided an example of a care team organized to give both technical care and emotional support to the ill person on a 24-hour basis. Roy described a process of organizing a care team and playing the administrator role until he became exhausted with the demands of high gear care.

> So we had the team. They were kind of hand picked. Doug had a lot to do with that. It was "Who are you comfortable with? Who do you want doing what?" By that time, I really learned, you give Doug as much control as he can handle, and is willing to handle. I wanted him to be able to feel he was calling as many of the shots as possible. And he agreed that I'd be the chief. I'd kind of control it. But he could designate who we want. I would pretty much brief people in advance telling them what sort of technical duties they would need to expect to do. There was only one other person that Doug

> would allow to bath him and that was his sister. Then Doug was having tremendous problems with holding his food down. You'd give him a meal and within half an hour or sometimes 10 minutes, up it would come. Meals, medication and all. So that became an issue that you had to let people know about, and how to deal with that. And you kind of got to know what the pattern was. If you fed him a meal you kind of had to really pay attention right after that meal for at least a half hour, 10 minutes to 45 minutes because, if it was gonna occur, it was gonna occur within that time frame. And so I would brief people on the technical aspects of what to expect.
>
> When Doug came back from the hospital...there was always 24 hour care. There were enough people who had volunteered that we'd been kind of setting it up gradually. So it was really a challenge to put this schedule together because there were people we had to say "no" to and finally we got it to the point where there was the caregiving team who gave technical care and there were the caregiving personalities who were there for moral support and social support and these people would be scheduled in on different times to be there.
>
> So you just have to be really organized for people if you're the primary caregiver. I think one of your functions is to make the job easy for the people who are helping you on the team and easy for yourself and that requires some extra organizing.

In his narrative, Roy described a highly organized team of caregivers who used shift schedules, shift reports, medication schedules and logs to communicate and stay organized. Intense 24-hour, in-home care was made possible by the friends who volunteered to care for Doug. Their abilities as hands-on caregivers or emotional support caregivers were recognized and utilized. Roy shared practical knowledge of caregiving with team members who had intermittent contact with Doug. An example of his practical knowledge was Roy's recognition of patterns and his ability to anticipate responses, such as knowing the most likely times for Doug to become nauseated.

Home care teams present trade offs for the primary caregiver and the ill person. The benefits include relief from constant physical work and maintenance and social and emotional support. The negative trade offs for the caregiver include the expenditure of extra time coaching, briefing, and instructing the team members on technical and intimate care; keeping up with the tight time schedule; balancing the personalities of the care team members with the needs of the ill person; and adapting to the loss of privacy in the home.

At the end of an exhausting period of time, Doug was admitted to the hospital for uncontrolled seizures. This marked the move to palliative care for Roy and Doug. This shift in care and concern was signalled by medical doctors who stated they could do no more to help Doug. The care team was disbanded and Doug remained in the hospital to die. At this juncture, Roy recalled feeling the relief of the decision to forego the pressured high gear technical care he had sustained with the help of the care team. Though Roy was probably able to buy some time for Doug, he welcomed the move to palliative care. As Roy stated:

> There was a transformation in this team care issue too where I found that I really was becoming this incredible technical coordinator. And it finally just occurred to me that that's not what this is about. I was falling into that by default just because I'm good at it. I'm organized and I'm a fixer kind of person. But the kind of care I really wanted [to give] was the emotional support.
>
> When we were at home, we were constantly dealing with needles and what if he had another convulsion and what if he had a seizure because he was having seizures rather regularly. And that wasn't giving care at all. That was just being in panic mode all the time. And being in the hospital and knowing if he had another convulsion, another seizure that all you had to do was push a button and that a <u>real</u> technical person would be there to aid you and assist you and you could do the kind of caregiving of holding a hand, and being there, and supporting. Being there for that person there emotionally.
>
> That was important and I just couldn't give any more technical care. But even though, even during that period in the hospital I was there every time the

> nurses changed him. I was there to help roll, and change, and move the sheets and I mean I never gave up the technical care, but I was sure thankful for that extra technical support so I could give the other kind of emotional care. Which was paramount and absolutely the most important type of care that you wanted him to get.

Here Roy articulated the transition in understanding and meanings of care that had occurred for him over time as a caregiver. He grasped that in his own experience there were different kinds of care that he could give. As the course of illness progressed, the caring practices that gained greatest importance included emotional presence, staying out of panic mode, being able to hold and be there for Doug.

Accepting Palliative Care

Caregivers in this study were not directly asked to describe their understanding of palliative care or describe the transition in their understanding that the ill person had entered the processes of terminal illness. However, the move toward palliative care was suggested in the narratives as a period in the continuum of care when caregivers shifted their concerns and caring practices to issues of comfort, both in the physical and emotional sense. This shift might have occurred only a few days before the death of the ill person, if aggressive medical interventions were being pursued. Or it might have taken place many months in advance of the ill person's death. In many situations, caregivers did not acknowledge the terminal phase until medical doctors stated that nothing more could be done to treat the disease.

Some families pursued aggressive treatments for as long as possible. Others chose limited involvement with highly technical medical regimens, electing few treatments or medications. Others chose a middle way. Jared's story represents a situation where the ill person and the caregiver pursued the middle road by deciding to underg a trial of risky medical therapy and then deciding the time had come to abandon treatments in favor of palliative care. In the following narrative, Jared explained the transition to palliative care for Dennis, who was diagnosed with progressive multifocal leukoencephalopathy four months before he died.

> In September we began to realize something was going on with Dennis, that things were beginning to happen....He began to find his writing was getting difficult, that holding a pen was more difficult and that the clarity of his signature was a problem...And he initially associated that with what he thought was a reoccurrence of the Dupuytren's syndrome in his hands. But then he also began to realize that he was grabbing onto corners for balance...I can remember doing a walk where it's like, "Hey are you limping a little bit?" And it was sort of about that time when he began to say "Hey, you know there are these other things going on"....we moved very quickly then in terms of setting up an appointment. By Friday, Dennis was in for the MRI. From that initial assessment, the doctor knew that probably there was something going on that was brain involvement and did not waste any time in going to assessing him.

Jared described his on-going practices of watching for changes, noticing patterns, interpreting symptoms, and piecing a picture together that would signal the need to get help. The initial cues of PML were unclear and confused with a former, less threatening syndrome. With passing time, vague indicators began to form an ominous picture and only in retrospect was Jared able to pinpoint a time when "things were beginning to happen."

Jared continued to describe the progression of events that led to the shift in his concerns toward palliative care.

> He had a brain biopsy. PML or HIV virus were probably the likely candidates. That began our process of educating ourselves about what can we do. With PML came the first information of how quickly this could move. I mean it's four to six months. Basically, t was put a six month prognosis....We then did research. It was only after we did the research and

> reading on it that we began to realize that there are things people have been trying, some of which has been successful. We tried to gather further information on that and to educate our doctor and say "Are these viable options for us to explore?"
>
> One of which is a cancer drug which was given as an IV but is also given what's called intrathecally, directly into the spinal column which is probably the most effective way of delivering it. But also the most difficult and risk taking. It was our physician's advice not to go that particular route. I think the feeling was "Let's give it a shot; see what it does." Satirabine, which is the drug ARAC. You basically go a course of I think four or five days treatment with an IV and they'll monitor you for a couple of weeks to watch your blood count and then do another. It will drop and then it'll build back and, assuming it's doing okay, they'll do another round again. This drug, they typically were not seeing responses until after the third round of treatment, so we sort of knew not to initially look for stuff. And that's like any other cancer drug. He tolerated it pretty well. Still, it's not an easy, it's not an easy drug; it's a toxin.

During this downturn in the progression of Dennis' illness, Jared described responses and practices that he and Dennis had used in the past. They maintained a hopeful attitude and were proactive; they researched information and worked with their doctor to get help. After three rounds of chemotherapy, they looked for positive affects. The symptoms progressed, however, and they made the decision to stop treatment. After the decision to stop chemotherapy, Dennis progressively lost energy, motor control, and speech. For both Jared and Dennis, the available world began to constrict. Going out was more and more of an ordeal and less pleasurable. Conserving energy was a primary concern. Old friends and family who wanted to see Dennis for a last time came for visits. Jared's concerns shifted to altering the caring space in the home, getting help with household chores and having someone present in the house with Dennis when he needed to go out for errands. Physical care and assistance became a fulltime endeavor.

> There was a steady progression in the deterioration of all the motor skills and that included speaking. So over the course of time, communication began to be harder and harder and harder....and I began to realize...as his speech was getting more difficult and energy conservation was an issue, that many times my role was a caretaking role and taking care of appointments and taking care of food, and being stable and doing organizational stuff and some level of emotional stuff. My role was sort of automatic and assumed and just a given. I needed to be there as his caretaker and caregiver and be supportive and demonstratively love him and love and provide all the way through.

As terminal care progressed, Dennis withdrew and became less and less available to Jared in an emotional sense. Like other caregivers, Jared described an understanding of this period of withdrawal and letting go and articulated shifts in his own role as a committed, supportive and loving caregiver throughout the process.

Summary

As the HIV infection advanced in the ill person, caregivers reconsidered the pace, focus or goals of their caring practices. Caring practices followed a general continuum of care shaped by particular manifestations of progressive disease. Learning about and living with the diagnosis; supporting the one cared for in times of wellness; shifting concerns and practices with the onset of persistent illness; getting settled for caregiving; shifting into high gear; and moving toward palliative care were identified as parts of the continuum. I turn next to concerns and caring practices that were notable at the time of death--the final stage in the continuum of care.

Caring Practices At the Time of Death

Caring practices at the time of death marked the final stage in the continuum of care for the person with AIDS. Caring during this stage of the illness was influenced by background social and cultural contexts and by meanings and moral concerns that the caregiver and ill person brought to the situation. The practices described in this chapter were characteristic of primary caregivers were from mostly white, middle-class backgrounds. Aspects of the culture background that were not pointed out in Chapter 4 will be considered here.

Cultural views on death in everyday life. The United States has been called a "death-denying" society, in which death has taken on the status of a taboo (Backer, Hannon, & Russell, 1994). In earlier eras, death was familiar and near. One could not be isolated from death, and death appeared to evoke less fear or avoidance. The traditional attitude toward death was one of resignation and acceptance. In the mid-nineteenth century, a cultural change happened where death no longer occurred primarily in the home, but in the hospital. This cultural change broke the close connection between family, home and the dying person. Funerals were not held in the home but in special "parlors." Progressively, silence about death prevailed, and death lost its place in everyday life (Backer, Hannon, & Russell, 1994).

A number of social critics have commented on the death-avoiding character of contemporary American culture. In this study, Terry, an urban gay man who has been involved with the AIDS epidemic for over a decade, captured this commonly accepted notion about the death-denying character of contemporary American culture. Contrasting historical practices and attitudes toward death with those of contemporary times, Terry remarked:

> Caring for a dying person happened a hundred years ago in the home, and for centuries and centuries and centuries, and forever ad nauseum before that. It was probably more prevalent in the beginning of time than it has come to be in this amazingly modern age--That particular aspect of human behavior, caring

> for a dying person. In this century we shipped people off to hospitals and I'm not saying that hospitals are bad, mind you, but I'm saying as human beings we became divorced from the death process and then we hired people to take care of the burial and all that kind of stuff. And we just freak out about death as if it weren't a 100 percent certain part of life....What's different now is that the system has a whole lot of complications it didn't use to have and that the family unit is no longer present. Not around the death scene. I think that we all know that the family has undergone a lot of change and because contemporary American culture divorces itself from death completely, we're oblivious to the fact that death used to be a much greater part of life.

In this passage, Terry reflected on prevailing beliefs about a larger contemporary cultural attitude toward death. These notions, however, stand in sharp contrast to Terry's own experiences with death. As an urban gay man involved with the AIDS epidemic in his own community, Terry has experienced the loss of multiple friends and acquaintances who died from AIDS and cared for four friends who died in his own household.

Social attitudes toward death and dying change over time, and while most of us do not deal easily with death, our times seem to be moving away from a "death denying" stance where cultural silence about death prevails. For the past several decades, death has regained attention in our culture. Examples are the attention paid to Kubler-Ross in the sixties, the founding of the hospice movement; the AIDS epidemic; the highly publicized cases of Karen Ann Quinlan and Nancy Cruzan; Derek Humphrey's <u>Final Exit</u>, and recent controversy over the place of assisted suicide in our culture (Sankar, 1994). A hugh academic literature exists on the technical, emotional, psychological, and ethical aspects of death and dying.

Kellehear (1984) commented that we have moved from a death denying society to one that attempts to "contain" death. We have developed systems for identifying the controllable parts of death--suffering and pain, premature death, or accidental death. We have begun to focus on containing these aspects of death rather than denying death (Backer, Hannon, & Russell, 1994). With the help of science, technology, and efficient life styles, death is to be forestalled or contained for as long as possible. Future-orientation continues to be an habitual way of being in contemporary America, where the prolongation of life is valued and members of the middle class expect to live into old age.

In addition to cultural contexts, personal experiences with death and dying may shape caring practices at the time of death. Caregivers in this study had varying experiences with death. Terry, for example, participated in several careteams, contributed to producing a training film on caring for a dying person, and cared for four friends who had died from AIDS in his home. During our interview, Terry showed me a collection of framed pictures of gay men whom he referred to as his "warriors"--over 50 friends who had died or were currently ill from AIDS.

Terry's experiences were in sharp contrast with those of Gloria, the mother who helped Terry take care of her dying son Dewey. Gloria's experiences with death and with HIV disease were limited. As death neared for Dewey, Terry often served as a coach for Gloria and the rest of Dewey's family. As Terry remarked:

> When I'm around family and stuff I routinely encourage them....They don't even know they have an opportunity sometimes. That part of their earth is flat. Particularly around HIV where the victims, if I can use the "V" word, are so young. See frequently their parents have very little experience around death. They haven't even lost their grandmother. The grandma's still alive, so they haven't even gone through the experience of "Oh there's some things that I wish I had told mom."

Like other gay male caregivers in the study, Terry used his past experience and practical knowledge about caring at the time of death to coach Gloria and other family members on how to attend the dying person.

Caring practices for a person dying from AIDS were shaped by attitudes and understandings about death that exist in the culture, by the particular manifestations of the disease, and by the personal experiences of the caregivers and the ill person. Though local communities, the specific course of HIV disease, and past experiences with death varied among the participants in this study, common patterns of care and concern emerged in the collected narratives. The following is an account of these concerns and practices, supported by narrative text and viewed in the light of similarities and contrasts that showed up in their stories.

Preparing for death. Death from AIDS is expected and usually occurs after protracted decline, rather than in a precipitous fashion. The deaths described by caregivers occurred mostly in the privacy of the home. Because there was time to think and talk about death, caring practices around death could to some extent be anticipated and planned. In some instances, preparing for death in a psychological or spiritual sense occurred early in the trajectory of illness. Preparing in this sense mainly took the form of talking about the time of death.

Caregivers in this study referred to several aspects of talking about death with the person they cared for. In a culture that doesn't support openly discussing death, the caregivers often had to "feel their way" in relation to when to talk about death and what to say. There was a sense that timing was important and that one needed to "walk the line" between hope and facing death openly. Talk about death frequently followed the lead of the ill person, centering on that person's fears, concerns, or needs for reassurance.

Many caregivers described having conversations with the ill person regarding their fears and existential questions about death. In their exchanges with the ill person, participants described the dying person's fears of physical pain, dependency during the dying event, or an existential fear arising out of facing the unknown.

Roy, a gay man who cared for his partner Doug, described several conversations with Doug, a educated, verbal man who talked in a direct manner about his own death. Doug had been a man accustomed to his own power and independence. One of his pressing concerns had to do with the fear of total dependency at the time of death.

> We talked about mind over matter kind of philosophies. How much does an individual really have? How much control do you really have with fighting and continuing to hold on to your life and how much mental control do you have over the process? And can you literally decide it's time to go and assist nature? We talked about what he thought. He'd ask my opinion and I'd share my opinion with him. I think Doug agreed with me. My thought was that when it's time to go you can. You know when to let go mentally. You know when to say goodby. And that he would be able to do that for himself. There was kind of this reassurance that was needed. What he needed was, "Am I just completely at the mercy of everyone around me in the world or do I have some control too?" And I said, "Doug if you believe that you have the control, you can mentally say goodby when you're ready, and we'll be watching your signals and we'll be trying to read your signals and we'll be trying to go with you when you want to let go."

Though preparing for death may occur months before death actually becomes imminent, caring and understanding may show up in the caregiver's ability to talk about death, pay attention to fears, and share his own thoughts with the ill person.

Roy allayed some of Doug's fear through his reassurance that his concerns were understood, that family members would not overstep their bounds, and that they would watch for "signals," making sure that Doug remained in the lead and retained some control over his own death.

Several caregivers described talks with the dying person that touched on fears of the unknown and uncertain beliefs about the meaning of life and death. For some, preparing for death took the form of an extended exchange with the ill person about confronting death and constructing meaning in life. Fred, for example, described Paul's "dark night of the soul" and the process Paul followed in discovering meaning and a centeredness in life.

> He really had what I call a sort of dark night of the soul. He stayed up one night in the hospital and just wrote. He really was doing this sort of review of his life. He talked about when you have HIV, you think it's gonna go on 10, 14 years. I have time. So there is sort of that need to hurry on with your life. If there's something you really want to do, you need to start moving toward doing it. But when you have that diagnosis of AIDS, you hear "average lifespan 24 months." So that shocked him and he really went through a lot of depression. Feeling like a failure on a lot of levels. So he was just right in the thick of "What have I done in my life?" kind of feeling. He talked about that and I found all the papers that he created after he died. He just wrote and wrote and wrote. And...at the end of that night, this came from his papers and also from talking to him, he came to a sense of what his life was about and what he had accomplished. But it was like you had to tear your life apart and then see what's really there, what was essential.
>
> The other half of the conversation was the sort of resolution of the depression and discovering the meaning of his life and some acceptance and some centeredness with what he was and with what he had done.

Fred used the metaphor of "having a conversation" to frame the process that Paul went through to prepare for and confront death. One half of the conversation was the process of "taking his life apart"; the other half was the resolution, finding some acceptance and centeredness.

Paul confronted death through writing but also through long conversations with Fred, who listened as his went through depression and stayed with him as he went through the "other half of the conversation" which focused on meaning and acceptance.

Preparing for death also included more mundane matters--making concrete plans for the dying event, the funeral, burial or cremation. Roy reported that Doug made detailed plans about who should be at his death bed, how his funeral should be conducted, and what should be done with his ashes.

In some situations, talking about death was limited and preparing for the death event was specifically proscribed. Theresa, a 32-year-old woman who cared for her friend JR in a small rural community, stated that JR "never wanted to talk about it." During his illness, JR was progressively affected by AIDS dementia, which eventually limited most forms of purposeful communication. Following JR's lead, Theresa maintained silence about issues of death and dying. On one occasion, she gained insight into JR's feelings about death.

> We talked about death one other time after we came back from the doctor. And his son was in the car, and he was telling me how scared he was. And ah, he was very scared to die. He didn't want the suffering, but he was afraid of the actual transition itself. He believed in God and he loved God. His spiritual faith was there, that there was a God, and he did believe in Him and love Him, but God had never told him what was in store for him. He had heard from different people what their descriptions of what it's like when we make that transition, but it's still basically an unknown until you get there. And JR was very afraid of that unknown.

Unlike other caregivers, Theresa did not openly prepare for JR's death. Talking about death or making plans were not allowed. When death came, the actual dying event seemed more difficult for Theresa to contend with than for most others. The actual death event occurred while she was carrying out her household chores. Though she described an intuitive awareness that JR had died, Teresa continued with her chores and avoided the JR's bedside well past the moment of his death.

<u>Attending to the dying space</u>. Heidegger distinguished between physical space and the lived space that human beings experience through their concerns in the everyday world. Lived space refers to an "existential spatiality" and is characterized as person centered, as opposed to physical space which is "pure extension" and which has no center (Dreyfus, 1991). Heidegger's attention to the notion of spatiality prompted thinking about how participants in this study talked about space. Caregivers alluded to attending to the living space of the ill person, especially near the end of life or when sickness had confined the person to a single room--or in the case of severely limited mobility--to a single view. Organizing and maintaining particular kinds of spaces suitable for giving and expressing care was recognized in this study as a specific caring practice. A caring space is understood in the Heideggerian sense as having both physical and psychological or person-centered dimensions conducive to providing human care. As illness progressed and the dying person became bedfast, space constricted so that the available world was drastically narrowed. This space I refer to as the "dying space" and in this section I note ways in which caregivers attended to the space where death occurred.

Personalizing the dying space was described by several caregivers in the study. Familiar things from the past were brought into the room and placed in the dying person's line of vision. Access to a window, to a view of the out-of-doors, to the light and warmth of the sun, to the sound of birds was an important consideration for many. Some caregivers moved the ill person into a living room where access to children, family or friends would be easier. Some spaces were highly systematized and organized to contain medications, IV bags and other equipment, and when this occurred, it was typically out of the view of the ill person.

The presence of a hospital bed was a difficult adjustment for both the caregiver and the ill person. Though useful, the hospital bed was like a rupture in the lived space of the home, interrupting habitual ways of being for partners, and symbolizing another step closer to death for the ill person.

Some caregivers regarded the dying space with a spirit of reverence. Jeannette described lighting candles in the bedroom when Brian was dying, and Margaret described the living room where Mark died as taking on the feel and mood of a "temple."

Many spaces were perfused by music, especially during the very last hours of life. The music may have suggested a mood of rest and calmness; often favorite music that linked the ill person to enjoyments of the past was played. Caregivers also attended to other people in the dying space--how many were present and how they comported themselves. In some situations, the dying person had wanted specific persons nearby. When these wishes were explicit, a small inner circle of family or friends kept a vigil at the bedside. Examples of these practices are offered in the following excerpts.

Jeannette described personalizing the bedroom where Brian was cared for after he came home from the hospital to die.

> We had the hospital bed there when he came home. I had arranged all of his cups from all of our trips in his room so that he could look at them. All the cups were there and I lined them up on his bookshelf. We took out all of the stuff he had there. And he just loved it. We put his cups up there so he could look at them. And I hung one of his favorite Star Trek items. It was a plate that he ordered before we left on the trip. I hung the plate up where he could see it. He had a picture of me when I'm 30 that he always had in there. And he had his stereo and his TV. We had it set up so was everything that he loved in there.

Brian's favorite souvenirs from travelling, his TV and music created a space that connected Brian with meaningful times from his past. Taking Brian's bed away was a regret for Jeannette, who understood that the bed symbolized a link with Brian's lover Scott who had also passed away. Jeannette explained her regrets about placing Brian in a hospital bed and how this was a key trade off in her ability to keep Brian at home.

> The hospital bed brings back really hard memories. It was Scott and Brian's bed. Scott had built the bed actually. It was like this on the floor [indicates about 18 inches off floor]. You can imagine trying to get him out of there into the wheelchair. I mean, we couldn't do it. Or to bathe him and take care of him? So we told him, we were really sorry, but when he came home, there was gonna be a hospital bed....I guess it had to be three weeks before he died....we had no choice. We would not have been able to take care of him. And I felt really badly about it. Real bad. But we still wanted all his things around. We made it real soft underneath just like he had his bed because of his KS. We had a down comforter underneath and also a foam pad and I made sure that all that was there. So it would feel the same even if it wasn't.

Jeannette described a room filled with signs and symbols of Brian's past and former self. Though intrusive, the hospital bed was a necessity for Jeannette who tried to make it acceptable to Brian by adding pads and comforters so it would "feel the same." For partners, accepting the hospital bed in the home had additional implications. Terry described the implications of caring for Dewey in a hospital bed.

> The God damnable [with emphasis] hospital beds. There absolutely, positively has to be a way to make some pull out kind of deal on a hospital bed so that two people can get in the hospital bed. And still reduce the bed to a narrow, single bed as necessary to work....You know when you're trying to do something with a person and they're in a water bed and it's this tall and that big, it's really difficult. But what I really hated letting go of was being in bed with Dewey. You can lay next to a person in a hospital bed for awhile, but depending on what's going on for them, it really is hard to do it for a very long period of time. I hated that part. My relationship with Dan was a very, very, very, very, very, very, very, very physical one. And you know we slept together spooned at night. We cuddled a lot at night. It was a very physical relationship, particularly in association with night time in bed. So when it was no longer really possible for either of us to sleep properly in a hospital bed, that was the other hugh loss for me.

The interruption caused by the hospital bed was a deeply felt loss for Terry and for others in the study. The bed interrupted not only a space but a past life of physical touch and comfort. The interruption caused by the hospital bed was not acceptable for some. Art, a gay man who cared for his partner Stan, described Stan's reactions regarding the hospital bed.

> Hospice said that he needed a hospital bed...so finally I convinced him. I says, "Stan, it's up to you but I think it's a good idea." He finally agreed and so we fixed the TV room and got everything out so they could bring this hospital bed in and Stan called me at work and he says, "I've changed my mind." And so I says "OK it's up to you. It's your decision." So he called them. And he says, "I'm not dying in a hospital bed." So that was the end of that. So the hospital bed never got here....I don't know. Just that idea of hospital beds and everything. That's scary. He didn't even want the idea that there was going to be one there.

Throughout the illness, what was important for Art and Stan was to limit the disruptions of medical regimens, keep to their usual habits, and live their lives as normally as possible. The intrusion of a hospital bed in the lived space of their home was contrary to the whole approach that Art and Stan took toward Stan's illness.

Physical space was shaped not only by objects such as beds or cherished items, but by sound as well. Several caregivers described using music as a way to shape the feeling of the space where they cared for the dying person.

Fred explained the importance of music he played in the house the night Paul died.

> I was playing the music that night. And music was really a nice connection between Paul and I. That was something we always sort of did together. One of the things we did very early on and throughout our relationship. We'd love it when we would just have a night or an afternoon in the house to ourselves. We'd put on music and listen to it and cry sometimes, or dance, we'd sit around and sort of hold each other and sort of dance around the house. It was just a fun time, it was a fun interaction. So that was always a connection and when he died I was playing a Linda Ronstadt album we both liked. So I was in his room I had been playing...people he liked a lot...it seemed important for me to have that music going in that room. It just felt comforting.

The special music mentioned in this exemplar provided comfort, connection, and meanings from the former life that Fred and Paul had shared as partners. The spaces described by caregivers in this study were attended in a way that honored the dying person; they were filled with meaningful objects, calmed by music, connected through windows to sights, sounds, and sun from the outside world, and opened to special people. When dying at home was not possible, some of the same efforts were made to shape the lived space of the hospice or hospital room where death occurred.

A special way of being at the time of death. Caregivers in this study shared common concerns, not only about the lived space in which dying occurred, but also about a special way of being at the time of death. One common concern was for caregivers and others at the bedside to provide a reassuring presence. It was important to be tranquil, to stay quiet, and to fall into a mode that suggested peace and calm. Panic and fear were the opposite extremes of how to be at this time. Though not all caregivers described these concerns, for those who stood a vigil at the bedside, these mannerisms were important ways of comporting themselves.

Caregivers worked out subtle ways of communicating, squeezing a hand, or watching for a blink of the eye, to reassure the dying person that they could still be heard, that their needs could still be met, and that they were not alone. They responded to the dying person's "symbolic language" or "confused speech" in ways that appeared to help the dying person find what was needed to die. One caregiver carried out a nightly ritual of talking with the dying person about approaching death, wishing him well, and asking him to make contact "from the other side."

Roy explained the importance of a reassuring presence and the freedom to give emotional care to Doug as death approached.

> I was just trying to be there and physically present. And emotionally present for Doug. If he should wake up or come to consciousness and be at all concerned about where he was or what was going on, there would be someone there to hold his hand, a familiar voice, to say "It's OK." "What do you need?" "What do you want?" "Everything's under control." And if he was conscious enough to ask about his condition, [I would] be able to calmly sit and say to him "I just spoke with the doctor and he says this and we're trying that and how do you feel about?" I mean just making sure that he never had to fumble around and try to reach for a nurse's button for one thing, or if he messed his pants, that he wasn't gonna panic about that. At first when that first started happening, that panicked him and it made him very uncomfortable and it made him very embarrassed. So we had to kind of get him through that and let him know it was OK.

Roy valued the ability to be near in a reassuring and familiar way, to sit calmly, to hold Doug's hand, to ease any sense of panic. His special way of being communicated a sense of sureness, focus, calm and a patient, steady purpose of being nearby and available to Doug. In a similar way, Fred referred to a base of love that was important for Paul during his dying hours. Near Paul's death, Fred remarked, "It was more important for me that we created a base of love and caring for him than that we did things right." Fred described a moment of panic at the time of Paul's death, which was opposite to the way of being Fred desired.

> What happened was Paul was choking and everybody panicked. People were trying to get Paul to sit up and it seemed like he couldn't do that. We just tried to get him elevated and have him breathe better....It just became this flurry of activity and I just remember sort of stepping back and saying, "I don't like this." I guess I had this image of Paul dying peacefully and what was happening in front of me was, "Oh we gotta do this! Get him up! Get him up!" I didn't have any control in that room. And Dee was just grabbing at Paul's pump and just pumping it. Where you can press it to give an extra dose of morphine and I had already increased it. I just felt it was a knee-jerk reaction and she was just pumping Paul full of extra morphine and I thought, "I don't want him to die snowed under." Somehow they got stabilized with this stuff and so I just gathered people and I said, "I'm really upset. I didn't want that room to have panic and fear. It's more important for me that we create a base of love and caring for him than that we do things right. I don't want him to die in a panic attack. I don't want that to be his last moment." And I didn't want to be in that space myself.

Fred had envisioned a way of being at the time of death much like that articulated by Roy--an atmosphere of reassuring calm, tranquility and peacefulness. His response to the frantic reactions of friends helped to reordered the room where Paul was dying. Fewer people were present at Paul's bedside and Fred was able to calmly hold his hand when Paul died.

Jeannette referred to bathing her son Brian near the time of his death to control his fevers and also, she claimed, in a symbolic way to remind him of the days when he was a champion swimmer.

> I just kept talking to him. And trying to tell him just how much I loved him and rubbed his hand. And that night he started running a temperature again. He started this real shallow breathing and I knew he was going to go that night. Or that day. So I just bathed him all day and tried to make him as comfortable as I could and talk to him.

In some situations, family members and friends kept a vigil at the bedside. Margaret described the vigil she kept for Mark during his protracted death.

> I was about as physically exhausted as a person can be and [still be] up on two feet. When all this happened ...what I couldn't shake was the Bible story about Jesus in the garden of Gethsemane and how the apostles couldn't stay awake with Him in His last agony and so one of the things that I think needed to do was to keep the vigil.

Keeping a vigil until the death occurred was described by several caregivers in this study. For some, it was keeping the commitment that the ill person would not die alone. In the religious sense alluded to by Margaret, the vigil took on the symbolic meaning of a period of devotional watching preceding a holy time. Though a time of intense emotional and physical exhaustion for caregivers, keeping a vigil marked the final period of watchfulness and being present to the dying person. Margaret, like other caregivers, played special music, described a calm and controlled demeanor, and in her case, a devotional attitude at the time of death.

Letting go. A nearly universal practice was reflected in a shared discourse about "letting go" at the time of death. The common language of letting go and holding on had shared meanings among the caregivers in the study. One meaning referred to the ill person's letting go of life, giving in to the irreversible disease processes of the body, and letting go of the loved ones around him. A second meaning had to do with caregivers, friends, and family members letting go in the sense of releasing their hold on the dying person. As expressed in these narratives, holding on and letting go were relational processes. In the continuation of a passage alluded to earlier, Roy expressed the reciprocal nature of letting go.

> My thought, and I think Doug agreed with me, was that when it's time to go, you can. You know when to let go mentally. You know when to say goodby. And that he would be able to do that for himself. There was kind of this reassurance that was needed. "Am I just completely at the mercy of everyone around me in the world or do I have some control too?" And I said, "Doug if you believe that you have the control, you can mentally say good by when you're ready, and we'll be watching your signals and we'll be trying to read your signals and we'll be trying to go with you when you want to let go."
>
> There was another thing of him feeling like "Well, I can't let go if you can't let go" and part of the hard part of dying is leaving the people behind that you love and that you care for. It's hard to let go of your own life maybe if you feel that there are people still hanging on to you...If people won't let go of you and you're trying to die, it makes it harder for you to let go. I think there are dynamics like that go on. And that it's really important to be sensitive to that, to pay attention to that.

The discourse of "letting go" showed up repeatedly in the stories in this study. Like other caregivers, Roy tried to release Doug from his concerns of leaving loved ones behind: "We will be watching your signals and we'll be trying to go with you when you want to let go."

At one point, Roy understood that Doug was ready to die. Roy described an episode when Doug announced "it's time." Doug summoned his mother, father, and sister to the bedside. Roy interpreted the announcement and summons as Doug's "signal."

> It was a signal. It was an important signal that Doug was ready. He was reaching a point where he knew he wasn't gonna fight. He wasn't gonna continue to try to fight something that was obviously irreversible. And he was

ready to go. He died a week later.

Understanding Doug's signal helped the family know that the time for them to let go of Doug was at hand. Letting go of Doug meant that his caregivers were adjusting their focus of care. The decision was made to discontinue Doug's medications. Roy gave up being the "technical coordinator" of Doug's care team. The decision was made to keep Doug in the hospital so Roy could be free to focus on giving Doug love and emotional support.

Letting go was experienced differently by Jared a 38-year-old gay man who cared for his partner Dennis. Jared described letting go as a process that extended over time and that accompanied the grieving of small and large losses occurring in the relationship. For Jared, letting go was experienced as the gradual but progressive relinquishing of customary ways of living his life with Dennis.

As part of his caregiving, Jared described the practice of lying next to Dennis, holding him, and spending quiet intimate time together. Eventually, however, Jared recognized that Dennis was ready to let go. On one occasion, Jared wanted to hold Dennis and asked Dennis if it would allow himself to be held. Dennis rejected Jared's offer--a gesture that signalled Dennis' readiness to let go.

> It was not okay; I got back a "No" response and that marked a transition into his is shutting down and he was not in a space where he could be available to me. That was a very clear transition, that we were past a point of that type of communication occurring. And I needed to recognize and let go of that, of being able to. That my role was switching to a support and palliative role. It had moved past the emotional bonding time and it was clearly time to be letting go at that point. He needed to be in a letting go mode. And for me to try and keep him emotionally entwined just was going to make it hard for him to die. And let go. And it was easier to just recognize and honor his need to let go.

Here Jared comprehends the reciprocal nature of letting go and the difficult, yet important, role the caregiver plays in recognizing this transition. For Jared, there were no final or dramatic goodbyes. Letting go occurred in increments, over time, and as the relationship shifted, Jared as well as Dennis let go of mutually comforting aspects of their former shared life.

Caregivers expressed discomfort when the processes, signs, and signals of letting go were not evident, did not occur or were avoided. Laurie stated that when her husband Kiko died, she was momentarily in another room and was not able to hold him and tell him it was "OK to let go." Teresa talked about her belief that dying was actually harder when no one lets go at the time of death. Recalling that JR did not want to talk about death, Teresa stated:

> He did not want to talk about it, and I respected that and so we did not discuss it. So when the time got close and I knew it was close, I was not able to look at him and say "let go." And I think that would have helped him not to have stayed bedridden and stuff for so long if I had been able to release him and his loved ones could have released him. I think it would have helped. But as it was, nobody mentioned it. Therefore he clung on to the bitter end, and he had such a desire to live and fight. I don't think he would a fought so hard if the family and I could have told him "It's OK, we'll be OK without you here." If we could have released him and said, "We'll be alright, you go and do what you've gotta do. Don't stay here for us." If we could have done that I think it would have helped him and eased his transition a little better. And made it less painful.

The discourse of letting go, even when not carried out in caregiving, is connected in our culture practices with attending the dying person. Some caregivers were actually coached by hospice team members to talk with the dying person about letting go. Not all caregivers received such coaching, yet believed in the importance of helping the dying person in this way.

Summary

This chapter has considered concerns and practices of caregivers throughout the continuum of care for a person with AIDS. This continuum is shaped by the general course of HIV disease and the specific manifestations of disease in the ill person. Caring practices and concerns during latent infection or during prolonged periods of wellness were not clearly distinguished in this data; this was related to a retrospective study design that solicited stories of care after the ill person had died. Though caregivers may have many concerns and may effect subtle caring practices designed to sustain wellness, these stories may have been overshadowed by more dramatic episodes of care that occurred during advanced stage disease or terminal illness.

The continuum of care outlined here included concerns and caring practices related to adjusting to the diagnosis; caring during times of wellness; adjusting to the onset of persistent illness; getting settled for caregiving; shifting into high gear; moving toward palliative care; and caring at the time of death.

This chapter underscores the notion that within any particular situation caring practices and concerns cannot be static. Practices developed, changed, and sometimes stopped. Likewise, caregivers' concerns shift, fade or intensify.

Some common concerns and practices at the time of death were identified. Preparing for death referred to the work caregivers do to help the ill person gain acceptance or construct meaning in their situation. It involved conversing about issues of dying, from the mundane to the existential. Such talk did not occur in all situations and almost always followed the lead of the ill person. A special way of being at the time of death among this white, middle-class sample of participants reflected values related to controlling emotions, maintaining a calm, reassuring presence, holding or touching, and suppressing extreme grief, fear or panic.

Letting go was a nearly universal discourse present in the narratives of the caregivers, which involved acknowledging a need to tell the dying person that it is "OK to die and to let go." Letting go occurs at the time of death but may also extend over a period of time and involve the gradual relinquishing of a lifestyle or relationship.

CHAPTER 8

SUMMARY AND DISCUSSION

AIDS is now a world wide pandemic characterized by widely differing demographics and contexts of care. Though primary family caregivers represent only one kind of care for persons with AIDS, these caregivers provide an essential cornerstone of the social response to AIDS (Brown & Powell-Cope, 1991). This study provides professionals and future family members access to the world of family caregiving for a person with AIDS.

Eighteen primary family caregivers were interviewed about their experiences of caring for a person with AIDS. Participants included 10 males and 8 females between the ages of 26 and 52. Four caregivers lived in rural settings; the remainder lived in urban centers located in two northwestern states. The persons cared for were white males, with the exception of one Mexican male.

Looking to family caregivers for their practical knowledge and capacities of care can uncover knowledge about human caring and contribute to information available to future AIDS caregivers and health professionals who support them. By entering the caregiver's world, both through practice and through the study of interpretive accounts, the professional provider can better understand, help, coach, and negotiate with future clients who struggle to cope with similar situations. Because it has the capacity to show up meanings and concerns that arise from lived experience, phenomenological research can contribute to more tactful and thoughtful practical engagement with clients (Leonard, 1994).

Limitations

A limitation of the study was that the sample did not include sufficient racial or ethnic representation. All of the participants were middle-class, Euroamericans. None of the caregiving situations included caring for a woman or child with AIDS. Only one situation involved caregiving for a person from an ethnic minority. Parallel studies among other ethnic groups need to be done to compare concerns and caring practices across cultural groups. Additionally, family caregiving for women and children with AIDS needs to be studied to understand how practices vary in relation to the gender or age of the ill person. Though findings cannot be generalized from small samples such as the one studied here, phenomenological research enhances understanding of a life world and explicates the possibilities inherent in particular practices. Such understanding may be shared with future family caregivers or may enhance the practices or insight of professional caregivers.

A second limitation relates to the retrospective design of the research and the timing of interviews. Interviews were aimed at collecting detailed descriptions of care which would disclose as clearly as possible the caring practices and concerns of participants during AIDS caregiving. The aim was to capture stories of the entire caregiving experience. All interviews took place between 3 months and 24 months after the death of the person with AIDS. A weakness of this approach was that the passage of time may have caused caregivers to forget details of specific episodes of care. Additionally, caregivers were in various stages of bereavement which may have influenced the concerns that were incorporated in their narratives. For example, stories about death were prominent in the data. These concerns may have unduly overshadowed the work that caregivers do early in the course of illness to help the ill person cope, maintain hope, or promote health.

Discussion of Findings and Implications of Results

Studying entire stories of care after they have been lived through may have allowed aspects of the interpretative account to show up in ways that would not otherwise have been possible. For example, it was possible to detect in the narratives a general continuum of care; this was considered a general pattern rather than a predictable chronology of caring practices since specific caring practices were highly variable, dependent upon the particular course of HIV disease, and changed across the trajectory of illness. It was nonetheless possible to discern dominant, sustaining moral concerns, such as the concern for dignity and a sense of self, throughout the continuum of care.

Though negative consequences of caregiving were not a major focus of the study, incidental findings from the present research corroborated anecdotal reports and research on AIDS caregiver stress (Folkman, in progress; Geis, Fuller, & Rush, 1986; Giacquinta, 1989; Matocha, 1992; Pearlin, in progress; Pearlin, Semple, & Turner, 1988; Raveis & Siegel, 1989). Caregivers in the present study, for example, described multiple sources of stress, and several reported episodes of depression during caregiving. Two caregivers reported episodes of suicidal ideation during particularly intense periods of caregiving. In short, stories of care could not be told outside of the contexts of emotional, psychological, physical, and financial stress experienced during caregiving.

An overall interpretive scheme emerged during analysis of data and was used to present the interpretive account. See Figure 1. The thesis of the overall interpretive account was that caring practices and concerns are shaped by three broad aspects of experience--namely, the cultural and family contexts of care, the moral meanings and concerns of caregivers, and the specific course of HIV disease in the ill person. The cultural contexts of AIDS care attest that social stigma and the negative metaphors associated with AIDS continue to affect persons with AIDS and their families, even as we progress well into the second decade of the world-wide pandemic. The effects of stigma were experienced by most caregivers though to different degrees. Urban gay men in this study were less affected by stigma than heterosexual couples or rural caregivers. Concealment, silence, avoidance, and isolation marked the caregiving experience of participants who were not connected with a gay community. Caring practices were affected in ways that could be predicted by Goffman's (1963) analysis of stigma. To varying degrees, caregivers attempted to control social information. Many claimed that AIDS was really another condition such as cancer, tuberculosis, meningitis or diabetic neuropathy. They disclosed the AIDS diagnosis to only a very close inner circle of friends or withdrew from social contact.

These findings support Powell-Cope and Brown's (1992) results on "guilt by association" and on strategies AIDS caregivers use such as living with secrecy and balancing concealment and openness.

One implication of this finding is that health care professionals must not become inured to the impact of social stigma on persons effected by AIDS. Family caregivers who have no connection with the gay community may be especially effected by AIDS stigma and consequent social isolation. The effects of isolation were not fully explicated in this study, however, the experience of isolation appeared to have significance in caregivers' stories and warrant further study.

Local community was seen as another powerful context of care. Two contrasting kinds of communities were seen: the urban gay community and rural communities. The evolution of home care teams among members of the urban gay community was identified and discussed. The present study provides a beginning understanding of the historical antecedents of such teams and the practical knowledge gained by family and friends who participated in a team model of care.

No research in the professional literature was identified which explored the historical contexts, philosophies, values, structure or function of home care teams. These findings recognize and give voice to the practical knowledge and caring practices worked out among team members and within the urban gay communities that spawned such teams. Future questions might include how care teams are the same or different in different localities; whether care teams can be a model of care outside of the urban gay community; what the benefits and burdens of the care team model are for the primary caregiver and the person with AIDS; and what conditions make care teams possible. Further study into the phenomenon of care teams is warranted before implications for practice can be clearly understood. However, professional health care providers may explore with family caregivers how this model of care might meet the needs of the caregiver and ill person. Unlike urban gay partners or friends, rural caregivers and a category of caregivers called "disenfranchised" caregivers told stories of isolated caregiving. As stated earlier, the effects of isolation on the caregiver and on the quality of care given are not well known; however, the data suggested the caregivers' need for increased support from professionals, local communities, and volunteer networks if possible.

Family was viewed in this interpretive account as both a context and a concern for AIDS caregivers. The research calls for health professionals to recognize the importance of family caregivers when working with persons with AIDS and to include in their awareness the critical role that primary family caregivers play in maintaining wellness or a tolerable life for the ill person.

Patterns of family context were identified, including involved families, estranged families, the reconciled family, and families in conflict. The intent of this interpretation was not to pathologize families, but to bring attention to concerns related to relationship issues within families and between families of origin and families of choice. Additionally, caregivers with children had special concerns about the participation of children in caregiving. Narratives from this sample of caregivers did not supply enough information about children as caregivers to make conclusions or draw implications for practice. However, the narratives suggested that this is an area for further research. Little is known about how children are involved in the family care of parents or other relatives who have AIDS. There was a suggestion in the data that primary caregivers may try to find a comfortable balance between including children in caregiving, while not placing an undue burden of care on their shoulders.

Research such as the present study calls for broader social definitions of family (Macklin, 1989). In over half of the situations in this sample, care was provided by the family of choice. Additionally, understanding family as a context of care promotes awareness among practitioners that human care is embedded in the background meanings and traditions of any given family situation. Working with members of a family requires working within those meanings and traditions.

Since the sample of caregivers was mostly limited to participants who had cared for gay, white men, this study may provide only limited understanding of how cultural or family contexts impact the care of women or persons from racial or ethnic minorities. The findings point out, however, that attention to family and cultural context is an important dimension in supporting family caregivers, regardless of ethnic origin or sexual orientation. It is important for nurses to maintain professional practices that are culturally sensitive, and such practices call for an understanding of the contexts in which families and patients cope with illness and disease.

The second aspect of this interpretive account is that caring practices are shaped by the moral meanings and concerns of caregivers. The findings of this study contributes to knowledge about AIDS caregiving by identifying and explicating moral meanings and concerns in the lived experience of AIDS family caregivers. Loss was viewed as a context which sets up the conditions for moral concern. The meanings of loss include a profound sense of the loss of "world" for the ill person. The significance of loss was intertwined and inextricably tied to the ill person's way of being in the world. Cumulative loss signified the steady "chipping away" of the ill person's former self. Loss of relationship; loss of future time; and loss of control created moral concerns about dignity and sustaining the ill person's sense of self. Caring practices related to preserving dignity and a sense of self included protecting the ill person from humiliation and shame, keeping the ill person in control, respecting the decisions of the ill person, keeping things the same, and respecting the spiritual self.

The issues of loss and control were present in all of the narratives in this study but were particularly dominant in the stories of gay, male caregivers. As mentioned, all of the caregiving situations in this sample involved caring for men. Understanding the additive effects of multiple loss as the loss of control over one's life may be particularly salient for males in a culture that emphasizes male dominance and control. Keeping the ill person in control was a frequent caregiver response in this sample but may not characterize responses of caregivers who care for women or for children with AIDS.

This interpretive account frames loss as a moral concern for caregivers and thus expands the discussion of loss by Brown and Powell-Cope (1993). These authors discussed caregivers' experiences of loss using a framework of anticipatory loss and grieving, pointing out the profound losses that caregivers themselves go through. Strategies caregivers used in facing loss and in dealing with a sense of transformed time included taking one day at a time, living fully in the present, and actualizing future dreams.

The findings of the present study corroborated the caregiver strategies reported by Brown and Powell-Cope (1993) and expanded the discourse by viewing loss as a context for moral concern. In this study, caregivers told about the suffering involved in being a witness to extreme losses experienced by the one cared for. Caring practices were aimed at minimizing the "de-worlding" effects of loss in the person cared for.

Moral concerns, such as the concern for dignity or the concern to "be there" for the ill person, were seen as primary and as fundamental to caring practices observed throughout the continuum of care.

The practical implication of these findings include the importance of grasping the moral issues of care as understood and defined by caregivers themselves--rather than by "top down" models of moral rules and principles. The moral meanings of loss were linked with the suffering of the ill person and also the suffering of family caregivers. Attempts to mitigate the effects of losing one's world were seen in the caring practices of caregivers.

The moral meanings, concerns and responses of caregivers in this interpretive account could not always be constructed as moral "dilemmas" which demanded moral judgments. The loss of one's world or the loss of one's customary way of moving and acting in the world are human problems that must be faced. The challenge is how one best faces up or how one best lives with the situation. In many situations, the best caregivers could do was to "be there" to deal in a morally sensitive way with loss and suffering.

In situations of profound and irreparable loss, "being there" may be the appropriate model of care for health professionals as well. "Being there" may simply involve one's silent presence, may include touch, or may involve conversations with caregivers and ill persons about their deepest concerns. Conversations with family about suffering, loss, and moral concern are often difficult and are not always appropriate; however, health professionals need to remain open to this aspect of the caregiving experience and be able to respond with respect and sensitivity to the caregiver's world. This view is similar to Kleinman's (1988) call for the professional practice of empathic witnessing--the attempt to be with the other in "the ambit of suffering," to make sense and give value to the experience. Much about the moral experience of caregivers remains to be understood; this study offers only a beginning understanding of this facet of AIDS family caregiving. However, the results suggest that it is important to understand the moral ends that caregivers move toward and to examine professional practices that may unduly obstruct those ends.

The third aspect of this interpretive account was that the particular course of HIV disease shapes caring practices across a continuum of care. Common stages in this continuum of care could be identified in the narratives. These included adjusting to the diagnosis; caring during wellness; making changes in caregiving with the onset of persistent illness; getting settled for full-time caregiving; moving into "high gear"; and moving toward palliative care. "High gear" was a term used to describe a physically and emotionally intense period of technical and intimate care that may be taken up during the late stages of AIDS. Not all caregivers and persons with AIDS pursued complex, highly technical care.

Most caregivers anticipated and prepared for the death of the ill person long before death became imminent. As the ill person grew closer to death, caring practices centered on attending to the details of a dying space, being sensitive to a tranquil way of being at the time of death, and going through the final processes of letting go.

Working out the general outlines of a continuum of care may be useful for professional and family caregivers who may want some basis for anticipating how the course of illness will affect caring practices. Since any specific course of HIV disease is idiosyncratic, highly uncertain and unpredictable, specific practices within the continuum of care are linked with the particular course of HIV disease in the ill person and therefore cannot be predicted or controlled. The shared aspects of an overall continuum of care may nonetheless serve as a general chronology of common caring practices and concerns. AIDS caregivers may consider such chronologies if they wish to anticipate possibilities of care or plan for acquiring new skills.

Anticipatory planning with families is generally recognized as a desirable clinical therapeutic; however, anticipatory guidance by professional providers may need to be approached with caution in this population. The narratives suggested that sustaining hope was an important part of living with HIV disease. Often families chose not to know and avoided projecting themselves into the future as a strategy for sustaining hope. Anticipatory guidance should be undertaken when families indicate their readiness and ability to deal with such information.

The findings of this study provided confirmatory stories for the theory of AIDS family caregiving proposed by Brown and Powell-Cope (1991). Additionally, the present study extends Brown and Powell-Cope's theory by pointing out moral dimensions of AIDS family caregiving. One example of how this study might extend theory is in the observation that caregivers can act morally by resisting the urge to "leap in." Instead of doing for the ill person, caregivers may serve the moral end of protecting dignity by not doing for the ill person. Examples of this concern were found in stories of returning control and respecting decisions of the ill person. This interpretation extends the discourse on managing the illness by locating instances where the strategy of doing for was resisted because it did not serve the moral ends of caregiving. Another example of extending theory might be seen in the present interpretation of loss, which was seen not only as a context for anticipatory grieving, but also as a context for moral concerns related to preserving dignity and a sense of self for the ill person.

This research points toward several areas of further study. On the basis of this study, further research is warranted (1) on caring practices developed in local gay communities such as the home care teams described in this account; (2) on the participation of children in caring for a parent, sibling, or other relative with AIDS; and (3) on the moral concerns and practices of AIDS family caregivers.

The interpretations offered here must be considered in relation to the sample of caregivers included in the study. This interpretive account may be relevant in only limited ways to a more diverse sample of caregivers. Therefore, parallel studies among caregivers of diverse ethnic groups need to be conducted to compare caring practices across cultural contexts. In addition, interpretive work cannot make the claim of producing a complete picture of the participants' world. Additional practices and concerns not mentioned here may not have been voiced by participants in this study or may not have been present in their experience.

Phenomenological research aims at generating an interpretive account that is sensible and useful. The account must be plausible, must offer increased understanding of the world it interprets, and must explicate the practices, meanings, concerns, and practical knowledge of participants engaged in that world (Benner, 1994). In relation to family caregiving for persons with AIDS, this study has allowed meanings and concerns, caring practices and practical knowledge to be seen and interpreted. The narratives provided confirmatory stories for extant theory on AIDS family caregiving and extended that theory by disclosing moral dimensions of family caregiving for a person with AIDS. In addition, the research uncovered new areas for further research including research on the role of children in AIDS family caregiving, further research on the moral meanings and concerns of caregivers, and further research on the practical knowledge and specific caring practices used by members of home care teams.

REFERENCES

Abel, E. (1990). Family care of the frail elderly. In E. Abel & M. Nelson (Eds.), Circles of care, work and identity in women's lives (pp. 65-91). Albany: State University of New York Press.

Abel, E. K., & Nelson, M. K. (1990). Circles of care: An introductory essay. In E. K. Abel & M. K. Nelson (Eds.), Circles of care: Work and identity in women's lives (pp. 4-34). Albany, NY: State University of New York Press.

Addison, R. B. (1992). Grounded hermeneutic research. In B. F. Crabtree & W. L. Miller (Eds.), Doing qualitative research (pp. 111-124). Newbury Park, CA: Sage Publications.

Allen, D., Benner, P., & Diekelmann, N. (1986). Three paradigms for nursing research--methodological implications. In P. L. Chinn (Ed.), Nursing research methodology (pp. 23-38). Rockville, MD: Aspen Publishers.

American Medical Association. (1988). Ethical issues involved in the growing AIDS crisis. Journal of the American Medical Association, 259, 1360-1361.

Anderson, E. A. (1989). Implications for public policy: Towards a pro-family AIDS social policy. In E. D. Macklin (Ed.), AIDS and families (pp. 187-228). New York: Harrington Park Press.

Archbold, P. (1990). Family caregiving to older persons: A nursing perspective. The Tenth Helen Nahm Research Lecture, University of California, School of Nursing. San Francisco, June 1, 1990.

Archbold, P., & Stewart, B. (March, 1988). Effects of organized family caregiver relief: Final report to the National Center for Nursing Research. Oregon Health Sciences University School of Nursing, Portland, OR.

Aroskar, M. (1990). Research in community-based care of persons with AIDS: an ethical framework. In Community-based care of persons with AIDS: Developing a research agenda (pp. 127-131). Rockville, MD: US Dept. of Health and Human Services, Agency for Health Care Policy and Research.

Backer, B. A., Hannon, N. R., & Russell, N. A. (1994). Death and dying: Understanding and care (2nd ed.). New York: Delmar Publishers.

Bayer, R. (1990). Caring for HIV-infected individuals in the community: Ethical issues in the epidemic's next phase. In Community-based care of persons with AIDS: Developing a research agenda (pp. 117-126). Rockville, MD: U.S. Dept. of Health and Human Services, Agency for Health Care Policy and Research.

Bayer, R., & Kirp, D. (1994). The United States: At the center of the storm. In R. Bayer & D. Kirp (Eds.), AIDS in the industrialized democracies (pp. 7-47).

Bayer, R., & Kirp, D. (1992). The United States: At the center of the storm. Chapt. 1. In D. Kirp & R. Bayer, (Eds.), AIDS in the industrialized democracies: Passions, Politics, and Policies. New Brunswick, NJ: Rutgers University Press.

Beauchamp, T. L., & Childress, J. F. (1989). Principles of biomedical ethics (3rd ed.). New York: Oxford University Press.

Bell, J. P. (1988). AIDS has created a new form of bereavement. American Journal of Hospice Care, 5, 25-31.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. Advances in Nursing Science, 8, 1-14.

Benner, P. (1984). From novice to expert, excellence and power in clinical nursing practice. Menlo Park, CA: Addison-Wesley Publishing Co.

Benner, P., Tanner, C., & Chesla, C. (1992). From beginner to expert: Gaining a differentiated clinical world in critical care nursing. Advances in Nursing Science, 14, 13-28.

Benner, P., & Wrubel, J. (1989). The primacy of caring. Stress and coping in health and illness. Menlo Park, CA: Addison-Wesley Publishing Co.

Bennett, F. J. (1987). AIDS as a social phenomenon. Social Science and Medicine, 25, 529-529.

Bishop, A. H., & Scudder, J. R. (1991). Nursing: The practice of caring. New York: National League for Nursing Press. (Pub. No. 14-2442)

Bishop, A. H., & Scudder, J. R. (1990). The Practical, moral, and personal sense of nursing. Albany, New York: State University of New York Press.

Bok, S. (1983). Secrets, on the ethics of concealment and revelation. New York: Vintage Books.

Bonuck, K. A. (1993). AIDS and families: Cultural, psychosocial, and functional impacts. Social Work in Health Care, 18, 75-85.

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

Brown, M. A., & Powell-Cope, G. (1993). Themes of loss and dying in caring for a family member with AIDS. Research in Nursing and Health.

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

Buehler, J. W., Petersen, L. R., & Jaffe, H. W. (1995). Current trends in the epidemiology of HIV/AIDS. In M. A. Sande & P. A. Volberding (Eds.), The medical management of AIDS (4th ed.). Philadelphia: W.B. Saunders.

Bureau of Census. (1990). Summary population and housing characteristics for Oregon. 1990 Census. U.S. Department of Commerce.

Cameron, M. E. (1993). Living with AIDS. Newbury Park: Sage Publications.

Carmack, B. J. (1992). Balancing engagement/detachment in AIDS-related multiple losses. Image: Journal of Nursing Scholarship, 24, 9-14.

Carper, B. A. (1978). Fundamental patterns of knowing in nursing. Advances in Nursing Science, 13-23.

Carson, V. B., & Green, H. (1992). Spiritual well-being: A predictor of hardiness in patients with acquired immunodeficiency syndrome. Journal of Professional Nursing, 8, 209-220.

Carter, D. B. (1989). Societal implications of AIDS and HIV infection: HIV antibody testing, health care and AIDS education. In E. D. Macklin (Ed.), AIDS and families (pp. 129-186). New York: Harrington Park Press.

Cartwright, J. C. (1993). Enrichment in family caregiving to frail elders. Unpublished Ph.D. Dissertation, Oregon Health Sciences University, Portland, OR.

Centers for Disease Control. (1992). Facts about the scope of the HIV/AIDS epidemic in the United States. November, 1992.

Chesla, C. A. (1994). Parents' caring practices with schizophrenic offspring. In P. Benner (Ed.), Interpretive phenomenology (pp. 167-184). Thousand Oaks,CA: Sage Publications.

Chesla, C. A. (1991). Parents' caring practices with schizophrenic offspring. Qualitative Health Research, 1, 446-468.

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

Coles, R. (1989). The call of stories. Boston: Houghton Mifflin.

Connor, S. S. (1989). AIDS: Social, legal, and ethical issues of the "third epidemic". In AIDS, Profile of an epidemic (Pub. 514 ed., pp. 141-158). Washington, DC: Pan American Health Organization.

Deatrick, J. A., Knafl, K. A., & Guyer, K. (1993). The Meaning of caregiving behaviors: Inductive approaches to family theory development. In S. L. Feetham, S. B. Meister, J. M. Bell, & C. L. Gillis (Eds.), The nursing of families (p. 308). Newbury Park, CA: Sage Publications.

Dreyfus, H. L. (1991). Being-in-the-world, a commentary on Heidegger's being and time. Cambridge, MA: The MIT Press.

Dreyfus, H. L., Dreyfus, S. E., & Benner, P. E. (1990). Acquiring ethical expertise in nursing. A paper in preparation for publication, University of California, Berkeley and University of California, San Francisco. February 20, 1990.

Duffy, V. J. (1994). Crisis points in HIV disease. AIDS Patient Care, 28-32.

Eidson, T. (Ed.). (1988). The AIDS caregiver's handbook. New York: St. Martin's Press.

Farran, C. J., Deane-Hagerty, E., Dupferer, S., & Wilken, C. S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. The Gerontologist, 31, 383-389.

Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. In E. K. Abel & M. K. Nelson (Eds.), Circles of care: Work and identity in women's lives. Albany: State University of New York Press.

Folkman, S. (In progress). The coping project: The effects of bereavement on partners of men with AIDS. In progress research funded by the National Institutes of Mental Health.

Folkman, S., Chesney, M., & Christopher-Richards, A. (In press). Stress and coping in caregiving partners of men with AIDS. In L. Zegans & T. J. Coates (Eds.), Diagnosis and management of psychiatric manifestations of HIV disease, psychiatric clinics of North America. Philadelphia: W.B. Saunders.

Fox, R. C., Aiken, L., & Messikomer, C. (1990). The culture of caring: AIDS and the nursing profession. The Milbank Quarterly, 68(Suppl. 1), 226-256.

Frankena, W. K. (1973). Foundations of philosophy. Ethics (2nd ed.). Englewood Cliffs, NJ: Prentice Hall.

Gadow, S. (1989). Clinical subjectivity. Advocacy with silent patients. Nursing Clinics of North America, 24, 535-541.

Gadow, S. (1988). Covenant without cure: Letting go and holding on in chronic illness. In J. Watson & M. A. Ray (Eds.), The ethics of care and the ethics of cure: Synthesis in chronicity (p. 55). New York: National League for Nursing.

Gadow, S. A. (1985). Nurse and patient: The caring relationship. In A. H. Bishop & J. R. Scudder (Eds.), Caring, curing, coping: Nurse, physician, patient relationships (pp. 31-43). University, Alabama: University of Alabama Press.

Garfield, C., & Spring, C. (1993). AIDS caregiving: Lessons for the second decade. San Francisco: Jossey Bass, Inc. Audiotape.

Geertz, C. (1973). The interpretation of cultures. New York: Basic Books.

Geis, S. B., Fuller, R., & Rush, J. (1986). Lovers of AIDS victims: Psychosocial stresses and counseling needs. Death Studies, 10, 43-53.

Giacquinta, B. S. (1989). Research the effects of AIDS on families. American Journal of Hospice Care, May/June, 31-36.

Gilligan, C. (1982). In a different voice. Cambridge, MA: Harvard University Press.

Given, B. A., & Given, C. W. (1991). Family caregiving for the elderly. In J. J. Fitzpatrick, R. L. Taunton, & A. K. Jacox (Eds.), Annual review of nursing research (Vol. 9, pp. 77-101). New York: Springer Publishing Company.

Glaser, E. (1991). In the absence of angels. New York: Berkley Books.

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

Gordon, D. R. (1994). The ethics of ambiguity and concealment around cancer: Interpretations through a local Italian world. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 279-322). Thousand Oaks, CA: Sage Publications.

Graham, H. (1983). Caring: A labour of love. In J. Finch & D. Groves (Eds.), *Labour of love, women, work and caring* (pp. 13-30). London: Routledge & Kegan Paul.

Gregory, D., & Longman, A. (1992). Mothers' suffering: Sons who died of AIDS. *Qualitative Health Research*, *2*, 334-357.

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

Harman, G. (1977). *The nature of morality*. New York: Oxford University Press.

Hepburn, K. (1990). Informal caregivers: Frontline workers in the chronic care of AIDS patients. In *Community-based care of persons with AIDS: Developing a research agenda* (pp. 37-42). Rockville, MD: U.S. Dept. of Health and Human Services, Agency for Health Care Policy and Research.

Horowitz, A. (1985). Family caregiving to the frail elderly. In M. P. Lawton & G. L. Maddox (Eds.), *Annual review of gerontology and geriatrics* (Vol. 5, pp. 194-246). New York: Springer Publishing Company.

Kelleheear, A. (1994). Are we a death denying society? A sociological review. Social Science and Medicine, 18, 717-720.

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

Kobasa, S. (1990). AIDS and volunteer associations: Perspectives on social and individual change. The Milbank Quarterly, 68 (suppl 2), 280-293.

Leonard, V. W. (1994). A Heideggerian phenomenological perspective on the concept of person. In P. Benner (Ed.), Interpretive phenomenology: Embodiment, caring, and ethics in health and illness. Thousand Oaks, CA: Sage Publications.

Levine, C. (1990). AIDS and changing concepts of family. The Milbank Quarterly, 68(Suppl. 1), 33-58.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Beverly Hills: Sage Publications.

London, A. (1988). Stories from the front: Daniel, my son. In T. Eidson (Ed.), The AIDS caregiver's handbook (pp. 100-108). New York: St. Martin's Press.

Lyons, N. P. (1983). Two perspectives: On self, relationships, and morality. Harvard Educational Review, 53, 125-145.

MacIntyre, A. (1984). After virtue (2nd ed.). Notre Dame, Indiana: University of Notre Dame Press.

MacIntryre, R. C. (1993). Sex, drugs and T-cells: Symbolic meanings among gay men with asymptomatic HIV infection. Doctoral dissertation. University of California, San Francisco.

MacIver, R. (1970). The primacy of community. In r. MacIver's On community, society and power. Chicago: University of Chicago Press.

Macklin, E. D. (Ed.). (1989). AIDS and families. New York: Harrington Park Press.

Magee, B. (1987). The great philosophers: An introduction to western philosophy. London: BBC Books.

Marshall, P., Thomasma, D., & O'Keefe, J. P. (1991). Disclosing HIV status, ethical issues explored. Journal of the American Dental Association, 122, 11-15.

Matocha, L. K. (1992). Case study interviews: Caring for persons with AIDS. In J. F. Gilgun, K. Daly, & G. Handel (Eds.), Qualitative methods in family research (pp. 66-84). Newbury Park, CA: Sage Publications.

Mayeroff, M. (1971). On caring. New York: Harper & Row, Pub.

McDonell, J. R., Abell, N., & Miller, J. (1991). Family members' willingness to care for people with AIDS: A psychosocial assessment model. Social Work, 36, 43-53.

McKusick, L. (1992). Counseling across the HIV spectrum. HIV frontline, 8, 1-8.

McKusick, L. (1993). Riding the HIV roller coaster: Counseling and care in later-stage illness. HIV Frontline, 11, 1-6.

Meleis, A. I. (1991). Theoretical nursing: Development and progress (2nd Ed.). Philadelphia: J.B. Lippicott.

Moffatt, X. (1986). When someone you love has AIDS. New York: NAL Penguin Inc.

Monette, P. (1988). Borrowed time. An AIDS memoir. New York: Avon Books.

Morse, J. M. (Ed.). (1991). *Qualitative nursing research: A contemporary dialogue* (2nd ed.). London: Sage Publications.

Munhall, P. L., & Oiler, C. J. (1986). *Nursing research, a qualitative perspective*. Norwalk, CT: Appleton-Century-Crofts.

Noddings, N. (1984). *Caring. A feminine approach to ethics and moral education*. Berkeley: University of California Press.

Oiler, C. (1982). The phenomenological approach in nursing research. *Nursing Research*, *31*, 178-181.

Omery, A. K. (1985). *The moral reasoning of nurses who work in the adult intensive care setting*. Unpublished Doctoral Thesis, Boston University, School of Nursing.

Packer, M. (1985). Hermeneutic inquiry in the study of human conduct. *American Psychologist*, *40*, 1081-1093.

Packer, M. J., & Addison, R. B. (1989). Evaluating an interpretive account. In M. J. Packer & R. B. Addison (Eds.), *Entering the circle, hermeneutic investigation in psychology* (pp. 275-292). Albany: State University of New York Press.

Packer, M. J., & Richardson, E. (1990). Analytic hermeneutics and the study of morality in action. In W. Kurtines & J. Gewirtz (Eds.), *Handbook of moral behavior and development* (Vol. Volume 1: Theory). New York: Erlbaum.

Pantaleo, G., Graziosi, C., & Fauci, A. S. (1993). Natural history of HIV infection and disease. *New England Journal of Medicine*, *328*, 327.

Paton, S. (1992). Stress and the informal caregiver. *Focus, A guide to AIDS Research and Counseling*, *7*, 1-3.

Pearlin, L. I. (In progress-a). Family care study: Stress and coping among AIDS family caregivers. In progress research funded by the University of California.

Pearlin, L. I. (In progress-b). Stress and coping among AIDS caregivers. In progress research funded by the National Institutes of Mental Health.

Pearlin, L. I., Harrington, C., & Wardlaw, L. (1992). The structure of AIDS caregiving relationships. Research in progress, presented at the annual meeting of the American Public Health Association, Washington, D.C., November, 1992. Supported by NIMH Grant #RO1-MH44600.

Pearlin, L. I., Mullan, J. T., Aneshensel, C. S., & Wardlaw, L. (In progress). Family caregivers for persons with AIDS. Research in progress, supported by NIMH Grant #RO1-MH446600.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-593.

Pearlin, L. I., Semple, S., & Turner, H. (1988). Stress of AIDS caregiving: A preliminary overview of the issues. Death Studies, 12, 501-517.

Pepin, J. I. (1992). Family caring and caring in nursing. Image: Journal of Nursing Scholarship, 24, 127-131.

Phillips, L. R. (1989). Elder-family caregiver relationships, determining appropriate nursing interventions. Nursing Clinics of North America, 24, 795-807.

Phillips, L. R., & Rempusheski, V. F. (1986). Caring for the frail elderly at home: toward a theoretical explanation of the dynamics of poor quality family caregiving. Advances in Nursing Science, 8, 62-84.

Pohl, M., Kay, D., & Toft, D. (1990). The caregivers' journey, when you love someone with AIDS. New York: Harper Collins Publishers.

Polkinghorne, D. (1988). Narrative knowing and the human sciences. Albany: State University of New York Press.

Polkinghorne, D. (1983). Methodology for the human sciences: Systems of inquiry. Albany, NY: State University of New York Press.

Powell-Cope, G. M., & Brown, M. A. (1992). Going public as an AIDS family caregiver. Social Science and Medicine, 34, 571-580.

Preston, J. (Ed.). (1989). Personal dispatches, writers confront AIDS. New York: St. Martin's Press.

Price, D. (1991). What should we do about HIV-positive health professionals. Archives of Internal Medicine, 151, 658-659.

Price, M. E. (1989). Shattered mirrors: Our search for identity and community in the AIDS era. Cambridge, MA: Harvard University Press.

Rabinow, P., & Sullivan, W. M. (1979). Interpretive social science: A reader. Berkeley, CA: University of California Press.

✓ Rait, D. S. (1991). The family context of AIDS. Psychiatric Medicine, 9(3), 423-439.

✓ Raveis, V., & Siegel, K. (1990). Impact of caregiving on informal or familial caregivers. In Community-based care of persons with AIDS: Developing a research agenda (pp. 17-28). Rockville, MD: U.S. Dept. of Health and Human Services, Agency for Health Care Policy and Research.

Reamer, F. C. (Ed.). (1991). AIDS and ethics. New York: Columbia University Press.

Relman, A. (1985). AIDS: The emerging ethical dilemmas. The Hastings Center Report.

Ricoeur, P. (1979). The model of the text: Meaningful action considered as a text. In P. Rabinow & W. M. Sullivan (Eds.), Interpretive social science: A reader. Berkeley, CA: University of California Press.

Rieder, I., & Ruppelt, P. (Eds.). (1988). AIDS: The women. San Francisco: Cleis Press.

Ross, J. W. (1988a). Ethics and the language of AIDS. In C. Pierce & D. Vandeveer (Eds.), AIDS: Ethics and public policy (pp. 39-48). Belmont, CA: Wadsworth Publishing Co.

Ross, J. W. (1988b). An ethics of compassion, a language of division: Working out the AIDS metaphors. In I. B. Corless & M. Pittman-Lindeman (Eds.), AIDS: Principles, practices, and politics (pp. 81-95). Washington, DC: Hemisphere Publishing Corp.

Ruddick, S. (1989). Maternal thinking, toward a politics of peace. New York: Ballantine Books.

Salsberry, P. J. (1989). Phenomenological research in nursing: Commentary and responses. Nursing Science Quarterly, 2(1), 9-19.

Sankar, A. (1991). Dying at home, a family guide for caregiving. Baltimore: The Johns Hopkins University Press.

Sarter, B. (Ed.). (1988). Paths to knowledge. Innovative research methods for nursing (Pub. No. 15-2233). New York: National League for Nursing.

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: A central concept in nursing. Image: Journal of Nursing Scholarship, 26, 119-127.

Schutz, A. (1972). The phenomenology of the social world. London: Heinemann Educational Books.

Sebesta, D. S. (1992). Community integration of caregivers to persons with HIV disease. Paper prepared for presentation at the Annual Meetings of the American Public Health Association, Washington, DC, November 10, 1992.

Seidel, J., Friese, S., & Leonard, D. C. (1994). The Ethnograph, Version 4.0. Qualis Research, Amherst, MA.

Shilts, R. (1987). And the band played on. New York: Penguin Books.

Simpson, M. (1988). The malignant metaphor: A political thanatology of AIDS. In I. B. Corless & M. Pittman-Lindeman (Eds.), AIDS: Principles, practices, and politics (pp. 193-208). Washington, DC: Hemisphere Publishing Corp.

Sontag, S. (1979). Illness as metaphor. New York: Vintage Books.

Sontag, S. (1989). AIDS and its metaphors. New York: Farrar, Straus and Giroux.

Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27, 616-626.

Strauss, A. L. (1984). Chronic illness and the quality of life (2nd ed.). St. Louis: C.V. Mosby.

Sussman, M. (1989). AIDS: Opportunity for humanity. In AIDS and families (pp. 229-239). New York: Harrington Park Press.

Swanson, K. M. (1991). Empirical development of a middle range theory of caring. Nursing Research, 40, 161-166.

Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. (1993). The phenomenology of knowing the patient. Image: Journal of Nursing Scholarship, 25, 273-280.

Thompson, J. L. (1990). Hermeneutic inquiry. In L. E. Moody (Ed.), Advancing nursing science through research (Vol. 2, pp. 223-286). Newbury Park, CA: Sage Publications.

Tiblier, K. B., Walker, G., & Rolland, J. S. (1989). Therapeutic issues when working with families of persons with AIDS. In E. D. Macklin (Ed.), AIDS and families (pp. 81-127). New York: Harrington Park Press.

Van Manen, M. (1990). Researching lived experience. London, Ontario, Canada: State University of New York Press.

Velimirovic, B. (1987). AIDS as a social phenomenon. Social Science and Medicine, 26, 541-552.

Wros, P. L. (1994). The ethical context of nursing care of dying patients in critical care. In P. Benner (Ed.), Interpretive phenomenology: Embodiment, caring, and ethics in health and illness (pp. 255-278). Thousand Oaks, CA: Sage Publications.

Appendix A

Consent Form

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM

CARING PRACTICES IN FAMILIES OF PERSONS WITH AIDS

PRINCIPAL INVESTIGATOR:	Linda J. Budan, MA, MSN, RN Doctoral Student School of Nursing, Oregon Health Sciences University 503-494-3855 Advisors: Patricia Archbold, RN, DNSc (503-494-3840) and Christine Tanner, RN, PhD (503-494-3742)
CONSENT FORM:	To be used with family members and friends who have been primary caregivers for a person who has died from complications of AIDS

STUDY PURPOSE

The purpose of this research is to learn about the caring practices of family members or friends who were primary caregivers for a person who died from AIDS. I will be interviewing caregivers in order to obtain their stories about how they cared for the person with AIDS and what kinds of practical knowledge they developed during their caregiving experience. I will also explore with caregivers their concerns and meanings that were related to the caregiving experience.

PROCEDURES

If you agree to participate in this study, you will be interviewed, at least once, at a time and place that is agreed upon by yourself and the investigator. If agreed to by you, you may be interviewed two times or more in order for the researcher to obtain a complete story of your experiences as a caregiver. Each interview will last approximately one to one and a half hours.

I will ask you questions about your past relationship with the person with AIDS, the history of your involvement as a caregiver, everyday events and episodes of giving care, and the concerns and meanings that you may have experienced as a result of being a caregiver. I will ask you to supply additional information about yourself including your age, your approximate yearly family income during caregiving, your years of education, your racial or ethnic group, your employment status during caregiving, the number of months engaged in caregiving, and the length of time you have known the person with AIDS.

RISKS AND BENEFITS

Some parts of the interview may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics that may be uncomfortable for you. You may choose to stop the interview at any time, and you may choose not to be interviewed at another time.

If I feel that follow-up counseling or discussion of emotional upsets would be helpful for you or if you request such follow-up counseling, I will offer my assistance in making such referrals.

Participating in this interview may provide some benefits for you. Talking about your past experiences of caregiving may allow you to ventilate your feelings and may result in new insights or understandings about situations or episodes of caregiving. A more complete understanding and description of family caring practices for persons with AIDS will contribute to nursing science by suggesting possible models for AIDS care. This knowledge may be used to benefit future family caregivers and to educate nurses and others involved in AIDS care.

CONFIDENTIALITY

Each interview will be audio taped and written notes may be made by the researcher during and after the interview. The tapes will be typed word for word with all personally identifying information deleted in the typed record. Names and places will be deleted or changed in order to protect the confidentiality of all persons mentioned during the interview. After each typed interview is complete and has been reviewed for accuracy, the audio tapes will be destroyed. Personally identifying information will be deleted from all written notes.

Each typed interview will be given a study number. Only the investigator will have access to the information that links your name with this study number. This information along with signed consent form will be kept in a locked file drawer which only the research will be able to access.

Typed interviews containing no identifying information will be reviewed by the researcher and by faculty advisors. These interviews may be shared with two doctoral students who will assist in data analysis. Any publications, including the dissertation report, will include necessary precautions to protect your identity. Neither your name nor your identity will be used for publication or publicity purposes.

COSTS OF PARTICIPATION

There are no monetary costs to you for participating in this study. You will be contributing your time as a result of agreeing to participate in interviews. There will be no reimbursement or compensation to you as a result of participating.

LIABILITY

The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

YOUR RIGHTS AS A PARTICIPANT

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care you receive at the Oregon Health Sciences University.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Linda Budan at (503) 537-0371 or (503) 494-3855. If you have further questions, Dr. Christine Tanner, RN, PhD at (503) 494-3742 or Dr. Patricia Archbold, RN, DNSc, at (503) 494-3840 have offered to answer questions about this research study. If you have questions about your rights as a research subject, you may contact the OHSU Institutional Review Board at 503-494-7887.

You will receive a copy of the signed consent form. Your signature below indicates that you have read the foregoing and agree to participate in this study.

____
Signature Date

____
Witness Signature Date

APPENDIX B

INTERVIEW GUIDE

CARING PRACTICES IN FAMILIES OF PERSONS WITH AIDS

INTERVIEW GUIDE

The purpose of our conversation today is to talk about your experiences as a caregiver for ____. I would like to ask you about the history of your relationship and about your experiences and concerns as a caregiver.

I am interested in hearing specific examples of caregiving episodes, so please feel free to include as much detail in your story as you can recall. I will ask about the feelings and concerns that you had at the time.

1. First I would like to gain a sense of the past history of your relationship with _____. Tell me about your relationship before your became the caregiver.

2. I'm also interested in learning about the history and chronology of _____'s illness. Could you start at the time of the diagnosis and tell me how the disease progressed?

   You might prefer to briefly write this down in the form of a timeline on a piece of paper. Knowing how the disease progressed will help me ask about the caring practices that you used during the caregiving experience.

3. Starting around the time of the diagnosis, or earlier if that is appropriate, I'd like you to describe episodes of care. (The timeline obtain in question 2 is used to guide questioning about caring practices that developed as the disease progressed.)

4. When you think about all that you did for _____, what stands out as really important and worthwhile in your care?

5. Tell me about a time that you felt bothered or upset and that you wished had turned out differently. What do you wish you could have done differently for ____?

6. Were there times that you had to make a really difficult choice in relation to ____'s care? Did you face any conflicts between caregiving and your own well being or the well being of others in the situation?

7. What were some of the hardest things you had to face during this experience? What stands out as the worst part of it?

8. Some people have said that the experience of taking care of a friend or family member with AIDS has changed them in some way. Is that true for you? What has changed for you?

Study Number ________

APPENDIX C

DEMOGRAPHIC DATA COLLECTION FORM

OREGON HEALTH SCIENCES UNIVERSITY

CARING PRACTICES IN FAMILIES OF PERSONS WITH AIDS

DEMOGRAPHIC INFORMATION

1. Study number ____________________

2. Relationship to person with AIDS ____________________

3. Months involved as a caregiver ____________________

4. Length of time acquainted with person with AIDS ____________________

5. Work status during caregiving ____________________

6. Approximate yearly family income during caregiving ____________________

7. Age of person with AIDS at death ____________________

   Age of caregiver at the time of ill person's death ____________________

8. Gender of person with AIDS ____________________

   Gender of caregiver ____________________

9. Ethnic/racial group of person with AIDS ____________________

   Ethnic/racial group of caregiver ____________________

APPENDIX D

TAGGING SCHEME USED TO MARK TEXT FOR DATA RETRIEVAL

Tag Word	Initial meanings
Bepresent	Text referring to importance of "being there" or "being present" for the ill person. A nonintrusive, nondemanding way of being near.
Carespace	Text segments or exemplars referencing caregivers concerns and actions around setting up a physical and psychological space appropriate to the demands of caregiving. May include references to equipment, such as hospital beds, or other items which carry symbolic meanings for caregiver or ill person.
Careteam	References to the organization and working out of a careteam approach to care in the home.
CGRelation	A general tag word that refers to history and nature of past relationship between the caregiver and ill person.
Children	References to the involvement of children in caregiving or concerns of caregivers about the welfare of children in the family.
Community	Text segments that refer to caregivers sense of participation or exclusion from local communities. Includes different forms of community, such as urban gay communities or underground networks of AIDS workers in rural communities.
Context	Refers to text that reflects multiple contexts of care, including broad cultural and social contexts, communities, and families.
Control	References to beliefs and values about keeping the ill person in control and strategies used to return control.
Death	A general tag word for any aspects of text having to do with death and dying. Also includes caregivers concerns about the dead body.
Diagnosis	Concerns and actions related to learning about and living with a positive HIV test or AIDS diagnosis.
Dignity	Text or exemplars describing caregivers' concerns about dignity. Includes sources of dignity and indignity for the ill person and ways to keep dignity in tact.
Dyingspace	References to the physical and psychological space where death occurred.

Family	Narrative references to family of origin and/or family of choice. Text may allude to conflict within or between families or support from family members.
Gayissues	References to concerns about gay identity or gay community and the AIDS epidemic. May include references to homophobia or heterosexism in the culture.
Humiliate	Text or exemplars describing caregivers' awareness of the ill person's vulnerability to shame and humiliation.
Intimate	Includes caregiver descriptions of intimate care such as diapering, bathing, toileting, etc., tactics used, and responses of the ill person. Sensitivity to issues of modesty and cultural boundaries set up around nudity and bodily functions.
Isolation	Exemplars or text segments describing isolated caregiving. May be linked with female gender of caregiver, rural communities, or need to keep conceal an AIDS diagnosis.
Letgo	References to letting go. May include letting go of a familiar life style or letting go at the time of death.
Loss	Text segments that describe caregivers' understanding of losses experienced by the ill person.
Moralcon	Text segments, exemplars or paradigm cases of a moral concern.
Promise	Situations or exemplars where keeping a promise is a strong motivation behind caregiving.
Protect	Examples of protecting the ill person from harm. May include minimizing or avoiding loss, protecting from shame, protecting from physical harm or pain.
Rural	Rural caregivers and/or contexts of care that were particularly salient in rural settings such as distance from professional providers, isolation, or lack of connection with local community.
Secrets	References to situations where caregivers keep a secret. May center on concealing the AIDS diagnosis and include covering for the ill person, telling lies or staying silence as ways of keeping the secret. May also include keeping secrets about the ill person's degree of illness or disability.

Spiritual	Text segments referring to person's spiritual beliefs or concerns.
Staycalm	Text that refers to staying calm as a valued way of being for caregivers.
Stigma	Text that refers to concerns about rejection, discrimination and negative judgments of others.
Suicide	Text that refers to caregivers' beliefs about suicide or conversations with the ill person about suicide.
Techcare	References to ways caregivers managed technical care including IV lines, injections, morphine pumps, central venous catheters, urinary catheters, medication schedules, or pain control.