THE MEANING OF GRIEVING
FOR FAMILIES LIVING WITH AIDS

by

William Kershaw Cody

Bachelor of Science
University of the State of New York, 1986

Master of Science
Hunter College of the City University of New York, 1989

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Major Professor, Chairperson of the
Examining Committee

Committee Member

Committee Member

Committee Member

Committee Member

Dean of the Graduate School
Dedication

This work is dedicated to all those who were and are with me in my struggles.

Ethel May Hancock Cody
Steven Warner
Rosemarie Rizzo Parse
Nancie Phillips
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None of you will ever fully know what you mean to me,
but it is beautiful and wonderful beyond words.

"Have you met my family?
Wouldn't take long to know them well...
Though they number from one to a million,
In this house they all dwell."

-- Pam Nestor / Joan Armatrading

Blessed be.
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Pamela N. Clarke, RN; PhD
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W. Richard Cowling, III, RN; PhD
Jerald T. Wallulis, PhD

Someday a young nursing scholar may read this while contemplating the undertaking of a qualitative nursing study challenging some of the assumptions of conventional research. These people have helped to make that possible. Most especially, Rosemarie Rizzo Parse is to be acknowledged for creating the very possibility of a work such as this. If my work proves to be even a pale reflection of hers, then I will have succeeded beyond my wildest ambition. The guidance and scholarly critique provided by the committee members constantly challenged me, and, I hope, propelled this work toward a depth and clarity that is evident in the final product. I, of course, must take full responsibility for any shortcomings in the work that remain.
ABSTRACT
THE MEANING OF GRIEVING FOR FAMILIES LIVING WITH AIDS
William Kershaw Cody

The purpose of this nursing study, guided by Parse's human becoming theory, was to investigate the meaning of grieving for families living with AIDS. Parse's research methodology was used to uncover the meaning of grieving for the participant families and to integrate the findings with Parse's theory. Families were considered to be "close others" from the perspective of those involved. Through dialogical engagements with the researcher, which were videotaped, ten families described their lived experiences of grieving in relation to death and other losses. Through dwelling with the descriptions in the process of extraction-synthesis, the researcher generated the structure of grieving for the participant families. This structure is: easing-intensifying with the flux of change through bearing witness to aloneness with togetherness, as possibilities emerge with ambiguity, confirming realms of endearment. Integration with the theory led to the proposal that the meaning of grieving is: pushing-resisting with diverse rhythms of communion-solitude unfolding with certainty-uncertainty through honoring the treasured. Conceptual interpretation led to a theoretical structure drawn from Parse's theory, in which grieving is: powering the connecting-separating in originating valuing. The view of grieving as a multidimensional, intersubjective process of becoming, rooted in Parse's nursing theory, differs from theories of grieving from other disciplines, which are predominantly rooted in an objectivist, linear, homeostatic view of health. This study expands and specifies the theory in the substantive area of grieving and confirms that Parse's methodology is a valuable mode of inquiry for family-centered nursing research. Considerations in the use of videotape with the method are explored. Recommendations for further research include additional research with families and further investigation of lived experiences related to the core concepts in grieving extracted from the descriptions. A practice proposition, congruent with Parse's practice methodology and with the extant
Parse studies, is proposed as a heuristic in understanding grieving. The practice proposition is: struggling with the ambiguity of a changing now through bearing witness to an absent presence sheds light on what really matters, as creating new possibilities shifts priorities.
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CHAPTER I
INTRODUCTION

The purpose of this study was to investigate the meaning of grieving for families living with AIDS. The phenomenon central to the study is grieving, the human experience related to loss (Cody, 1991). Loss and grieving are experienced in every human life. Although grieving has been closely associated with bereavement, death, and dying, it is not confined to these situations, and has been studied in relation to numerous other losses (Bowlby, 1980; Marris, 1974; Schoenberg, Carr, Peretz, & Kutscher, 1970; Werner-Beland, 1980). Grieving is believed to occur with any event experienced as loss (Cowles & Rodgers, 1991; Peretz 1970; Schneider, 1984). Loss, then, can be identified definitively only by those experiencing it. Despite wide acknowledgement of the importance of the personal meanings of loss and grief, grieving has been studied only rarely with a concerted attempt to understand the phenomenon from the perspective of those living the experience. Theoretical frameworks with narrow parameters of normality have guided scientific inquiry on grieving from the earliest modern investigations (Freud, 1917/1957; Lindemann 1944). In this investigation, by contrast, grieving was studied as a humanly lived experience. An understanding of grieving was sought through dialoguing with those who were living it.

Although a few scholars have addressed family relationships in grieving (Bowlby, 1980; Knapp, 1986; Pincus, 1974; Rosenblatt, 1983; Weber & Fournier, 1985), the phenomenon has not been explored in depth with a focus on the meaning of the grieving experience for the family. In addition, nearly all of the extant family-centered studies on grieving have been concerned with death, with minimal attention to other losses. While the intense experience of loss and grieving clearly involves one's significant others, grieving is also a deeply personal process (Marris, 1974; Peretz, 1970, Schneider, 1984). Families'
experiences have not been explored previously in conjunction with the deeply personal nature of loss and grieving.

The researcher's perspective, Parse's (1981, 1992) human becoming theory, is a theory of nursing rooted in the human sciences. The theory articulates principles and concepts through which an understanding of patterns of human becoming, such as grieving, can be reached. Parse's theory was the context in which the study was conceptualized and in which the researcher sought to enhance understanding of grieving. The mode of inquiry used in the study was Parse's (1987a) research method, which was used to uncover the structure of grieving in families living with AIDS, and to link these findings to the concepts in the theory, expanding the theory and the body of nursing knowledge.

Families living with AIDS comprised the population for this study. The Human Immunodeficiency Virus (HIV) epidemic has had a broad impact on personal and family life and the health-care disciplines. In order to enhance the substantive knowledge base of nursing as a human science, research on the human experiences of those who live with HIV and AIDS was and is needed. "Acquired immunodeficiency syndrome" per se was not a focus of this study; it is a pathophysiological entity which is not defined as a lived experience. The acronym, AIDS, has entered into the vernacular and has acquired a meaning that the medical term, acquired immunodeficiency syndrome, does not encompass (Altman, 1987; Monette, 1990; Schecter, 1990; Weitz, 1991). "Living with AIDS" refers in this study to the meaning that those who are experiencing it give to it. Living with AIDS commonly entails multiple losses, including strength, mobility, employment, financial security, social support, patterns of living, appearance, and plans and hopes for the future (Dreuilhe, 1987; Monette, 1990; Nokes & Carver, 1991; Weitz, 1991), which link the experience with grieving. Like other critical life situations, living with AIDS involves those who are close to any person directly involved. For this reason, families living with AIDS were chosen as the population for this study.
The Phenomenon of Interest: Grieving

Grieving is viewed as the humanly lived experience related to loss (Cody, 1991; Cowles & Rodgers, 1991; Haylor, 1987; Viorst, 1986; Werner-Beland, 1980), and has long been closely associated with health (Bowlby, 1980; Freud 1917/1957; Lindemann, 1944; Parkes, 1972/1987; Schoenberg et al., 1970). As a universal humanly lived experience related to health, grieving is an appropriate phenomenon for study from the perspective of Parse's (1981, 1992) theory, which focuses on the human's qualitative participation with health experiences. While grieving is commonly associated with the loss of a loved one through death, it is not limited to this situation. Viorst (1986, p. 2) writes, "We lose not only through death, but also by leaving and being left, by changing and letting go and moving on." Marris (1974, p. 3) says that grieving may occur in "any situation where the pattern of life has been radically disrupted." Cowles and Rodgers (1991, p. 123) state that "grief may be preceded by any situation in which there is a perceived loss."

In most scientific studies of grieving, the process has been portrayed as one that begins with the perception of actual or anticipated loss or separation (Bowlby, 1973; Küber-Ross, 1969; Lindemann, 1944; Parkes, 1987; Sanders, 1989; Schneider, 1984). Most of the extant theories have referred to that which is lost and grieved as the "object," as, for example, in the psychoanalytic theory of object relations (Bowlby, 1969; Peretz, 1970). Grieving is conceptualized as a "response" that may be initially intense or numbing, and proceeds through a variety of feelings manifest in different ways, involving sadness and suffering, pain, rage, fond reminiscences, and yearning. It is acknowledged in the literature that these "responses" are poorly understood (Cowles & Rodgers, 1991). Most theories of grieving emphasize the resolution of grieving in one way or another, characterized as "acceptance" by Küber-Ross (1969), and as "reorganization" by Bowlby (1980).

The nursing perspective of this study differs significantly from the theoretical perspectives in the literature in several ways. The first is in contradistinction to the view
wherein "object relations" and stimulus-response mechanisms are theoretically meaningful. From the perspective of Parse's (1981, 1992) theory, loss and grieving are seen as aspects of a unitary pattern of intersubjective relating. The second distinction is counter to the view in which resolution and homeostasis are valued. Parse (1981) speaks rather of "cotranscending with the possibles" (p. 41), in a context of continuous change and increasing diversity. The third is counter to the linear thinking that is still prevalent in science. Parse regards human experience as multidimensional; that is, the human-universe interrelationship unfolds at many realms all at once. A fourth and final distinction is that between the goals of scientific paradigms. Whereas, historically, the accepted goal of the preponderance of scientific endeavors has been to predict and control, the goal of Parse's research method is to understand lived experience. This study, guided by Parse's theory, offers the opportunity for insight into the phenomenon of grieving that conventional views do not encompass.

Clarification of Terms

Many different terms have been used in this area of study, including grieving, grief, loss, death, dying, mourning, bereavement, coping, change, and transition. Grieving is distinguished from bereavement in that grieving is not only experienced with the death of a loved one, but with any loss. For most authors, grieving now encompasses "bereavement" and "mourning," and may be associated with losses of many different kinds (Cowles & Rodgers, 1991). This is a shift from the traditional psychoanalytic usage, originated by Freud, for whom "mourning" was more general, and "grieving" referred to the overt behavioral manifestations of mourning (Freud, 1917/1957). Coping, unlike grieving, has no inherent reference to loss, though it has been studied in conjunction with loss and the term is often used in the grief literature (Carmack, 1992; Parkes, 1987; Schneider, 1984; Videka-Sherman, 1982). The concept of coping fits with a scientific paradigm that holds homeostasis as a value, views loss as a stressful stimulus, and therefore views coping as an adaptive response. From the perspective that guided this study, in contrast, loss and grieving are considered not as separate and distinct events, but as recognizable patterns of
human becoming within the coherent whole of lived experience. The meaning and significance of loss can only be ascertained by attending to the personal meaning of the loss for the one experiencing it. Losses that are perceived by others as equivalent may hold very different meanings to those experiencing them. Grieving may be distinguished from the concepts of change or transition insofar as grieving is preeminently a lived experience, whereas change and transition are more abstract and include loss and grieving and many other phenomena, such as growth and maturation (Bridges, 1980; DeFeo, 1990). Several noted grief researchers, in recognition of the variety of losses that are associated with grieving, have enlarged their scope to change and transition as an area for study that encompasses loss and grieving (Marris, 1974; Murphy, 1990; Parkes, 1971).

Families Living with AIDS as the Population for the Study

The population chosen for this study was families living with AIDS. Since the lifestyles of persons with AIDS had been widely publicized, it was known that these families were likely to differ from the standardized nuclear family model. For this study, family was defined as "the others with whom one is closely connected" (Parse, 1981, p. 81). This definition was considered within the context of the human becoming theory as a whole (Parse, 1981, 1992). According to the theory, the rhythms of involvement-noninvolvement with others and the processes of choosing value priorities, living commitments, and confirming cherished connections are coconstitutive of reality itself. The family is a flowing configuration of interrelationships cocreated through experiential processes of human-to-human relating (Parse, 1981). This unrestricted view of family differs from the mainstream view in family theory and research.

Among the conceptualizations of family that have been constructed in science, the most common characteristic is the assumption of the criteria of marriage, birth, and adoption. Many otherwise diverse concepts of family have shared this often unstated assumption. The dominant view of family is clearly based on the "nuclear family," two married parents (a breadwinner father and a homemaker mother) and their children (Bane, 1976; Beavers, 1977; Bradshaw, 1988; Burr, Hill, Reiss & Nye, 1979; Christensen,
1964b; Duvall, 1977; McCubbin & Figley, 1983; Olson, Russell, & Sprenkle, 1983; Turner, 1970). This model, however, currently reflects only a small proportion of American families, estimated to be as low as 14% (Gershwin & Nilsen, 1990). The U.S. Census Bureau (1990) defines family as "a group of two or more persons related by birth, marriage, or adoption, and residing together in a household" (p. 5). By this definition, projections for the year 2000 yield an estimated 40 million "nonfamily households" and 16 million single-parent households, comprising more than half of the projected total of 110 million American households (U.S. Census Bureau, 1990, Table 56, p. 45). Over 60% of American mothers of minors are currently employed (U.S. Census Bureau, 1990, Table 230, p. 141), and most of these women will work more years outside the home than in childcare (Skolnick, 1991). Approximately 14% of the adult population are divorced (U.S. Census Bureau, 1990, Table 51, p. 43); over 35 million persons are stepparents (Rubin, 1986); it is estimated that up to 10% of the population is gay (Irvine, 1990). These figures indicate the limitations of the nuclear family model as the model of families.

Since the early 1980's, there has been increasing acknowledgement of diversity among families and a shift in the discourse on families toward a more inclusive conceptualization (Boh, et al., 1989; Hoffman, 1990; Lindsey, 1981; Skolnick 1991). Research on "nontraditional family forms" is not new; however, the emerging trend is significant because it is different at the level of the assumptions made. "Nontraditional" families previously have been defined only by their differences from the "traditional" nuclear family (Macklin, 1980). Research using a more inclusive definition at the conceptual level is still rare, despite the fact that families closely resembling the "norm" are now in the minority. This study represents an attempt to answer the need for substantive research using a conceptualization of family more adequate to describe the relationships and experiences of persons actually living as families.

The family constellation for persons living with AIDS is often comprised of lovers and significant others not included in the conventional definition of family (Callen, 1990; Dreuilhe, 1987; Monette, 1990). Studies have found these relationships to be of great
importance in the lives of many persons living with AIDS (Brown & Powell-Cope, 1991; Geiss, Fuller & Rush, 1986; Greif & Porembski, 1988; Nokes & Carver, 1991; Sowell, Bramlett, Bueldner, Gritzacher, & Martin, 1991). The approach taken in this study was to regard these relationships as familial. The family is seen from Parse's perspective as a flowing configuration of close human interrelationships irrespective of societal norms.

The phrase "living with AIDS" was chosen to reflect a focus on living. This was not intended to negate the feelings of those who are living their dying, but to acknowledge that there are innumerable other aspects of living for persons with AIDS as well, such as living with other losses. One nurse author stated, "Ultimately, AIDS is about the young adult who is dying. The role of health care providers is to provide guidance and support..." (Herman, 1988, p. 66). This approach is common in the literature, though it is often perceived by persons living with AIDS as fatalistic and patronizing (Callen, 1990; Dreuilhe, 1987). "Living with AIDS" has been a theme of the AIDS self-help literature for years (O'Connor & Gonzalez-Nunez, 1986). For this study, "living with AIDS" was offered as a generic qualifier in invitations to potential participants, and was interpreted by the participants themselves, a procedure that is consistent with Parse's theory. The emerging view of AIDS in the health sciences is one of chronic illness (Durham & Cohen, 1991). The median survival after diagnosis of AIDS is approximately 18 months in the United States, and is steadily increasing (Centers for Disease Control [CDC], 1990). The period after HIV infection and prior to AIDS diagnosis may be 10 years or more (Durham & Cohen, 1991). A few individuals have lived over 10 years with "full-bown" AIDS (Callen, 1990). There are presently over 100,000 persons diagnosed with AIDS and an estimated minimum of one million persons with HIV infection living in the United States (CDC, 1991). The descriptive phrase, living with AIDS, is thus also consistent with the study of grieving as the universal human experience related to loss (any loss), and differentiated as such from dying and bereavement.

Purpose of the Study

The purpose of this study was to investigate the meaning of grieving for families
living with AIDS. In a previous study guided by Parse's theory, the researcher uncovered the structure of the lived experience of **grieving a personal loss** (Cody, 1991). In that study, it was found that patterns of relating with close others were meaningful in the grieving experience. The findings were interpreted in light of Parse's (1981, 1992) theory, and a theoretical structure of grieving was generated. In the present study, the researcher sought to expand nursing's knowledge base on grieving by studying the meaning of the experience with families, within the framework of Parse's theory of human becoming.

**Specific Aims**

The specific aims of this study were as follows:

1. To enhance understanding of grieving as it is lived in families living with AIDS.
2. To expand nursing's theory base on grieving while building on prior research.
3. To contribute to the expansion and specification of the human becoming theory through generating a theoretical structure of the meaning of grieving as it is lived in families.
4. To extend and refine the use of Parse's research methodology
   (a) with families, and
   (b) with the use of videotape.

**Research Question**

The research question for this study was: What is the structure of grieving for families living with AIDS?

**Nursing Perspective: Parse's Human Becoming Theory**

Parse's (1981, 1992) human becoming theory is a theory of nursing rooted in the human sciences. The term "human becoming" specifies Parse's conceptualization of nursing's phenomenon of central concern, the human-universe-health process (Parse, 1992). Parse drew on Rogers (1970), Heidegger (1927/1962), Sartre (1943/1966), Merleau-Ponty (1945/1974), and her own long involvement with nursing (Parse, 1974), to synthesize the assumptions underpinning the theory. She posited the human-universe-health interrelationship as an irreducible unitary phenomenon, and she reconceptualized health to generate a theoretical perspective of the human-universe-health process, as human
becoming, that is consistent with ideas from Rogers's (1970, 1983) "science of unitary human beings" and ideas from existential phenomenology. Parse's theory is a unique, coherent structure with a focus on lived experience that is not found in Rogers's work, and a focus on health that is not found among the European authors. From Parse's perspective, the human, the universe, and health constitute a unitary, multidimensional phenomenon characterized by meaning, rhythmicity, and transcendence. Health, for Parse, is essentially synonymous with becoming. Health is an open, experiential process, a living, changing pattern of value priorities, the quality of life as experienced (Parse, 1981, 1987a, 1990a, 1992).

The focus of nursing science, from this perspective, is the lived experience of health. Entities for study are identified as universal humanly lived health experiences, such as suffering, struggling, feeling confined, waiting, desire, changing patterns of daily living, conflict, loneliness, hope, love, and laughter. Universal health experiences are experiences related to quality of life, personal value priorities, and the unfolding of the human-universe-health process (Parse, 1987a, 1992); in short, they are lived experiences of human becoming. The designation of universally lived health experiences as the phenomena for study indicates the core of the domain for knowledge development in nursing science.

In the first publication of the theory in 1981, Parse posited nine philosophical assumptions that underpinned the theory. The first assumption (restated without the term "man" in 1992) is: "The human is coexisting while coconstituting rhythymical patterns with the universe" (p. 38). Thus, from its very foundations, the theory specifies the human as participating with others in the coconstitution of reality. Other assumptions articulated by Parse include: "Becoming is a rhythmically coconstituting process of the human-universe interrelationship," and "Becoming is the intersubjective process of transcending with the possibles" (p. 38). Thus, a basic assumption underpinning this study is that all human beings are involved with others in the cocreation of reality. Parse has stated her assumptions succinctly in three sentences that reflect the philosophy underlying the theory.
• Human becoming is freely choosing personal meaning in situations in the intersubjective process of relating value priorities.

• Human becoming is cocreating rhythmical patterns of relating in open interchange with the universe.

• Human becoming is cotranscending multidimensionally with the unfolding possibilities (Parse, 1992, p. 38).

These assumptions clearly articulate Parse's view that the human "is not alone in any dimension of becoming" (1981, p. 20). Yet the human is also posited as "freely choosing personal meaning," a view that explicitly acknowledges the uniqueness of the individual. Differentiating self from others is inherent in "the intersubjective process of relating value priorities" (1991, p. 38). The human coexists with others, coconstitutes reality through interrelating with others intersubjectively, and differentiates self as a unique being through relating personal value priorities. Parse's view is similar to that of von Hildebrand (in Owens, 1970), who called attention to the "paradox of subjectivity." Both communality and individuality are intrinsic to being human; there is no degree of individuality that can eradicate communality as constitutive of being human, and no degree of communality that can eradicate the uniqueness of the individual. Buber (1938/1965) expressed a similar view when he wrote, "The fundamental fact of human existence is neither the individual as such nor the aggregate as such....The fundamental fact of human existence is man with man" (pp. 202-203).

The principles of the theory articulate Parse's view at the theoretical level, and further specify the processes of human becoming by introducing discrete concepts which are interrelated in the structure of the theory. The three principles of Parse's theory are as follows.

1. Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging (Parse, 1981, p. 42).

This principle interrelates the concepts of languaging, imaging, and valuing. Languaging is one's way of sharing with others the meaning of personal experiences. Languaging encompasses speaking, moving, gesturing, and being silent (pp. 46-49). Imaging is the
simultaneous shaping of personal knowledge prereflexively and reflectively, tacitly and explicitly, and integrating the new with the familiar all at once (pp. 42-44). Valuing is the continuous process of choosing, owning, and prizing in the human-universe interrelationship (pp. 45-46).

2. Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating (Parse, 1981, p. 50).

This principle interrelates the concepts of revealing-concealing, enabling-limiting, and connecting-separating. Revealing-concealing is "the simultaneous disclosing of some aspects of self and hiding of others" (p. 52). Self-disclosure is choosing to be a certain way with others and is always an aspect of one's presence. Enabling-limiting is cocreated in every choosing. One cannot do or be at once all that one might wish; going with one opportunity surfaces limitations in other directions (p. 53). Connecting-separating is the rhythm of involvement and noninvolvement with relationships and activities. By committing self to an involvement one simultaneously distances self from others. Patterns of connecting-separating unfold as one chooses closeness or distance in relation to others in living day to day (pp. 53-55).

3. Cotranscending with the possibles is powering unique ways of originating in the process of transforming (Parse, 1981, p. 41).

This principle interrelates the concepts of powering, originating, and transforming. Powering is the "force of human existence" (p. 57). It is the continuous affirmation of self in light of the possibility of nonbeing. Originating is the process of distinguishing self as an individual while coexisting with others. It is living rhythms of conformity-nonconformity by choosing ways of becoming in situations while the outcomes of choices are never completely certain (p. 59-62). Transforming is "the changing of change, coconstituting anew in a deliberate way" (p. 62). Change is a continuous process. Transforming is a change in the patterning of one's life. Collectively, the three principles describe human becoming.
Parse (1981, p. 81) has defined family as "the others with whom one is closely connected." It is necessary to consider this view of the family in the context of the theory as a whole to appreciate its meaning. The "others" to whom the definition refers are continuously coconstituting, cocreating, and cotranscending with others as well. Every human interrelationship is one wherein the individuals are continuously coconstituting reality, cocreating patterns of relating, and cotranscending with the possibles.

The recognizable pattern of family interrelating is encompassed by the principles of the theory. The principle of structuring meaning multidimensionally means that family interrelationships cocreate values that are lived as persons coconstituting the family language their perspectives of life situations (Parse, 1981, p. 81). The principle of cocreating rhythmical patterns of relating means that family patterns of interrelating generate opportunities and limitations, as persons coconstituting the family reveal and conceal aspects of self in rhythmic involvement-noninvolvement with family and others (pp. 81-82). The principle of cotranscending with the possibles means that family interrelating energizes transforming with each family life situation through choosing unique ways of living from among the many possibilities available in the ever-changing health process (p. 82). Through living patterns of close interrelationships, the family cocreates health.

The perspective of the family within Parse's theory, then, may be described, in short, as "synergistic family becoming" (Parse, 1981, p. 129). She also states, "One's perspective of health...can be known only through a personal description even though it is cocreated through interrelationships with others" (p. 81). This aspect of the theory is crucial to understanding Parse's focus on lived experiences. "An experience of a situation," she writes, "while cocreated with others, belongs to one human being only" (p. 30). "Perspectives of self emerge in human encounters as individuals view themselves as well as view themselves being viewed by others" (p. 64). Both reflective and prereflective awareness of one's own and others' perspectives are present in the human experience of a life situation. The dynamic cocreation of life situations intrinsically involves one's close others and one's predecessors, contemporaries, and successors all at once (p. 26). The
family cocreates (with the universe) each individual; thus, family health is the living of
struggle and commitment, the experience of closeness and distance, opportunities and
limitations, and the sharing of meanings and values—pushing-resisting and creating anew

Grieving from a Human Becoming Perspective

The theory of human becoming focuses on humanly lived experience unlike any
other nursing theory. Lived experience is characterized by most scholars in the human
science tradition as a unitary phenomenon (Dilthey, 1883/1988; Schutz, 1932/1967;
Merleau-Ponty, 1945/1974), although specific descriptions of the characteristics of lived
experience differ. From this perspective, then, loss and grieving constitute a unitary
phenomenon. In the original publication of her theory, Parse wrote:

[The human] is touched by birthings and dyings, which are
the rhythmical happenings in day-to-day living. These
happenings are created as [the human] chooses the meanings
of a situation and, through this choosing, the possibilities that
[one] can become. Choosing meaning points to the birthings
and dyings inherent in each decision. This means that, in
choosing one thing, [one] gives up another and in this way
is both enabled and limited....Possibilities...are relational in
that [the human] and environment coparticipate in their
emergence (Parse, 1981, p. 27).

Persons participate in cocreating a loss through their involvement and cherishing. That
which is cherished and lost is paradoxically absent yet present for the person experiencing
the loss. As Colette wrote in My Mother's House, "It is the image...that links us to our
lost treasures, but it is the loss that shapes the image, gathers the flowers, weaves the
garland" (quoted in Moffat, 1982, p. 193). Parse's theory is unique in its potential to
describe these complex, multidimensional, and paradoxical aspects of lived experiences
such as grieving.

A structure of the lived experience of grieving a personal loss was generated in a
previous study by this researcher, using Parse's research method.

Grieving a personal loss is intense struggling in the flux of
change, while a shifting view fosters moving beyond the
now, as different possibilities surface in dwelling with and
apart from the absent presence and others in light of what is
cherished (Cody, 1991, p. 64).

This structure was integrated with the theory and interpreted conceptually as follows: "Grieving a personal loss is powering transforming through the connecting-separating of valuing" (Cody, 1991, p. 66). This theoretical structure represents the researcher's understanding of the phenomenon of grieving at the outset of this study. Grieving was understood as a pushing-resisting process experienced by persons living with loss, while moving onward in life, abiding with the cherished in a new way. In the experience of grieving, involvement-noninvolvement rhythmically unfolds complex patterns of being with and apart from the absent presence and others. Participants in the previous study spoke of involvements not only with the absent presence but with close others, sharing the meaning of the grieving or turning attention to someone or something else. These patterns of relating were described as helping participants to move beyond the pain of the loss and to gain a new perspective of their life situations. This characteristic of grieving led to the idea for the present study with the intention of further illuminating grieving as it is lived in families. The primary goal of this study was to enhance understanding of grieving as described by the participants. This research was not a test of the theory or of the structure of grieving. The findings of this study will be discussed with reference to the previously uncovered structure of grieving, in Chapter V, Discussion of Findings.

Significance of the Study for the Enhancement of Nursing Science

A goal of any research is to contribute to the general knowledge base. This study contributes to the general knowledge base, primarily on grieving but also on families and living with AIDS. The significance of the study for the enhancement of nursing science is threefold, corresponding to the theory-research-practice triad. A strength of Parse's framework is the integration of the theory base throughout specific research and practice methods. The significance of the study in these three areas is detailed as follows.

Significance for Theory Development.

It has become clear that the phenomena of central concern to nursing science have been inadequately addressed by theories from other disciplines. Nursing scholars such as
Rogers (1970) and Parse (1981), believing that nursing contributes uniquely to the fund of human knowledge, have created theories that describe the phenomena of concern to nursing in ways specific to the discipline. The meaning of grieving in families living with AIDS is of concern to nursing. Knowledge of this phenomenon that contributes substantially to nursing science, therefore, logically can be generated only within a theoretical perspective specific to nursing.

The significance for theory development in this study is in the expansion of Parse's theory. This study expands and specifies the theory of human becoming by generating a structure of the meaning of grieving for families living with AIDS. Expansion of the human becoming theory through this research thus expands nursing's substantive knowledge base and enhances understanding in these areas.

Significance for Research

Research guided by the theory of human becoming has entered into a second generation. Studies suggested by prior research are being undertaken as the knowledge base related to the theory expands. Examples are Parse's (1987c, 1990a, in press) research on laughter among elders, and Mitchell's (1992b) study of the lived experience of restriction-freedom. This second wave of research is significant for the expansion of nursing science. It means that the substantive knowledge base specific to nursing is growing. This study contributes to the second wave of research within the human becoming perspective by building on prior research to generate new knowledge of grieving as it is lived in families.

Although the discipline of nursing historically has given considerable attention to family health, along with the health of individuals, comparatively little nursing research has focused on the family. Family nursing research guided by theory specific to nursing science has been minimal (Feetham, 1984; Gilliss, 1989). Four family-centered Parse studies preceded the present study: a study of an intergenerational family (Sklar, 1985), one of hope for two families with chronically ill children (Brunsman, 1988), one of hope for families of critically ill persons (Smith, 1990a), and a case study of "family
transformation" taken from practice (Butler, 1988). This study answers a need for more research illuminating experiences in family life situations from a human becoming perspective.

The researcher also sought to make a methodological contribution in this study. Parse's (1987a, 1990b) research method had been used in a number of studies in which descriptions of lived experiences had been recorded in discussion with individuals using audiotape (for example, Cody, 1991; Mitchell, 1990a; Parse, 1990b). In only one of these studies, Smith's study of hope (1990a), were descriptions recorded with families in group discussion, and most of Smith's dialogues were recorded with individual family members. Also in only one other study (Parse, in press) has videotape been used to record the descriptions. In this study, descriptions of grieving were recorded with families in group discussion using videotape. Both of these procedures represent expansions in the use of the methodology. This study illuminates these variations in the research processes of Parse's method for future researchers.

**Significance for Practice**

Nursing is viewed increasingly as a human science, not only by Parse but by other nursing leaders as well. This means that the focus of nursing is shifting toward greater understanding of lived experiences of health (Mitchell & Cody, 1992; Munhall, 1989; Watson, 1985). This study enhances understanding of the lived experience of grieving, thereby providing knowledge which may enhance practice for nurses in general. As in research within any theoretical framework, the knowledge generated has specific relevance for those who practice guided by the theory.

The arena for Parse practice is the nurse-person-family interrelationship, and the mode of practice is presence. Practice is construed as the "performing art" of nursing, the goal of which is enhanced quality of life from the client’s perspective (Parse, 1987a, 1992). Nursing practice is an "intersubjective participation with persons and their families" (Parse, 1981, p. 81). The nurse who is present with a grieving person or family may better understand the meaning of grieving as illuminated through this research. The way
one understands a situation, from Parse's perspective, is expressed in the way one is in the situation. This does not mean that the nurse knows what the family is experiencing or can predict the occurrence of particular feelings. The nurse's understanding of the phenomenon is expressed through the nurse's own presence, through being there in a loving way. A passage from Isadora Duncan's autobiography may serve to illustrate this point. Duncan's two children had died in a drowning accident. Tortured with unrelenting grief, she went to stay with her friend, Eleanora.

She used to rock me in her arms, consoling my pain, but not only consoling, for she seemed to take my sorrow to her own breast, and I realized that if I had not been able to bear the society of other people, it was because they all played the comedy of trying to cheer me with forgetfulness. Whereas Eleanora said: "Tell me about Deirdre and Patrick," and made me repeat to her all their little sayings and ways, and show her their photos, which she kissed and cried over. She never said, "Cease to grieve," but she grieved with me, and, for the first time since their death, I felt I was not alone (quoted in Moffat, 1982, p. 35).

This passage, of course, illustrates a meaningful moment of friendship, rather than nursing practice. The meaning of true presence with the grieving person, however, is clear. True presence is not an intervention but a participation, a way of being with another with reverent attention to the other's lived experience, whatever it may be. Through greater understanding of lived experiences such as grieving, nursing science can enhance the quality of this coparticipation.

Summary

In this chapter, the phenomenon of interest in this study, grieving, has been introduced and clarified as the universal humanly lived experience related to loss. The relevance of grieving to the population chosen for the study, families living with AIDS, has been explained in relation to grieving as a phenomenon that unfolds through family interrelationships, and in relation to the multiple losses experienced by families living with AIDS. The theoretical perspective has been presented, with explication of the understanding of families, and of grieving, offered by the theory. The significance of the
study for the enhancement of nursing science has been established in relation to expansion of the knowledge base on grieving from the nursing perspective of Parse's human becoming theory.
CHAPTER II

REVIEW OF RELEVANT LITERATURE

The review of literature for this study was guided by the research question, "What is the structure of grieving for families living with AIDS?" with the intent of uncovering what was previously understood of this phenomenon and this population. No prior study that investigated the meaning of grieving for families living with AIDS was located. In reviewing the voluminous literature on grieving, the researcher attempted to gain an understanding of what was known about the lived experience of grieving, and about grieving in relation to families. Since the theoretical perspective on families is specific to the theory of human becoming, and the concept of family is a matter of some concern in nursing, the literature on families was reviewed. The literature on living with AIDS was also reviewed. Since the literature that was found to address these elements simultaneously was minimal, the review of literature is presented in three parts, focusing on grieving, families, and living with AIDS.

Grieving

The literature on grieving extends back to the earliest of written history. Among the descriptions of grieving in the literature of Western antiquity are those of King David for the loss of his son, and Job, for his many sorrows, in the Hebrew Old Testament, and Seneca, in Hippolytus, and Sophocles, in Ajax, among the Greek tragedies (Moffat, 1982). Grieving is described also in the literature of other cultures dating back thousands of years. For example, the following lines were written in China in the first century B.C.:

In the white aspens sad winds sing;  
Their long murmuring kills my heart with grief.  
I want to go home, to ride to my village gate.  
I want to go back, but there’s no road back  
This verse illustrates that grieving is not only related to death, but to any of the irreversible changes in cherished involvements along life's course. The works of Shakespeare contain many notable expressions of grieving, among these, Constance grieving for her lost son, in *King John* (Act III, Scene 4). She says:

Grief fills the room of my absent child,  
Lies in his bed, walks up and down with me....

The complexity of grieving is also reflected in Shakespeare's words, "Each substance of a grief hath twenty shadows" (*Richard II*, Act II, Scene 2). Among other classic works that address grieving are Browning's poem "Grief," Coleridge's poem "Dejection," and Wordsworth's "She Dwelt Among the Untrodden Ways" (excerpted in Moffat, 1982). In this century, grieving has been a theme for Proust in *Remembrance of Things Past*; for Lawrence in his poem, "Brooding Grief" (excerpted in Moffat, 1982); for Agee (1969), in *A Death in the Family*; for the playwright O'Neill (1956), in *Long Day's Journey into Night*; for the contemporary poets Alice Walker (1973) and Adrienne Rich (1976), and many others. Major themes in the artistic literature on grieving are: intense pain and sorrow, communion, self-reflection, meaning, haunting memories, gaining wisdom, transformation, and transcendence. Grieving is portrayed as a complex experience that, even after many years and new involvements, remains profoundly meaningful, changeable, and ineffable. The scientific approach to grieving has been quite different.

**Conventional Scientific Views of Grieving**

The scientific approach to grieving began with studies of death, dying and bereavement. Prior to the twentieth century, death and bereavement were regarded as the province of family, community, and religion (Morgan, 1988). During the first half of the twentieth century, death, less frequent in relation to birth than in the past, was largely considered a distasteful or taboo subject. About thirty years ago, a number of ground-breaking works on death and dying appeared. These included Mitford's (1963) *The American Way of Death*, Feifel's (1959) *The Meaning of Death*, Glaser and Strauss' (1965) *Awareness of Dying*, and Kübler-Ross' (1969) *On Death and Dying*. 

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Major scientific theories and studies related to grieving (Engel, 1961; Freud, 1917/1957; Kübler-Ross, 1969; Lindemann, 1944; Parkes, 1972/1987) have been developed with reference primarily to bereavement, death, and dying, or, in the case of Bowlby (1973), separation. These theories have been widely applied in other instances, such as chronic illness (Stewart & Shields, 1985) and rehabilitation (Hohman, 1975). A dominant feature of these theories is the postulate of normative, sequential "stages" or "phases" in the grieving process. For Freud (1917/1957), the sequence was: anxiety, repression/depression, mourning, decathexis, and reinvestment; for Kübler-Ross (1969): denial and isolation, anger, bargaining, depression, and acceptance; for Bowlby (1980): numbing, yearning and searching, disorganization and despair, and reorganization; for Parkes (1987): alarm, searching, mitigation, anger and guilt, and gaining a new identity. In recent years those theorists who view grieving as a sequence of stages have said that stages may vary widely in intensity, duration, and sequence. Gullotta (1982) says that the term "stage theory," though frequently used, is inaccurate, for the reason just stated; he then describes a series of sequential events in grieving which he calls "phases." The normative stance of the conventional "stage" or "phase" theories remains essentially intact, in any case, because the view of health itself is one in which parameters of normality are assumed. Passage through the stages of grieving is commonly seen as the transit to healthy acceptance, resolution, or dying. This view is related to the paradigmatic assumptions of objectivism and linearity, and the values of homeostasis, prediction, and control, as mentioned in Chapter I.

The less rigid stance is seen in these lines from Kübler-Ross (1974): "The outline of these five stages is only the common denominator that we found in most of our terminally ill patients. Many do not flow from stage one to five in a chronological order....Our goal should be to elicit the patient's needs, to find out where he is, and then to see in what form and manner we can help him best" (p. 71). Such a flexible attitude is not, however, reflected in the greater portion of the literature on stages of grieving. For example, in 1987 Kübler-Ross herself wrote: "Those five stages have been found again
and again...in many different forms of loss besides critical illness; in couples who go through divorce or separation; in a family whose house burns down...[and several other examples]" (p. 2). There are no studies cited to substantiate these claims, as is most often the case in applications of the stage theories to situations other than dying (Hohman, 1975; Stewart & Shields, 1985). This is not to deny that grieving occurs in these situations, but to call into question applications of theory not originally conceptualized in relation to the actual phenomenon of concern. Kübler-Ross clearly takes the stages for granted, as in the following: "Not only do people with AIDS have to go through the 'stages of dying,' they are faced with issues the world never had to deal with to such an extent...." (1987, p. 4, emphasis added). The nurses Cowles and Rodgers (1991), in their concept-development paper on grief, note that in recent years the concept has become more dynamic and nonlinear for a number of theorists. Nonetheless, they conclude that there is "a clear consensus that there are limits to grief, beyond which it becomes inappropriate, unacceptable, or revealing of underlying or associated pathology" (p. 122).

For most of the major grief theorists, the passage through grief is seen as a sequence of tasks or coping skills. Failure to accomplish the tasks or to cope effectively results in dysfunction or pathology. If the grieving person does not move through the phases more-or-less as described by the theorist, the grieving is characterized as abnormal. Grieving persons must pass between the Scylla of "absence of grieving" and the Charybdis of "chronic grieving," or their behavior is labelled as pathological. Grieving is divided into "adaptive" and "maladaptive" modes, with the latter construed either as pathology itself or as leading to pathology (Bowlby, 1980; Engel, 1961; Lindemann, 1944; Murphy, 1983; Parkes, 1987; Sanders, 1989; Schneider, 1984; Schoenberg, et al, 1970; Worden, 1991). Although much of the foundational work on grieving was qualitative (Bowlby, 1969; Freud, 1917/1957; Kübler-Ross, 1969), the field has since moved in a quantitative direction, with attempts to measure grief (for example, Zisook, Devaul, & Click, 1982), and "controlled" studies. The demystification of death and dying that began in the 1960's has evolved into the "positive science" of bereavement and grieving.
A thorough appraisal of the voluminous conventional, quantitative research related to grieving is well beyond the scope of this chapter. In major overviews, Parkes (1987) cited over a hundred studies; Sanders (1989) cited over two hundred; and, since their theoretical perspectives differed, the overlap between the two was not large. The firm conclusions that they drew were few, and the reasons for this many, from rival theoretical interpretations to methodological problems. Both authors found there was no clear separation between "normal" and "abnormal" grief "reactions." Nonetheless, the attempt to delineate such a distinction was a major thrust of their own studies and of the greater portion of the existing research.

Sanders (1979) used a well known personality profile and a grief inventory to identify personality factors associated with different responses to grieving. She identified four groups based on their grief reactions: a "disturbed" group, a "depressed high-grief" group, a "denial" group, and a "normal grief-contained" group. Of the "disturbed" group, she wrote, "Their profiles look like that of a schizoid personality with depressive reactions....One common denominator in this group was clearly an ongoing difficulty with living" (in Sanders, 1989, p. 128). The "normal grief-contained" group was described as showing "emotional control, with little expression of confusion or unreality" (p. 130).

Horowitz, Wilner, Marmar, & Krupnick (1980) described three patterns of "pathological" grief: a "frighteningly sad" response to loss, "out-of-control" rage, and a deflated or hibernative response. Parkes (1987, chap. 8) examined 31 cases of "atypical grief." He found "that the bereaved psychiatric patients had experienced more or less the same grief symptoms as the widows in the normal samples studied. Only one symptom, ideas of guilt or self-reproach, was markedly more frequent in the psychiatric group" (p. 125). These studies demonstrate that what is or is not considered normal is very much in the eye of the researcher. Parkes (1987, p. 126) found the statement "I miss him every moment of the day" to be abnormal because it was uttered a year and a half after the death. Lindemann (1944), in his often cited study, interpreted anger expressed toward him as a "symptom" in the syndrome of acute grief.
A large number of studies have contradicted one another. For example, many researchers have found that sudden, unexpected death results in greater shock and after-effects (Glick, Weiss, & Parkes, 1974; Lundin, 1984; Parkes & Weiss, 1983; Raphael, 1984; Sanders, 1979; Vachon. et al., 1976), while others have found no correlation between the length of anticipation of death and the bereavement experience (Clayton, Desmarais, & Winokur, 1968; Maddison & Viola, 1968; Schwab, Chalmers, Conroy, Farris, & Markush, 1975). Parkes (1972/1987), from his earliest studies, found the sense of the presence of the deceased to be a significant factor in the grief experience; he looked for it and tabulated it, as did Hobson (1964), Yamamoto, Okonogi, Iwasaki, & Yoshimura (1969), and Marris (1958). It was found, in these studies, among 50-90% of bereaved persons. Sanders (1989) devotes only two paragraphs to this phenomenon in her book-length examination of grief. As a phenomenon outside the purview of objectivistic beliefs, it is regarded as something akin to an hallucination by both authors.

Among the few relatively stable findings of this body of research were the following. Illness and death were more frequent among bereaved adults than among non-bereaved adults (Clayton, 1974; Hobson, 1964; Lindemann, 1944; Maddison & Viola, 1968; Marris, 1958; Parkes, 1964). Younger widows tended to be more "symptomatic" than older widows (Ball, 1977; Kraus & Lilienfeld, 1959; Parkes & Weiss, 1983), but socioeconomic and other factors may have been implicated more than bereavement itself on this point. Guilt and self-reproach were associated with "pathologic" grief in studies framed in the psychoanalytic tradition (Lindemann, 1944; Parkes, 1972/1987; Parkes & Weiss, 1983). Social support was often found to be a significant mitigating factor, but it was the quality rather than the quantity of social support that was most important (Lopata, 1979; Raphael, 1977; Sanders, 1980-81). Gender differences were commonly found, but methodological problems undoubtedly were significant in this regard. The majority of bereavement studies have involved widows, who often experienced drops in income, losing their homes, returning to work, or working outside the home for the first time, concurrently with bereavement. Harvey and Bahr (1974, p. 106) contended that "the
negative impact sometimes attributed to widowhood derives not from widowhood status but rather from socioeconomic status." Overall, the best "outcome predictors" were common-sense factors, such as low income, high overall anxiety, an unanticipated death, attitude toward one's own death, concomitant losses, and intense involvement, such as long-term caregiving; and many scholars would disagree on any of these variables (Parkes, 1987; Sanders, 1989). The human experience of grieving remains poorly understood.

Family-Centered Research on Grieving

Few studies of grieving have focused on the family. Where family relationships have been mentioned, in most cases the theoretical formulation was still directed primarily toward the individual. Freud's central thesis was that experiences with mother and father in infancy and childhood were internalized symbolically and thereby determined adult behavior. His (1917/1957) work on mourning related to family relationships only as they influenced the intrapsychic life of the individual. Bowlby (1969) developed his "attachment theory" within this psychoanalytic tradition. Kübler-Ross (1969) studied individuals who were dying. A number of researchers have studied widows and widowers as individuals, as mentioned above. None of the major theorists on grieving have focused on the family as the primary subject, process, or situational context of grieving.

Some research on grieving in families has been done. Most of these studies focused on the death of a child, parent, or spouse within the nuclear family, and its consequences for the family or family members (Davies, Spinetta, Martinson, & Kulenkamp, 1986; Knapp, 1986; Kuhn, 1977; Paul, 1986; Pincus, 1974; Reilly, 1978). In these studies, the picture was often complicated by the combination of a normative, prescriptive model of grieving with a normative, prescriptive model of the family. Worden (1991) wrote, "One important reason for looking at a family systems approach is that unresolved grief may not only serve as a key factor in family pathology but may contribute to pathological relationships across the generations" (p. 118). Most often the approach has been to assign to individuals "functional roles" within the "family system," and to examine how "roles" change and how these changes affect family "functioning." There is little trace
of the lived experience in such reports.

**Limitations of the Extant Theory Base on Grieving**

The foundational work on grieving in relation to death, bereavement, and separation has contributed to an understanding of the phenomenon as a complex process that is lived by everyone and for which there is no easy "remedy." It has generated a vast body of literature on loss, grief, bereavement, death and dying, and change. It has contributed to changes in the way that health-care professionals and the public think about grieving, as evidenced by the rise of the hospice movement, the popularity of Kübler-Ross's work, and the proliferation of applications of these theories to various losses.

Several points about the normative stage theories of grieving are important in relation to the significance of the approach that was taken in this study. Firstly, the preponderance of the grief theories were developed as theories about dying and bereavement. There is little empirical support for the use of these theories with persons experiencing losses other than death. In this same vein is the lack of research related to multiple losses. In prior studies, the loss, usually death, was identified objectively at the outset, and the influences of other losses, if mentioned at all, were loaded onto a single variable. Secondly, explanation and prediction of "normal" and "abnormal" grieving have been central goals of grief theory since Freud's (1917/1957) *Mourning and Melancholia*, in which he sought to differentiate "mourning," construed as normal, from "melancholia," construed as abnormal. With an emphasis on explanation and prediction of "normal" and "abnormal" human behavior in grieving, in relation to objectively specified losses, the personal meanings of loss and grieving, which generate the phenomenon in the first place, have been given scant attention. Thirdly, the lack of attention to the family in research on grieving was posited by this researcher as another reason the phenomenon remains poorly understood.

Several theorists have sought to overcome the narrowness of the highly normative, time-bound, and death-related theories discussed above, and to articulate a more satisfactory general theory of grieving. Marris (1974) integrated the concepts of loss and
change, and studied various transitional experiences, such as slum clearance and students' transition to college life. For Marris, the "response to loss" is an aspect of all major life changes, whether the change itself is wanted or unwanted. He posits that "the impulse to defend the predictability of life is a fundamental and universal principle of human psychology" (p. 2). His notion of predictability is not a calculative one, but refers to "consistent patterns of meaning" in life (p. 8). For Marris, "grieving" is the "psychological process of adjustment to loss," which is "characteristically ambivalent" (pp. 4-5). He regards the meaning of the loss as crucial, and the process of grieving turns on the reformulation of the meaning of the loss. "When the loss is irretrievable, there must be a reinterpretation of what we have learned about our purposes and attachments...radical enough to trace out the thread again" (p. 21). He argues against the "substitutability" of the cherished object, maintaining that the "spurious rationality" of this idea "cannot comprehend grief" (p. 90). "Recovery from grief depends on restoring a sense that the lost attachment can still give meaning to the present, not on finding a substitute" (p. 149).

Marris's view moves closer to the lived experience by emphasizing the meaning of the loss and that the meaning changes in the process of grieving. Marris, however, adheres to a stimulus-response view, with an emphasis on predictability, whereas this researcher, in congruence with Parse's (1981, 1992) perspective, sees loss and change as a unitary unfolding, and focuses wholly on understanding.

Schneider (1984) formulated a general theory of grieving based on a stress-coping framework. He emphasizes the "unrecognized" and "ungrieved" loss hidden within the fabric of experience, and sees potential for loss and grieving in all of life's changes, including growth and achievement. With such a view, a rigid stage model would be inadequate, since "losses continue to occur throughout life and not usually at times when people have managed to resolve all the others" (p. 75). Schneider's (1984) model is presented as six phases: initial awareness, limiting awareness, awareness, gaining perspective, resolving loss, reformulating loss, and transforming loss" (p. 76). His suggestions for practice include inviting persons to "tell their story," which may be "all that
is needed as an aid to the bereavement process" (p. 254). The stress-coping framework, however, leads inexorably to parameters of "normal" grieving. Schneider's focus is on "grief as the normal, normative response to loss" (pp. 260-261). He lists ways of facilitating "normal grieving," including "humor, touch, imagination, music, the expressive arts, mutuality, trust, and the bonds formed in grief," but he cautions that these approaches could be harmful in the case of "pathologic grief" (p. 261). What harm these practices might have is not stated. Schneider underscores the universality and complexity of loss and grieving, and the primacy of the meaning of the loss. His dichotomous view of normal and abnormal grieving, however, preserves the central assumption of the earlier theories.

Cole (1992), in a book combining personal experience with journalistic interviews and review of the literature, examined loss, transformation, and healing. She was inspired to write the book after experiencing her mother's death, her husband's life-threatening and scarring illness, two pregnancy losses and infertility, and even being taken hostage. She writes, "After great pain came numbness, anger, guilt, and all the other stages of grief, in what seemed an endlessly protracted jumble....And then, finally, each time a new self emerged, one with a different vision of who I am, a different sense of what I could do or even wanted to do, and a different perspective on what my future might hold...." (p. 13). The theme of transformation is present in each experience. For example, "...when people say to me, 'Having children changes your life,' I respond, 'But not having children also changes your life.' And that is why, in the wake of a pregnancy loss or infertility, the challenge comes in discovering a way to transform the desire to be a biological parent into other positive channels" (p. 140). Cole repeatedly seeks out the threads in the conventional grief theories that speak to her own experience and cites several of the better known authors, yet her own story is unique and does not fit as a whole with any of the extant grief theories. One entire chapter is devoted to the meaningful experience of "a tangible absence," the lingering, transformative experience of cherishing another who has parted yet remains an enlivening force in the present (pp. 179-197). Reminiscing about her mother's death, she writes, "And so the past remains alive in the present, resonant with themes that
have undergone so many transformations from minor key to major that we hear a different music altogether, family harmonies carrying us all into the future together" (p. 186). Most assuredly, none of the well known conventional grief theories encompass such humanly lived experiences.

**Change and Transition in Relation to Grieving**

Change and transition theory is arguably just as pertinent to grieving as the human experience related to (any) loss as are the grief theories developed in relation to death and dying. Several of the contributors to change and transition theory (Lindemann, 1944; Marris, 1974; Parkes, 1971) have also been major influences in grief theory.

**The Non-Nursing Literature**

Schlossberg (1981, 1984) links transition with the human developmental process. She proposes that there are normative and nonnormative transitions, although to this researcher the distinctions appear somewhat arbitrary. According to Schlossberg, one's first job is a normative transition; a job change is nonnormative; widowhood is normative, divorce nonnormative. All of these, however, precipitate the transition process. For Schlossberg (1984), transition is a sequence of "assimilation phases," in which one is first absorbed in the change, and then gradually integrates it into the self. The phases are: introduction, in which one is pervaded by sense of change; disruption, in which old norms fade, new ones are established; and integration, which may take the form of renewal, acceptance, or deterioration (pp. 56-61). Schlossberg's view of transition is reminiscent of the conventional grieving theories.

Bridges (1980) sees transition as "the natural process of disorientation and reorientation that marks the turning points on the path of growth" (p. 5). The two "great transitions" of life are, for Bridges, the development of a separate self, and "movement beyond that separateness to something more complex, to a deeper sense of interrelatedness" (p. 32). A person in a relationship goes through personal transitions that the other does not always understand; but the process can "awaken or intensify similar issues in another, in the same way that one string can set another vibrating when it is plucked" (pp. 66-67).
Bridges sees the process of transition essentially as a process of ending, dwelling in-between, and beginning anew, and writes of the "paradox" inherent in transition, wanting to change and not wanting to change (p. 32). In explicating the "endings," Bridges proposes a series of phases: "disengagement" (from the familiar context), "disidentification" (giving up one's role), "disenchchantment" (the world no longer seems real), and "disorientation" (a sense of nothingness, void). This in-between time is a time of self-renewal which leads to new beginnings, inner awareness, motivation, hopes, and dreams. Bridges emphasizes personal experiences of growth through reflective engagement and disengagement with others.

Watzlawick, Weakland, and Fisch (1974) developed a systemic theory of change which distinguishes between first- and second-order systemic change. First-order change occurs within the existing system without changing the "rules" that make up the system. Second-order change is change in the system itself, "reframing" the situation so that the previous set of all possible changes is seen as but one set of alternatives, thus changing the meaning of the entire situation and the nature of first-order change within it. Such reframing, according to Watzlawick et al., "operates on the level of metareality, where...change can take place even if the objective circumstances of a situation are quite beyond human control" (p. 97). This brings into question the "concept of 'reality adaptation' as a criterion of normality" (p. 95). To what reality is the person "adapting," they argue, if "[t]ruth...is not what we discover, but what we create[?]" (p. 97). The work of Watzlawick and associates has been influential in family therapy (Hoffman, 1985), indicating its relevance to this family-centered study. From their perspective, the study of grieving in families would entail understanding the "reframing" of the situation, the new realities created by the changes in the family "system." Parse (1981) cited the Watzlawick group's work in explicating her theory with reference to the primacy of meaning in human situations and to the nature of change posited in her concept of transforming (pp. 62-64). There is a range in the change and transition literature, from a highly normative perspective, emphasizing renewal of former patterns of living and acceptance of change (Schlossberg,
1984), to a view more focused on human experience (Bridges, 1980), to a view of change in which people participate in creating change through assigning meaning, thus changing the very nature of the situation (Watzlawick et al., 1974).

The Nursing Literature

In recent years, change and transition have been posited as central concerns of nursing. An entire issue of the journal Holistic Nursing Practice (Murphy, 1990) was devoted to nursing care of "clients in transition." Chick and Meleis (1986) analyzed the concept of transition and developed a model emphasizing its perceptual, temporal, and "process" aspects. Citing Bridges and Marris, they propose that transitions are passages "from one life phase, condition, or status to another" (Chick & Meleis, 1986, p. 239). They maintain that transitions are to some extent self-limiting, and have beginnings, middles, and endings. Loss is listed as one event leading to a process of transition. Chick and Meleis (1986) emphasize perception and meaning, but, for them, the emphasis is on "preserving continuity of meaning, either by reestablishing disrupted connections or by substituting new ones" (p. 250, emphasis added), contradicting Marris's view about substitutability, and revealing a somewhat more static view than their emphasis on "process" would suggest.

DeFeo (1990) has posited the concept of change as a central concern of nursing. He proposes that change evolves along two dimensions, the "horizontal," associated with continuity and stability, and the "vertical," associated with potentiality and transformation (p. 89). DeFeo likens these two dimensions of change to the two paradigms in nursing, totality and simultaneity (Parse, Coyne, & Smith, 1985; Parse, 1987b). The totality paradigm is concerned with stability and equilibrium; the simultaneity paradigm with evolutionary process and becoming. DeFeo emphasizes the inherent creative participation of the human in the change process through choosing direction and risking. His view is therefore somewhat closer to the simultaneity perspective, although he sees merit in the totality perspective for investigating certain phenomena. He points to "the death of a loved one" (p. 94) as an example of the phenomena of change that nursing science could address.
within either paradigm.

This study unfolded within the simultaneity paradigm. Change and transition can be viewed either from a perspective which conceptualizes change as a shifting of a steady state in linear time, emphasizing the maintenance of stability through effective responses to stimuli, or from a perspective which conceptualizes change as a continuous multidimensional unfolding, emphasizing personal meanings in the process of cocreating patterns of becoming. Although the former view has been dominant in science, movement in the direction of the latter view is evident in the literature on grieving, change, and transition. There is as yet only limited research in the new paradigm, as methods appropriate to the philosophical base are only now being honed. This study contributes to the knowledge base of nursing's simultaneity paradigm on grieving as a way of becoming.

Existential-Phenomenological Perspectives

Perspectives from existential phenomenology are significant for the background of this study because these authors address aspects of human experience that are not addressed in the conventional scientific literature. The influential philosopher, Martin Heidegger (1927/1962), posited "Being-in-the-world" as the primordial, unitary structure of human existence, and asserted that the meaning of human existence (Dasein) is "care," or concernful Being-in-the-world. For Dasein, understanding is a way of being (pp. 182-195). Heidegger described human existence as disclosive involvement in the world, with other persons and projects, always already underway and always ahead of itself projecting possibilities. Human existence is oriented toward the future, toward possibility; therefore, "Being-towards-death" is a primordial characteristic of human existence (pp. 279-311). "Authentic" existence is projecting "one's ownmost" possibilities in "anticipatory resoluteness," and occurs only through the direct participation of self in the world (pp. 341-348). Heidegger did not directly address grieving, but it is clear that from his perspective grieving would not be construed as a phenomenon of object relations or homeostasis. For Heidegger, the meaning of human existence is "care," concernful Being-in-the-world. This points to the primacy of one's "ownmost" involvements, such as the meaning of loss. His
view that authentic existence is the self-projection of one's ownmost possibilities suggests that grieving is an unfolding of one's utmost personal meanings in on-going participation with the world.

Frankl (1969) also emphasizes the self-interpreting nature of the human being, and posits the "will to meaning," as the primary existential force. Frankl maintains that human beings have the innate capacity to transcend even the worst of conditions, to reach beyond the self to find meaning in life. For Frankl (1969) the pursuit of "homeostasis" tends toward the "pathological" (pp. 32-33); he says that "such human phenomena as the creativity of man, which is oriented toward values and meaning are scotomized in such a frame of reference" (p. 33). He writes, "Self-transcendence is the essence of existence. Being human is directed to something other than itself" (p. 50). Values are the "substrates" of meaning, and one always has the choice to accept or reject certain values (pp. 56-57); "values cannot be taught; values must be lived" (p. 87). Frankl suggests that suffering and pain, when given meaning, are transmuted into an achievement. One must take a stand with one's fate. "[M]an is responsible for what to do, whom to love, and how to suffer" (p. 74). Clearly, for Frankl, it is the meaning and value of the cherished that is central in human experiences of loss and grieving. The human being strives toward self-transcendence, and in so striving has the capacity to find meaning in life whatever the circumstances.

The exploratory approach taken by Moustakas (1972, 1977) could be characterized as existentialist-developmental. He has written eloquently on loneliness, which for him is inextricably interconnected with communion and love: "To be aware of love, in its real sense, is loneliness: the hopes, the joys, the ecstasy, all the tensions of loss and fulfillment, of dreams and despair; this awareness...that one reaches out to hold the moment and suddenly it is gone..." (1972, p. 143). That which is loved is experienced intrinsically in loneliness; one experiences relating with others in a different way. Moustakas sees the movement between solitude and community as a dialectical process. "To come back to the human community, one must know the agony of broken
communications, of unanswered doubt and question; one must know the clear visions of loneliness and solitude...[and] one must know the feeling of genuine communication and unity" (p. 145). Personal beliefs and values are, for Moustakas, at the crux of every transition. "The presence of the self, the valuing of my own being, the awareness of who I am and what I believe, ensures...an implicit faith in my own experience to guide me and move me forward in my growth" (1977, p. 69). Yet the experience of love and commitment with others is also essential. He writes, "Within this struggle is the challenge to remain alive as a unique and independent self while at the same time relating with others in an open and authentic way" (pp. 118-119).

The existential theologian, Paul Tillich (1952), has written of "the courage to be." Courage is defined as "the self-affirmation of being in spite of nonbeing" (p. 86). Self-affirmation has two sides, "the courage to be as oneself" (p. 87), and "participation in the power of being" (p. 89). For Tillich, "the self is self only because it has a world...to which it belongs and from which it is separated at the same time" (p. 88). Therefore, "self-affirmation necessarily includes the affirmation of oneself as 'participant'" (p. 89). The threat of nonbeing includes not only the loss of the self, but the loss of participation in the world. The individual suffering misfortune or experiencing oneself objectified by others experiences the threat of nonbeing. There are always forces that threaten one's being with nonbeing. Power is the possibility a being has to actualize itself against the resistance of other beings. The individual must have "the courage to take his despair upon himself and to resist the radical threat of nonbeing by the courage to be as oneself" (p. 140). Loss, then, is a disruption of one's participation in the world. In order to continue, one must reaffirm self as self-in-the-world. This means choosing a direction, then moving to actualize it. This is the courage to be as oneself in spite of nonbeing.

The insights of these existential-phenomenological authors are underpinned by assumptions that are different from those of the empirical-analytical tradition. Parse (1981, pp. 18-21) has identified the tenets of intentionality and subjectivity as fundamental to this perspective, along with the concepts of coexistence, coconstitution, and situated freedom.
For these authors, the human being is a participant in the creation of reality, experiences existence as coexistence, and is free to choose meaning in situations. The confrontation of being with nonbeing is an ever-present aspect of being human. The works of these authors illuminate profound human experiences in ways that are not accessible within the bounds of conventional science. Still they cannot logically guide nursing research or practice. Frankl's larger body of work is couched in psychiatry, Tillich's in theology, Moustakas's in developmental psychology. Parse (1981, 1992) draws on many of the same ideas as these authors, and has articulated insights from the existential-phenomenological approach in a theory specific to nursing. Her human becoming theory was therefore the logical choice to guide nursing inquiry on the lived experience of grieving.

**Nursing Literature on Grieving**

In comparison with the literature on grieving from other disciplines, the nursing literature is less extensive and relies almost exclusively on borrowed theory. The majority of the nursing literature focuses on bereavement following the death of a loved one, and most of the articles that address other instances of grieving are speculative applications of borrowed theory. Demi and Miles (1986) reviewed 37 nursing studies of bereavement published in the years 1970-1984. None appeared to have any link with nursing theory. Instead, the authors used or adapted a variety of grief theories from other disciplines, or used no explicit theoretical framework at all. Of the 37 studies, 19 examined bereavement among the widowed, 15 examined parental grief following the death of a child, and 3 examined the grief of children. The majority of studies looked at variables contributing to bereavement outcomes, such as age, gender, mode of death, concomitant stressors, and social support. Demi and Miles supported the apparent consensus of the authors they reviewed, that the use of "a multivariate conceptual model of bereavement...is essential" (p. 119). Shirley Murphy (1983), in a chapter on bereavement in the book, *Advances in Nursing Theory Development*, also advocated the use of a multivariate, predictive model, heavily citing Bugen's (1977) stress-coping model from psychiatry. There have also been attempts within nursing to measure bereavement grief (Remondet & Hansson, 1987).
An example of this type of research was Gass and Chang's (1989) test of a psychological model of "stress, appraisal, and coping" (Lazarus & Folkman, 1984) with widowed persons. The goal of the model was to predict "psychosocial health dysfunction" (Gass & Chang, 1989, p. 31). The sample consisted of 159 widowed persons, whose "resource strength," "appraisal of bereavement," "coping with bereavement," and "psychosocial health dysfunction" were measured (p. 32). Using path analysis, a correlation matrix for 13 variables was constructed, accounting for 30% of the variance in "psychosocial health dysfunction." The authors wrote, "Because problem-focused strategies are more adaptive and reality-oriented...one would expect less psychosocial health dysfunction. Emotion-focused strategies often prevent the person from confronting the reality of the situation by denying or avoiding it, or wishing things were different" (p. 34). The authors implied that widowed persons needed to be shown how to see their bereavement as a problem, to attenuate their emotions, and to "deal with" the death of their loved one just as any other problem. There was no discussion of the feelings or experiences of the widowed persons in the research report. Due to paradigmatic differences in basic views of human life, the greater portion of the quantitative nursing research on grieving was not reviewed, and the researcher focused on the qualitative research.

A number of nursing authors applied concepts and theories of grieving from other disciplines in situations involving loss, such as: spinal cord injury (Friedman-Campbell & Hart, 1984; Stanton, 1983; Werner-Beland, 1980), chronic illness (Miller, 1983), rheumatoid arthritis (Ignatavicius, 1987), divorce (Lambert & Lambert, 1977), amputation, loss of sexuality, infertility, loss of personal possessions (Lambert & Lambert, 1985), "acceptance of the homosexual identity" (DiAngi, 1982), and AIDS (Flaskerud, 1987). The level of scholarship in these articles and book chapters varied, but the majority, directed toward staff nurses, basically summarized one or more of the major grief theories as adapted to the situation specified. Haylor (1987) wrote, "Nurses found human-loss theory helpful in caring for those who were bereaved or dying....It helped us assess and
intervene with people experiencing other types of loss as well, such as role loss, loss of health or function, and loss of the imagined perfect child with the birth of a handicapped child" (p. 64). Haylor applied generic "human-loss theory" to children of "blended families," wherein the loss was that "the nuclear family is defunct [for the children]" (p. 66). Her recommendation, in its entirety, was: "Nurses working with these families must assume there will be rough times. Normalizing those rough times by sharing how common they are to blended families may help parents accept needed support" (p. 66). There was little or no nursing theory in these applications, and the borrowed theories had not been empirically supported with the populations and situations to which they were applied.

**Qualitative Nursing Research Related to Grieving**

There has been some original qualitative nursing research in this area. Johnson-Soderberg (1981) analyzed "grief themes" in Ibsen's play, *Little Eyolf*, about a family's experience after the drowning death of a child. She wrote, "A dying person is a part of a family and cannot be viewed in isolation" (p. 15). Busick (1989) described grieving as "a hero's journey," drawing on Jungian psychoanalysis and mythology. Van Dongen (1990), using the grounded theory method, studied experiences of survivors of persons who had committed suicide, and identified the core process as "agonizing questioning" (p. 224). Van Dongen found family relationships to be crucial. "During the first week after the suicide, communication among family members was intense...Survivors described family members as being supportive of one another. However, subjects also stated they often avoided sharing their emotions..." (p. 227).

Smith (1990b), in a Parse study of "struggling through a difficult time for unemployed persons," extracted the core concept, among others, of "grieving the loss of what was cherished" (p. 22). The losses included "a significant life's work, a hoped-for future, a valued image of self, fulfilling relationships with coworkers, the respect of family and friends, a comfortable lifestyle, and personal possessions" (p. 25). Smith noted, "As participants engaged in the struggle, new meaning was given to the losses. The new meaning contextualized the pain of grieving so that although present, it was experienced..."
differently" (p. 25).

Carter (1989) analyzed 30 narrative accounts of grieving (bereavement), and identified themes and "metathemes." She described the theme of being stopped as an "I can't" experience, going through the motions or falling apart (p. 355). Hurting was described as sorrow, sadness, feeling wounded or crushed. Missing was described as "an acute awareness of all that has been lost" (p. 355). Holding was described as "preserving the lost relationship" in such ways as "carrying on his legacy" and "feeling him present' from time to time" (p. 356). Seeking was described as a search for help, "which takes the form of seeking comfort and meaning" (p. 356). The metatheme of change referred to the "wave like" quality of the grieving process, in which relationships were altered and "the world itself was said to have changed" (pp. 356-357). The metatheme of expectations referred to a sense of "oughtness" about the grieving process, "a right way to grieve, mourn, feel, honor, and conduct oneself" (p. 357), or feeling that one "must" go through the "stages" of grieving. The metatheme of inexpressibility referred to the inadequacy of words to describe the experience. The "contextual theme" of personal history underscored the subjective and relational nature of grieving. It was important to participants that it be understood "what their hopes, dreams, and shared experiences were" (p. 357). These are rich experiential descriptions, but Carter did not link them to any theoretical perspective of nursing, presenting them as a panoply of disparate ideas. Carter compared her findings to the perspectives of Freud, Kübler-Ross, and existential-phenomenology. She said, "None of the three theoretical perspectives...were found to provide a wholly adequate base for nursing care" (pp. 357-358), which points to the need for nursing theory development in this area, although Carter does not state this.

Watson (1985) conducted a phenomenological investigation of loss and caring among the aboriginal people of Australia, interpreting her findings in accord with her "caring" framework. Here the loss was death. The investigation yielded a description of "caring wanted by Aboriginal from nurses during loss" (p. 87). Watson found that "[p]eople want comfort by nurses during immediate loss experience," expressed "by
holding and embracing that shows the nurse cares" (p. 87). Another important element for the aboriginal people was time "to be left alone...a rest day [which] extends to include the community....The nurse needs time for caring to be known. The person needs time to be alone, to mourn, rest, have time out, time off..." (p. 87). The raw data for Watson's study was full of vivid expressions of the aboriginal experience: "A sorrowful feeling is someone trying to take the land--destroy our very being inside....Dreamtime told us the Dreamtime man is so powerful that he destroyed everything before him..." (p. 86). To this researcher, it appeared that Watson's focus on the nurse's caring left out the richest part of the data. Her words reflected the portion of the original narrative on death, bereavement, and caring; but the person's experiences apart from the nurse were ignored, except that the bereaved ironically insisted on time away from the nurse. Watson's interpretation was, however, congruent with her caring framework, with its focus on the nurse caring for the person, rather than the lived experience of the person. Watson's study was one of very few studies located that used a nursing framework.

Sowell et al. (1991) studied "the lived experience of survival and bereavement following the death of a lover from AIDS," using a phenomenological approach. In their article, bereavement was identified as a "psychological stress," a task to be resolved at the risk of "mortality and morbidity" (p. 89), and nursing was not mentioned at all until the final two sentences. The researchers identified categories and themes of "losing a lover to AIDS." Themes within the category of isolation/disconnectedness were "isolation from family," "isolation from friends," and "disconnectedness from self" (Sowell, et al., p. 91). Parse (1981) maintains that such paradoxical rhythms manifest at times with one side of the rhythm, like isolation, more apparent than the other. Through dwelling with the meaning of the situation, the other side of the rhythm surfaces. Sowell et al. (1991) reported several instances of closeness and support that respondents described as "valued and treasured," but did not explain why these aspects of the experience were absent from their categories and themes. Themes within emotional confusion were "guilt," "loneliness," "anger," and "ambivalence" (p. 91), related not only to losing a lover but also to the participants' having
the HIV infection. Themes within acceptance/denial were "loss" and "threat" (p. 91). The authors concluded by endorsing Sanders's (1989) theory of grieving, from psychology. When they finally mentioned nursing, it was in the form of a mandate to develop interventions to facilitate resolution of grief in this population and "to enable the bereaved to effectively access support resources" (p. 93). By eschewing nursing theory in their study, however, the researchers had little basis on which to propose guidance for nursing practice.

Carmack (1992) investigated the process of "coping" in relation to AIDS-related losses. Using the grounded theory method, she interviewed 19 people who knew or had known persons with AIDS. The basic process identified was "balancing engagement and detachment" within the context of a "redefinition of values" (p. 11). Carmack identified four ways of coping: "functional engagement, dysfunctional engagement, functional detachment, or dysfunctional detachment" (p. 11). Maintaining the balance between engagement and detachment was identified as "the integrative process" in "coping with AIDS-related multiple losses" (p. 11). Losing this balance, according to Carmack, resulted in dysfunction. In the redefinition of values, "[p]revious goals, values and priorities were simultaneously and interactively appraised and reappraised" (p. 12). This study documents the extent to which others not personally infected are nevertheless involved in living with AIDS. It sheds light on the rhythmic process she calls "engagement and detachment," and on the centrality of personal values in grieving. The unstated use of a mechanistic stress-coping framework with an evaluative stance toward "function" and "dysfunction" detracts from the study's elucidation of personal values in "coping" with loss.

Cowles and Rodgers (1991) in their concept-development paper on grief, found that the concept was "plagued by vagueness and ambiguity" (p. 119). In order to "clarify this important concept for nursing" (p. 119), they reviewed a sample of 74 articles in medicine and nursing on "grief" and "grieving" from 1985 through 1988. Based on this analysis, Cowles and Rodgers defined grief as "a dymanic, pervasive, highly individualized process with a strong normative component," the "human response" to generic loss, rather than death alone (p. 121). They took note of "a consensus in the
literature that grief does have identifiable phases" (p. 121); but "an individual was thought to move continually across all 'phases' throughout the grief experience," although "[s]ome authors...refer to grief as having 'steps' and a linear progression" (p. 121). References in the literature to "clusters or phases of activity," and "the work of grieving," were interpreted by Cowles and Rodgers as a "process...possibly limitless in time" (p. 121). That grief was discussed in the literature in relation to myriad manifestations and "symptoms" led the authors to specify grief as "highly individualized" (p. 121). That grief had been studied in relation to a number of physical, social, cognitive, affective, and spiritual variables led them to characterize grieving as "pervasive" (pp. 121-122). "Any combination or degree of symptoms or manifestations seemed to be possible in association with a grief experience" (p. 122). Nonetheless, based on their review of the literature, they concluded that "there are limits to grief, beyond which it becomes inappropriate, unacceptable, or revealing of underlying or associated pathology" (p. 122), leading to their inclusion of "normative" among the defining characteristics of grief.

Cowles and Rodgers suggested that "the recognition of grief in nursing clients is best directed toward the determination of an antecedent loss and the individual's self-reports of 'grief'" (p. 124). They stated that there is "a need for additional research on grief that utilizes in-depth interviews as a primary source of data" (p. 125). They also suggested that research is needed "in regard to responses to various types of loss such as those associated with AIDS, institutionalization, and chronic illnesses..." (p. 125). The "human response" paradigm guiding Cowles and Rodger's work differs from this researcher's perspective, as does their interpretation of the grief literature. Their blending of the "highly individualized," "dynamic," "process" view with the "normative" view strains logic. Nonetheless, their recommendations for in-depth qualitative research and studies of the losses experienced by persons with AIDS, support the intent of this study.

Families

Bohannon (1985) has stated, "The literature on the family is one of the largest in all of social science. It is also one of the worst. The primary reason is that social scientists
are as subject to the prejudices of their time as anyone else” (p. 236). The stance taken in this study was that there were few assumptions about families that could be taken for granted if the goal of the research endeavor was to understand the lived experiences of persons living as families.

**Conventional Scientific Approaches to Family Study**

Family is a human universal, present in some form in all cultures (Brown, 1991). The earliest model of the family in scholarly discourse, dating back centuries, was the family as institution (Sirjamaki, 1964). Around the turn of the century, the institutional approach was supplemented by "social Darwinism," with its view of society evolving toward higher forms. According to Christensen (1964a), social Darwinism provided an impetus for social "reform" during this era, expounding the belief that the Victorian family was the ultimate achievement in the evolution of the family. The modern nuclear family, historically linked with the Victorian model (Skolnick, 1991), is not a human universal, and in many cultures living arrangements bear little resemblance to it, except for the "core" of "mother and children" (Brown, 1991, p. 136).

An influence on family theory that often remains implicit in discourse on the family is the concept of the "ideal type," first proposed by Weber (1925/1964), and unquestionably a great boon to turn-of-the-century social science. According to Sirjamaki (1964), "[S]ocial scientists construct ideal types of societies or institutions based on pure or exaggerated traits, which they conceive of as hypothetically concrete entities useful in comparative studies" (p. 37). Monogamous marriage is an ideal type, one of many types of marriage found around the world. The nuclear family is another. A close reading reveals that much discourse on the family is underwritten by the concept of the ideal type. The resulting "typology" of families reflects the continuing influences of the institutional approach and social Darwinism, and the notion of the nuclear family as institution, ideal, and norm, is quite prevalent in the literature.

In the mid-twentieth century, with what Christensen (1964a, p. 10) called the practice of "empirical, value-free investigation," modern family science emerged. In the
1960's, scholars called for acknowledgement of family science as distinct from the disciplines in which it arose (Christensen, 1964b; Hill & Hansen, 1960). For thirty years various family scientists have maintained that concepts describing individual development, behavior, and experience are inadequate to encompass the family. Sociologists often leave this assumption unstated, since the focus on group phenomena is inherent in their discipline (Burr, Hill, Reiss, & Nye, 1979). Family therapists (Bowen, 1978; Haley, 1963; Minuchin, 1974) have espoused the notion that individual psychopathology is symptomatic of pathology in the family. Family practice in medicine has also become a specialized field, centered on the family as the locus for health promotion, prevention, and treatment of chronic illness (Doherty & McCubbin, 1985).

Major schools of thought on the family have included social exchange, structural-functionalist, systems, interactionist, and developmental perspectives, although there are few "pure" models from any one school. Thousands of studies have also been conducted with little reference to the grand theories. As it was not possible to review all of this body of research, the researcher's aim in reviewing the general family literature was to gain an overview of the study of families. Selected major schools of thought are summarized and critiqued in this section.

Structural-functionalism was the dominant paradigm in sociology at the dawn of the modern era of family science (c.1950's). This school of thought, led by Parsons (1951), regarded the family as a part of the social system, and individuals as parts within the family system (Pitts, 1964). The key concept, function, was defined as a relationship between two variables, deemed necessary for the two and for the system to continue (Pitts, 1964). "Function" and "dysfunction" of the family referred to the family's "utility for the social system" (Pitts, 1964, p. 54). The goal of Parsonian structural-functionalism was to classify social systems, such as the family, and to identify their "functional prerequisites." Role specialization was a focal point; Parsons (1951) assigned to the husband an "instrumental" role and to the wife an "expressive" role. Today structural-functionalism is waning, but its ideas have been enormously influential, and much of its basic terminology
is common currency is many fields, including nursing.

In social exchange theory, the "exchange" refers not only to money, property, or labor, but also "statuses, relationships, interaction, experiences...and feelings" (Nye, 1979, p. 2). Key concepts in this paradigm include: choice, rewards, costs, reciprocity, power, conflict, obligation, and equality (Nye, 1979; Scanzoni, 1970). Exchange theory analyzes choice, power differentials, reciprocity, and equity in relation to societal norms and family roles. This paradigm focuses on the relation of the individual to all society more than the family as a unit, drawing on works in which kinship has been studied as social exchange (Lévi-Strauss, 1976). A frequent topic of study using exchange theory has been the effect on the family of the employment status of the husband or wife (Burr, Hill, Reiss, & Nye, 1979). Elements of exchange theory also are used to argue for public policy on the basis of equity (Nye, 1979; Scanzoni, 1983).

There are many varied interpretations of systems theory (Beavers, 1977; Bowen, 1978; Bronfenbrenner, 1979; Doherty and McCubbin, 1985; McCubbin and Figley, 1983; Minuchin, 1974). The family system may be "open" or "closed," depending on the theory. A system is generally said to possess the attributes of isomorphism, equifinality, the ability to process matter, energy, and information, dynamic interaction, and progressive differentiation. The family system is composed of members who cooperate but also may act alone (though not without affecting the system); the system has a hierarchy of values, has the capacity to adapt and evolve, and has a sort of permeable boundary defined by membership in the family (Beavers, 1977). Aspects of certain systems theories, such as isomorphism and equifinality, are incongruous with the fact that families change their very constitution and reconfigure, as noted by Broderick and Smith (1979), who state that one way out of this dilemma is to postulate "a standardized set of positions or roles that can be held to exist in all families" (p. 113). Systems theories also take up the terminology of "functionality" and "dysfunctionality," and often include the postulate that "pathology" in the individual is indicative of dysfunction in the system as a whole (Beavers, 1977; Bowen, 1978; Minuchin, 1974).
The interactionist school of thought (Mead, 1934) was introduced into family science early in its development. Interactionism stresses the symbolic meanings of interactions among persons. Social reality, the self, and the family are seen as products of these interactions. The individual and society are believed to be inseparable, although the social influence in creating the symbolic environment is generally emphasized over the individual's latitude to interpret (Turner, 1970). The concept of role is crucial in interactionist theory. Roles are "integrated sets of social norms that are distinguishable from other sets of norms" (Burr, Leigh, Day, & Constantine, 1979, p. 54). This concept is shared with the paradigms previously described, but in interactionism norms are regarded as social creations, and thus contingent and situational (Hess & Handel, 1959).

The developmental or "family life-cycle" paradigm was the first theoretical treatment of the family to emerge within family science. It evolved from the paradigms discussed above, in combination with theories of individual development. The model is based essentially on the assumption of the nuclear family, a "conjugal unit" that bears children and continues until the death of the last surviving spouse (Duvall, 1977). The "family life-cycle" is a sequence of developmental tasks conceptualized according to the norms of the nuclear family model. The concepts of role, function, and system, are used to describe the developmental tasks. According to Holman and Burr (1980), the developmental approach reached its apex in the 1960's and has since waned, due to increased emphasis on individual life-span issues that do not fit with the model of the family life-cycle. For example, the majority of mothers are now employed, and can expect to live over thirty years after the last child leaves home (Skolnick, 1991). Actual "family life-cycles" are very different from the model for childless couples, persons who divorce, women who have their first child earlier or later in life, families of gay persons, and others (Macklin, 1980).

There are many traditions of family and kinship not encompassed by any of the conventional scientific models of the family. Many different notions of kinship have been noted in the anthropological literature (Brown, 1991). Traditional beliefs within Christianity, freemasonry, labor unionism, socialism, fraternities, and sororities entail the
notion of their participants being brothers and sisters. The concept of "sisterhood" has been central in the feminist movement (Daly, 1973), which has been an important force in changing the image of the family in recent decades (Skolnick, 1991). In the gay community, the word "family" is used as a sub rosa synonym for "gay." These notions of nonmatrimonial, nonbiological kinship figure prominently both in individual lives and in history, yet have been completely ignored by family science in deference to the nuclear family. The view of the family as an hypothesized entity defined by biological and legal norms, with the nuclear family as the exemplar, is common to all the major theoretical perspectives in the field.

The historical reality of nuclear families is a matter of some debate (Ariès, 1962; Demos, 1986; Skolnick, 1991). Donzelot (1979) argues that the standardized (French) family was created as a unit of labor production and social control, and regards the "norms" applied to it as modes of "policing" actual families. The solidification of the modern nuclear family model in American science can be traced to the 1950's. Following the depression and the war, there was great value placed on a return to normality. The GI Bill fostered employment opportunities for "breadwinner" fathers; women workers were replaced by men returning from the war; the baby-boom distanced women from paid employment; McCarthyism portrayed beliefs and behaviors outside a narrow range of the "norm" as un-American; suburbs expanded in the post-war economic boom; and media images of families such as "Ozzie and Harriet" proliferated. Family science emerged during this era, and accepted the prevailing circumstances as the norm for families (Scanzoni, 1983; Skolnick, 1991). The extent of the emphasis on family norms is reflected in the popular old joke about the middle-class family with 2.4 children. The standardized model of the family that was promulgated over the past decades now seems to be a Procrustean bed that few families are willing to lie in, as the census data presented in Chapter I illustrated.

Family scientists have sought for decades to develop an objectivist, "value-free," quantitative science with prediction as its major goal (Burr, Hill, Reiss, & Nye, 1979;
Christensen, 1964). Meanwhile, new configurations and attitudes have transformed the relational milieu for many families, particularly where women, unmarried couples, single parents, gay people, and children of these groups, are concerned (Skolnick, 1991; Weston, 1991). Far from being prescient or educative regarding the changing realities of families, most family scientists have evidenced little understanding of these changes, and have spoken of "the new families" only as deviations from the standardized norm (Bane, 1976; Burr, Hill, Reiss, & Nye, 1979; Dornbusch & Strober, 1988; Duvall, 1977). Even sympathetic researchers on "nontraditional" family forms have emphasized the differences between "traditional" and "nontraditional" families. Eiduson and Alexander (1978) stated explicitly: "The alternative families function in other ways than do nuclear families; their membership is different, their structure is different. They present to the child an environment or family milieu which differs...from what we have come to know as characteristic of the nuclear family" (pp. 149-150). Similarly, in a review of research on "nontraditional family forms," Macklin (1980) included under this rubric "all living patterns other than legal, lifelong, sexually exclusive marriage between one man and one woman, with children, where the male is the primary provider and ultimate authority" (p. 905).

Macklin cited well over a hundred studies on families of divorce, one-parent families, dual-career families, "binuclear" families, childless families, "cohabitation," "reconstituted" families, homosexual families, and so on, delineating an expanding typology of families. The peculiar characteristic of this typology, however, is that all other "types" are compared to the nuclear family "type" and defined by their variation from it. Minimal research has been done with populations of generic or self-defined families, unconstrained by designations such as nuclear, traditional, nontraditional, alternative, or a specified type. The limitations and inadequacies of the predominant approaches to family study confound the attempt to understand patterns and meanings of family life as it is humanly lived. The researcher concluded that an approach foregoing structural and behavioral assumptions about the family was needed to surface the meaning of family interrelationships.
Unconventional Views of Family

A different view of family life is offered by Kempler (1974), a Gestalt family therapist, who likens the family to "a cluster of islands surrounded by the common waters of time flowing...towards the sea....The various shapes of these juxtaposed islands create unique currents...which, in turn, influence the contours--the personalities--of each" (p. 9). Kempler's view of the family is open to the perspectives of the family members themselves. He says, "There can be no adequate terminology for labelling families. Not because there are so many factors at play, although that would be reason enough, but because one does not in fact talk about the families at all when describing them. One talks only about one's own perspective" (p. 10). Kempler refers to "objectivity" as "the concept of the immaculate perception" (p. 81). Participation is the keynote in his view of family therapy, rather than objective analysis. Kempler speaks of "the underlying paradoxical desire to be both with and apart, to join and to separate, that is everyone's lot" (p. 10). He writes, "Family is a kind of relatedness" (p. 17); the question is not if persons are related, but how (p. 64). Separation often leads to a higher order of union, as in the happy separateness of children at play, secure in the knowledge of a certain communion with their parents (p. 65).

In the recent family science literature, there is evidence of a small but growing movement with a different view of the family, characterized by a more inclusive view of who constitutes a family, and a minimalization, if not outright elimination, of normative, prescriptive ideas about family processes. Kinley's (1981) Friends as Family describes non-genetic, non-legal relationships that are lived as family; Weston's (1991) Families We Choose explores lesbian and gay kinship; and Burton (1990) describes teenage childbearing as an "alternative life-course strategy in multigeneration black families" creating a matrilineal sub-culture. According to Rapoport (1989), in a report on changing family life in 14 European countries, although there are certain cultural "ideologies" and forms of family in each culture, "Diversity prevails, and, being seen to prevail, is being normalised" (p. 55).
In family therapy, there are also signs of a new approach, stemming from and moving beyond second-order systemic family therapy (de Shazer, 1991; Fine & Turner, 1991; Golann, 1988; Hoffman, 1985, 1990). For Parry (1991, p. 42) the focus of family therapy is the story that the family tells in relating their lives. Parry advocates the elimination of "the gratuitous attempt to explain the meaning of a person's story with regard to a normative structure concerning what makes individuals, families, or systems in general tick" (p. 42). Fine & Turner (1991, p. 307) reject the view of the therapist as a "privileged, objective management-consultant" in favor of the family therapist as one who "collaborate[s] with clients in co-constructing new realities," and they characterize the contrast as that between "tyranny" and "freedom." Hoffman, one of the early advocates of second-order therapy, recently authored an article in which she abdicated the systemic ("cybernetic") approach altogether and describes her practice simply as "postmodern."

The postmodern therapist comes into the family...without any set idea about what should or should not change. Together, while talking, interviewer and family may come up with some understandings or ideas for action that are different from those the family may originally have had in mind, and also different from those the therapist may originally have had in mind (Hoffman, 1990, pp. 10-11).

Similarly, Anderson and Goolishian (1990) write:

"For us, psychotherapy is in a conversational domain, and the art of psychotherapy is a conversational art. The theoretical base that informs and develops the vocabulary of understanding for therapy should reflect this position (p. 161).

Such articles have spurred responses from other scholars citing various points of doctrine and questioning the pragmatics of the new form of therapy (Atkinson & Heath, 1990a, 1990b). The process that is unfolding has all the hallmarks of a paradigm shift. The old paradigm in family therapy is objectivistic and causal, and its values are explanation, prediction, and problem-solving (for example, Bowen, 1978). The emerging paradigm is relativistic, interpretive, and acausal, and its values are freedom, openness, and coparticipation (de Shazer, 1991; Fine & Turner, 1991). The comments of Anderson and Goolishian (above) strongly imply that the old paradigm theories are inadequate to guide
practice with the new perspective of families. The change of approach is more than just adding a humanistic touch to a predictive, manipulative theory base; an entirely different theory base is necessary. The recognition of a similar need in nursing led Rogers (1970) and Parse (1974, 1981) to construct new theories to guide nursing practice, which gave birth to a new paradigm in nursing. This study sought to expand and specify the theory base that guides open, nonjudgmental, coparticipative nursing practice with families.

**Nursing Literature on Families**

This section examines selected theoretical and conceptual issues regarding the family in nursing science. Although nurses have worked with families since Nightingale (1860/1969), and the family is often emphasized in nursing textbooks, there are as yet no "models" of the family in nursing science that are used as extensively as the models from other disciplines (Gilliss, Highley, Roberts & Martinson, 1989; Miller & Winstead-Fry, 1982). Another notable aspect of the family nursing literature is that there appears to be no limit to the range of phenomena to be considered. For example, in the book *Toward a Science of Family Nursing*, (Gilliss et al., 1989) there are detailed chapters on nutrition, culture, and social support, as well as numerous specific diseases, each summarizing knowledge gleaned from other sciences. If the purpose of the book is, as its title suggests, to contribute to the evolution of nursing science, the editors have chosen a circuitous route, as there are fewer than a dozen references to nursing theories in the entire 500-page book.

In 1983, Clements and Roberts published chapters by several nursing theorists explicating their theories with regard to the family. These included Roy's (1976) adaptation theory, King's (1981) theory of goal attainment, and Rogers's (1970) unitary conceptual system. For King (1983), "families are small groups of people bound together by a common purpose, who help the young grow into adults" (p. 179). For Rogers (1983), the family is "an irreducible, four-dimensional, negentropic...energy field," and, she states, "For purposes of study a definition of a family field is operational and more or less arbitrary" (p. 226). Parse's (1981, 1992) view of the family has been explicated in this proposal. There is no shortage of conceptualizations and theories pertinent to family
phenomena in nursing. Yet the preponderance of family-centered nursing research and literature has ignored this body of theory.

The researcher's view is that nursing is a scientific discipline, and there is a domain of knowledge that can be fully developed only through the formal study of nursing (Parse, 1981). The evolution of nursing as a scientific discipline, with a unique contribution to make to knowledge about the family, depends on nursing theories that provide a unique perspective of family phenomena. Susan Murphy (1986) has argued just the opposite of this position, maintaining that the future of family nursing is in interdisciplinary collaboration, rather than a discipline-specific approach, which she terms "parochial." She says that the field of family study is too broad for any one discipline to encompass. But Murphy misses the point. The purpose of discipline-specific theory is to map out the domain of knowledge that is germane to the discipline. Through theory development and research from an explicit theoretical perspective, a discipline develops a body of knowledge, illuminates its domain, and contributes to the fund of human knowledge in a unique way.

Feetham (1984, 1991), Gilliss (1983), and others, have promoted the family as the "unit of analysis" in nursing research. Feetham (1991) regards this as the criterion to differentiate between "family-related research" and "family research." She attributes to "family-related research" a focus on individual family members, and to "family research" a focus on the family as a whole as the unit of analysis. In the latter type of research, "Individual family members are not considered explicitly. Rather, family unit behavior is taken into account" (p. 56, emphasis added). This argument has received much attention in the family nursing literature (Moriarty, 1990; Whall & Fawcett, 1991). It is not accidental that those who endorse this view (Gilliss, 1983; Feetham, 1984; Whall & Fawcett, 1991) are quantitative researchers. From a quantitative perspective, the "functioning" of the family (or some other attribute) can be measured as a single construct, reduced to one number. "Function," for example, is essentially a correlation (perfect function = 1.0). The current interest in the notion of "the family as the unit of analysis" becomes more
understandable in light of the fact that over 90% of all family research is quantitative (Moriarty, 1990). Considerable effort has been extended in nursing to measure the construct of "family functioning" (Lasky et al., 1985). The "family as the unit of analysis," in the objectivist sense in which these scholars use the concept, cannot be translated into qualitative research with logical coherence. If one has any interest in the family members' humanly lived experiences, then the "family as the unit of analysis" in the sense that "[i]ndividual members are not considered explicitly" (Feetham, 1991, p. 56) is impossible.

Feetham (1984, 1991) also suggests that nurses study families using the existing family theories of other disciplines. No explicit reasons are given for this stance, other than the notion that the family must be taken as the unit of analysis for "family research." It may be that the lack of a body of family research in nursing comparable in extent to that of other disciplines leads Feetham to assume that nursing is too far "behind" in family science to develop its own theories. But if the family as the "unit of analysis" in this strict sense is not a salient feature of nursing's extant body of theory, this attribute of nursing's knowledge base may have to do with nursing's unique perspective, concerned with every individual's quality of life, and it may be unwise to import a substantially different perspective from other disciplines focusing on group dynamics.

In their book, *Family Theory Development in Nursing*, Whall and Fawcett (1991) review developments in some of the major nursing theories, such as those in the Clements and Roberts (1983) book. Greater attention, however, is given to theories about the family from other disciplines, with the suggestion that nurses adapt these theories to their needs. Whall and Fawcett (1991) also clearly favor the family-as-unit-of-analysis view. Although they state in their introduction that the distinction is not a value judgment, three chapters are primarily devoted to the complexities of this approach. Fawcett is well known as an advocate and spokesperson for the "metaparadigm" concepts of person, environment, health, and nursing, the four concepts that, in her view, specify the content domain of nursing (Fawcett, 1984). It is surprising, therefore, to note that Fawcett, with Whall,
suggests that these metaparadigm concepts are inadequate to encompass family nursing (Whall & Fawcett, 1991, p. 3) unless "person" is replaced with "family."

It is illogical to suggest that families and individuals are central foci of nursing, and yet to maintain that different concepts and propositions are needed to address them. From this researcher's perspective, Fawcett's jettisoning of the "metaparadigm" concept of person for the purposes of family theory development reflects the inability of the conventional, objectivist view of the individual to encompass the "paradox of subjectivity" described by von Hildebrand (in Owens, 1970), and expressed in a slightly different way in Parse's (1981, 1992) theory of nursing. All of the nurse authors advocating the family as the unit of analysis also espouse an open definition of the family. Nonetheless, it is evident that the heavy emphasis on the family as the unit of analysis, as they portray it, is underpinned by the assumption of the nuclear family, as well as the objectivist view of science and the subtle influence of the ideal type.

From this researcher's perspective, families can only be understood in depth by attending to the personal meanings, values, relationships, and hopes and dreams of the family members. It is the kind of understanding that one seeks that makes the crucial difference. Individuality and communality are inseparable. The interrelationships among person, family, community, and others are both cocreated by and reflected in the individual simultaneously. Focusing on the family, from a human science perspective, means focusing on the lived experiences, meanings, values, patterns of relating, and possibilities of the persons who cocreate the family. "The family" may be quite different for each one of them. This study, guided by Parse's (1981, 1992) human becoming theory, which addresses these complexities of intersubjective relationships with depth and clarity, therefore makes a unique contribution to nursing's knowledge base on family phenomena.

**Living with AIDS**

In congruence with the focus of this study on lived experiences, an attempt was made to locate qualitative, experientially oriented reports on living with AIDS. Research of this kind has been very limited. The annotated Selected Bibliography on AIDS for Health
Services Research (Agency for Health Care Policy and Research, 1990) listed 243 studies, none of which had an experiential focus. In a survey of the nursing literature on AIDS, Larson and Ropka (1991) identified 54 studies on aspects of HIV/AIDS published between 1987 and 1990. The subjects in 34 of the studies were not persons living with HIV or AIDS, but nurses or other health-care workers. No studies included in the survey had families living with AIDS or families of persons with AIDS as their subjects. Persons with AIDS were the subjects of 13 of the 54 studies. Of these studies, the majority focused on identifying needs and concerns, psychosocial assessment, or "informational needs."

For example, Longo, Spross, and Locke (1990), sought to identify "major concerns" of persons with AIDS. They interviewed 34 persons medically diagnosed with AIDS using an interview tool comprised of 40 questions, pre-tested in a prior study and validated by "expert critique by clinical specialists" (p. 22). The researchers grouped the subjects' concerns into five categories: uncertainty of the future, desire to maintain physical and/or psychological health, social unacceptability, fatigue, and weight loss (p. 23). Once these categories were established, the researchers interpreted "uncertainty of the future" using Fink's (1967) rehabilitation model, and the "desire to maintain...health" using Erikson's (1963) developmental model. There were no in-depth descriptions of any aspects of actually living with AIDS presented in the research report. The preponderance of qualitative studies located were of this kind, and therefore provided relatively little insight into what it means to live with AIDS. The few exceptions will be highlighted in this section.

Review of the non-nursing literature was directed toward evaluating current knowledge of what it is like for families who suffer losses and grieve while living with AIDS. Altman (1987), Shilts (1987), and Weitz (1991) provide detailed accounts of the history of the HIV epidemic. Innumerable influences have gone into what Weitz (1991) calls the "social construction" of AIDS, including: the initial lack of knowledge about the syndrome, pre-existing homophobia and racism, the equation of AIDS with death, the silence of political leaders, the lack of research funding, inadequate public health education,
condemnation of persons with AIDS by religious leaders, anti-gay discrimination rationalized with reference to AIDS, overcrowding of urban hospitals, irresponsible journalism, and open hostility to persons with AIDS by health-care professionals.

Recurring themes for persons living with AIDS have been identified as stigma, homophobia, racism, fear, loss of strength, loss of financial security, loss of attractiveness, loss of interpersonal contacts, bureaucratic incompetence, prejudicial reporting, and dissemination of misinformation (Altman, 1987; Shilts, 1987; Weitz, 1991). With regard to death and dying it is more often the way the person envisions this eventuality than the fact of dying that is of utmost concern. These themes are echoed in reflective works on AIDS by Sontag (1990) and Schecter (1990). For gay men there is a feeling that their community has been virtually dissimated, although those who struggle with AIDS are sometimes brought together in a new way. Altman writes, "[A] man in an outdoor bar tells me he has left San Francisco because he cannot live any longer surrounded by dying friends" (p. 7). Sontag (1990) says that AIDS has become "the generic rebuke to life and to hope" (p. 112). Schecter (1991) writes, "Where once there was a sense of community, now there is silence and at times what Arendt referred to in another context as the huddled warmth of pariah peoples, outcasts, lepers even, which takes the peculiarly modern form of a well-nigh unbearable solitude" (p. 25). The themes of loss and intensified patterns of human relationships, in a context of near-ubiquitous suffering, death, and dying, are found pervasively. Sontag (1990) writes, "Plague' is the principal metaphor by which the AIDS epidemic is understood" (p. 132).

**Autobiographical Accounts**

The most revelatory descriptions of living with AIDS are first-hand reports authored by persons living with AIDS. The historico-cultural elements mentioned above are interwoven in the experience of living with AIDS, and these authors refer to them often. Not surprisingly, they often make reference to a lack of understanding among health-care personnel. The following excerpts are taken from Emmanuel Dreulhe's (1987) journal. These quotes (and those from Monette, which follow) were selected by the researcher to
illustrate aspects of the author's account relevant to the present study.

The loss of my companion...has filled me with a thirst for revenge, a profound hatred for the virus that killed him and for the society that looked on his struggle with indifference, even a touch of revulsion (p. 26).

I mustn't panic and go to pieces, but instead believe profoundly in my own values, which are traditional to me even though they don't correspond to those of the majority (p. 37).

Oliver's death and endless agony...loosened all the ties that still bound me to the world of healthy people. Most of them would never have been able to understand what we went through. Oliver, his mother, and I, all three of us shut up in our space capsule, companions in misfortune on this nightmarish journey (p. 40).

Dan, my visiting nurse...brought me an article about the daily acts of charity he was performing...assigned to outpatients like myself with AIDS. A quotation from him...sums up the message of the article: "They're all going to die"...He doesn't really believe in my crazy dreams of getting well again: he thinks I'm just tilting at windmills (pp. 46-47).

Living in this hell is the only way to understand that the actual experience of something dreadful is sometimes easier to bear than what one has feared and imagined....It would be...hypocritical on my part to claim that AIDS is livable, but the rest of society's irrational terror might lead to the adoption of draconian measures, because they forget that we're still human beings....(p. 94).

My wife for ten years...now my companion, was asked...[during an interview]: "How do you feel, watching him die before your very eyes?" She answered like a soldier, replying that I'm not dying of AIDS, but living with it, and that she is there to help me live with it (p. 123).

The author/poet, Paul Monette (1990) authored a detailed autobiographical account of living with AIDS with his lover, Roger, who had the virus. He speaks the strength of the bond between them:

Whatever happened to Roger happened to me, and my numb strength was a crutch for all his frailty. It didn't feel like strength to me, or it was strength without qualities, pure raw force....In a way, I am only saying that I loved him....increasingly every day that love became the only untouched shade in the dawning fireball. What Tillich calls God, the ground of being (Monette, 1990, p. 65).

In the following scene, Monette has gone with a friend's family ("his parents, his
sister, his friend Jimmy") to scatter his ashes from the ferry at Fire Island.

Bruce's cousin passed the box around, and I watched Jimmy cradle it and start to cry. Then he passed it to me. It was heavier than I expected...and it felt truly as if I were holding the final weight of a man. That's when I cried for Bruce. An hour later on the dunes I cried for Cesar, whose ashes I never held, dispersed I know not where. Then I cried all the way back to L.A. on the plane, for Roger mostly by then, but really for all of us, this generation of widows and groping survivors (pp. 222-223).

Monette's lover lived about a year and a half after his diagnosis with AIDS. Much of the book is devoted to describing the way of life the two created for themselves as one loss after another ensued: no more vacations, lost business opportunities, wilting dreams of the future, friends who died and those who stopped coming by, the loss of Roger's eyesight, and finally his law practice, until there was just a core of what really mattered:

The summer days were so lambent now, even as the summer waned—mornings in the garden while I read him the paper, evenings reading Plato, the smell of anise when we walked at night. These brief, immediate goals of the day-to-day we had come to cherish, no matter how constricted our movements (p. 307).

As their experience unfolded, the pattern of daily living came to be more and more disrupted by difficulties with infections, drugs, health-care personnel, finances, and increasing restrictions on their activities. One morning Roger suddenly rose out of bed, and, speaking incoherently, urinated and defecated incontinently, a new and frightening turn of events. But Monette says of this:

I helped him to his feet, cleaned him up and got him comfortable in bed. By now he was saying he was all right, he just wanted to sleep. So did I. All I wanted to do was sleep, and that's what I did for an hour. In that moment when I should have had us in the car on the way to the hospital, I couldn't cope anymore (p. 330).

Monette writes, "The 'what ifs' do not go away" (p. 291), and his story includes a number of possibilities that were not to be. For Roger, Paul, and their family and friends, life with AIDS became very centered on priorities. "Loss teaches you very fast what cannot go without saying" (p. 227).

Rudd and Taylor (1992) edited an international anthology of short writings by
women living with HIV. The accounts, mostly from nonprofessional writers, are presented with little comment by the editors. Rudd and Taylor state, "Most of the submissions that we received are included in this book" (p. 17), since the major goal of the anthology was to represent the spectrum of women who live with HIV. It is therefore interesting to note the editors' remarks: "The pieces in this anthology are overwhelmingly affirmative. In some, this upbeat tone may seem to cover fears that are too raw and threatening to be expressed. In other cases, death and loss and separation are faced squarely, yet something of worth always remains. These voices, sometimes plain and uneducated, affirm the unusual and exceptional in women's lives along with the value of daily life" (p. 17). The following are excerpts from the women's stories.

Lori Lynn Ayers (USA):

No one was more shocked than I when I received my diagnosis....I was alone and the sky was falling in. I didn't realize then what is so wonderfully clear now: that this diagnosis would turn out to be an incredibly positive force for change in my life (p. 22)....I know that when I die I will be satisfied with my life as I have lived it, in a way that I might not have if I hadn't had this virus in my life. I will never give up hope and joy. I'll "survive" this plague, I have already survived it in that I can grow, learn and experience being alive today (pp. 24-25).

Rosemary Mulenga (Zambia):

I am HIV positive, but AIDS has not beaten me. I will fight this monster and its effects on me personally, on my family and on my community, as long as I am alive (p. 30).

Dina (Switzerland):

I seem to fly from the heights of happiness into the depths of despair—my moods are like the high waves in the ocean....I am so alone and at the same time have the feeling that I am never really capable of being alone (p. 83)....I cannot come to a standstill in my inner development or even put in a pause....Every single day is filled with so many experiences that bit by bit I am forced to live a richer and deeper life (p. 86).

M (Switzerland):

...I don't feel well. I am sad. All my hope is destroyed. I will have to leave my job....When I get sick, when I am despairing, who will be here to embrace me, to comfort me?...My last period of life has begun, my old age, the evening of life. And for all that, I am only 27 years old and
have not yet lost my will to live (p. 94)....I dreamt I was pregnant and would have a child and there was no risk involved. But, this dream is a dream. Sometime, when some cure is found, I will be too old (p. 98)....What can one make out of one's life? Most people at our age are established....But we....must look for other ways, must set other goals, must find other experiences and meanings (p. 100).

Isabel (Zimbabwe):

...I am still hoping to have a child. I know many of you will be horrified by this. I have been told that it is totally selfish, that I have no right to inflict the potential for suffering on an as yet unborn child. Who says I have no right? If I am lucky enough to become pregnant my child will be loved and wanted (p. 130).

Roseanne (Canada):

When our little girl was barely two months old, I decided to defy the doctors and death and I became pregnant again. Call it risky...even downright dumb, I wanted another child. It was an act of defiance (p. 135)....My husband...and our two beautiful daughters...are [HIV] negative....We will teach them to love as we love and to respect life as we do. So maybe one day they will be able to say they were proud to be my children. I gave them life and in turn they brought hope into mine (p. 139).

Michael Callen's (1990) unique work is entitled Surviving AIDS. His text begins: "[O]f the 1,049 Americans diagnosed with AIDS during 1982, twenty-five are still alive. I am one of the lucky ones" (p. 1). Callen investigated long-term survivors of AIDS to see what, if anything, they had in common. After examining the statistics and consulting with epidemiologists, Callen (1990) reports that the three-year, post-AIDS-diagnosis survival rate is about 9%, and the five-year survival rate about 3% (pp. 24-26). In addition, the period of HIV infection prior to AIDS diagnosis is estimated to be up to 10 years. Yet the tone of most AIDS reporting has been so utterly fatalistic that Callen refers to it as "the propaganda of hopelessness" (p. 53).

Callen relates his own story, and interviews 13 other long-term survivors. He concludes that the qualities that are characteristic of long-term survivors of AIDS are: "grit," hope, pragmatism, optimism, skepticism, being opinionated, and being passionately
committed to living. For example, one man, when asked what he did to heal himself, answered "Believe in the possibility, first of all...." (p. 85). Another said, "Each one of us has his own recipe for living. All I can talk about is me" (p. 99). Still another stated simply, "I'm alive...because I chose to be alive. I really want to discover what all the other things are that I'm here to do" (p. 144). Callen concluded, "There are as many different ways to survive AIDS as there are survivors. What stood out from the interviews was an ineffable quality of joie de vivre....These people didn't just believe that life was worth living--they all said...life was worth celebrating, and they were each busy doing precisely that" (p. 183).

**Qualitative Research on Living with AIDS**

The first studies to be addressed in this section echo Callen's (1990) findings. Allan (1990), a nurse, studied "self-care practices" of seropositive gay men, and identified "focusing on living, not dying" as a central theme (p. 56). From interviews with 11 HIV positive gay men, Allan gleaned 51 specific self-care behaviors. Among these were "keep stress low," "meditate," "increase vegetables," and life-style changes such as exercise and decreasing alcohol (p. 60). "Focusing on living, not dying," is one of a number of the practices that reflect a similar theme, such as, "stay busy," "live each day to the fullest," "find a reason to live," and "establish priorities for living" (p. 60).

Hall (1990) studied "the struggle to maintain hope" for 11 men diagnosed with HIV infection. She reports that "Although all the informants experienced definite periods of shock, anger, and giving up hope for the future, with the exception of only one of the 11 men, they all regained a measure of hope..." (p. 181). Some initiated new projects, such as reestablishing old relationships or returning to school. Hall writes, "Even people in the late stages of HIV disease do not want to use up the rest of their lives...coping with illness and preparing for death. Like everyone else, they want to live for as long as possible and not be set aside from the living" (pp. 182-183). One informant did not appear to regain hope in the same way as the others. "His partner had died of AIDS, and he said that he could not wait to join him" (p. 183). Hall, who was with the man when he died, writes "I
did not sense in him any reluctance to die...[I] think he was very settled about his death..." (p. 183). She concluded that "it is just as important to have hope in the hour before one's death as it is to have hope in the other stages of one's life" (p. 183).

Geiss, Fuller, and Rush (1986) investigated stressors and counseling needs of lovers of persons with AIDS who had died. They identified stigma, changing rules of infection control, and rejection by their "families" as stressors. No explicit definition of "family" is given, but the differentiation of "lovers" and "family" would seem to indicate a conventional view, differentiating the lover from the family. Klein and Fletcher (1986) studied a grief recovery group of 32 gay men, most of whom were grieving AIDS-related deaths. They found that the men often spoke of the difficulties involved when they were de facto the only "real" family of the deceased, yet were not acknowledged as such by law, nor by health care professionals, nor by the birth families of the deceased in relation to funeral plans or estate settlements.

Greif and Porembski (1988) interviewed 11 "significant others" of persons with AIDS who had died, including parents, friends, lovers, and siblings. The study was guided by the question, "[W]hat helped and hindered the significant other's coping and which significant others were most at risk emotionally[?]" (p. 261). "What helped" and "what hindered" were both found mainly in the ways that others interacted with the respondents. Among the hindering influences were fear that friends would stop seeing the respondents and reluctance to tell friends about the significant other having AIDS (p. 261). The way the person with AIDS was with the illness "helped" or "hindered" the significant others, described by the researchers as either having "a good attitude" or "not coping well." Another hindering factor was that, while lovers were often the primary caregivers, parents often assumed decision-making authority. Few of the respondents named health-care professionals as helping. Respondents complained that diagnoses and prognoses were given to them without hope, as a "death sentence" (p. 262). The researchers interpreted this complaint as frustration on the part of the respondents with their inability to use "denial" (p. 262). The study provides evidence that close others are intimately involved
with the grieving process when a person has AIDS, and that these interpersonal relationships influence the way the grieving unfolds.

Brown & Powell-Cope (1991) described "the experience of AIDS family caregiving." Their sample consisted of 53 "family caregivers," 32% of whom were gay lovers, 43% of whom were friends, and 26% were related by birth or marriage. The family caregivers were asked, "What has it been like for you living with and taking care of someone with AIDS?" (p. 339). "Uncertainty" was identified as the basic process and "transitions through uncertainty" as the "core category" of AIDS family caregiving (p. 340). The uncertainty theme was linked to loss and dying, interpersonal relationships, and other issues. The researchers stated that "widespread intolerance of nontraditional family compositions undermined the ability to maintain relationships" (p. 340). Uncertainty about loss and dying was described as being told such things as, "He might die tonight, he might die in six months" (p. 342). Uncertainty about interpersonal relationships centered on whether or not to continue in the role of caregiver with the tremendous day-to-day difficulties and awareness of impending death (p. 343). "However, many caregivers did not recall consciously choosing to become a caregiver, and instead naturally assumed the role given the nature of their relationship" (p. 343).

O'Brien (1992) is currently heading a longitudinal, mixed-method study of the "coping response in HIV infection" with an initial sample of 133 gay men. Some qualitative data from the study have been published in book form as Living with HIV: Experiment in Courage (O'Brien, 1992). Although the study was designed primarily as a quantitative study, utilizing no fewer than 11 formal instruments, O’Brien's book focuses on the participants' descriptions of their experiences, which are vivid and eloquent, although the excerpts provided are brief. Themes emerging from the qualitative data include "the importance of relationships with significant others...needing them to know; being pressed for time, regarding uncertainty of prognosis; modification of long-term goals or stopping to smell the roses; and turning to religious faith for solace and support...." (p. 205). O'Brien interprets the data in relation to various mid-range theories within an
adaptation (stress-coping) paradigm. The attempted blending of quantitative and qualitative approaches results in a peculiar dissonance, as the author vacillates between objective appraisal and subjective reports. For example, a chapter entitled "The Survivors: A Typology of Coping Styles in Living with HIV" begins with an eloquent statement about the courage of "choosing to live" with life-threatening illness. The centerpiece of the chapter, however, is the "typology" of five coping styles as objectively appraised, including, among other variables, "compliance behavior" (p. 164). The relation between the experiential data and the empirical-analytical theory base is very unclear, especially in the absence of the quantitative data. The importance of attempting to understand humanly lived experience, however, is evidenced by O'Brien's production of a full-length book focusing on "courage" from a study in which the theoretical framework does not encompass (or even acknowledge) such a phenomenon.

Nokes and Carver (1991), in a purely qualitative study, investigated "the meaning of living with AIDS," guided by Parse's theory, although they did not use her research method. The researchers interviewed fourteen persons diagnosed with AIDS. The study was guided by a theoretical structure developed by Parse, "originating is a manifestation of enabling-limiting valuing," which can be explicated as "creating anew shows one's cherished beliefs and leads in a directional movement" (Parse, 1987a, p. 170). The researchers investigated, specifically, the "essence" of living with AIDS, the opportunities and limitations in living with AIDS, and the possibilities unfolding while living with AIDS (Nokes & Carver, 1991, p. 176). Eleven themes were identified and described in detail in the research report. These themes were interpreted in light of the theory, yielding three statements representing the core ideas. (1) "An abrupt shift in patterns of becoming gives rise to changing priorities." The subjects "experienced multiple losses including friendships, family, employment, and hope for a long life," giving rise to reconsiderations of drug use, sexual practices, and/or personal relationships. (2) "Fluctuating possibilities arise in the unpredictability of being with and away from close others." Participants spoke about their children and significant others, sometimes expressing "hope for reconciliation"
from estranged family members. (3) "Different hopes and dreams surface from the insights of suffering." Participants spoke of their wishes for spiritual strength, "to see all my kids married," or "to accept things around me more clearly" (pp. 177-178). The three propositional statements were then fused in one statement: "Living with AIDS is an abrupt shift in patterns of becoming, sparked by unpredictable changing relationships with others as different hopes and dreams unfold amidst suffering" (p. 177). This study shows several ways that losses are experienced by persons living with AIDS and that families figure significantly in the experience. The proposed investigation will further illuminate the meaning of loss and grieving in the context of family relationships.

Beauchamp (1990) investigated "the lived experience of struggling with making a decision in a critical life situation" for persons with HIV," guided by Parse's (1981) theory and using her method. Through "dialogical engagement" (Parse, 1987a) with ten persons living with HIV, Beauchamp (1990) uncovered the structure of the lived experience:

Struggling to make a decision in a critical life situation is affirming self through confronting uncertainty in moving toward the not-yet, while risking disclosing self with important others, as vacillating between options unfolds through envisioning what might be in light of what was and is (p. 73).

The structure was interpreted with concepts from the theory as "powering originating through the revealing-concealing of imaging" (p. 74). "Powering originating" refers to the participants' "affirming self through confronting the pushing-resisting of uncertainty in moving toward the not-yet" (p. 85). The themes of struggle and uncertainty, evident in other studies related to AIDS, surfaced in this study also, with the difference that the findings were integrated into Parse's (1981, 1987a) nursing perspective. Powering is affirming self in light of the possibility of nonbeing (Parse, 1981, pp. 58-59). Originating is living patterns of conformity-nonconformity by choosing ways of becoming while outcomes are never completely certain (Parse, 1981, pp. 59-62). Revealing-concealing reflects the participants' descriptions of "sharing self with self and important others" (Beauchamp, 1990, p. 82). This refers to telling and not telling others about the HIV as well as disclosing and not disclosing self with self in living with HIV from day to day.
Imaging refers to the participants' descriptions of picturing possibilities in the process of making a decision, "vaccillating between options" (p. 73).

Beauchamp (1990) concluded that Parse's method "was found to be an appropriate and adequate mode of scientific rigor for the study of lived experiences" (p. 92), and that his study, using the method, "expands nursing science in that the focus of the study is grounded in the discipline of nursing" (p. 92). These considerations are important in light of the results of the review of literature, in which conventional scientific approaches research were found to shed little light on the lived experiences of persons living with AIDS, and most of the nursing studies were found to be unconnected with nursing's unique theory base.

Summary

Review of the literature reveals that grieving is a complex, personally meaningful experience that involves interrelating with close others. A number of scholars have recognized the centrality of meaning in the grieving process. The interface of grieving and patterns of family interrelating has not been explored extensively and is not well understood. The preponderance of the scientific literature on grieving is highly normative in approach, and does not elucidate the lived experience. There are two approaches to the study of change and transition, one that emphasizes equilibrium and stability, and one that emphasizes transforming and becoming, which is consistent with the researcher's perspective. The existential-phenomenological perspective was shown to describe human experience with greater depth of meaning than the conventional scientific approach. Parse's human becoming theory, which guided this study, incorporates insights from some of these sources into a coherent theory specific to nursing. The nursing literature was found to rely primarily on borrowed theory in quantitative studies related to death and in clinical applications to other losses. Qualitative research on grieving has generated findings highlighting common themes in the grieving experience, while few studies were found to integrate findings with nursing theory, which is a major strength of this study.

The preponderance of studies on family phenomena were found to be restricted by
the assumption of the nuclear family as the norm. Prevalent ideas in family science, such as family functioning and roles, were found to be restrictive in terms of understanding humanly lived experience. The mainstream of family science, which is objectivist, predictive, and quantitatively oriented, has been ineffective in illuminating common family phenomena as they are lived. The notion of the family as the "unit of analysis," if construed to preclude inquiry into individual experience, was found to be inappropriate for the study of lived experience.

With regard to living with AIDS, the majority of the research has been quantitative or factor-isolating. Autobiographical sources and qualitative studies have shown that living with AIDS involves living with multiple losses in close interrelationships with others. For persons and families living with AIDS, living with multiple losses while creating patterns of relating based on value priorities often surfaces a focus on living, rather than dying. Yet neither grieving for multiple losses nor patterns of family interrelating in grieving are well understood. The review of literature clarified the central goal of the study, to enhance understanding of the meaning of grieving for families living with AIDS.
CHAPTER III

METHODOLOGY

The mode of inquiry used in this study was Parse's (1987a, 1990b) research method. This is a phenomenological method developed by Parse in congruence with the philosophy and principles of her theory of nursing. In this chapter, the background of the method, the specific processes of the method as described by Parse (1987a, 1990b), and the design for this study are presented.

Background of the Method

Parse's research method is specific to nursing, and was invented for research guided by the theory of human becoming (Parse, 1981, 1987a, 1990b, 1992). While the method is similar to other phenomenological methods, it is distinct from all other methods in its theoretical underpinnings and its specific processes. This attribute of the method is significant for the development of nursing science. The development of distinct modes of inquiry is characteristic of a mature scholarly discipline. Until Parse authored her research methodology in 1987, nursing had no research methods of its own, and relied on borrowed methods from other sciences. It is the responsibility of nursing scholars to hone the methods that are specific to nursing. One of the aims of this study was to make a contribution in this area by expanding the use of Parse's method.

Assumptions

Key assumptions underpinning Parse's research methodology are as follows. (1) "Descriptions of lived experiences enhance knowledge of human becoming. Individuals and families can describe their own experiences in ways that shed light on the meaning of health" (Parse, 1992, p. 41). (2) "Researcher-participant dialogical engagement uncovers the meaning of phenomena as humanly lived. The researcher in true presence with the participant can elicit authentic information about lived experiences" (p. 41). (3) "The researcher, through inventing, abiding with logic, and adhering to semantic
consistency during the...[processes of the method], creates structures of lived experiences and weaves the structure with the theory in ways that enhance the knowledge base of nursing" (p. 41). These assumptions make explicit the beliefs about nursing inquiry into lived experiences of health that underpin the use of the method.

Purpose of the Method and Entities for Study

The purpose of the research method is to enhance understanding of humanly lived experiences of health, and to integrate this knowledge with the human becoming theory (Parse, 1987a, 1990b, 1992). Entities for study with the method are universal lived experiences related to health, as health is defined in the theory; that is, experiences of becoming, relating value priorities, and quality of life as it is humanly lived (Parse, 1987a, p. 174). The phenomenon central to this study, grieving, is such a universal health experience.

Prior Research Using the Method

Prior to this study, about a dozen studies had been completed using Parse's method (for example, Beauchamp, 1990; Cody, 1991; Parse, 1990b; Mitchell, 1990a; Smith, 1990a, 1990b). Prior to the development of the method, at least twenty qualitative studies guided by Parse's theory were completed (for example, six studies in Parse et al., 1985; Banonis, 1989; Jonas, 1989; Santopinto, 1989; Wondolowski & Davis, 1991). The method has been found to be a valuable mode of inquiry for investigating the meaning of health experiences. Findings have furthered understanding of the lived experience of hope (Parse, 1990b), struggling with making a decision in a critical life situation (Beauchamp, 1990), grieving (Cody, 1991), taking life day-by-day (Mitchell, 1990a), struggling through a difficult time (Smith, 1990b), and health among the oldest old (Wondolowski & Davis, 1991), among others.

Description of the Method

The specific processes of the method are (1) participant selection, (2) dialogical engagement, (3) extraction-synthesis, and (4) heuristic interpretation (Parse, 1987a). Each
process will be described according to Parse's original description, followed by a
description of the process as actualized in this study.

Participant Selection

An assumption of this method is that persons who agree to participate in a study
about a lived experience can provide authentic descriptions of their own experiences (Parse,
1987a, 1992). Such direct personal descriptions are considered to be the best source of
knowledge about humanly lived experience. "Participant selection is carefully done"
(Parse, 1987a, p. 175). This means that prospective participants are persons who "can
articulate the meaning of an experience" in discussion with the researcher (Parse, 1992, p.
41). The number of participants is not predetermined, but is deemed sufficient when
continued participant engagements result in redundancy; that is, when no new themes
emerge from additional engagements.

Study Design: Families as Participants

Families living with AIDS were invited to participate in the study through
HIV/AIDS-related service agencies and through advertising in two large-circulation
newspapers, two smaller gay-oriented newspapers, and one "alternative" newspaper. Staff
members in the service agencies informed clients about the the study and provided clients
with a printed invitation to participate in the study. The study was also announced in
intramural communiques within several of the service agencies, some of which served
multiple counties and larger geographical areas. The majority of the contacts between the
researcher and service agencies were unproductive, with 0 responses, for reasons that are
unknown to the researcher. Responses to the invitation from one agency evidenced a
"snow-ball" effect, eventuating in the participation of five families. The remaining five
families responded to the invitations printed in the newspapers. A number of individuals
(approximately 10) responded to the invitations, but were unable or unwilling to speak with
the researcher with any other family members.

The definition of family as "the others with whom one is closely connected" (Parse,
1981, p. 81) was shared with prospective participants. All prospective participants who
met the selection criteria and were able and willing to speak with the researcher with at least one other family members were accepted into the study. It was made clear to participants that the discussion of grieving need not relate to death or to AIDS, but to whatever their own actual experiences with grieving were.

The selection criteria for participants (who consented individually) were: (a) self-identification as "living with AIDS," by at least one person per family; (b) the ability to speak English, for all participants; and (c) willingness to participate in a researcher-participant discussion of grieving and to have the discussion videotaped. The person who contacted the researcher was asked to invite his or her entire family to participate in the study. The willingness of persons to participate in this explicitly family-centered study was accepted as evidence of a familial relationship. Initially, a discussion was to be scheduled if the person contacting the researcher affirmed that the "most important" family members could be present for the discussion. After very few persons responded to widely distributed invitations, this was amended so that callers were asked that at least one other "close family member" participate with them in the discussion. Eight of the ten families entered into the study after this point. Provision was made for the participation of minors in the study with the consent of and in the presence of a parent or guardian (see Informed Consent Form, Appendix). One minor participated in the study.

The researcher described the study to participants by telephone, and scheduled researcher-participant discussions with those who agreed to be in the study. The setting for the discussion was chosen by the participants. For clarity and ease of reading, the participant families are described prior to the findings for each family, in Chapter IV. The ten families were comprised of: three gay male couples; a husband and wife; a couple (woman and man) with the woman's daughter; two sets of companions ("partners" not sexually involved); two sisters (twins); a gay man and his mother; and a woman, her lover (a woman), and her brother.
Dialogical Engagement

In the next process of Parse's method, participants discuss their lived experiences in a dialogue with the researcher. "Dialogical engagement" is a specified form of researcher-participant discussion in which the researcher is present with the participant(s) as the description of the lived experience unfolds (Parse, 1987a, p. 176). The researcher remains centered and open to the meaning of the lived experience for the participant(s) throughout the dialogical engagement. Parse describes dialogical engagement as follows.

This is an intersubjective "being with," in which researcher and participant live the I-thou process as they move through an unstructured discussion about the lived experience. The I-thou process is one in which the researcher is truly present to the participant in discussion as the remembered, the now and the not-yet unfold all at once (Parse, 1987a, p. 176).

Dialogical engagement is "not an interview but rather a true presence" (Parse, 1992, p. 41). The researcher guides the discussion only to the extent that the focus remains on the experiences of the person or family related to the phenomenon under study. The discussion is taped and transcribed for the extraction-synthesis process. Parse (1990b, p.11) has suggested that the discussion be videotaped when possible.

Study Design: Engagement with Families, Recorded on Videotape

In this family-centered study, the dialogical engagements involved at least two participants other than the researcher. Each dialogical engagement began with the researcher asking participants to relate their experiences of grieving. Only if the discussion clearly strayed from the topic of the lived experience of grieving did the researcher re-direct the conversation, by posing a simple question such as, "How does that relate to the grieving?" Throughout the conversation, the researcher remained centered on the descriptions offered by the participants. All questions asked by the researcher were open-ended, such as, "What was most important to you in that situation?" or "Could you tell me more about that?" The discussion concluded when participants indicated that they had described their experiences of grieving completely.

The discussions were videotaped, as suggested by Parse (1990b). A camera
operator was used for five sessions, and for five sessions a stationary camcorder on auto-
focus was used. It was believed that videotaping the discussions would enhance the
researcher's immersion in the discussion during the processes of extraction-synthesis.
Discussions were also audiotaped for transcription. The discussions were recorded in

Extraction-Synthesis

In this process of the method, the researcher "dwell with" each description, while
immersed in the dialogue through listening to and viewing (if videotaped) the tapes of the
discussions and reading the transcripts. "Dwelling with" means that the researcher centers
on the meaning of the lived experience through long and thoughtful "dialoguing" with the
descriptions (Parse, 1987a, pp. 176-177). Through intuiting from the entire dialogical
engagement, the researcher extracts the essences of the lived experience. "An extracted
essence is a complete expression of a core idea described by the participant" (Parse, 1987a,
p. 176). Meaning is revealed in human relationships not only through speech, but through
facial expression, touch, gestures, moving toward or away from others, and silence (Parse,
1987). It was believed that videotaping the discussions would be useful in the researcher's
immersion in the dialogue and thus in staying true to the meaning of the experience as
described by the families. The extracted essences are written in the language of the
participants.

Through the process of synthesizing essences, the researcher expresses the core
idea of the extracted essences on a more abstract level, working toward a conceptualization
of the phenomenon in the language of nursing science. A synthesized essence takes the
description to a higher level of abstraction while abiding with the essence of the original
description. The researcher then formulates a proposition, which captures the participant's
experience in "a nondirectional statement conceptualized by the researcher" (Parse, 1987a,
p. 177). The proposition represents the essential structure of the lived experience for one
participant. "The findings of the study are in the essences of the propositions" (p. 177).

Core concepts of the phenomenon are then extracted from all of the propositions.
An extracted concept is one which represents a recurring theme in all of the descriptions. A structure of the lived experience is then synthesized from the extracted core concepts. "Structure is the paradoxical living of the remembered, the now moment and the not-yet all at once" (Parse, 1987a, p. 175). The written structure is an abstract statement interrelating the core concepts, representing the "living" structure. The structure of the lived experience as evolved answers the research question.

There were no essential differences between extraction-synthesis as described by Parse and the actual process in this study. The multiplicity of perspectives expressed in each family dialogue, however, did introduce new levels of complexity into the process. Initial attempts to express participants' meanings with only a few words seemed to blur the distinctly different views of individual participants, and to lack the richness and vigor of the participants' original descriptions of their grieving experiences, which had been described in vivid detail. After consulting with Rosemarie Parse (personal communication, Sept. 1, 1992), it was decided to present an extracted narrative for each family, preceding the extracted essences. The extracted narrative, written in the language of the participants, discloses the richness and vigor of the dialogue and enhances the readability of the extracted essences.

Heuristic Interpretation

The final process of the method, heuristic interpretation, connects the findings explicitly to the theory of human becoming and interprets the structure of the lived experience in the language of the theory. "Structural integration is connecting the proposition and the structure of the theory" (Parse, 1987a, p. 177). This means expressing the meaning of the phenomenon at a higher level of abstraction, in a statement that articulates the nursing perspective of the phenomenon. "Conceptual interpretation" further specifies the structure of the lived experience with the concepts of the human becoming theory, "leading to a specific theoretical structure from the principles" (p. 177). There were no variations of the method related to heuristic interpretation.
Rigor and Credibility

Parse's research methodology is a formal method as described by Kaplan (1964), and specific assumptions, processes, and details of the method have been made explicit (Parse, 1987a, 1990b, 1992). A number of studies in which the method was used, as highlighted above, have uncovered the meaning of lived experiences of health and connected the findings to nursing's extant theory base.

Five overall standards for qualitative research have been proposed by Burns (1989, p. 44). These are descriptive vividness, methodological congruence, analytic preciseness, theoretical connectedness, and heuristic relevance. These criteria will be used to address the issues of rigor and credibility more specifically.

(1) Descriptive vividness. The dialogical engagements elicited detailed and, in some cases, lengthy descriptions of grieving, which are reflected in the first level of extraction-synthesis, extracted essences, written in the participants' language. Narratives of the descriptions have been included to enhance clarity and readability. At the level of synthesized essences the researcher's intent is to be true to the meaning of the original description, in a more abstract statement reflecting the researcher's nursing perspective and way of understanding. This allows readers to re-trace the progression from the participants' descriptions to the findings and the theoretical interpretation. Levine (1988) stated that Parse "uses the language of passion and compassion" and "recreates the reality of the human experience...the exaltation and anguish of a lived life" (p. 185).

(2) Methodological congruence. In this study, the nature of the phenomenon studied, the theoretical perspective, the specific aims of the study, and the purpose and processes of the method to be used were all fitting. The method is uniquely appropriate for this investigation of the meaning of grieving, for families living with AIDS. There is no other method which attends more closely to the quality and meaning of lived experience.

(3) Analytic preciseness. Parse (1987a, p. 176) clearly states that adherence to logic and semantic consistency is essential to the method. The "audit trail" (Lincoln & Guba, 1985) of decisions made by the researcher is easily discernable in this completed
study, since every level of extraction-synthesis is included. Parse's method and this study specifically are significantly more conceptually oriented than the preponderance of qualitative research in nursing, as evidenced by the review of literature. Whether or not a reader agrees with the interpretation in this study, the basis for the interpretation is readily apparent in the participants' descriptions and in the theory. Conversely, the research also offers the opportunity to expand and specify the theory.

(4) Theoretical connectedness. This study used the method developed by Parse from her theory of human becoming, which guided the study, and the findings were integrated with the theory through heuristic interpretation. The internal consistency and logical coherence of theory and methodology guiding this study are explicitly stated and open to critique.

(5) Heuristic relevance. Parse's research method is unique among available methods in that it coheres with a formal theory of nursing that is currently in use in research and practice. The value for nursing in this linkage is that phenomena may be understood within the context of a theory of nursing rather than as they are understood by different sciences with different goals. Nurses often encounter persons and families experiencing grief. By advancing nursing knowledge of the phenomenon of grieving in the context of Parse's theory, the study offers an opportunity for enhanced understanding of lived experiences in these practice situations. The findings also go beyond the extant theory and offer opportunities for further research to specify greater understanding of lived experiences related to loss and grieving.

Ethical Considerations

The proposal for this study was approved by the Internal Review Board (IRB) of the University of South Carolina and by the IRB, equivalent, or chief executive officer of all agencies used in the course of the study. Care was taken to provide for the comfort and confidentiality of all participants throughout the research process. Participant selection was based on voluntary contacts with the researcher by persons self-identified as living with AIDS or persons in their families. All participants were informed verbally and in writing of
the nature and purpose of the study and of their right to end their participation and withdraw consent at any time. All participants signed a consent form (Appendix A) detailing their rights and the measures taken to protect these rights, and were given a copy of the consent. Participants were given the researcher's name, address, and telephone number, and were invited to contact the researcher at any time with regard to any concern about the study. There were no withdrawals from the study and no negative concerns about the study voiced by participants.

No documentation of medical information on the participants was made in this study other than what is freely introduced into the discussion by the participants, in which case these comments naturally appeared on the tapes. All transcriptions utilized pseudonyms for all participants and persons named by participants (with the exception of public persons), and readily identifiable details were altered to preserve confidentiality. No one other than the researcher, his faculty advisors, and a transcriptionist had access at any time to recorded materials which might reveal a participant's identity. Three camera operators and one transcriptionist were employed for the study. These persons were known to the researcher and agreed to maintain confidentiality. Each participant family was contacted by telephone at least once to inquire as to any further thoughts, feelings, or wishes related to the discussion or the study. Although all participants had in their possession a copy of the signed consent form, with the researcher's phone number and an invitation to call at any time should they have any concerns about the study, no such calls were received.
CHAPTER IV
PRESENTATION OF FINDINGS

This study evolved through dialogical engagements with ten participant families. The discussions ranged in length from 20 minutes to 3 hours, and were recorded in a variety of settings, two in the researcher's home, three in an HIV/AIDS service agency, and five in the participants' homes. The discussions were video- and audiotaped, then transcribed verbatim, excepting alterations to preserve confidentiality. The transcripts ranged in length from 6 to 34 pages, totalling 173 single-spaced typed pages. The researcher dwelled with the experience of the dialogical engagement, the transcript, the videotape, and the audiotape, during the processes of extraction-synthesis with each participant family's description of grieving.

Extraction-Synthesis

During the extraction-synthesis process, the plurality of views expressed and the complexity of the descriptions presented the researcher with the challenge of distilling and concentrating a great deal of complex description into the concise form of extracted essences. In order to enhance clarity and readability, extracted narratives for each family are presented in this chapter preceding the extracted essences. Following each narrative are the extracted essences, the synthesized essences, and the propositions for each family. The extracted core concepts and the synthesized structure drawn from all participant descriptions follow, and the heuristic interpretation concludes this chapter.

The findings for each family are arranged in the following format. (1) Description of the family, (2) extracted narrative, which ends with a page break, and (3) the extracted essences, synthesized essences, and proposition for the family.
Family Number 1: Rob and Jeff

Rob, age 23, was told his HIV test was positive three years ago, when his relationship with Jeff, also age 23, began. Jeff's HIV test has been negative. They live with Jeff's mother, and Jeff helps to care for his grandfather. Rob's mother is dead, and both men are estranged from their fathers. They elected to speak with the researcher in the researcher's home, and spoke for 1 hour and 15 minutes.

Extracted Narrative

Rob and Jeff see living with HIV as the loss of everything all at once, including their hopes and dreams. Though there are things they still can do, it is hard "to be confined to a certain way of life" at a young age. They lost many friends, which hurts Rob especially. The loss of his father hurt and angered Rob; he doesn't think about it much but is trying to salvage the relationship. He is faced with giving up his way of life and involvements like smoking and hanging out with "Dead-heads" that are comfortable even though they may shorten his life. When Rob's dying became real for Jeff, he "cried for three hours and couldn't stop." The faith in people and in God that he had worked for has been taken away, and life is hell-like, a "constant battle to get some faith" in something. Still they say they are lucky, since they are together, and Rob has yet to experience the worst of AIDS.

What's most important is staying together, and they are looking toward a ceremony of holy union. For Jeff it's more important how he feels about Rob than what others think. They hope to "prove people wrong" about them by using their experience to help others, to have something affirming to show for being together. Jeff wants them "to really live together, and if that means just one more day, to make the most of it." Rob agrees, but while Jeff has changed his "torrid" lifestyle and is now "prudish," Rob still enjoys the old ways. Jeff knows he can't project his wishes on Rob. He feels stretched thin, and wants Rob to "live in a bubble" to safeguard his health; it would be okay since he would be in there with him. For Rob the boredom and inactivity would be "hell." Though he knows he should do it, he doesn't know which is worse, to live in a bubble or lose some years and enjoy life while he has the chance. The arguments can be rough and depressing, but
they're working for "progress not perfection." Jeff relentlessly looks for new sources of support, but both find that few people understand their relationship or share their beliefs. They discuss possible what to do, and with whom, with different opinions on which way to go. Rob plans to go along with the changes Jeff wants, but isn't sure he can.

It's hard not knowing about tomorrow. For Rob, there is "so much to do, so little time" that it's hard to decide. He isn't sure what he's going to do next except find a new doctor. Jeff feels they have to do everything now. They wanted to go to Europe, so Rob could experience some of Jeff's background, but they're not sure they can afford it now, or how Rob would do with the touring since he tires easily. He sees himself with Jeff many years from now "sitting on the back porch watching the grass grow," though he knows he may not live to experience it. When friends die with AIDS, it scares the hell out of him, and when they survive a bout with illness, it gives him hope.
Family Number 1: Rob and Jeff

**Extracted Essences (Participants' Language)**

1. Facing overwhelming loss, giving up familiar ways, and Rob's possible death prompts, for Rob, a hurtful striving to hold on to small comforts and, for Jeff, a hell-like battle to regain faith, while they feel fortunate for what they still have.

2. Being together and living each day fully are important to Rob and Jeff, and they hope to affirm their relationship more demonstrably, contradicting others' disapproval. Jeff busily seeks safety and support, while Rob, not wanting to give up enjoyment for a longer life, isn't sure he can change.

3. With tomorrow unknown, deciding what to do is hard for Rob, while Jeff wants to do everything now. Rob's fatigue, possible death, and other losses render their plans unsure, while awareness of what could happen sparks fear and hope.

**Synthesized Essences (Researcher's Language)**

1. Anguished struggling toward a constricting-expanding not-yet surfaces gratitude for what is and what is not.

2. Shared and unshared priorities fortify commitment and clarify personal perspectives while distancing-relating surfaces aloneness with togetherness.

3. Possibilities envisioned with ambiguity pulse with ease-unease.

**Proposition**

For Rob and Jeff grieving is

anguished struggling toward a constricting-expanding not-yet with gratitude for what is and what is not
while clarifying personal priorities fortifies commitment as distancing-relating surfaces aloneness with togetherness as possibilities envisioned with ambiguity pulse with ease-unease.
Family Number 2: Alice, Joe, and Hannah

Alice, age 43, received a diagnosis of AIDS after experiencing a year-long complicated illness. Alice lives with Joe, about the same age, her daughter, Hannah, 13, and a son, 8, who did not participate in the discussion. An adult son lives in another state. Joe also has a son, who lives with Joe's ex-wife in another state. They elected to speak with the researcher in the researcher's home, and spoke for 1 hour and 35 minutes.

Extracted Narrative

During her illness, Alice felt life leaving her; she had lost her self; she felt empty, unable to share, and hopeless. She was ready to die and "death was warm and fuzzy." Joe felt anger and helplessness that nothing could relieve her suffering, but didn't want to believe she was dying. Not knowing why this happened, Hannah was angry. She didn't want to leave her Mom for fear that she would die. Alice was angry when she got better; it was like "being played with by God." Now she misses the way the family used to be, but with hope renewed, she realizes that today is what matters. She is grateful for every moment she can share with her family; it is not always pleasant, but comfortable and good. Though she may not be able to share with her grandchildren, she has immortality through her children, who will. Joe appreciates day-to-day things and special happenings more, but worries whether he'll be there to guide his kids and watch them mature. Hannah is calmer through prayer, thinks about her feelings more, and realizes it's easier to live with the HIV one day at a time. She's not sure of anything, knowing that anybody could get sick and die, but says "I'm mostly afraid for my Mom."

Alice had felt like a burden and not a mother to her children, knowing "it was devastating" for them; but with no energy there was nothing she could do. Joe and Hannah cared for her. Joe would never have walked away; "in a situation like that you need help." Alice couldn't relieve their hurt, which was painful for her. But this is something she has to do all alone. The others are not in the same mode, don't feel as strongly as she does. At times a TV show or baby's picture will bring her to sudden tears and anger, and they just back off. She told Joe she was mad that he didn't have AIDS, but worries constantly that she has given it to him. He doesn't deal much with pain; his only emotion is anger. Alice
says he feels nothing while she feels everything, which makes her angry and sorry for him for keeping it all inside. Alice worries that Hannah doesn't "say how she feels in her gut." Hannah tries to do everything right so her Mom will be happy, but she forgets, and then she feels worse. She only thinks about it a few minutes at a time unless she has to. They tease and joke even in talk of conflicts and dying. In the short time they have on earth, it's best to laugh; it doesn't hurt as much if you do.

Alice was going to see her grandchild by September no matter what; now she has to say, "If there's anyway possible." She doesn't plan years ahead anymore, doesn't put her dreams into then, but lives them now. Joe says they "just take small bites of the future and nibble on them, you can't take a big bite not knowing if you'll be there to complete it." AIDS took away freedom of expression and action from Alice and everyone around her. She lives with changes in activity and diet, and they are all cautious. But that changes the focus from dying of AIDS to living with HIV. For Joe, it was easier to adjust once they knew what the long illness was. Alice misses the energy to do the things she wants to do; at times she cries because she can't be what she hopes to be. But with attention to what's most important there is "more freedom and unburdening" than she's ever experienced. Once she recognized the loss, she turned it around and became a better person. When Alice found out she had AIDS she felt like, "I want my Mama!" Closing her eyes she can be in mother's lap even now. She wants to know that Hannah has that same feeling when she's gone, and strives to make memories that will last a long time.
Family Number 2: Alice, Joe, and Hannah

Extracted Essences (Participants' Language)

1. Alice felt life leaving her, hopeless and empty, and welcomed death, while Joe felt helpless and got angry and Hannah lived in fear. With hope renewed, though Alice misses the way things were, she is grateful to share today. Joe appreciates today and worries about his kids' future, while Hannah quietly explores her feelings, still fearful for her Mom.

2. Alice feels everything deeply and is pained by Joe and Hannah's hurt, while they are less intense and sometimes back off. Joe is committed to stay, though he doesn't show emotions; Hannah doesn't say how she feels, but tries to make Alice happy. They tease and laugh a lot so it doesn't hurt as much.

3. Alice has to live her dreams now and plan on an if-possible basis. They have lost some freedom in living with HIV, but that shifted the focus from dying of AIDS. Alice cries over unrealizable hopes, yet attention to what's important brings freedom and unburdening. Comforted by remembering her mother, she strives to make lasting memories with her daughter.

Synthesized Essences (Researcher's Language)

1. Struggling together through harrowing personal agony confirms endearment.

2. Bearing witness uncoversaloneness with togetherness in pulses of divulging-hiding and ease-unease.

3. Opportunities and limitations emerging with ambiguity evolve new perspectives.

Proposition:

For Alice, Joe, and Hannah, grieving is

struggling together through harrowing personal agony
confirming endearment
as bearing witness uncoversaloneness with togetherness
in pulses of divulging-hiding and ease-unease
while opportunities and limitations emerging with ambiguity
evolve new perspectives.
Family Number 3: Beryl and Cheryl

Beryl and Cheryl are twins. Beryl found out three years ago that her HIV test was positive. Beryl lives in a multigenerational household with her grandmother and several children. Cheryl lives elsewhere with her husband and child. Their age was not given, but they appear to be about 30 years old. They elected to speak with the researcher in Beryl's home, where there was much activity. They spoke for 20 minutes.

Extracted Narrative

Beryl has lost hope, her best friend, and respect for herself. She is afraid. She doesn't want to die, and worries about leaving her children. She tries not to think about it, doesn't talk about it much, but it still comes back to her. Cheryl is losing her only sister; it hit her hard; she loves Beryl and doesn't want her to leave. She doesn't know what she is going to do without her, just that she will be lonely. Beryl tells her to play it safe, not wanting her to "go down this lonely road." So that she won't suffer and her children will be taken care of, Beryl wrote a living will and gave it to her family. It took her a month to get the nerve to do it, but she knew she had to. Now her grandmother will care for her kids when she's gone and "everything will be wonderful." Making the will gave her a scary feeling it was time to die. But life is too precious to think about dying. She's going to keep enjoying herself and taking care of her family. She can't let HIV put her down. When it's time for Beryl to die Cheryl sees herself there, guiding her, holding her hand, talking with her, and praying for her.

For Beryl, her family doesn't talk about her HIV or dying. It's hard for her to talk to them about it, so she talks about it with her support group and feels better. Cheryl says sometimes they tell one another how they feel, cry together, and hold hands, but not recently. Cheryl tearfully tells Beryl she loves her and hates that she may die soon. Beryl didn't know Cheryl felt that way since she never told her, and she really appreciates it. Cheryl says she has felt that way all along. For Cheryl, daily life in the family is the same as before, but for Beryl it has changed; her family always used to ask her how she was doing, and now they don't. When she grieves she goes to her room, shuts the door, and cries to herself. It hurts that they don't cry with her. She needs them to tell her how
they're feeling, but she isn't going to push them, she's sure someday they'll come to her and tell her how they feel. Beryl felt better when her mother shed just a few tears because it let her know her mother had feelings about her, but Cheryl worries how their mother will be when she really starts the grieving.

Cheryl doesn't want her sister to leave, but knows there's "nothing anybody can do." She is glad that Beryl is okay now and likes the times when she is happy. Cheryl doesn't want Beryl to let HIV take its toll, but to fight if she can, and enjoy life while she's here, because they don't know how much time they have. She sees how Beryl suffers, thinks about all they do, and hears her saying the things she says. Even though they're twins, she can't feel her pain; she wishes she could take some of the pain for her but she can't. She will be right there for her when she gets sick. Beryl cries with her and hugs her.
Family Number 3: Beryl and Cheryl

Extracted Essences (Participants' Language)

1. Beryl lives with immense loss, fear, and worry, but feels better knowing she won't suffer and her kids will be cared for; life and family are too precious to think about dying now; she's got to keep going. Cheryl is losing a beloved sister; she sees herself comforting Beryl when she dies, but sees only loneliness when she is gone.

2. Beryl says they don't talk about dying, while Cheryl says they share feelings and cry. Cheryl tearfully says she loves Beryl and doesn't want her to die, and Beryl appreciates that. She knows her family cares, and will wait for them to show it more, while Cheryl worries about how that will be.

3. Cheryl doesn't want her sister to give in to HIV. Not knowing how much time is left, she is glad when Beryl is happy and thinks of all they do together, but also sees her suffer. She can't take Beryl's pain on, but she says she'll be there for her, and they cry and hug.

Synthesized Essences (Researcher's Language)

1. Anticipating possibilities while abiding with imminent death fortifies intentions emerging with mutual concern.

2. The comfort-discomfort of divulging-hiding surfaces aloneness with together.

3. Bearing witness confirms endearment in the face of unwelcome change.

Proposition

For Beryl and Cheryl, grieving is

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\text{anticipating the possibles while abiding with imminent death fortifies intentions and the comfort-discomfort of divulging-hiding surfaces aloneness with togetherness as bearing witness confirms endearment.}
\]
Family Number 4: Bonita, Faye, and Eddie

Bonita, age 30, had a positive HIV test 4 years ago. She has retired from a career as a cook. She lives with her sons, age 14 and 10, and her lover, Faye. She has 22 brothers and sisters. She invited her sons to participate in the discussion, but one was not available, and one did not wish to participate. One brother, Eddie, took part in the discussion. They elected to speak with the researcher in Bonita's home, and spoke for 40 minutes.

Extracted Narrative

When Bonita found out her husband had given her HIV, she was so angry she got back on drugs, but one day got tired and went into treatment. It hurts when she can't be near her sisters' kids or her friends because they think they can get it. The worst moment in her life was when her sister stopped her niece from kissing her saying she'd catch AIDS. HIV took something away from her that she can't get back. She loved her job, and now she can't work. She wishes it could be the way it used to be. Every night she fears she isn't going to wake up. But she's "going to fight on," whatever she has to go through. She wonders where her children will be when she's gone. They say, "Mama, you're dying, you don't care about us." She doesn't want to get close to anybody, it's bad enough that her kids are going to be without her. She wants her mother to make a panel for the AIDS quilt so she will always be remembered. Faye and Eddie aren't feeling a loss. Eddie says she still has her sense of humor and is still loving and giving. Faye says it means a lot to see her laugh and smile. If they lose her body, she will still be there; they will still have the memories and love. Her twin brother will remind them of her when she's gone.

Bonita says her family supports her. When she gets discouraged her baby tells her he loves her and that keeps her going; her other son checks on her day and night; they hug and kiss her, and she feels blessed. She can call her Mom anytime just to hear her tell her she loves her, and Faye left the military to be there for Bonita and the kids. Bonita doesn't talk about having HIV or dying. She tries to keep it within herself, if she doesn't talk about it, she doesn't have to deal with it. She just "stays in a little shell all the time" because nobody knows what she's going through; they don't have it. Faye says that an
HIV-positive person feels like they're all alone; it's important to be there for them. After talking about grieving and loss with Faye and Eddie, Bonita says she can talk about it now, she can deal with the hurt.

Bonita comes and goes when she wants, but she gets tired and has to rest. She is grateful not to be in a wheelchair. It's hard for her knowing people love her and if she doesn't do this or that it might mess up her immune system and mean trips to the hospital. Though she can't correct the mistakes she made in the past, she doesn't have to make mistakes today. She avoids extra activity so she can spend time with her boys. Today she's not worried about dying, but about her babies, "that's all that matters." Faye tries to spend time with the boys and help them out. Eddie says they'll be taken care of by the family. Bonita's husband said he married her just to hurt her, but if HIV was the hurt he gave her, it didn't hurt her, it made her stronger. "You don't die from AIDS, you die by giving up," and she's not willing to give up. She doesn't know what tomorrow may bring but today she wants to live. Maybe the reason she got HIV was to get her off the streets to be a mother to her kids. She's never been glad of anything in her life but her kids, but she's glad that she's HIV-positive because she can slow down and be responsible. It's been like that for four years and every year gets better and better.
Family Number 4: Bonita, Faye, and Eddie

Extracted Essences (Participants' Language)

1. Losing friends, loved ones, and career hurt Bonita deeply, but she fights on, wishing it could be the way it used to be. Her children tell her they know she's leaving them. She wonders where they'll be when she's gone, and wants to be remembered. Faye and Eddie focus on her liveliness now and aren't feeling a loss; if they lose her body, she will still be there.

2. Bonita's family supports her; she gets constant love from her children and mother, and Faye gave up her job to be there. They don't talk about having HIV or dying; Bonita stays in a little shell because nobody knows what it's like if they don't have it. Having spoken with Faye and Eddie about loss and grieving, she says she can talk about it and deal with the hurt.

3. Though it's hard trying to do the right thing, worrying, and getting tired, all that matters for Bonita is her children, and Faye and Eddie offer their help. Living with HIV has made her stronger; she's glad to be able to slow down and be responsible, and it keeps getting better.

Synthesized Essences (Researcher's Language)

1. Cherished mutual involvements evolve through anticipating an absent presence differently.

2. Bearing witness to suffering while divulging-hiding surfaces aloneness with togetherness.

3. Limitations and opportunities clarify priorities fortifying intentions easing-intensifying mutual concerns.

Proposition

For Bonita, Faye, and Eddie, grieving is

- evolving cherished involvements through anticipating an absent presence differently as bearing witness to suffering surfaces aloneness with togetherness as limitations and opportunes clarify priorities and fortify intentions easing-intensifying mutual concerns.

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Family Number 5: Max and Terry

Max, a gay man, received a diagnosis of AIDS eight years ago when he was in his 20's. He met Terry, an advocate for persons with AIDS, three years ago through a service agency. She is estranged from her family of origin as a consequence of her work. Max and Terry are committed to each other as life partners. They elected to speak with the researcher in a private office at the agency where Max works, and spoke for 45 minutes.

Extracted Narrative

Max went into crisis three years ago, fell apart, and had no one to share it. When he met Terry she soon became his care-giver, soul-mate, and partner. Many of their friends have died. At memorial services Terry holds Max's hand and thinks of him; she "grieves dually." Max avoided the last one, saying he "just couldn't stand another funeral." At times he grieves wishing he could have done more to help others. For Terry, loving someone who's terminally ill and not having any power over it is the most horrible thing imaginable; she wishes she had a magic wand to fix it.

Max and his father were both fighting terminal illness and thought, "We're gonna beat this together." Max wishes his Dad had known the person he had become, but is glad that he got to tell him he loved him and was proud to be his son before he died. He is overwhelmed with worry about losing his Hickman [a surgically implanted central venous line] to an infection; but he's not going to let them do anything until after the summer so he can lie out on the beach. He grieves the loss of an affluent lifestyle and has to take care of the nice things he has because he can't replace them. But that's not what matters now. The work he's doing is important; it's the "legacy" he's leaving behind, and "positive grieving" for them both, which is "making things count." They prize every sunset and sunrise, walks in the park, and going to Florida, a trip that became a celebration of Max's life with memories that will last forever. He has been thinking of what he wants on his quilt--a picture of himself looking bronzed--and his memorial service, favorite music to be played, and what should be said.

Max says Terry grieves more than he and worries about him when she shouldn't. Terry says Max broods, while she likes to talk things out. She longs for them to capture

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moments and prepare for his dying, but Max just wants to rest and take his time. They go by two different watches. She thinks about AIDS night and day, trying to stay one step ahead, while Max says, "Let's go watch TV and forget about it." He rarely considers that he's going to die; he sees himself as a long time survivor, and thinks about AIDS mostly at the agency in relation to others. Two or three days a month he has bad days.

When Terry says, "Can we talk?" Max just rolls his eyes. He thinks "if you talk about it, it'll jinx it." Terry says they're almost telepathic. Max never talked with her about his memorial service and only once about his quilt. Max says his stepfather is the only one who doesn't know the truth. Terry says he does know, just won't talk about it except in codes; he talks to Terry, and she tries to make that safe for him. Max says she's been a great help. Max had not told his sister, for fear that her husband wouldn't let him touch his "pride-and-joy" nephews. But after he told her, he went to see the new baby, and they put him in his arms and walked away. It was a wonderful feeling. Max's family members ask Terry, "How is he really?" She longs to tell them to capture every moment, but she doesn't.

The trip to Florida was "getting away from it all," and made for lots of jokes and embarrassing photos, though they still did IV treatments in the room. You have to have a sense of humor to get through it. Max recalls sharing chemo jokes with his father. Max misses the "main-gay-stream," doesn't go out, dress up, or drink, but he pushes himself in his work. Terry says he pushes too hard; Max says he has trouble setting boundaries. By repeatedly bouncing back he has been an inspiration for others. He's a real fighter, a real tough cookie. A year ago he couldn't walk, which was scary and tough for them both; six months later he was rollerblading and broke some ribs. Now he says he's got to get going again.
Family Number 5: Max and Terry

Extracted Essences (Participants' Language)

1. As partners and soul-mates, Max and Terry grieve for others while Terry always grieves for Max as well. At times there's too much death for Max; his own grief is for not helping others, while Terry feels powerless and wishes she had a magic wand to relieve the horror.

2. Max grieves the loss of his Dad, his former lifestyle, and the possible loss of his Hickman, but what matters most is his work; it is his legacy. Max and Terry make things count, like the work, sunsets, a trip celebrating Max's life, and making memories, while Max ponders how he wants to be remembered.

3. Terry worries day and night about AIDS and Max's dying, while Max rarely thinks about dying, wants to rest and take it slow. Max and Terry go by two different watches.

4. Max, Terry, and others talk and don't talk. Telling his sister led to a special gesture leaving him with her baby. Max says his stepfather doesn't know, while Terry says he speaks of it in code when she makes it safe, and she longs to tell them to capture every moment, but doesn't.

5. Even with treatments and inconveniences Max and Terry enjoy humorous times that help them get through it. Max misses his former activities, and sometimes things are rough for them both, but he pushes hard to bounce back and keep going.

Synthesized Essences (Researcher's Language)

1. Bearing witness to anguish through dwelling with and apart from absent presences confirms endearment.

2. Struggling with change evolves visions of the not-yet in light of priorities.

3. Personal views emerge with variant tempos.

4. Divulging-hiding expresses mutual concern surfacing aloneness with togetherness.

5. Mutual burdening-unburdening intensifies and eases the struggle.

Proposition

For Max and Terry, grieving is

bearing witness to anguish through dwelling with and apart from absent presences confirming endearment while mutual burdening-unburdening intensifies and eases change as personal visions of the not-yet evolve with variant tempos and divulging-hiding surfaces aloneness with togetherness.
Family Number 6: Leo and Phil

Leo and Phil, both successful in business, live in a house filled with art and fine furniture. Their ages were not given, but the discussion suggests they are in their 30's. Leo's first lover died with AIDS six years ago, and Leo found out his HIV test was positive. Later, Leo met Phil, whose HIV test is also positive. Leo's family of origin lives on the opposite coast, and is neither very close nor estranged; Phil's family of origin was not mentioned. They elected to speak with the researcher in their home, and spoke for 40 minutes.

Extracted Narrative

When his first lover died, Leo watched helplessly as he diminished until there was nothing left. He had a wrenching, eerie feeling, couldn't walk or think straight, and daily living was hard. He was told he had HIV and was going to die within a year. He went to bed for several days, believing he was going to die. Then he came out of it, went away by himself and soul-searched. He had ups and downs, was extremely sad at times, but soldiering for himself and thinking about what happened built his character. He sold the house and made a complete change, which finalized the grieving. He wondered whether he should have a relationship with Phil, since he was going to die in a couple of years. Then he decided, "Hell no, I won't die," and became stronger. He stopped checking for spots and started to live again, and as the years went by it got better. Leo and Phil have taken a sad situation and turned it into a positive one with a new, forceful grieving instead being negative or sad. Phil was once shy, but now says what he wants, and asks, "What are they gonna do to me, kill me?" He's sorry that he had to go through this to become a better person, but he had to learn the hard way. Knowing that either of them could die in the near future, they are looking for a fresh start now, planning to sell their house and businesses and move cross-country to meet new people and have new experiences.

Leo and Phil have watched many friends with HIV die. It gets tougher as more and more die, but now they tend to mourn for only a day or two and get on with life. Phil was upset and teary-eyed over one friend and started a memorial quilt, but he didn't finish it. He just goes to bed at night and the next day the mourning is over. There is no point in mourning other people's deaths at length anymore, a realization he's come to only through having HIV. Even for each other's death, they "haven't got that kind of time." Leo
believes it scares Phil that he may die, but Phil dreads either of them being sick much more than the thought of dying. For Leo, mourning is a feeling of tenseness while helplessly watching a person deteriorate, and the only thing that releases that tenseness is the person's death. Then he doesn't have to worry about them. Maybe the years of watching people die have hardened him, or maybe he's changed his views of "what death and life are all about." If Leo has a long illness and dies, Phil will have all the plans made, business will be taken care of, they'll have a party to celebrate the end of his suffering, and life will be back to normal; Leo concurs. Each will do fine without the other. They feel that "the grieving has already been done."

Now they've learned to spend their time enjoying life and each other; career and money are not important anymore. With the reality of HIV, "things have changed both a little and a lot, but the biggest change is the change of values." Material things now have little meaning. They are looking for a simpler life, don't want the "social bullshit" anymore; life is too short. They're looking out for each other and looking for the best of life. Phil likes the beach, and Leo likes skiing; they both want to live where they can hug and hold hands without being afraid, so they're moving to a place where they can do these things. They want to break ties, go off together on an extended vacation, divorce themselves from mundane life, and spend their time playing; and "that way it's going to be okay."
Family Number 6: Leo and Phil

Extracted Essences (Participants' Language)

1. Immobilized with agony over his lover's death and his own HIV, Leo soul-searched on his own, got stronger, and made a complete change. He refused to die and became involved with Phil, who learned the hard way to say what he wants now. They have turned a sad situation into a positive one, and plan to move away and explore.

2. Watching many friends die while living with HIV got progressively tougher, so Leo and Phil now mourn only briefly and get on with life. If either of them dies, the other will do fine; the grieving has already been done, and they haven't got that kind of time.

3. With life so short, Leo and Phil's values changed from material things to a simpler life without hassles. Looking out for each other and looking for the best of life, they're going to an agreeable place to play.

Synthesized Essences (Researcher's Language)

1. Confronting mortality fortifies intentions giving rise to bold initiatives.

2. Bearing witness to loss while anticipating personal possibilities surfaces new perspectives.


Proposition

For Leo and Phil, grieving is

confronting mortality with fortified intentions
giving rise to bold initiatives
as bearing witness to loss while anticipating personal possibilities
surfaces new perspectives
and comfort-discomfort mobilizes distancing-relating
in light of what is cherished.
Family Number 7: Carl and Eric

Carl and Eric, who are now lovers, have each experienced the AIDS-related death of a prior lover and both have tested positive for HIV. Carl is very active in the HIV/AIDS support community, and Eric is somewhat involved. They appear to be in their late 20's. Both are in contact with their families of origin. They elected to speak with the researcher in a private office at the agency where Carl is a volunteer, and spoke for 55 minutes.

Extracted Narrative

Carl and Eric recall their grieving for their previous lovers. For Carl, who feared not being able to control the disease and not knowing what would happen, it was extremely disruptive. He wanted his lover, Wayne, to die, "prayed for it," for Wayne's sake, but also to get on with his life. When Wayne died, Carl didn't allow himself to grieve and had dinner as if nothing had happened. When Wayne's mother died, the combined grief was suddenly passionate. Seeking help, he got therapy, and told his parents everything for the first time. They responded well and have been supportive. When Eric's lover, Brian, was diagnosed, he was afraid, didn't know who to tell or what to do. They fumbled their way through. His worst fear was for Brian, not fear of death, but whether he could stay strong, and what others' reactions would be. When they started opening up to people, many were "wonderful." But the fear turned into numbness; having emotions would have been admitting it was all true. Everybody knew it was coming but him; he heard what was said differently. After Brian died, he wandered around, tried to keep busy. He sought medical services and started finding out what he needed to do for himself.

While Wayne was dying, Carl isolated himself from any reminder, felt empty, but couldn't say what was missing. He wondered if he was capable of living alone. Wayne became catatonic and was dead for Carl long before he actually died. He felt for Wayne's mother, knowing she wished her son dead. Later he realized that Wayne had been "in there" while for Carl he had been dead. Eric, still thinking that Brian was coming home until the end, wondered whether he could make it alone only after Brian died. With a feeling of vacancy he'd never had before, he relied on others. Recently, Carl and Eric cared for Larry as he was dying. The more Larry declined the more he looked like Wayne.
When he died, they were happy that it was a peaceful death. Eric says they supported each other when Jerry died, but each processed it in his own way. Carl says they were a support system for Jerry, not each other; grieving is a private thing "you do in your head" and nothing from outside makes it easier. Eric thinks sometimes it does. Eric grieves more openly than Carl, who withdraws, and Eric gives him his space, while Carl is sensitive to Eric's need for other people and is good at being there.

After Wayne died, Carl went back and picked up where he left off, through therapy. Recounting it was almost reliving it. He's sorry it had to be horrible and ugly for Wayne, but it was a positive experience for him. He used to feel guilty about treating him like a corpse; now he sees it as doing his best in an impossible situation. He's glad it happened as it did because he's more compassionate and stronger. For Eric, Brian's dying seems quick now, but at the time seemed like forever. They were fortunate that few friends abandoned them and Brian's employer was supportive. It was a good time in his life in ways, with people coming by to visit. His grieving made him a stronger and others' deaths easier to accept. Carl says having support makes his own potential loss of self easier to bear. If he should lose Eric, having been through it before, he knows not to stuff or run or deny himself anything.
Family Number 7: Carl and Eric

Extracted Essences (Participants' Language)

1. Carl prayed for Wayne's death and refused to grieve, while Eric didn't want to admit Brian was dying and stayed numb. Both were afraid of the unknown and limited their thoughts till it was over, when they sought what they needed.

2. Carl isolated himself from Wayne's dying, believing he was already dead, while Eric thought Brian was coming home until the end, and each wondered if he could make it on his own. Now when they grieve Carl needs his space and says it's private, while Eric needs people and says they support each other.

3. Carl is sorry that dying was horrible for Wayne, but feels he did his best in an impossible situation and became more compassionate, while Eric remembers good times with friends when Brian was dying, and now feels deaths are easier to accept. They both became stronger by living through it.

Synthesized Essences (Researcher's Language)

1. Struggling with divulging-hiding in the midst of ambiguity surfaces personal priorities.

2. Bearing withness to suffering prompts aloneness with togetherness.

3. The ease-unease of opportunities and limitations engenders self-affirmation.

Proposition

For Carl and Eric, grieving is

\[
\text{bearing witness to suffering} \\
\text{which prompts aloneness with togetherness} \\
\text{as struggling with divulging-hiding in the midst of ambiguity} \\
\text{surfaces personal priorities} \\
\text{while the ease-unease of opportunities and limitations} \\
\text{engenders self-affirmation.}
\]
Family Number 8: Frankie and Jane

Frankie, age 36, and Jane, age 30, have been married for nine years, and describe themselves as recovering from drug addiction. Frankie found out three months ago that his HIV test was positive. He says he contracted the virus through bisexual activity. Jane's HIV test was negative. She grew up in a household with "terminally ill" parents and lost her parents at a young age. They elected to speak with the researcher in their home, and spoke for 2 hours, 15 minutes.

Extracted Narrative

As a child, Frankie was told he was going to be just like his father, a saintly ghost he never knew. He couldn't be like him, was deeply hurt, and felt he was always going to mess up. The hardest grieving was for his ex-lover, Charles, whom he loved very much, but while they were together he used dope and was unkind. When Charles died [a non-HIV-related death], he felt he couldn't go on, drank to cover up his guilt, and "hit rock bottom." But a good thing came out of it, getting clean. In treatment he wrote a letter telling Charles what he felt. The grieving was not just losing Charles but coming to grips with how he felt about himself, and he learned to be a better person. Jane cries remembering her mother's long illness and dying. The rest of the family agreed with everything her mother said, but Jane argued with her. When she died, Jane shut off her feelings and did drugs. She decided not to get close to people so it wouldn't hurt when she lost them. She grieved years later. The feelings were overwhelming, but she learned to feel things as they come, and to look not at what she did wrong but what she did right. Now she sees that her mother enjoyed the fights because she was able to come alive, disagree, and yell. Jane enjoys nearly everything now, even things that aren't comfortable.

Frankie sees himself telling Charles he loves him and wishes things had been different. He wants to make amends, feels a need to go back to the mountains where Charles's ashes are scattered, and tearfully remembers flying Charles's kites at the beach, feeling that he was still with him. Thinking about his own death, he recalls people he didn't even know, how they too had to die and had no choice. Jane believes the people she has lost are still there in some form. She talks to them, gets comfort, and learns from them. Frankie cries as Jane talks about her mother. He feels close to her through Jane, though
they never met, and he knows that Jane can feel how he misses Charles, which makes them closer.

Frankie feels fortunate to be able to look into himself, to have people who will hug and cry with him when he's hurting. He is afraid they won't hug him or come when he calls if they know about the HIV. What hurts most is not dying but knowing that his time is limited. He believes something positive is going to come from having HIV, and he's trying to figure out how to take care of himself. Not knowing what's going to happen scares him, but he wants to live with that. When she found out Frankie had HIV, Jane screamed to her higher power that this was not right. HIV showed her what powerlessness is, made her realize how mortal we are. But life is not over. She looks for the good things, like not having to say she should-have because she has the chance to do it now. She still has many plans, though she doesn't know if they will be fulfilled. She's "not looking far down the road anymore," but at what she can do today.

When Jane had HIV testing, she didn't think about Frankie and was wrapped up in her own stuff. Frankie says although he's not comfortable with his bisexuality, the HIV has more to do with just "being in a marriage and being honest." He worries about Jane's finances if he has a long illness, doesn't want her to go through what she did with her mother. He believes his commitment is to carry a message, so he has no right to end his life. Jane's grieving is caring and not being able to fix it, while also being able to give of herself by staying with Frankie. She can't change what he's going through, but she can make do the best she can. She wants Frankie to be the person he wants to be, no matter what it means to her. She believes there's a reason for them to stay together after all they've been through. They are almost like one person, and she is afraid of the loneliness if she has to go back out there and be alone.
Family Number 8: Frankie and Jane

Extracted Essences (Participants' Language)

1. Frankie and Jane recall enormous hurtful losses throughout their lives, which led each to use drugs to shut off feelings. Learning to feel the feelings and tell about it helped Frankie to be a better person and Jane to enjoy life.

2. Frankie and Jane feel the close others they've lost with them, bringing tears and comfort. Understanding how each misses others makes them closer.

3. Frankie feels fortunate and fears losing what he has to HIV; the not knowing hurts, but he wants to live with it and feels something positive will come. The HIV enraged Jane, showed her the meaning of powerlessness and mortality; so she tries to make the most of today and doesn't look far down the road.

4. Frankie ponders his sexuality, HIV, and honesty in marriage, and worries about Jane, while renewing his commitments. Jane's grieving is caring and not being able to fix it, while wanting Frankie to be the person he wants to be and not wanting to be alone again.

Synthesized Essences (Researcher's Language)

1. Expressing anguished struggling surfaces new views.

2. Dwelling with and apart from absent presences and close others pulses with ease-unease.

3. Anticipating possibilities in the midst of ambiguity clarifies priorities.

4. Bearing witness to suffering while owning personal choices confirms cherished involvements.

Proposition

For Frankie and Jane, grieving is

- surfacing new views through expressing anguished struggling
- as dwelling with and apart from absent presences and close others
- pulses with ease-unease
- while anticipating possibilities in the midst of ambiguity
- and bearing witness to suffering
- as owning personal choices confirms cherished involvements.
Family Number 9: Michael and Betty

Michael, age 31, a former country club manager, has known his HIV test was positive for four years. He has been active in the HIV/AIDS service community. He is in a relationship with a man who is HIV-positive, who did not participate in the discussion. His mother, Betty, has become involved in AIDS-related volunteer work through her close association with Michael. Michael is the youngest of her five children. They elected to speak with the researcher in Michael's home, and spoke for 1 hour.

Extracted Narrative

Michael and his Mom, Betty, thought HIV was "a death sentence." He was absorbed in anger, sorrow, frustration, and fear, blamed himself, and considered suicide. His brother, Jack, told him it was God's punishment. It was like the bottom fell out of his world. Talking with others with HIV gave him strength and hope, but then he had to deal with their deaths, making his own possible death more real. Through long hard work he started loving himself and realized that he didn't deserve it but had to go on. An inner strength let's him know he is not alone, though in a crisis he forgets it's there. He had to go through loneliness and isolation to start opening up. At least in prayerful meditation now he has a source he can turn to. Michael has relied on his Mom a lot. At first she wondered how they could face his death. Then she thought, he's here, he's alive, and got busy learning and garnering support. Jack's condemnation, a loss of support when they needed it most, hurt the entire family. Betty dreaded family gatherings but was ready to defend Michael. When she gets too unhappy she turns it over to God. She believes God doesn't send her more than she can handle.

Michael and Jack finally talked; Jack reached an acceptance and welcomed Michael in his home. Things are changing. Michael was devoted to AIDS activism for years. He spoke publicly about HIV, even in rough places like prisons. Now he's resigning from the boards, changing his diet, working out, and studying spirituality. Acceptance gave him the chance to start living with the disease versus dying from it. He used to call his Mom frantically, but has tapered off since he got stronger. Betty says if he needs to talk, she's there to listen. She visits a hospice, which is uncomfortable when it reminds her of Michael. Michael now looks at having HIV as a blessing in disguise. It's made the family

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stronger; they don't take time for granted, and are all a part of each other's lives.

Michael doesn't want to get sick, go through the pain, or subject his family to it. He's afraid of the "grotesqueness of the disease." He's known many who tried a positive approach and ended up dead; sometimes he fears that no matter what it's going to end up the same. Awareness doesn't prepare you for it. When he arranged his funeral it shocked Betty. He was focusing on the end rather than the fact that today he's fine. By enhancing mind, body, and spirit he believes he will be a long-term survivor. He has learned to have a zest for life, thinks maybe he should not live by a calendar and just do whatever he wants each day. He thinks, "If I were to die, have I done everything I wanted to do?" But he hates all the what-ifs. Not looking beyond today helps Betty through the rough times. Betty can't help visualizing what he might look like when he gets sick, but doesn't dwell on it. She reads everything on AIDS, and while the future is frightening the education gives her strength.

At first Michael went to work as if everything were fine. When the lying got more difficult, he quit work. The family didn't talk about his illness or talked only on the surface. Michael wanted more from his family and started telling the truth. What helped Betty most was finally being able to share it with friends, who cried with her and offered their support. Then she found it easier to talk to others. Special occasions were difficult for Michael, who thought each would be his last and said so, he laughingly recalls. Humor helps them get through it. Betty can sense when he is down; she doesn't get down in the dumps with him but says something off the wall to get a laugh. She doesn't tell him when she's upset, but turns to others for that. Michael says he's fortunate to have the love of his family; they're an invaluable help in getting through.
Family Number 9: Michael and Betty

Extracted Essences

1. Michael and Betty intensely felt the news of his HIV as a death sentence, but through hard work and contact with others Michael moved through loneliness to inner strength and self-love, although others' deaths reminded him of his own. Betty rejected the idea of his death and garnered support, placing her trust in God, ready to defend Michael from others.

2. Betty was there to listen when Michael called. Acceptance from himself and others gave him the chance to start living with HIV, and he now looks at it as a blessing in disguise that brought the family together and made them stronger.

3. Michael doesn't want himself or his family to go through the grotesqueness for which nothing prepares you and has shifted from a focus on the end to have a zest for life, doing what he wants, while he ponders and hates the what-if's. Not looking beyond today helps Betty through rough times while getting more information scares and strengthens her.

4. Talking about the HIV and not talking about it are hard as Betty shares Michael's downs but tries to get a laugh. The humor helps the family through the ups and downs.

Synthesized Essences

1. Being with and apart from others while abiding in faith eases-intensifies anguished struggling with mortality.

2. Bearing witness to suffering surfaces new perspectives.

3. Anticipating the not-yet with ambiguity gives rise to cherishing the now.

4. Burdening-unburdening surfaces mirth and mutual concern.

Proposition

For Michael and Betty, grieving is

being with and apart from others while abiding in faith which eases-intensifies anguished struggling with mortality as bearing witness surfaces new perspectives and anticipating the not-yet with ambiguity gives rise to cherishing the now as burdening-unburdening surfaces mirth and mutual concern.
Family Number 10: George and Richard

George, age 47, is an artist who was diagnosed with AIDS about nine months ago without having known he was HIV-positive. His companion, Richard, about the same age, is an arts administrator. They have lived as partners for several years. George is close to a sister and has contacts with others in his family of origin, some unfriendly. Richard did not discuss his family of origin. His four closest friends are HIV-positive. They elected to speak with the researcher in their home, and spoke for about 3 hours.

Extracted Narrative

During long, painful bouts with life-threatening illness, there was nothing George could do except hope that he survived. All he knew was to be calm, conserve energy, and learn. Every item in his room reminded him of a loss. He had no energy or desire, didn't go into his studio, kept it dark, and lay on the sofa for months. To Richard it seemed George was wasting precious time; he had become a lump exuding negative energy. Concern turned to anger; Richard felt that George might as well be dead, and told him. Then a miracle occurred, a change in perception. George got it, and was pulled up by Richard's love and encouragement. He redid his room to be bright, open, better than before. He's back, and he and Richard are partners again. George is grateful to Richard, who says the only one who could turn it around was George. George is not grieving like he was, but grieving is part of everyday. Painting or listening to music are happy times. He puts out positive energy, which includes expressing his anger and sadness. He has met the challenge of a great adversary and won.

George recalls grieving for the others, many of whom were close. He had strong feelings about the waste of human life, but stayed numb to keep from being overwhelmed. He dedicated his garden to the dead, hoping their spirits would share it as he meditated and grieved, not a sorrowful but a joyful grieving because it was beautiful. He voiced his opinion, did things to make a difference. About friends who've died, he wonders, Why them and not me? Death was intellectual before, now it's a personal reality. He has been scared, but is not afraid of death. Dying does not mean one's presence cannot be felt in another way. He trusts in spirit. Richard is anticipating the loss of all his close friends, his generation about to crest, and grieving over a long time has become a fact of life. He
spends much of his time preparing in emotional and practical ways, like helping with wills. He feels guilty that they are HIV-positive and he is not. Yet he grieves for himself knowing in a few years a substantial portion of his life will not be there. He thinks it will be very lonely, but he will go on. Their decision to move in together arose from loneliness. George loves Richard and it saddens him that when he is gone Richard will be lonely again. George's closest sister has been kind and supportive, but he is not welcome in another's home and can't see his nephews. The last person he expected to turn on him was the first. There's been a lot of that, and it's hard, hurtful. He wonders why he should be treated more cruelly now when who knows how much time he has.

George doesn't dwell on the past, but he remembers. He is aware of so much he can do now. He doesn't rush to the future, but he can share dreams. Richard's dream is a house out west, and George would like to be there with him, but if not he hopes Richard will dedicate his garden to him. Richard believes that one's death should be a celebration of one's life. George has a case of champagne to be consumed when his ashes are buried, and he expects to be around. When he gets to a point with the positive attitude, it scares him. He doesn't want to get over-confident; it could all change just like that. He believes that at some time he has to give his life over to a higher power, but if he's suffering, he wants to have euthanasia and doesn't want to be kept alive by machinery. His spirit tells him he still has time, but he better do it right: with nothing to waste, make the most of each day. There doesn't have to be anything wrong with him unless he wants it to be. He cares about all humankind, and finds more sadness in his nephew's recent diagnosis with HIV than for himself. He has reassembled the people and things that are important to him, doesn't want the other stuff, the crap. He doesn't care what people think of him anymore and says, "I'm just me, and that's why I'm happy." He lives each day with gratitude for little pleasures, like smoking, and even enjoys them more. For Richard, the change of attitude meant there's a friendship again, with communication, smiles, and laughter.
Family Number 10: George and Richard

Extracted Essences (Participants' Language)

1. Living with pervasive loss, all George knew to do was hope and stay calm, while Richard saw his inactivity as a waste. A change in perception prompted by Richard's encouragement pulled George out of it, and he and Richard are partners again. Though grieving is part of the ups and downs of everyday, George has met the challenge and he has won.

2. George's grieving started as profound grief for others, but now death is a personal reality, and while he has been afraid, the fear is not of death since he believes in spirit. Richard is anticipating loneliness with the deaths of close friends. Others are sometimes supportive and kind, and sometimes shunning and cruel.

3. George and Richard remember and dream and celebrate George's life, but sometimes George thinks it could all change instantly. His spirit tells him he has nothing to waste as he examines options while facing death with great care and is happy being himself with renewed friendship bringing smiles and laughter.

Synthesized Essences (Researcher's Language)

1. Views of personal anguish emerging with harmony-discord mobilize intentions.

2. Dwelling with and apart from absent presences and close others surfaces aloneness with togetherness.

3. Possibilities evolve with joy and caution as abiding with imminent death clarifies personal priorities in light of what is cherished.

Proposition

For George and Richard, grieving is

mobilizing intentions
through the harmony-discord of personal anguish
while dwelling with and apart from absent presences and close others
surfaces aloneness with togetherness
and possibilities evolve with joy and caution
as abiding with imminent death
clarifies personal priorities in light of what is cherished.
Further extraction-synthesis involved the propositions for all ten participant families. Four core concepts were extracted from all of the propositions. These four extracted concepts were then interrelated to arrive at the structure of grieving for the ten participant families. The extracted concepts and the structure are presented below.

**Extracted Concepts**

1. Easing-intensifying with the flux of change
2. Bearing witness to aloneness with togetherness
3. Possibilities emerging with ambiguity
4. Confirming realms of endearment

**The Structure of Grieving for Families Living with AIDS**

For the ten participant families in this study, the structure of grieving is:

- easing-intensifying with the flux of change
- through bearing witness to aloneness with togetherness
- as possibilities emerge with ambiguity
- confirming realms of endearment.

**Heuristic Interpretation**

The processes of heuristic interpretation, which are structural integration and conceptual interpretation, specify the structural and conceptual linkage with Parse's human becoming theory.

**Structural Integration**

The structure of grieving for families living with AIDS is:

- pushing-resisting with diverse rhythms
- of communion-solitude
- unfolding with certainty-uncertainty
- through honoring the treasured.

**Conceptual Interpretation**

As a theoretical structure expanding the human becoming theory, the structure is:

**powering the connecting-separating in originating valuing.**

The progressive abstraction of the concepts comprising the theoretical structure is illustrated in Tables 1-4.
Theoretical concept: Powering

Structural integration: Pushing-resisting with diverse rhythms

Extracted concept: Easing-intensifying with the flux of change

Concept as evident in the propositions of participant families:

1. anguished struggling...puls[ing] with ease-unease...
2. struggling...through...ease-unease...
3. abiding with imminent death fortifies intentions...
4. suffering...fortifying intentions easing-intensifying...
5. anguish...intensifies and eases change...
6. confronting mortality with fortified intentions...
7. suffering...struggling...ease-unease...
8. anguished struggling...pulses with ease-unease
9. eases-intensifies anguished struggling with mortality
10. mobilizing intentions...personal anguish...abiding with imminent death

Table 1
Theoretical concept: Connecting-separating
Structural integration: Communion-solitude
Extracted concept: Bearing witness to aloneness with togetherness

Concept as evident in the propositions of participant families:

1. commitment... distancing-relating surfaces aloneness with togetherness...
2. bearing witness uncovers aloneness with togetherness...
3. aloneness with togetherness... bearing witness...
4. involvements... absent presence... bearing witness... aloneness with togetherness...
5. bearing witness... dwelling with and apart from absent presences... aloneness with togetherness...
6. bearing witness... distancing-relating...
7. bearing witness... aloneness with togetherness...
8. dwelling with and apart from absent presences and others... bearing witness...
9. being with and apart from others while abiding in faith... bearing witness...
10. dwelling with and apart from absent presences and others surfaces aloneness with togetherness...

Table 2
Theoretical concept: Originating

Structural integration: Unfolding with certainty-uncertainty

Extracted concept: Possibilities emerging with ambiguity

Concept as evident in the propositions of participant families:

1. possibilities envisioned with...ambiguity...
2. ambiguity evolve[s] new perspectives...
3. anticipating possibilities...comfort-discomfort...
4. anticipating [an absent presence] differently...
5. visions of the not-yet evolving with variant tempos...
6. bold initiatives...while anticipating personal possibilities...
7. divulging-hiding in the midst of ambiguity...
8. anticipating the possibilities in the midst of ambiguity...
9. anticipating the not-yet with ambiguity...
10. possibilities evolve with joy and caution...

Table 3
Theoretical concept: Valuing

Structural integration: Honoring the treasured

Extracted concept: Confirming realms of endearment

Concept as evident in the propositions of participant families:

1. gratitude for what is and what is not...clarifying personal priorities...
2. confirming endearment...
3. comfort-discomfort...confirms endearment...
4. cherished [involvements]...clarify priorities...mutual concerns...
5. confirming endearment...
6. comfort-discomfort...loss...what is cherished...
7. personal priorities...
8. owning personal choices confirms cherished [involvements]...
9. prizing the now...mirth and mutual concern...
10. clarifying personal priorities in light of what is cherished...

Table 4
CHAPTER V

DISCUSSION OF FINDINGS

The research question for this study was, "What is the structure of grieving for families living with AIDS?" The structure as evolved through the study answers the research question. The structure of grieving for families living with AIDS is:

easing-intensifying with the flux of change
through bearing witness to aloneness with togetherness
as possibilities emerge with ambiguity
confirming realms of endearment.

This structure will be discussed in relation to the four principal aims of the study outlined in Chapter I. These were: (1) to enhance understanding of grieving as it is lived in families living with AIDS; (2) to expand nursing’s theory base on grieving, building on prior research; (3) to contribute to the expansion and specification of Parse’s (1981, 1992) human becoming theory; and (4) to extend and refine the use of Parse’s (1987a, 1990b) research methodology.

The structure of grieving for families living with AIDS generated through this study interrelates four concepts. These have been structurally integrated and conceptually interpreted in light of Parse’s human becoming nursing theory. Each concept in the structure will be discussed in depth in this section.

The first aim of the study was to enhance the general knowledge base on grieving in families living with AIDS. Accordingly, discussion of the first aim will include comparison of the findings to the relevant literature. The second and third aims were concerned with building nursing’s own theory base, and will be discussed specifically in relation to Parse’s human becoming theory. This will be followed by discussion of the fourth aim, regarding the methodological aspects of the study.
Easing-Intensifying with the Flux of Change

The first concept, *easing-intensifying with the flux of change*, is the rhythmic interplay of struggle, conflict, suffering, and anger, with harmony and comfort, which was evident in various ways in all ten families' descriptions. This concept encompasses mobilizing and fortifying intentions in the face of opposition and imminent death, personal and shared struggles to be with loss in new ways, and moving toward comfort through self-assertion and affirmation.

Illustrations from the Dialogues

Family Number 2 described at length their struggle through Alice's long illness, but Alice also said, "This disease has given me more freedom to be me than anything else that has ever happened in my life," and she insisted on a long put-off vacation to New Orleans, saying, "I can't afford it, I've heard it's too hot....But I'm gonna do this." In Family Number 4, Bonita described a time when her sister stopped her niece from kissing her as "the worst moment of my life," but her own children kept her going with hugs and kisses. She said, "It gets me down every now and then, but I go on....I refuse to go out without a bang....I'm not gonna let HIV take control of my life, under no circumstances. Today I'm willing to live."

In Family Number 5, Terry said Max always "bounced back" from serious illnesses, and Max characterized himself as "a real tough fighter, a real tough cookie." Though they had to perform Max's intravenous treatments and carry a cooler full of medicine when they travelled, a trip to Florida was a "real celebration." In Family Number 7, Carl said of his lover's death, "Now...I see that it was a growth experience, something really positive came out of it....I'm glad it happened." Though he was sorry it had to be so horrible for Wayne, he said, "I'm glad it happened the way that it did, for me...because it helped...me to be who I am now."

In Family Number 9, Michael recalled a long struggle with self-blame, rough times at work, a brother's condemnation, and tensions within the family, until he learned to "start loving Michael," and things started to turn around. He said, "When you're going through
it, you don't realize where it's coming from, this strength. And then you make it through, and you go, well, if I can make it through that, I can make through anything." In Family Number 10, George's retreat to the sofa almost brought about the end of his partnership with Richard, until Richard's "encouragement" to get up and do something, expressed in anger, pulled him out of it. Describing the recent changes in his life, George said, "I have met the challenge...and I have won!"

Heuristic Interpretation

The extracted concept of easing-intensifying with the flux of change was structurally integrated with the theory through an interpretive linkage with "pushing-resisting," according to Parse (1981, p. 58) a rhythmical process that occurs in all human-universe interrelating, "creating tension and sometimes conflict." She continues, "Tension is the struggling between pushing and resisting while contending with others, issues, ideas, desires, and hopes all at once" (p. 58). Pushing-resisting is the rhythm of powering, one of the central concepts in the theory. Powering is "incarnating one's intentions and actions in moving toward possibilities" (p. 57). Powering is the first concept in the theoretical structure of grieving, in light of its congruence with the core concept of easing-intensifying with the flux of change.

Comparison with Related Literature

The conceptualization of easing-intensifying with the flux of change enhances understanding of grieving by offering a non-linear alternative to the stages theories. Easing-intensifying with the flux of change suggests a view of grieving as a rhythmical, multidimensional process unbounded by calendar time and geographic space, a process of human-universe coparticipation in which an individual affirms personal existence through continuously becoming the who that one is in the face of unwelcome change.

The terms and concepts that seem to refer to this recognizable pattern of grieving in the conventional theories include alarm, shock, anger, disorganization, despair, bargaining, and mitigation (Bowby, 1969, 1973, 1980; Kübler-Ross, 1969; Lindemann, 1944; Parkes, 1987; Sanders, 1989). Grieving has often been described as a confusing panoply

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of emotions, including futile rage with a reality in which the cherished "object" does not exist or soon will not exist. Many attempts have been made at explaining these emotions from a perspective in which these experiences are considered little more than physiological responses to unpleasant stimuli that are "normally" resolved through the processes of homeostasis. The incongruence of multidimensional lived experience and sequential stage theories has been recognized in the literature, but with little alteration in the linear structure of the extant theories. Approaching grieving as lived experience, however, offers enhanced understanding of the meaning of the human struggles, changing intentions, feelings, and patterns of relating that are experienced in grieving, without reducing the complexity of the phenomenon to a sequence of responses. This family-centered study revealed some of the shared and unshared concerns that mobilize the pushing-resisting process to assert the self as the who that one is, and thus shed light on the complex patterns of intensity and ease in grieving without resorting to a simplistic linear model.

The findings of this study are consistent with the broadening of the concept of grieving to apply to a wider variety of losses and integration of the study of grieving with the study of change and transition (Marris, 1974; Parkes, 1971). Participants in the study explicitly stated they were grieving many losses, including the anticipated loss of self, anticipated or actual loss of someone close, and/or career, money, friends, close relationships, energy, freedom, hopes, and dreams. The rhythmic process of easing-intensifying with the flux of change is proposed as an apt descriptor of grieving multiple losses on many levels all at once.

The existential-phenomenological movement has offered insight into the primacy of meaning in human experience and the nature of becoming as affirming oneself as being-in-the-world (Heidegger, 1927/1962; Frankl, 1969; Tillich, 1952). Easing-intensifying with the flux of change reflects a similar yet subtly different view. Parse (1981, 1992) posits a more radically unitary view, and describes the human-universe "unfolding" as a rhythmical, cocreated process. Easing-intensifying with the flux of change refers to self-affirmation in the face of change through the continuous rhythmical process of pushing-
resisting in human-to-human and human-universe interrelationships.

Parse's (1981, 1992) theory provided a nursing perspective within which to interpret the findings from this study. Prior nursing studies of grieving have been rich in descriptive content but lacking in conceptual interpretation. For example, Carter (1989) uncovered themes like "being stopped," "hurting," and "seeking" (pp. 355-356), which were supported by vivid quotes from study participants. These findings, however, were allowed to stand as a disparate collection of particulate findings without a conceptual framework to guide the interpretation. Carter also specified a metatheme of "change," a "wave like" quality in the grieving process (p. 356), but made no attempt to formulate a proposition pulling together the elements she had uncovered. Similarly, Brown and Powell-Cope (1991) identified the core concept in "AIDS family caregiving" as "transitions through uncertainty," but left this construct unconnected with any theoretical perspective. In contrast, the conceptualization of easing-intensifying in the flux of change, linked with Parse's concept, powering, offers a specific interpretation of the lived experience of grieving at an appropriately abstract level for theory expansion.

Bearing Witness to Aloneness with Togetherness

The second extracted core concept in grieving that surfaced in this study was bearing witness to aloneness with togetherness, which is being authentically present with self and others multidimensionally, attesting to the lived reality of simultaneous individuality-communality. This concept encompasses the distancing-relating processes of bearing witness to suffering, anticipating an absent presence diversely, and dwelling with and apart from the absent presence and others, which were evident in various ways in all ten participant families' descriptions. The most frequent expression of this theme in the dialogues was "being there" for someone. Multiple close, meaningful relationships were described by every family, including some from childhood, some with persons who had been dead for years, and some that were both cherished and painful. Participants also pictured what close relationships might be like in the future. Nonetheless, the participants also described a strong, pervasive sense of solitude in grieving. The personal meanings of
the losses brought the aloneness of grieving to the fore, as persons in even the most intimate and committed relationships saw the "same" things differently. **Bearing witness to aloneness with togetherness** thus also relates to the sharing and not sharing that was brought to the fore in a number of the descriptions.

**Illustrations from the Dialogues**

In Family Number 1, Rob and Jeff felt that "People just don't understand....They don't even want to admit that it's a real thing." But Jeff said, "It's more important how I feel about Rob than what other people feel about me loving him"; while Rob said that "losing the friendships...hurts the most." Aloneness with togetherness was also evident in Rob and Jeff's debate about "life in a bubble," which Rob saw as "hell," while Jeff thought it would be "okay," since they would be in there together.

In Family Number 2, Alice stated plainly, "This is something I have to do all alone," while much of the family's discussion was devoted to sharing and not sharing their feelings, their mutual concerns, and their focus on sharing in the now. In Family Number 3, Beryl said she didn't know if the rest of the family grieved for her. She said, "I grieve. I go to my room and shut the door and cry to myself." While her sister said, "We...tell each other how we're feeling...and we all cry sometimes...all holding hands." Cheryl talked about feeling that there was "nothing anybody could do" about Beryl's suffering or dying. "I can understand what she's talking about, I just can't feel her pains....I wish I could take some of it, but I can't."

In Family Number 4, Faye and Eddie spoke of how Bonita was still with them and would "still be around" after her death. They spoke about "being there" for the family, and Bonita spoke lovingly of the support her children gave her. Yet she said, "I just stay in a little shell all the time...because nobody knows what I'm going through." In Family Number 7, "support" was a major topic of discussion for both men, while Carl also insisted that "grieving is something you do in your head" and "no amount of...outside support is gonna make that any easier."

In Family Number 8, Frankie's relationship with Charles and Jane's with her
mother and Charles, both of whom were deceased, were clearly very important in the participants' daily lives. Jane described being "wrapped up in [her] own stuff" and distant from Frankie while waiting for her test results. She also spoke of her commitment to Frankie, while wanting Frankie to "be the person he wanted to be." Meanwhile both spoke of what it might be like for Jane to go on alone.

**Heuristic Interpretation**

The extracted core concept of **bearing witness to aloneness with togetherness** was structurally integrated with Parse's theory through an interpretive linkage with **communion-solitude**, a recognizable paradox of human relations addressed in slightly different ways by Parse and others (Buber, 1938/1965; Kempler, 1974; Moustakas, 1972). Parse (1981, p. 51) says, "Both aspects of the rhythm are a source of human unfolding." In this study, multidimensional communion-solitude was strongly evident in all the families' descriptions. Communion-solitude relates specifically to **connecting-separating**, one of the central concepts in Parse's theory, which she describes thusly: "Two or more people come together in an intersubjective relationship; that is, they are truly present to each other, simultaneously unifying and separating as their togetherness evolves" (p. 54). **Connecting-separating** is the second concept in the theoretical structure of grieving, in light of its congruence with the core concept of **bearing witness to aloneness with togetherness**.

**Comparison with Related Literature**

The conceptualization of **bearing witness to aloneness with togetherness** sheds light on lived experiences of family interrelating in grieving. Only a small body of literature on grieving in families exists (for example, Pincus, 1974; Knapp, 1986). In most of these works, as outlined in Chapter II, the combination of two prescriptive bodies of theory results in a sterile theoretical view of grieving in families, well removed from the lived experience. The literature generally reflects the assumptions that loneliness is a problem to be solved, and that (nuclear) family cohesiveness is a goal to be pursued. Rarely have scholars writing about loss and grieving in families held these assumptions in abeyance to
develop a clear understanding of the experience of grieving in families as it is lived. Interventions and ways of resolving the conflicts are often proposed almost as soon as the issues of loneliness and/or family cohesion are introduced (Walker, 1991; Worden, 1991).

**Bearing witness to aloneness with togetherness** represents a view that persons who are closely connected in grieving find their own ways of being with loss, choose from options, and incarnate these choices in daily living with and apart from others. The conventional view responds to the grieving person's often heard statement, "There is nothing I can do except be there for [her/him]" with a plethora of suggestions for action, skipping over the very primacy of personal presence in and of itself. Yet it is this human-to-human relating that actually cocreates the family, as personal meanings and choices lead individuals to commit to relationships and thus to be truly present with the other during times of strife and struggle. Bridges (1980, p. 32) said that the two "great transitions" of life are the development of a separate self and movement beyond separateness to "a deeper sense of interrelatedness," a view that is similar, broadly, to the findings of this study. From Parse's nursing perspective, however, interrelatedness is not something that has to be achieved, but is inherent in being human.

Comparing the findings with the related literature, **bearing witness to aloneness with togetherness** also brings into question what it means to be alone. A strong influence in modern grief theory has been the work of Bowlby (1969, 1973, 1980) on "attachment theory." This view is rooted in an objectivist view of reality. According to this view, "attachments" are formed as a part of the natural development of the human being as one moves from the complete "narcissism" of infancy to be able to form relationships with other "objects," i.e., mother, father, siblings, friends, and eventually a mate. When one is separated from an "object" of attachment, physiological forces prompt "yearning" and "searching," which are to no avail, since the object is gone. Healthy grieving is conceptualized as a "reorganization" of one's life, thoughts, and feelings, adjusting to the reality that the object of attachment is no longer (Bowlby, 1969, 1973, 1980). Following "separation," new attachments must be formed, the old ones allowed to fade in priority, to
promote healthy grieving. The influence of this way of thinking is reflected in the nursing literature. For example, Carnack (1992) conceptualized the process of coping with AIDS-related multiple losses as "balancing engagement and detachment," wherein either engagement or detachment ran the risk of becoming "dysfunctional" (p. 11). In the conventional scientific work on grieving, such experiences as expecting a husband to come home from work a year after his death are viewed as pathological (Parkes, 1987), while in the family literature both "isolation" and "enmeshment" are viewed as problems to be resolved (Olson, Russell, & Sprenkle, 1983; Walker, 1991).

In contrast, Parse begins with the assumption that the human being "is not alone in any dimension of becoming" (1981, p. 20). Aloneness is relative and perspectival; presence is not merely bodily location in space but is intentional; the two are not mutually exclusive. For example, George, in Family Number 10, while living five miles out, "alone" in the woods, invited the presence of the many who had died with AIDS to be with him in his garden, which he dedicated to them. Frankie, in Family Number 8, came to know and love Jane's mother, "Aunt Aggie," through Jane's sharing of her memory, and said, "I'm real close to Aunt Aggie." Jane was most explicit in describing the experience of the absent presence of the deceased, as she said, "I still talk to these people...I still believe they're around...I get comfort from them...I still believe that they teach you stuff while they're dead." Carl, in Family Number 6, described "isolating" himself from all reminders of his lover's dying at that time, and said, "We treated him like a corpse," while he was dying. After Wayne was dead, Carl realized "he was still in there."

Yalom and Greaves (1977), in an article on group therapy with the terminally ill, differentiate between two kinds of loneliness: existential loneliness, "which cannot be allayed or taken away; it can only be appreciated," and "secondary interpersonal loneliness," which "can be effectively dealt with in the group" (p. 398, emphasis added). Persons coparticipate in "existential loneliness" in that they bear witness to the other's becoming through personal presence. Few scholars have explored the paradoxes of absence-presence or aloneness-togetherness, since the recognition of these phenomena is
incommensurate with the objectivistic view of reality. Conversely, among authors in the existential-phenomenological tradition, in which paradoxes such as these are believed to be inherent in the human condition, there have been few empirical investigations.

Moustakas (1972) holds that, in loneliness, help comes "not through words...or approbation, but by the honest, full presence of real persons and by their respect for solitude and privacy," their willingness to be with the other as he or she "risk[s] the darkness and go[es] within alone" (p. 10). Yet in solitude there is another kind of presence that also must be appreciated. Cole (1992), writes of experiencing "a tangible absence," following the death of her mother. "The...conversations that I had carried on with my mother in times of confusion and sorrow now bubbled forth in the form of nurturing memories....[which] brought multiple insights....And although I could not converse with her in person, these dialogues brought us closer in ways I could not have imagined" (p. 185). Bearing witness to aloneness with togetherness, linked with Parse's concept, connecting-separating, offers a way of understanding lived experiences of absent presence and aloneness with togetherness at an appropriately abstract level for theory expansion.

**Possibilities Emerging with Ambiguity**

The third extracted core concept in grieving was possibilities emerging with ambiguity, the process of choosing how to be in life situations while never fully knowing what is yet to be, which was evident in the descriptions of all ten participant families. As new views surfaced in dwelling with loss, participants saw themselves as like and unlike close others, and personal choices in light of close relationships moved them onward in life without knowing what the actual outcomes would be. This concept encompasses the choosing of meaning and action engendered through anticipating and envisioning multiple possibilities, which were sometimes similar but always subtly different for the persons in each family. The concept also relates to the lived experiences of wanting to change and not wanting to change, hoping to live while preparing to die, the complexity of telling and not telling in light of unsureness, and the interplay of personal perspectives and priorities in creating the evolving situation for the family.
Illustrations from the Dialogues

In Family Number 2, Alice spoke of making plans strictly on an if-possible basis, while Joe said, "As soon as you find out [about HIV] you...think of the next day, of the month, of the next year. What's gonna happen? Will I be there?...Could I handle it? I didn't know." Hannah said it was "hard...thinking about...what might happen if [my Mom] gets sick." She said, "I'm afraid...and not sure of anything....It could happen to anybody." The uncertainty of the future gave rise to a new pattern of living for Alice's family, concentrating on today and prizing special moments.

In Family Number 3, Beryl said, "I don't want to die now, but I know everybody's got to die sooner or later....It's a scary feeling." Cheryl tried to picture, "What am I gonna do without my sister?" She said, "I really don't know. I knew it would be lonely." The sharing of feelings brought a new comfort for Beryl, who told Cheryl, "I appreciate what you said, because I didn't think you felt like that." Beryl was hurt that her family didn't express their grief for her, but she said, "Sooner or later they'll come to me and talk to me, and let me know exactly how they feel. Like she did today."

In Family Number 6, both Carl and Eric were moved by their experiences with their dying lovers to tell their parents that they were gay, that they were involved with other men who had AIDS, and that they were HIV-positive themselves, while not knowing how their parents would respond. A new pattern in their family relationships emerged when, to their surprise, their families were supportive. Family Number 7, Leo and Phil, knew that their time might be limited and their deaths painful. That sparked an exploration of possibilities that led to their selling their home and businesses and setting out on a cross-country adventure. Leo said: "Life's too short....We want to enjoy the time we have, whether it's a year, whether it's thirty years....And the only way to do that is to explore."

In Family Number 8, Frankie didn't know how HIV might change his life; he thought it might be to "carry a message" as he did for addicts, but he poked fun at the "living with HIV, not dying of AIDS" idea by saying it in a humorous voice. Jane didn't know how long Frankie might live, but she knew from experience that losing someone

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close involved a lot of "should-have's," and said "At least I get the chance to do all the things I wished I had done, and say all the things I wished I had said."

Family Number 9, Michael and Betty spoke of the "grotesqueness" and "ugliness" that they had seen in others with advanced AIDS. This image sparked Michael's efforts to "enhance mind, body, and spirit," believing he would be a long-term survivor. His view of the possibilities, early in his grieving, prompted him to arrange his own funeral, which later brought laughter, when the possibility of his dying sparked "the zest for life," and the question, "If I get sick and go downhill...have I done everything I wanted to do?"

Heuristic Interpretation

The extracted core concept of possibilities emerging with ambiguity was structurally integrated with Parse's theory through an interpretive linkage with the paradoxical rhythm of certainty-uncertainty. "The paradox of living certainty-uncertainty surfaces in human encounter as individuals make concrete or clear their choices in situation yet, simultaneously, live the ambiguity of the unknown outcomes" (Parse, 1981, p. 60). Choosing a path while dwelling with the ambiguity of unknown outcomes was a strong theme in the descriptions of grieving offered by all ten families, whether the descriptions involved anticipated or retrospective loss. The choices of meaning and action made by each person in the midst of ambiguity evolved the family situation while clarifying the unique selfhood of the individual in relation to the others. Certainty-uncertainty relates specifically to originating, one of the central concepts in Parse's theory, which she describes as "choosing a particular way of self-emergence through inventing unique ways of living" (1981, p. 60). Faced with options in a life situation, one strives to envision what each choice would mean, while the quality of certainty-uncertainty bears on the decision-making along with the comfort-discomfort of the individual with being like-unlike others. Originating is the third concept in the theoretical structure of grieving, in light of its congruence with the extracted concept of possibilities emerging with ambiguity.

Comparison with Related Literature

The conceptualization of possibilities emerging with ambiguity enhances
understanding of grieving by offering an alternative view to that which emphasizes prediction, control, and "management" of grief, based on the homeostatic model of health and the objectivistic view of reality. It is perhaps an understatement to say that the preponderance of scholars writing on grief have been less than open to possibilities. There is a deep and pervasive assumption reflected in the literature that there are healthy and unhealthy, functional and dysfunctional, adaptive and maladaptive ways of grieving. Benchmarks of healthy grieving traditionally have included acceptance, transition to new "roles," and resolution of uncertainty (Gulotta, 1982; Kübler-Ross, 1969; Schneider, 1984). As Cowles and Rodgers (1991) noted, the tone of the greater portion of the grief literature has been that "there are limits to grief, beyond which it becomes inappropriate, unacceptable, or revealing of underlying or associated pathology" (p. 122).

**Possibilities emerging with ambiguity**, as a core concept in grieving, reflects a fundamentally different view, rooted in Parse's theory. The lived experience of ambiguity in grieving is the continuous multidimensional unfolding of opportunities and limitations within the context of unwelcome change and challenges to personal values. What constitutes opportunity or limitation is relative to the person experiencing it. For example, living with AIDS was described as both a limitation and an opportunity for self-realization in various ways by many of the participants in this study.

The uncertainty inherent in change has been well noted in the literature on change and transition, in such works as those of Bridges (1980) and Marris (1974). There is, however, the implication in these authors' works that successful transition includes the resolution of uncertainty and a return to relative stability, as Bridges writes of "reorientation," and Marris of defending the "predictability" of life. Watzlawick, Weakland, and Fisch (1974) are somewhat more radical in their interpretation, in that they posit participation in change as creating reality rather than adapting to it.

DeFeo (1990) described the view of change in nursing's simultaneity paradigm as an evolutionary process involving choosing direction and risking. Mishel, a nurse, published, in 1988, a stress-coping model of "uncertainty in illness." Through critical
appraisal of the theory, focusing on its admitted "biases" toward a mechanistic worldview valuing prediction and control, Mishel reconceptualized the theory in 1990. She then stated "the nature of uncertainty has to be accepted as the natural rhythm of life...Belief in a conditional world opens up the consideration of multiple possibilities since certainty is not absolute" (p. 260). The concept of possibilities emerging with ambiguity as a central theme in grieving is consistent with the emerging view of change as a coparticipative evolutionary process.

In this family-centered study, it was clear that the interplay of shared and unshared personal perspectives and priorities cocreated the possibilities envisioned by the participants. The possibilities had little relation to the societal norms and expectations that currently dominate family theory, but rather they were perspectival in relation to the persons cocreating the family. For example, Leo chose to move ahead with a relationship with Phil though he had just lost his lover, had been told he was HIV positive, and would be dead in a year. The experience of choosing based on personal values was repeatedly underscored as participants in every family described how living with loss brought personal priorities to the fore. At times priorities were shared and energies were channeled toward a shared goal. At times priorities were unshared, and persons moved in different directions. In either case, new patterns of relating were cocreated. For example, Leo and Phil described their experiences in very similar ways, and were clearly united in their intention to move cross-country. One of their considerations, however, was being near a beach, for Phil, and near snow skiing, for Leo, which helped to define the possibilities for a new location. Being similar in some ways and different in others, for each family, led to the creation of new living situations with new possibilities. Thus, possibilities emerging with ambiguity, as a concept linked with Parse's concept of originating, offers insight into the cocreative process of the family in living with loss and grieving.

Confirming Realms of Endearment

The fourth extracted core concept in grieving that surfaced in this study was confirming realms of endearment, which represents the prizing of cherished involvements
and clarifying of priorities that was evident in the descriptions of all ten participant families. This concept encompasses the many descriptions of what participants were most concerned about in the grieving, what was important, what mattered, and what prompted gratitude and appreciation, all of which varied greatly, but was most often specified as relationships with close others and living for today. The concept relates also to the meanings of comfort, discomfort, enjoyment, suffering, other values mentioned by the participants, and to the meaning of loss itself.

Illustrations from the Dialogues

In Family Number 2, all three participants spoke in highly individual ways of their deep concerns for one another. Alice spoke at length about how she missed "the way we used to be" and having the energy to do the things she wanted, while the potential loss of the opportunity to see her children grow up prompted living for today and striving to "make memories" so that Hannah could remember her. In Family Number 3, the profound love between Beryl and Cheryl was not only evident in the verbal transcript, but was witnessed in the actual dialogue and strikingly apparent on videotape as they hugged and cried together as they spoke of Beryl dying.

In Family Number 4, Bonita said, "I lost a whole lot by finding out I was HIV," including her career as a cook, being close to nieces, nephews, and friends, and being able to do what she wanted without getting tired. Yet her chief concern was for her children, and she said she was glad that she could "be responsible...get out of the streets...and be a mother to my kids," and furthermore, "glad that I am HIV positive, because I can slow down...stay settled." In Family Number 6, Leo and Phil made very clear what their priorities were. They were ready to alter major aspects of their lives to move away from what "didn't matter anymore," their careers and material things, and toward what did, "enjoying life and each other."

For Family Number 9, Michael and Betty, the grieving prompted a renewal of faith for them both, prompted "the zest for life" in Michael, and eventually brought the family closer together. In Family Number 10, George described in detail what it meant to lose so
many cherished friends to the epidemic. Richard described the imminent loss of "virtually all of my close friends," but also described being "reassured" when friends experienced a change of perception like George's, prizing today and celebrating the life that was. That change of attitude for George and Richard renewed their partnership, and brought back smiles and laughter.

**Heuristic Interpretation**

The extracted core concept of **confirming realms of endearment** was structurally integrated with Parse's theory through an interpretive link with the idea of **honoring the treasured**, which is linked to the central concept of **valuing**, from Parse's theory. Parse says that valuing is the process of confirming cherished beliefs through "choosing from imaged options and owning the choices" (p. 45). Personal values form a matrix of beliefs "through which is screened all that is imaged from one's multidimensional experiences" (p. 45). **Valuing** is the fourth concept in the theoretical structure of grieving, in light of its congruence with the extracted core concept of **confirming realms of endearment**.

**Comparison with Related Literature**

The conceptualization of **confirming realms of endearment** enhances understanding of grieving as it is lived in families living with AIDS by shedding light on two key issues. The first is one of the crucial ideas in the evolution of grief theory, namely, that loss can only be defined by those who live it. The second is that family relationships are highly significant in grieving.

**The Phenomenology of Loss**

There is a range among theories of grieving in relation to what constitutes loss. Attachment theory (Bowlby, 1969, 1973, 1980), delineates an objectified notion of separation and loss, virtually devoid of any element of personal choice. Indeed, Bowlby drew heavily on ethological studies in formulating attachment theory, a procedure which he defended with statements such as the following: "A goose can court a dog-kennel and mourn when it is overturned. Ethological data and concepts are therefore concerned with phenomena at least comparable to those we as analysts try to understand in man" (Bowlby,
1969, p. 7). Although "attachments" may form in relation to virtually any "object," Bowlby clearly does not see this as a choice. Other theorists, such as Marris (1974) and Schneider (1984), do emphasize the personal meanings of loss, but their assumptions about loss and grieving as stimulus and response, stress and coping, reveal an underlying worldview in which the human being is a reactive organism; they do not see the making of meaning as the core of the phenomenon of grieving itself, but rather as one of the processes through which the human being adapts to an objective reality. The view of Parkes (1971) is similar to Bowlby's, albeit with more attention to personal meanings, in that he proposes that loss requires a restructuring of identity and worldview. His is still an objectivist view, however, in that the purpose of restructuring the "assumptive world" is to reconcile discrepancies between inner and outer reality. Even among those authors who reject the subject-object dichotomy, chiefly those in the existential-phenomenological tradition (Frankl, 1969; Heidegger, 1927/1962; Tillich, 1952), there is no recognized phenomenology of loss and grieving in the literature.

For this study, participants were asked to discuss grieving in relation to any loss or losses they had experienced. As there was at least one person with a potentially fatal infection in each family, and grieving is commonly associated with death and dying, it is not surprising that the majority of participants spoke about death and dying. Even so, their concerns within that context varied greatly, reflecting personal values. In addition, many participants spoke about a variety of other losses, including the "Dead-head" lifestyle (Rob), "the way we used to be" (Alice), a career as a cook (Bonita), an affluent lifestyle, a Hickman catheter (Max), John Lennon (Frankie), "a healthy immune system" (Michael), and a pet dog, some fifty years previously (Betty). This study, then, provides empirical substantiation for the centrality of personal meanings in loss and grieving. Persons coparticipate in creating a loss through the valuing of the relationship. Living with loss involves honoring the absent presence of the treasured as one moves on in life. This is reflected in the concept confirming realms of endearment.

The values most commonly and strongly expressed by participants in the study
were those of close relationships with others and prizing the now, which were usually mentioned in conjunction; that is, what was most often mentioned as a priority was sharing today with one's family in light of uncertainty about what was yet to be. The concept of confirming realms of endearment, is interrelated with the other three concepts in the structure of grieving, in that confirming realms of endearment relates to defining the loss, defining personal comfort, choosing to be present with close others, and defining the emerging possibilities. This view is congruent with Parse's view that valuing is an aspect of cocreating reality (1981, p. 42), and consistent with Frankl's (1969) view of values as the "substrates" of meaning. From this perspective, a human science cannot eschew values, as many objectivist scholars have tried, but can only develop through acknowledging that human values are fundamental to reality, and that science itself moves in that realm.

Family Relationships in Grieving

The participants in this study experienced significant changes in their family relationships while grieving, as described in the preceding sections. Some of the changes were related to others' views on AIDS. The significance of other's condemnation and ostracism related to AIDS, for this study, was primarily in the way it was experienced by participants as loss. But changes in relationships in light of personal values during grieving were described at times by a number of participants without reference to HIV or AIDS. For those anticipating personal death, being with close others brought comfort and assumed a new importance in their lives. For those anticipating the loss of someone close, making the most of the time they had with the other and prizing special moments were often mentioned as priorities. For those who described loss and grieving in the past, the experience often brought them closer to others and brought the value of the commitment to the fore. At the same time, different personal meanings of loss with shared and unshared priorities were interwoven in the patterns of relating, creating diverse textures and tensions, as persons in the family lived shared and unshared values all at once. All of these ways of owning and living choices in relationships with close others are encompassed by the
concept confirming realms of endearment. This concept, rooted in Parse's theory and linked with the concept of valuing, elucidates the cruciality of personal values in grieving as it is lived in families.

The Structure as a Whole:

Grieving as Becoming, a Nursing Perspective

The structure of grieving that emerged from this study is as follows:

- easing-intensifying with the flux of change
- through bearing witness to aloneness with togetherness
- as possibilities emerge with ambiguity
- confirming realms of endearment.

This structure and its conceptual interpretation within the context of Parse's theory, powering the connecting-separating in originating valuing, offer an alternative to the linear, homeostatic view of loss and grieving that is dominant in the literature. From Parse's perspective, change is a continuous, unitary process manifested in rhythmical patterns, and persons coparticipate in change, loss, and grieving. This view contrasts sharply with the predominant view (Bowlby, 1980; Parkes, 1987; Sanders, 1989; Schneider, 1984) in which the unitary human-universe interrelationship is not recognized. Further, this research offers a conceptualization of grieving that is not restricted by narrow parameters of normality, and is thus open to a greater range of human experience.

Frankl (1969) held that the "will to meaning" was the primordial force in human existence, that the human being was imbued with an innate capacity to transcend even the worst conditions through meaning making. The works of existentialist mental health practitioners like Frankl (1969) and May (1983) reflect a view with which this researcher's perspective and the findings of this study are generally consistent. Notable within works of existential psychoanalysis and psychology, however, is the tendency for existentialist beliefs, such as human freedom, self-realization, and transcendence to become goals of therapy. Parse's (1981, 1992) theory, by contrast, assumes a more radical unitary perspective in which "structuring meaning multidimensionally is cocreating reality" (1981,
Persons cannot not coparticipate in the creation of what is, was, and will be. The findings of this study were synthesized from the participant descriptions while abiding with this belief. Participants were found not merely to "respond" to loss through grieving the lost "object," but to coconstitute loss through living cherished beliefs and to dwell with the absent presence in their grieving. The multidimensional meanings of the loss and of day-to-day evolved through the grieving experience as new possibilities were cocreated with close others.

Existential psychoanalysts and psychologists have largely integrated the language of existential phenomenology with that of the disciplines in which they practice (Frankl, 1969; May, 1983). Frankl's "logotherapy," for example, was offered as an alternative mode for the practice of psychiatry. Parse's theory is specific to nursing, with clear links to nursing's heritage of attending to the whole person and incarnating a caring presence irrespective of societal norms. The findings of this study, guided by Parse's theory, offers a view of grieving that is specific to the discipline of nursing. From Parse's perspective, the person is a unity of the human-universe interrelationship, and possibilities are untethered by normative parameters as to what human beings "should" think, feel, or do.

The goal of nursing research, according to Parse (1987a), is understanding lived experiences of health from the person's perspective. The findings of this study, generated within this context and with this goal, contribute to the expansion and specification of nursing's body of knowledge through expansion and specification of Parse's theory in the substantive area of grieving.

The Findings in Relation to the Principles of Parse's Theory

Parse's (1981) first principle states, "Structuring meaning multidimensionally is cocreating reality through the languaging of valuing and imaging" (p. 42). The meaning of grieving for the families in this study was structured through the mutual reflection of cherished images of what was, had been, and was yet to be. This process cocreated the reality lived uniquely by each person in the family. What was, had been, and was yet to be continuously changed as cherished images evolved through living with the losses. The
concept confirming realms of endearment was structurally integrated with the theory by specifying this process as honoring the treasured, which relates to the concept of valuing. This interpretive linkage expands and specifies the theory by illustrating that the first principle enhances understanding of confirming realms of endearment in the lived experience of grieving for families living with AIDS.

The second principle of the theory states, "Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing, enabling-limiting while connecting separating" (p. 50). Grieving, for families living with AIDS, involved living with opportunities and limitations, presence and absence, divulging and hiding all-at-once; but what was brought to the fore was the experience of the true presence of close others while dwelling with one's ownmost personal losses (absence). The concept bearing witness to aloneness with togetherness was structurally integrated with the theory by specifying this process as communion-solitude, which relates to the paradox of connecting-separating. This interpretive linkage expands and specifies the theory by illustrating that the second principle enhances understanding of bearing witness to aloneness with togetherness in the grieving of families living with AIDS.

Parse's third principle states, "Cotranscending with the possibles is powering unique ways of originating in the process of transforming" (p. 55). Grieving, for the families in this study, involved agonizing struggles fluxing with joys while confronting the enigma of what was yet to be, which engendered innovative changes in patterns of living. The concepts easing-intensifying with the flux of change and possibilities emerging with ambiguity, which encompass these experiences, were structurally integrated with the theory by specifying the processes as pushing-resisting with diverse rhythms and unfolding with certainty-uncertainty. Pushing-resisting is the rhythm of powering. Certainty-uncertainty is a paradox of originating. These interpretive linkages expand and specify the theory by illustrating that the third principle enhances understanding of easing-intensifying with the flux of change and possibilities emerging with ambiguity, two core processes in grieving, for families living with AIDS.
The Findings in Relation to the Literature on Families

This study sheds light on patterns of family relating in grieving. Prospective participants named the close others they considered family with no imposition of parameters from the researcher. Most of the relationships among persons in this study would not be considered "family" relationships according to conventional family theory, or would be labelled and typologized as various forms of "nontraditional" families (Bane, 1976; Burr, Hill, Reiss, & Nye, 1979; Duvall, 1977; Eiduson & Alexander, 1978; Macklin, 1980). For this study, it was each participant's view of the family relationship that was important. Those who bore witness to suffering and lived committed relationships through the loss and grieving were present by choice; some were related by birth or marriage, some were not. This study suggests that greater attention to the meanings of lived experiences for families and less attention to stereotypical roles and rigidly hypostasized family structures would enhance the quality of family-centered research. By focusing wholly on the meaning of lived experience for the families, the researcher uncovered dimensions of grieving in families that had not been previously addressed in the literature. Thus the study itself and its findings are similar to the non-normative approach advocated by family therapists on the cutting edge of their discipline, such as de Shazer (1991), Fine & Turner (1991), Golann (1988), and Hoffman (1990).

This study represents a contribution to the expansion and specification of nursing's theory base in relation to families. The review of literature found that very few nursing-theory guided family-centered studies have been done. Rather the dominant trend in the family-centered nursing literature has been to borrow theory from other disciplines (Feetham, 1991; Gillis, Highley, Roberts, & Martinson, 1989; Miller & Winstead-Fry, 1982; Murphy, 1986). When approached from a human becoming perspective, family phenomena emerge in a new light. This study illustrates that family-centered research guided by Parse's theory of nursing surfaces a view of family phenomena that is not encompassed by theories from other disciplines. The study supports and substantiates the unitary, transformative view of the human-universe interrelationship in nursing's
simultaneity paradigm, which is specific to nursing. Nursing theory-guided research contributes, through its uniqueness, to the general knowledge base. This study supports the idea of family cocreated health as specified by Parse (1981).

A prominent feature of the nursing literature on families is the advocacy by some scholars (Feetham, 1991; Gilliss, 1983; Whall and Fawcett, 1991) of the family as the unit of analysis for "family research," a circumscribed type of research that the present study, in their view, would not fit. Moriarty (1990), Whall and Fawcett (1991), and others have noted the extreme difficulty often encountered when attempting to recruit "entire" families to participate in research. But this is more than a matter of difficulties in recruitment strategy. In this study, participants "brought their families with them" in a different way, as family members, living and dead, near and far, coparticipated in the study. The meaning of "family," like other meanings, is personal, contextual, and changeable. Having completed this study, the researcher finds the very notion of an "entire" family to be arbitrary and ill-fitted to family-centered research focusing on the meaning of lived experience.

Different persons "in" a given family have different views of who is family and who is not. Persons dwell with and cherish others who are far away, quite "unrelated" in the conventional sense, and even close others who are long dead. Persons commonly coparticipate in multiple families, who are all continuously transforming and not infrequently reconfiguring with the flux of change in life itself. Thus the attempt to entrain the "entire" family into a research project surely represents an impossible goal, unless one merely wishes to study the structural dynamics of a particular "type" of family, which, clearly, would be a theory-dependent endeavor. As the typologizing of families has not been associated with any nursing theory, this kind of family research is not rooted in the discipline of nursing. The distinction between "family research" and "family-related research" (Feetham, 1991) is similarly theory-dependent, that is, dependent on a hypostasized model of the family, and therefore this researcher finds the distinction to be less than useful. A different term, "family-centered research," has been used throughout
this study to avoid confusion. This study supports Parse's (1981) view of living with
predecessors, contemporaries, and successors all at once and the multidimensional
connectedness with the universe. Viewing the family from a unitary, multidimensional
perspective allows the lived meaning of the family to emerge in a way that is simply not
accessible through the objectivistic, normative approach.

The Findings in Relation to the Literature on Living with AIDS

As outlined in Chapter II, there is a dearth of scientific literature with an experiential
focus on living with AIDS. There are a number of recently published works on various
aspects of living with AIDS, some that seek to be comprehensive, and some that are more
circumscribed in their approach (Bartlett & Finkbeiner, 1991; Dietz & Hicks, 1992;
Froman, 1992; Pohl, Kay, & Toft, 1991; Walker, 1991). In sharp contrast to the vivid
and eloquent autobiographical material (Callen, 1990; Dreuilhe, 1988; Monette, 1990;
Rudd & Taylor, 1992) reviewed in Chapter II, the majority of the health and social service
professionals who authored these recent books have adopted a highly didactic tone, with
some texts actually written in the imperative mood. The authors use the conventional stress-
coping theories and family system theories to address and advise about living (and dying)
with AIDS. The relative historical uniqueness of the HIV epidemic has moved these
authors only rarely to venture forth with new theoretical formulations. For example, in
concluding her report of a major, five-year family therapy project with families with AIDS,
Walker (1991) proposes an "ecosystemic" model, addressing the "adaptive fit between
individual, family, and environment" (p. 322, italics retained from the original). In
proposing this synthesis of system and adaptation theory, Walker suggests that attention to
individual and family concerns must be considered within their historical, cultural, and
political contexts in order to increase access to available, and potential, survival and coping
strategies. This proposal stems not from an enhanced understanding of living with AIDS
but from recognition of the shortcomings of the existing health-care system, already well
known.

It is obvious in the autobiographical writings and in dialogue with persons living

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with AIDS that those who are living it already know more about living with AIDS than the "experts." Comparison of the findings of this study, particularly the narratives in which more details about living with HIV and AIDS appear, reveals that the way in which this study reflects living with AIDS is consistent with the first-person accounts of living with AIDS by Callen (1990), Dreuilhe (1988), and Monette (1990), and those collected by Rudd and Taylor (1992) which were excerpted in Chapter II. This is not surprising in light of this study's intentional focus on lived experience.

While the central focus of this study was grieving, and participants were asked only to speak with the researcher about "their experiences of grieving," all participants did speak about living with HIV or AIDS, with varying degrees of specificity. Many of these descriptions were incorporated into the extracted narratives in Chapter IV. Extraction-synthesis was not focused primarily on living with AIDS per se, but on grieving, and therefore no formal conclusions were drawn about living with AIDS. One area of significant overlap between these grief-focused descriptions and many of the HIV-focused descriptions is the loss of friends, associates, and sometimes family members, attributed to the diagnosis of HIV infection. Stigma and ostracization are widely addressed in much of the literature on HIV and AIDS. In this study, loss of friends and associates linked with the so-called "stigma" (none of the study participants used that term) are among the multiple losses grieved in many of the families. The focus of this study, however, was the meaning of the grieving experience, and, consequently, it was the meaning of the losses that emerged in the descriptions. The descriptions of living with AIDS that appear in this study are significant in that they were offered by persons in discussions which were elicited and openly accepted by the researcher with the sole intent of understanding the participants' lived experiences.

It cannot be overemphasized that the focus on humanly lived experience in research requires an adequate theory base and a value for the quality of life as it is lived that cannot merely be grafted onto the conventional scientific approach. O'Brien (1992), a nurse, presents, in her book, Living with HIV, experiential data from persons living with HIV.
that were strikingly similar to many of the descriptions in the present study. Her stress-coping framework, however, leads not to a description of the experience of living with HIV, but to a "typology of coping styles" (p. 164) with five styles differentiated along eight variables. Included on just one page of O’Brien’s work (p. 161) are the following quotes from different participants:

I’ve grown so much as a human being that it surprises me.

I was able to start looking at everyday for today, and just enjoying. And I learned to love myself and work on my self-esteem. I can be happy right now and be happy just being me.

I started giving more value to people and to life; it made me more responsible and mature.

I reorganized my priorities....

In some ways it is a kind of blessing that I have had to change my attitude; Now [sic] when I make choices I decide what is really important.

These experiences are introduced and discussed by O’Brien solely as “secondary gains,” labelled as such because they are conceptualized as "a positive force in helping the patients cope with an intrusive and life-threatening illness" (p. 160). She closes the brief section as follows:

...[I]t is important to note that neither the author nor the study participants consider HIV infection in and of itself as having positive attributes. Care must be taken not to seemingly "romanticize" a devastating and life-threatening condition (p. 162).

It is difficult to see the logic in conceptualizing experiences of personal growth, being happy just being oneself, clarifying priorities, and "giving more value to people and to life" as merely secondary or contributory to coping. The excerpts above are so similar to participants’ descriptions in this study, as illustrated in Chapters IV and V, that it would be repetitive to quote them again. It is remarkable how different these experiences appear when one's basic assumptions posit the primacy of meaning and quality of life in humanly lived experience. Hardly "secondary gains," these experiences were presented by participants in the present study as important, valued, and very much in the fore of their
overall experience, in rhythmic fluctuation with the pain and struggle of multiple losses and imminent death. Yet O'Brien's interpretation of these aspects of living with HIV makes these achievements, which seem to this researcher to be somewhat beyond "coping," into something merely "secondary" to coping. It appears doubtful that this would have been the case had her theoretical framework been oriented toward humanly lived experience rather than objective appraisal.

One commonality between the two studies is in the theme of uncertainty. O'Brien writes, "When participants...were asked if they could identify the one most difficult thing about living with HIV, the answer was almost universally that of uncertainty" (p. 40). The participants in the present study spoke spontaneously about uncertainty of the future, often saying it was "scary," but they also frequently linked the not knowing with the knowing—that life might be short, that some things couldn't wait, and that being with close others in the now was what mattered.

Nokes and Carver (1991) identified 11 experiential themes of living with AIDS. These were abstracted by the researchers into three themes. The findings of the present study will be discussed in relation to each theme of living with AIDS.

1. "Prevailing thoughts about mortality surface and subside" (Nokes & Carver, 1991, p. 177). Certainly this theme was strongly evident in most if not all of the descriptions in the present study. A dimension that may be added to consideration of this theme is the talking about it and not talking about it with close others that in most cases went along with "thoughts" of mortality. The "talking" at issue was not always related to AIDS, but also to mortality itself, death and dying. For many of the participants, this topic was very difficult to broach with close others. In this same vein was the diversity of personal needs and desires to talk about it, with no consistent connection to whether the person was HIV-positive or living with someone who was; rather it seemed to be a matter of personal preference or worldview.

2. "Relationships fluctuate as priorities change" (p. 177). The findings of the present study are obviously similar to this theme. Both studies were focused on the lived
experiences of persons living closely with a diagnosis of terminal illness. Nokes and Carver's participants were individuals living with AIDS and the participants in this study were families living with AIDS. The detailed descriptions under this heading in Nokes and Carver's article are strongly reminiscent of the descriptions of patterns of relating by participants in the present study.

3. "Shifting expectations lead to thoughts about spirituality" (p. 177). "Spirituality" apparently refers here not only to a higher power but to purpose in life and hope in the midst of suffering. These themes were also present in the descriptions offered by participants in this study. Less explicit in Nokes and Carver's study than in the present one is the interplay of diverse personal perspectives within the family in giving rise to expectations, although this is mentioned briefly. Nokes and Carver formulated an abstract statement within the context of Parse's theory, which says, "Living with AIDS is an abrupt shift in patterns of becoming, sparked by unpredictable changing relationships with others as different hopes and dreams unfold amidst suffering" (p. 177). The findings of this study are consistent with their conclusion.

Beauchamp (1990) investigated the struggle to make a decision in a critical life situation, for persons with HIV, guided by Parse's theory and using her method. He generated the structure: "affirming self through confronting uncertainty in moving toward the not-yet, while risking disclosing self with important others, as vacillating between options unfolds vision of the what might be in light of what was and is" (p. 78). Conceptual interpretation led to the theoretical structure of struggling to make a decision in a critical life situation, "powering originating in the revealing-concealing of imaging" (p. 78). Here again, the telling and not telling was found to be meaningful in the lives of persons living with AIDS. More pertinent to the present study, however, are Beauchamp's findings related to powering originating. He wrote that "individuals [with HIV] living the experience of struggling to make a decision in a critical life situation are affirming self through confronting the pushing-resisting of uncertainty in moving toward the not-yet" (p. 85). This is very similar to the findings of the present study.
Hall (1990) studied "the struggle of the diagnosed terminally ill person to maintain hope" for 11 men who were HIV-positive. She strongly refuted the notion of hope in the face of terminal illness as "denial" or wishful thinking. In her study, persons diagnosed with HIV maintained hope in diverse ways that would not always meet with the criteria of the "experts," such as: refusing to go to support groups where people talked of dying; avoiding talking and thinking about AIDS whenever possible; believing that "my mind was stronger than to allow myself to get too sick, too soon" (p. 181); staying busy, "maybe too busy" (p. 182); and "believing that they are never going to die of AIDS" (p. 182).

In this study, two of the core concepts in grieving for families living with AIDS were: easing-intensifying with the flux of change and possibilities emerge with ambiguity. The participant descriptions that gave rise to these concepts were similar to those presented by Hall. Many of the participants spoke of hopes and dreams that would be deemed by conventional science to be unrealistic, like 23-year-old Rob's picturing himself with Jeff as old men in rocking chairs watching the grass grow. Hall proposes that some of the essentials of hope for persons diagnosed as terminally ill are: "Having a future life in spite of the diagnosis....Having a renewed zest for life....[And] finding a reason for living, usually one that was not evident before" (p. 183). The findings of this study are consistent with her conclusions.

Building on Prior Parse Research on Grieving

In a previous study, the researcher investigated the lived experience of grieving a personal loss through dialogical engagement with individuals (Cody, 1991). The structure of grieving that emerged from that study was: "intense struggling in the flux of change while a shifting view fosters moving beyond the now as different possibilities surface in dwelling with and apart from the absent presence and others in light of what is cherished" (p. 64). The theoretical interpretation of the structure was "powering transforming through the connecting-separating of valuing" (p. 66). More recently, Pilkington (in press) used Parse's method to study "grieving the loss of an important other," for mothers who lost their babies at birth. Pilkington generated the structure: "anguished suffering in
devastating void amidst consoling movements away from and together with the lost one and others while confidently moving beyond personal doubts." The theoretical interpretation of the structure was "valuing the connecting-separating in transforming."

Commonalities among the three Parse studies of grieving are evident in the linkage with the concept of valuing, from the first principle of the theory, and with the concept of connecting-separating, from the second principle (Parse, 1981). Both Pilkington and Cody found that personal descriptions of grieving focus on the meaning of the loss, the uniquely cherished qualities of the relationship with the other. In Cody's (1991) study, four participants described their grieving for lost relationships with close others, primarily through death. In Pilkington's study, the women spoke of "shattered hopes and dreams" for life with the new baby.

The present study further substantiates valuing as a central concept in grieving, while clarifying some dimensions of the process. Persons in every family expressed clearly different values and beliefs, and the shared and unshared priorities structured the reality of daily living for persons in the family. For those who were HIV-positive, the whole meaning of being alive changed in a way that few participants believed others who were not so near to death could understand. At the same time, shared values and priorities were a strong feature in all of the descriptions, which perhaps was to be expected, since all of the participants were already living the shared value of being a family. The constant interplay of shared and unshared values and priorities was a central theme in the descriptions. This finding thus contributes to the expansion and specification of the concept of valuing from the first principle of Parse's theory, structuring meaning multidimensionally.

Both Pilkington (in press) and Cody (1991) found that personal descriptions of grieving focus on being with and apart from the absent presence and others all at once, though each phrased it differently (this is Cody's wording). This study further substantiates connecting-separating as a central concept in grieving. The findings of this study are in congruence with the description of "being with and apart from the absent
presence and others," while surfacing a slightly different aspect of the experience, specifically named as "bearing witness to aloneness with togetherness."

"Bearing witness," in the context of Parse's theory, means being truly present with another, which is personally attending to the lived reality of the other though one cannot participate in it in the same way. The simultaneous living of aloneness with togetherness through true presence was a central theme. This study thus contributes to the expansion and specification of the concept of connecting-separating, from the second principle of Parse's theory, co-creating rhythmical patterns of relating.

Interpretation of the lived experience of grieving in relation to the third principle of Parse's theory, cotranscending with the possibles, has been more diverse. The researcher's first study (Cody, 1991) specified powering transforming as the way of "cotranscending with the possibles" characteristic of grieving, while Pilkington (in press) specified this process as transforming, and the present study specifies powering originating. Both of the previous studies also mention the emerging possibilities and the underlying certainty-uncertainty: Cody's (1991) structure specified "different possibilities surfacing in light of what is cherished" (p. 65), while Pilkington's structure specified "confidently moving beyond personal doubts" (emphasis added). These interpretations suggest that only a shift of emphasis might have eventuated in a focus on originating as a central concept in grieving. This discussion should not be construed as a debate of an either-or nature, since Parse's perspective is that all of the processes specified in the theory are continuous, simultaneous processes of human becoming.

This researcher's focus on the concept of powering in interpreting both of his studies emerged from the emphasis on intense struggle and self-affirmation that was voiced in the descriptions of grieving in the two studies. This was heightened in the present study by the persistent sense of pushing-resisting, the rhythm of powering, among the pluralities of persons in the families. The emergence of originating as a central concept in grieving as it is lived in families is related to the plurality of views in each family. Originating is "choosing a particular way of self-emergence through inventing unique ways of living"
(Parse, 1981, p. 60). That this concept surfaced in a family-centered study bears closer examination. The paradoxes lived in originating are certainty-uncertainty and conformity-nonconformity. These qualities of self-emergence in life situations reflect Parse's first assumption, that human beings experience existence as coexistence and coconstitute rhythmical patterns with the environment (1981, p. 26). In this study, the choosing of unique ways of self-emergence surfaced in descriptions by the families as persons spoke about the options presenting themselves in the context of the family situation, knowing and not knowing how others viewed the possibilities, and basing important personal decisions largely on how they would bear on those who were close. This study, then, offers an opportunity for Parse scholars to consider the context of family life situations in relation to the process of self-emergence specified with the concept of originating.

**Methodological Considerations**

This was the first Parse study in which all dialogical engagements were carried out with multiple persons in the family engaged in the same discussion. It was the second Parse study in which videotape was used to record the dialogical engagements, preceded by Parse's study of laughing and health (in press). Discussion of these innovations in the use of the methodology will be presented separately.

**Using Parse's Method with Families**

This study strongly confirms that Parse's research method can be used with families as participants. Indeed, the findings suggest that using the method with families may illuminate the complexity of lived experience in a unique way.

The choice to undertake the study with families as participants influenced the entire research process. The conceptualization of "family" in the theory was carefully considered and made explicit in the study. This conceptualization, presented in Chapter I, is essentially that the family is "close others" as viewed by those involved. Clarity on this point led to specific procedures in participant selection. Prospective participant families were sought by addressing the published invitations "to Families Living with AIDS," in large type, while also clarifying in the text of the invitation that "family members may
include lovers and/or friends." Prospective participants evidenced no difficulty in understanding this usage of the term "family." Some participants hesitated before making an explicit decision as to "who" their family was. For example, was a deceased lover's mother "family?" In only very rare instances did prospective participants view engaging with all their close others in the discussion as a possibility. Explanations for this were not routinely sought by the researcher, since most callers were persons with AIDS, but reasons offered by callers were geographical location, age (of children), and not wishing to discuss HIV or loss and grieving with certain close others.

The actual dialogical engagements were carried out in essentially the same manner as dialogues with individuals. One obvious difference was that persons in the families spoke with each other. Some persons spoke mostly in parallel tracks, first one, then the other, addressing the researcher. Others talked back-and-forth with one another as well. There was no attempt to "iron out" these differences or to seek a standardized way of guiding the conversation through such moments. In some discussions, persons described experiences in which the other was involved, without comment from the other. Some family members simply said a great deal more than others, or interrupted, or spoke over others, as sometimes happens in conversation. Here again, the researcher made little or no attempt to "rectify" these situations.

The researcher was engaged with the participants in true presence throughout the discussions, which is basic to the method (Parse, 1987a). Within that context, the researcher was hesitant to interrupt the conversation to ask a different person to speak, believing that this might break the flow of the description. The researcher also believed that silence on the part of participants was a way of languaging something. There was no effort to interpret the silences—they were there in the rhythm of the dialogue. Dwelling with the descriptions later, the researcher saw more clearly that much had been said by some persons about the other(s) with little or no comment from those person(s), and much had been said by certain persons about meaningful aspects of their experience without comment from the other(s) present. Most of the descriptions offered were lengthy and detailed, and
addressed many issues of great significance to the persons offering them, often from two or more perspectives. Since the Parse method seeks to understand lived experience from the perspective of those living it, these aspects of dialogical engagement with families complicated the extraction-synthesis process exponentially.

Condensing and concentrating the descriptions into the form of extracted essences proved to be very challenging, as mentioned briefly in Chapter IV. In addition to merely including the proper names (pseudonyms) that appear in each extracted essence, it seemed necessary to the researcher to clarify whose view was being expressed, which led to use of many phrases like "Max says...," or "Jane believes...," or "For Rob...," and so on, while writing the essences, in the effort to preserve the uniqueness of the personal perspectives of the participants. Although this was a family-centered study, both the theoretical perspective and the descriptions strongly suggested that an appreciation of individual perspectives was crucial to understanding the experience of the family.

Through consultation with Rosemarie Rizzo Parse (personal communication, Sept. 1, 1992), and at her suggestion, it was decided to present a condensed version of each family's description in the form of an "extracted narrative" preceding the extracted essences for each family. Presentation of the descriptions in the form of a narrative offered greater opportunity to share the richness of the dialogues. It further led to greater clarity and readability in the extracted essences. Otherwise the presentation of findings in this family-centered study follows the same form as other Parse method studies.

Moving from the level of extracted essences to synthesized essences, the researcher found that the family-centeredness of the study eventuated in a shift to descriptive words and phrases encompassing the thrust of the entire description at this level. That is, the synthesized essences, and thus the proposition for each participant family, refer to the entirety of the family's description. Thusly, each synthesized essence reflects two or more views, sometimes in harmony, sometimes in conflict. The researcher believes that these procedures led to a family-centered structural and theoretical description of grieving that takes into account the unique personal perspectives of the individuals in the family. This
discussion of the use of Parse's method with families in this study is offered as a contribution to the honing of the method for use with families or other groups of persons. This way of presenting the extraction-synthesis was extremely useful and the researcher would recommend that it be followed in other studies with families as the participants.

Using Videotape to Record Dialogical Engagements

The dialogical engagements for this study were recorded on videotape, and the videotapes were used by the researcher to immerse himself in the descriptions during the extraction-synthesis process. This variation in the method was less consequential than the choice of engaging with families in the dialogues. The researcher believes that the findings would have been very similar had audiotape alone been used to record the family descriptions. This does not mean, however, that there are not significant advantages and other important considerations in the use of video with Parse's method. The researcher would recommend use of video with the method whenever possible.

One clear advantage of using video with families was that the videos did frequently clarify who was speaking and to whom that person was speaking. In addition, the videos not infrequently captured smiles, silent laughter, tears, and gestures, such as turning away from the conversation, that would not have been apparent through an audio medium. The two tapes (audio and video) served as back-ups for each other in the inevitable instances of technical glitches and other eventualities that resulted in minor gaps in the recordings.

Some of the descriptions were significantly enriched with the addition of the visual dimension. For example, in Family Number 3, Beryl and Cheryl spoke through tears throughout much of their discussion, Beryl held her arm around Cheryl's shoulders, and they hugged. The audiotape and the videotape undoubtedly would have conveyed at least slightly different meanings to anyone not present. The researcher, however, was present with the women as the discussion unfolded, and would have been aware of the crying and hugging whether or not video had been used.

There were a large number of instances in the family discussions in which persons (who were not speaking at the moment) nodded, shook their heads, smiled, or laughed at
what another was saying. These moments captured on videotape were helpful in 
interpreting the descriptions. In these instances the visual dimension helped to clarify the 
subtle patterns of harmony and conflict in the family. The researcher, however, was 
extremely cautious not to critically analyze the nonverbal expressions of participants 
captured on videotape, since this would violate the focus on the unitary human's lived 
experience. For example, the following is an excerpt from the transcript of the dialogue 
with Family Number 6:

Phil: ...This may be our last healthy month. So you don't put it off! You 
put a for-sale sign out front, you take the first offer that comes along, 
you pack a truck, and you're gone.

Leo: And you live for today.

Phil: And everything's going to be okay that way. [Leo nods.]

This interchange, including Leo's nodding, was taken to mean that Leo agreed that 
"everything's going to be okay that way." However, there were also other indications in 
the flow of Leo's remarks that contributed to that understanding. The researcher avoided 
anchoring understanding of any participant's view solely on such gestures, when a nod or 
a gesture was the participant's only expression related to the topic at hand. The sense of 
the whole experience is what the researcher dwelled with.

Mention should be made of the added complexity and expense, and the involvement 
of more persons that the use of video entails. Some people do not mind having their voice 
recorded but do not want their picture taken. One dialogue was actually scheduled, to be 
audiotaped only, with a family who felt this way, but was canceled for other reasons. 
Other miscellaneous considerations included the following. For this study, the researcher 
did not have proprietary control of the video equipment, which resulted in added delays, 
expenses, and inconveniences. The use of a cameraperson added complexity (scheduling, 
transportation, training) to the overall procedures for recording the dialogues, but the 
presence of the cameraperson was not mentioned by the participants in a negative manner. 
When no cameraperson was available, the researcher used a stationary camera set on auto- 
focus, which resulted in videorecordings of inferior quality, as did, in some instances, the
use of amateurs as camerapersons. These practical considerations may be important to
researchers considering the use of video for recording dialogical engagements in the future.
CHAPTER VI
CONCLUSIONS, REFLECTIONS, AND RECOMMENDATIONS

The conclusions drawn from this study are related to its major overall aim, to enhance understanding of grieving as it is lived in families living with AIDS through expansion of Parse's (1981, 1992) human becoming theory, and to the significance of the study for the advancement of nursing science. Conclusions related to nursing theory expansion, nursing research, and nursing practice are presented in this chapter, followed by reflections on the study and recommendations for research and practice.

Conclusions

This study elucidated the meaning of grieving for families living with AIDS using Parse's (1987) research method, through which the meaning given to the lived experience of grieving in families living with AIDS was uncovered and interpreted in light of Parse's (1981, 1992) human becoming theory of nursing. The view that emerged from the study was one of grieving as a process of multidimensional coparticipative unfolding. The emergent view of grieving is new to the literature on grieving in nursing and other disciplines. This view provides a substantive alternative to the view of grieving in families that is predominant in the literature, wherein grieving is seen as a linear process of maintaining homeostasis through adapting to the loss of an object, and the family is seen as a set of pre-defined roles and functions.

The structure of grieving generated through this study sheds light on dimensions of grieving that have not been explored extensively in the previous literature on grieving, including coparticipation in loss, the multidimensionality of the lived experience of change, the paradox of communion-solitude, the cocreating of new ways of living through dwelling with ambiguity. The study further specifies the cruciality of personal meanings and values in grieving. The study also shed light on patterns of relating among families in grieving, revealing a diversity of perspectives that intensified and eased the struggle, shared and
unshared priorities that uncovered new possibilities, and a reaffirming of committed relationships through presence. These conclusions will be discussed with reference to the significance of the study for nursing theory expansion, research, and practice.

**Nursing Theory Expansion**

The view of grieving that emerged from the previous Parse studies of grieving (Cody, 1991; Pilkington, in press) was expanded and further specified in the present study. It is a perspective on grieving that is uniquely related to nursing’s traditional focus on the human, environment, and health, to nursing’s concern for whole human beings in life situations, and to nursing’s heritage of incarnating a caring presence unobstructed by societal norms. The structure of grieving generated through this study thus represents an advance for nursing science in the substantive area of grieving. This advance of nursing theory reflects the maturation of nursing science to the extent that its body of theory contributes new dimensions to the general knowledge base.

**Nursing Research**

Research guided by Parse’s human becoming theory has progressed rapidly over the past ten years, from research using non-nursing qualitative methods, to studies using Parse’s method, and now to Parse studies building on prior research and using the method in new ways. This study contributes to the honing of the method for use with families and with the use of videotape to record dialogical engagements. Many nursing scholars have called for greater effort among nursing researchers to investigate phenomena of relevance to families. This study, by enhancing nursing’s theory base on grieving in families, confirms that Parse’s method is a viable mode of inquiry for substantive family-centered research. The use of Parse’s method with families uncovered the complexity of life as it is lived, guided the researcher to seek an understanding of grieving in families without discounting individual lived experiences, and led to dialogical engagements in which family patterns of relating unfolded in the moment. The research report also details salient considerations in the use of videotape for Parse studies or similar qualitative approaches.
Nursing Practice

Nursing is increasingly viewed from within the discipline as a human science with its preeminent focus on quality of life and lived experiences of health. Practice in such a discipline is very different from traditional bio-medical or bio-psycho-social nursing practice. It requires the guidance of a well articulated and substantive theory base. This research contributes to the expansion and specification of Parse's human becoming theory in the substantive area of grieving. Continuing elucidation of the view of phenomena such as grieving as human becoming (a lived experience of health) is still needed in light of the proliferation of competing theories that infiltrate the related discourse on many levels. Enhanced understanding of lived experiences as lived experiences changes the way nurses are in practice with human beings. Parse's theory has already been empirically substantiated as a sound guide to coparticipative practice focusing on quality of life (Butler, 1988; Mattice, 1991; Mattice & Mitchell, 1990; Mitchell, 1990b; Mitchell, 1992a; Quiquero, Knights, & Meo, 1991; Rasmussen, Jonas, & Mitchell, 1991). Theory-guided research on lived experience, such as the present study, by expanding and specifying the theory base, enhances opportunities for nurses to understand lived experiences in new ways and to participate creatively with persons in their becoming.

Reflections on the Study

From its inception, this project involved many challenges for the researcher, while also providing the opportunity to participate in nursing research and theory expansion on the cutting edge of nursing science. A view of nursing as an autonomous science with a unique perspective and a knowledge base that is knowable only through the formal study of nursing was intrinsic to the entire project. This study offered the opportunity for the researcher to grapple with issues of significance in nursing in relation to its paradigms, its theory base, its own perspective relative to those of other sciences, its often stated but neglected attention to families, and the honing of a unique nursing research methodology. It further offered the opportunity to participate with families living with AIDS in exploring the meaning of their experiences with grieving. All of these aspects of the study are
attributable to Parse's human becoming theory of nursing.

Dialoguing with the participants in true presence as they described their struggles and joys was a profoundly rich experience for the researcher. The participants' candid and intimate telling of their deeply personal stories, even sharing with others in the family what had not been shared before, was convincing evidence of the value of true presence in surfacing the meaning of life situations and propelling beyond the now (even though the latter was not a goal of the research). The participants' seemed to know that their experiences would not be labelled and judged even though it was never verbalized. The researcher strived to carry out the responsibility of participating in the freely granted privilege of being truly present with persons as they languaged some of the most intimate and painful aspects of their lives, through generating a thoughtful, respectful, and dignified portrait of the anguish and beauty that was shared.

The one aspect of the study of singular importance is its realization as a nursing research project rooted wholly in the discipline of nursing, guided by Parse's theory to make a contribution to the evolution of nursing as a human science. Nursing, while being challenged, like other sciences, to become more open and sensitive to the actual values, experiences, and quality of life with which "real people" are concerned, is additionally challenged by its tradition as an applied-science discipline that merely utilizes theories from other disciplines in health-related service. The future of nursing as an autonomous science depends on the development of its unique theory base. The researcher believes that Parse's human becoming theory represents the apex of current nursing science on both of these fronts. The central challenge for the researcher, then, was to advance knowledge of quality of life as it is humanly lived while contributing to the expansion and specification of Parse's theory, which explicitly values this overall project as its central goal in inquiry.

Recommendations

Recommendations arising from this basic nursing research, that is, basic inquiry into the phenomenon of concern to nursing, range from the broad to the specific, and are primarily directed toward further nursing inquiry. Recommendations for nursing practice
are specific to practice guided by Parse's theory.

Recommendations for Nursing Research

This study supports the pursuit of nursing-theory guided research. The depth with which second- and third-generation nursing theory-guided research may enhance understanding of the phenomena of concern to nursing and uncover different dimensions of human experience is illustrated through this study. It is recommended that further Parse research be conducted on grieving, hope, laughter, struggling through a difficult time, and other phenomena on which one or more studies have completed.

The growth of the human becoming theory base may be enhanced by further investigation of the core concepts and related experiences in grieving that emerged from this study. Lived experiences that could be explored in this light include: (a) being with and apart from loved ones through a difficult time; (b) doing the best you can in an "impossible" situation; (c) bearing witness to suffering; (d) choosing a path while not knowing the outcome; (e) keeping a secret; and (f) restriction and freedom while living one's dying. In light of the relative diversity of findings on grieving related to Parse's third principle, as discussed in Chapter V, a priority for research on grieving that it guided by Parse's theory should be focusing on the processes of self-affirmation, self-invention, and transformation as lived in grieving. Lived experiences that could be explored in this light include: (a) struggling with unwelcome change; (b) choosing to be like and unlike others in a critical life situation; and (c) gaining a new perspective through living with loss.

Obviously, one option for future research that is supported by this study is the choice of families as participants. It is recommended that researchers conducting family-centered studies guided by Parse's theory closely attend to the meaning of Parse's definition of family as close others from the perspective of those involved. For family-centered research focused on lived experiences and quality of life, it is clearly more cogent to attend to the way the persons in the family view themselves and their own experiences than to map out the structural dynamics of a social grouping objectively identified as "the family." This certainly does not contraindicate studies with families resembling the nuclear
family model if this is the way they see themselves. Caution is warranted, however, in that the relentless pursuit of "entire" families for family research is likely to be unproductive and less than meaningful, given the multidimensionality of family life as experienced, which clearly suggests that drawing a boundary line around the family is arbitrary at best.

Researchers using Parse's method with families and groups are encouraged to be at ease with the silences and not to be concerned with ways of asking to hear from those who are silent. For nurse researchers with little experience in the method, the researcher advises adhering to the basic precept of the method in dialogical engagement, true presence. Introducing questions aimed at hearing from all participants would violate the assumptions upon which dialogical engagement is built. In this researcher's opinion, silence is languaging without words and is itself a message intrinsic to the whole of the situation. This reflects an intuitive belief, arising from the researcher's experience, that what is revealed in true presence uncovers aspects of lived experience that would remain opaque to intrusive questioning.

It is recommended that video be used whenever possible to record dialogical engagements, especially with families as research participants. The videotapes significantly enhanced the immersion process in dwelling with the descriptions in a way that other media could not. Lastly, it is recommended that family-centered studies using the Parse method include an "extracted narrative" prior to the extracted essences, as done in this study. This procedure preserved the richness and vigor of the original complex, deeply meaningful descriptions, and enhanced clarity and readability in the extracted essences.

Recommendations for Nursing Practice

Subsequent to the researcher's first study of grieving, the researcher began to evolve a practice proposition on grieving. The practice proposition reflects the essential meaning of the structure of the lived experience, on a lower level of abstraction appropriate to the immediacy of practice. The evolving practice proposition has been revised in light of the findings from this study, and now states, Struggling with the ambiguity of a changing now through bearing witness to an absent presence sheds light on what really matters as
creating new possibilities shifts priorities. This proposition is consistent with the findings of all three Parse studies of grieving. It is anticipated that further study will continue to evolve the practice proposition.

The proposition is also consistent with Parse's (1987a) practice methodology. The nurse practicing from the human becoming perspective has the opportunity to be with persons and their families with this knowledge base on grieving. Parse's (1987a) practice method is living the processes of: illuminating meaning through explicating, synchronizing rhythms through dwelling with, and mobilizing transcendence through moving beyond (p. 167). With an understanding of the lived experience, the nurse knows that grieving is both struggling and joying with change while bearing witness to a cherished-but-absent presence, which sheds light on what really matters, as shifting views of possibilities prompt movement toward the not-yet.
References


Dietz, S. D., & Hicks, M. J. P. (1992). Take these broken wings and learn to fly (second ed.). Tucson, AZ.


Nursing Science Quarterly, 3, 177-184.


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Pilkington, B. (in press). The lived experience of grieving the loss of an important other. Nursing Science Quarterly.


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Toronto, Ontario: Second Story Press.


Family Relations, 34(1), 43-49.


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Appendix

Informed Consent Form

In signing this document, I am giving my consent to participate with William Cody and my family members in a discussion of my family's experiences with grieving, as a part of a nursing research study. I understand that this discussion will be videotaped and audiotaped, and hereby give my permission for such recordings. I understand that I will be asked to discuss with my family and Mr. Cody my experience of grieving, and our experience of grieving as a family, and that our discussion may take about one or two hours to complete.

I understand that I may experience some uncomfortable feelings while discussing loss and grieving. I have been told that there are no known benefits to this discussion other than its contribution to nursing research, and the possibility of increasing understanding, as in any discussion. I have been told that the knowledge to be gained through this study may enable nurses in practice to provide better care for families who are grieving.

I have been informed that the discussion is entirely voluntary, and that I can terminate my participation at any time. I have been told that a transcript of the discussion will be prepared from the tape-recordings, and that quotations from the discussion may be used without real names in the report of the study, but that no report of this study will ever identify me or my family in any way. I have also been informed that my participation or non-participation in this study will have no effect on services that I or any other member of my family may receive.

I understand that I may contact the researcher at any time should I have any uncomfortable feelings about the discussion or the study. The researcher will contact me approximately one day, one week, and one month after our discussion to ask if I have any concerns regarding the discussion or the study. I understand that I can obtain the results of this study by contacting William Cody at [contact information], or by telephone at his home, and that Mr. Cody will answer any and all questions I may have about the study or my rights as a participant in the study. I will receive a copy of this signed consent form.

If I am signing this document as the legal guardian of a person under 18 years of age, I hereby acknowledge that I have discussed participation in this study with the child or minor named below, who has expressed a desire to participate in the study. I have agreed to allow the child or minor named below to participate in this study, and I agree to remain with the child or minor for the duration of the discussion.

_________________________________________  __________________________________________
Participant's Name as Stated                  William K. Cody, RN; MSN

_________________________________________  __________________________________________
Participant's Signature                     Researcher's Signature

Date                                            Date

_________________________________________  __________________________________________
Guardian if under 18 years of age                     Date

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