

AN ABSTRACT OF THE THESIS OF

Cheron J. Mayhall for the degree of Doctor of Philosophy

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Title: The Development of a Methodology to Study the Grief and
Adjustment Processes of Parents Following the Death of
a Young Child

Abstract approved:

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Mary Jane Wall, Ed.D.

Purpose of the Study

The primary purpose of this investigation was to develop a methodology by which to objectively study and assess the grief and adjustment processes of bereaved parents. An original research and counseling instrument, the Parental Bereavement Interview and Rating Scale (PBIRS), was formulated, field-tested in a preliminary study, and revised. In pursuit of this purpose, descriptive data about the grief of parents who lost a young child (1-20 years) due to sudden and unexpected circumstances were obtained and reported.

Research Questions

The thirteen research questions addressed fall into three main categories: (a) methodological considerations regarding the construction and format of the PBIRS, the protocol for its administration, and the age criteria used for selection of subjects; (b) quantitative data describing the nature of the parental grief and

adjustment processes; and (c) descriptive information about the general characteristics of the subject group in comparison to other bereaved parents in the U.S. and Canada.

Methodology

The PBIRS was administered between January and April, 1982, to 20 bereaved parents residing in northwestern Oregon. The instrument is based on an expanded version of Kübler-Ross' grief-stage theory, exploring the grief and adjustment processes through the stages of Denial, Anger, Guilt, Depression and Adaptation. A retrospective research method was employed to examine and assess the subjects' progression through the bereavement experience.

The Pearson product-moment correlation coefficient was computed to determine the test-retest reliability for PBIRS items. The data were further presented in graphic and tabular forms to allow for comparison between various time periods in the grief process, and between different sub-groups of subjects.

Findings

The research methodology and instrument were field-tested with satisfactory results. The preliminary reliability study showed 85 percent of the items to have test-retest coefficients of correlation significant at the .05 level. The instrument and the protocol for its administration were well-received by subjects and by leaders of self-help groups for bereaved parents.

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The Development of a Methodology to Study the
Grief and Adjustment Processes of Parents
Following the Death of a Young Child

by

Cheron J. Mayhall

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in charge of major

Redacted for Privacy

Dean of the School of Education

Redacted for Privacy

Dean of the Graduate School

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Typed by Donna Lee Norvell-Race for Cheron J. Mayhall

DEDICATION

❖ *This work is dedicated to the memory of our beloved son, Scotty. His creative and loving spirit continues to influence and inspire my life and my work.*

*Thomas Joseph Scott Mayhall
March 13, 1973 - July 22, 1977*

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Completing this project has been an important part of rebuilding my life over the past five years. I have gathered strength and support--brick and mortar--from many sources. I am deeply grateful to the following people who believed in the blueprint and assisted in the building:

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My husband, Bill, whose love and unquestioning support have sustained me and our children, Phillip, Laura and Katrina.

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The Development of a Methodology to Study the
Grief and Adjustment Processes of Parents
Following the Death of a Young Child

CHAPTER I

INTRODUCTION

Over the past two decades there has emerged a considerable interest in the study of bereavement and the process of coping with death. Today there is a demand for knowledge about the ways in which human beings experience the emotional and social impact of death. However, there is still very little available information about the processes of mourning and coping with the deaths of children other than infants, even though authorities have identified parental bereavement as the "most distressing and long-lasting of all griefs" (Gorer, 1965, p. 123).

Lily Pincus (1974), a British family therapist who writes extensively on loss and grief, calls bereavement through the loss of a child "perhaps the most painful loss of all in our small families" (p. 208). Gorer's (1966) clinical observations suggest further that the loss of a grown child often produces even more intense and prolonged parental stress than the death of a youngster. Others (Shirkey, 1976; Vanderpool, 1976), also considering the variable of age at time of death, point to the deaths occurring between infancy and young adulthood as being the most tragic and unacceptable.

People are expected to live long enough to finish their lives, and death for the young is feared and dreaded because they are denied the time to complete life's tasks and participate in the many enjoyable events that life can offer. Whatever the age, for a child to die before his parents is perceived as a violation of the

order of life and is, therefore, less easily accepted.

Researchers and other observers in the field have identified several factors which serve to increase the traumatic consequences of childhood death in modern society. Technologically advanced societies generally benefit from sophisticated medical practices and public hygiene which make childhood death relatively rare and lower the expectation of loss (Cain and Cain, 1964; MacCarthy, 1969; Bowlby, 1960). At the same time, American families now have fewer children than in the past, and there appears to be a greater emotional investment and potential for attachment associated with each child (Parkes, 1972; Switzer, 1970).

Industrial societies have largely eliminated the extended family and made the nuclear family the norm so there are fewer available substitute objects and fewer supportive family members to lessen the pain of separation. Furthermore, Krupp (1972) notes the current trend toward greater individual freedom within the family which weakens it as a unit in terms of control and intimacy among its members, meanwhile reducing its ability to be a source of comfort. This is often coupled with an emphasis on the uniqueness and worth of the individual, regardless of age, which defines the deceased as irreplaceable and deepens the sense of grief.

Many researchers have studied the reactions of parents to the death of an infant under one year, particularly the case of Sudden Infant Death Syndrome, or SIDS (Benfield et al., 1978; Row et al., 1978; Gardner, 1976; Mandell and Belk, 1977; Graves, 1978; Bergman, 1973). The present study omits infant death situations in an effort to concentrate on parental reactions to the deaths of older children, ages 1-20. It is not apparent whether or not the bereavement experiences differ significantly because the parents of older children have received negligible attention in the research literature.

Other investigators have studied and assessed the characteristics and behaviors of parents of children with terminal illnesses (Bozeman et al., 1955; Friedman, 1974; Solnit and Green, 1959;

Wallace and Townes, 1969; Hamovitch, 1964). A most important element in the coping pattern of these survivors is the process of "anticipatory grief," wherein there is a gradual intellectual and emotional acceptance of the diagnosis and a slow adaptation to the death prior to its actual occurrence.

Little research has been directed toward the observation and assessment of the experiences and characteristics of parents following the relatively sudden and totally unexpected death of a young child over the age of one year. These factors of age and suddenness are primary considerations in identifying subjects for the current study.

Whether the young child succumbs in infancy or later, whether the death is due to accident, murder, suicide or either acute or chronic illness, whether the death is sudden or anticipated over several weeks, months or years--whatever the combination of circumstances, the loss of a child is almost inevitably a tragic event for the family.

The death and dying of a child is always "untimely." In the literature, "untimely death" refers to the demise of a relatively young person at a disadvantageous time. It is generally accompanied by surprise, shock and lack of preparation (Engel, 1964; Lehrman, 1956). MacCarthy (1969) goes so far as to say that "the death of a child is never recovered from" and the impact of the sudden and unexpected death of a child is so overpowering that long-term repercussions are almost certain to arise from it. Such long-standing ill effects might include physical symptoms, behavioral changes, unresolved guilt, and inability of the parents to commit themselves wholeheartedly to their other children (Bozeman et al., 1955; Friedman, 1974; Hamovitch, 1964).

Anne Morrow Lindbergh's (1973) sensitive autobiographical work, written following the kidnapping and murder of her young son, attests poignantly to the unacceptability of losing a child due to accident or violence:

I will never accept it--cannot accept it or get used to it or past it ... it is not a normal sorrow ... it will not be absorbed but always be there, and always hurting, like something in your eyes. Nature does not absorb it but gradually provides a protective covering which numbs the sharp pain, but you are always conscious of it (p. 316).

Impetus for the Study: A Statement
in the First-Person

My interest in the plight of the bereaved family members who survive the death of a child is far from casual or purely academic or professional. It was the accidental death of my own small son, Scotty, which precipitated my involvement in this area and fostered my determination to pursue this investigation.

In the summer of 1977, in the midst of my doctoral study in counseling, our four-year-old was killed almost instantly as the result of internal injuries sustained in an automobile accident while riding with a baby-sitter. We had kissed and said good-bye that evening to a healthy, happy, beautiful child, and two hours later he was gone forever. Needless to say, that event has changed the course of our lives and will doubtless have a continuing impact on our behavior and our thinking for all the years ahead.

Almost immediately, my new role as a bereaved parent made me keenly aware of the lack of available information about parental bereavement in this situation. I was a counselor keeping professional and academic company with other counselors and teachers of counselors. We were all supposed to be proficient in helping people who were experiencing varying types and degrees of emotional stress. We had all counseled numerous clients through their experiences of loss and sadness. We had all known widows; each of us had at least one acquaintance who had suffered and died from a terminal illness. But Scotty was so young and so healthy, and it had all happened so quickly and so unexpectedly. The combined factors of

youth and suddenness were significant dimensions of the grief and coping processes which few of us had previously considered, either personally or professionally.

I felt a desperate need to know how other parents had experienced a loss such as ours, and I wanted to hear it directly from them. Most books and articles about grief I found to be ambiguous in that they attempted to explore and explain bereavement in very broad terms relevant to all survivors and situations. Most did not seem very pertinent to the youth and suddenness factors which were so important in my case. My study is designed to help meet the apparent need for such information.

Other counselor-friends, empathizing to a degree with my feelings of frustration and helplessness, asked me to share the professional insights I was gaining firsthand. Thus, I have always tried to discuss with them very openly my observations about parental bereavement. At the outset, such discussions were usually more personal and subjective. But, as my research has progressed and the temporal distance from Scotty's death has lengthened, I have attempted to add objectivity and clarity to my growing expertise on the subject.

I do not believe that this sort of investigation could be done as thoroughly and as sensitively by a researcher who had not lost a child of his or her own. I have been in a position to bring the necessary mix of personal involvement and professional objectivity to the project. From the personal standpoint, I have sought to make it meaningful and worthy of Scotty's memory. For me as a professional, and hopefully for other counselors as well, it is a study that can add new and positive dimensions to the work of clinical practitioners by (1) providing a counseling tool to aid in interview and assessment procedures with bereaved parents, (2) providing some data by which to measure the coping progress of clients who are bereaved parents, and (3) adding to the store of

general knowledge about parental bereavement.

The Purpose of the Study

It is the purpose of this investigation to develop a methodology by which to objectively study and assess the grief and adjustment processes of bereaved parents. An original research and counseling instrument, the Parental Bereavement Interview and Rating Scale (PBIRS), has been formulated and field-tested in a preliminary study. In pursuing this purpose, descriptive data about the grief of parents who lose a young child (aged 1-20) due to sudden and unexpected circumstances were obtained and reported.

Research Questions

The research questions addressed in the execution of the preliminary study and in the presentation of the data fall into three main categories: (A) Methodological considerations regarding the construction and format of the research instrument, the protocol for its administration, and the age criteria used for selection of subjects; (B) Quantitative data describing the nature of the parental grief and adjustment processes; and (C) Descriptive information about the general characteristics of the subject group and how they compare with those of other bereaved parents in the United States and Canada.

A. Methodological Considerations

1. Does the research instrument (PBIRS) have face validity as a measure of parental grief and adjustment?
2. What are the test-retest reliability estimates for the PBIRS?
3. Can the parental grief and adjustment processes be usefully and comfortably divided into three time periods: I = 0-6 months

after the death; II = 7-24 months after the death; III = 2-5 years after the death?

4. Is the designation of "young child" for children ranging from one to twenty years suitable and viable in terms of the characteristics of the parental grief process their deaths appear to precipitate? (See also research question 11.)

B. The Nature of Parental Grief and Adjustment

5. Does the intensity of parental grief responses (Denial, Anger, Guilt, Depression and Adaptation) decrease over time?

6. When do parents report negligible intensity for most grief responses?

7. When do parents complete the Denial stage and accept the finality of their child's death?

8. When do suddenly bereaved parents attain complete resolution of Anger?

9. When do suddenly bereaved parents attain complete resolution of Guilt?

10. When will most suddenly bereaved parents report a total or near-total level of Adaptation and grief resolution?

11. In what general ways is the grief process different or similar for parents with respect to the different ages and developmental stages of themselves and their deceased children?

C. Demographic Characteristics of Bereaved Parents/Subjects

12. What demographic features characterize the subjects in the pilot study?

13. How does this subject group compare with other bereaved parents surveyed in the U.S. and Canada in terms of (a) basic descriptive characteristics, and (b) the details concerning the deceased child and his/her death?

Definition of Terms

For the purpose of this study, frequently used terms are defined as follows:

1. The young child is one who has died between his first and twentieth birthdays. The lower limit was chosen to exclude deaths from SIDS and other fatal conditions of infancy since this area has already received much attention in the literature. It also reflects the researcher's opinion that the toddler or older child, moreso than the infant, has had the time and opportunity to more fully develop distinctive traits, features and achievements. This greater development of the child's unique personality serves to increase the likelihood of the repeated remembrances, comparisons and identifications which usually complicate and prolong grief work (Cain and Cain, 1964).

One bereaved father and pastoral counselor has written:

There is no sorrow quite so heartrending as the death of a little child. If the child lives long enough to walk and to talk, the faltering steps and childish prattle are like a lingering fragrance in the home that seems so strongly silent. The arms are empty, the eyes fill with tears, and the heart is like a vacant house (McGee, 1976, p. 9).

The upper limit is more arbitrary, but it is based on the observation that the end of the teen-age and high school period is generally accompanied by the development of greater independence from the family, and this might have added a highly significant dimension to the study.

2. A sudden and unexpected death is that of an apparently healthy child occurring within two weeks of the recognition of the life-threatening event--usually in an accident or acute illness. In such instances, there will have been little or no time for anticipatory mourning to occur.

3. Grief, mourning and bereavement have been variously defined and differentiated in the literature, one author's definitions often contradicting another's (Kastenbaum, 1977; Krupp, 1952; Parkes, 1972; Switzer, 1970; Keleman, 1974). For purposes of this study, the three terms have been used interchangeably and can be understood to mean a psychological process through which a person reacts to and copes with feelings of helplessness, sadness and loss subsequent to the death of an important, loved person. Experts have identified a characteristic series or group of stages in this process. The stages may be interchanged and the timeline for completing the process is highly variable, according to the social and emotional resources of the bereaved person. For this study, the process will focus on an adapted and expanded version of the five stages posited by Kübler-Ross (1974): Denial, Anger, Guilt, Depression and Adaptation.

4. Denial (D) is a stage characterized by a refusal or inability to believe the death has occurred. The bereaved person may appear dazed and confused. S/he may continue to talk of the deceased in the present and future tense, rather than in the past. There are conscious and unconscious efforts to recover and hold on to the decedent through dreams and fantasy as well as continued contact or association with tangible reminders of the child--his belongings, photographs, the burial site, etc. This stage allows for the avoidance or postponement of intense distress and expression of emotion while the reality of the loss is tested and gradually accepted. Denial is usually a short, transitional stage, prominent during the first week or two of bereavement, but it may return at times during later stages, especially through dreams.

5. Anger (A) is an essential stage in the course of grief work during which the bereaved person reacts to feelings of helplessness and rages against the injustice of death. Anger can be

either rational or irrational and may be directed at the deceased, the self, friends or relatives, medical personnel, God, fate, the person or circumstances responsible for the death, or any combination of these.

The stage is commonly characterized by hostility, irritability, bitter accusations, self-reproach, resentment, envy and blame. The anger often arises unexpectedly and is difficult to control. This stage usually follows Denial and serves to relieve some of the anguish of facing reality. The ability to feel, and the opportunity to vent, one's anger toward other persons and circumstances may facilitate adaptation by reducing self-blame and guilt. However, since the angry mourner is asking, "Why me (my child)?," and because the "Why?" is frequently unanswerable, the anger may never be totally resolved, only reduced to within manageable, non-debilitating limits.

6. Guilt (G) is the stage during which the mourner berates himself for a wide variety of his/her feelings and behaviors with respect to the deceased and his/her death. It involves coming to grips with negative feelings toward the deceased and often includes exaggeration of past acts or fantasies of hostility, inconsiderateness or unkindness. There may be guilt for having a sense of "relief" that the death has occurred, or for having a sense of joy for having survived.

There is commonly a haunting preoccupation with feelings of responsibility for the death or feelings of failure and regret regarding the relationship with the deceased. Guilt may also be displaced through blaming and scapegoating behaviors. The intensity and duration of guilt varies widely, but may be especially pervasive among bereaved parents. As with anger, it may never be totally resolved, only attenuated to within non-debilitating limits.

7. Depression (DP) is a stage of disorganization characterized by apathy, despair and depersonalization. It is reality-based in

that the death is understood and accepted as unchangeable. Yet there are feelings of unreality, change and strangeness in relation to oneself, others and the world. The depressed mourner may experience a failure to perceive feeling and emotion and may manifest social and emotional withdrawal. (There is usually a concurrent recession or withdrawal of external support systems during this period.) Most mourners experience a greater need for sleep to avoid, or to gain a periodic relief from, the continual suffering and distress. For most it is an extremely painful period out of which the organism struggles to regain equilibrium and progresses to a period of reconstruction.

8. Adaptation (AN) is the stage wherein the mourner reconstructs his/her life and re-aligns self- and world-concepts to fit his/her new state of affairs, i.e., life without the deceased. The mourner is not observably depressed or angry, and hope becomes evident. It is a time of emotional calm--no great fear, joy or sadness. There is a transfer of interest from the deceased to the living world and a change of focus from the past to the present and future.

Lindemann (1965) sees Adaptation and grief-resolution as "emancipation from the bondage to the deceased, readjustment to the environment in which the deceased is missing, and formation of new relationships" (pp. 10-11). Some bereaved persons may engage in adaptive behaviors concurrently and intermittently with all other grief stages, but true adaptation and grief-resolution will only be accomplished when the other four stages have been satisfactorily completed.

9. The intensity of a grief response is a measure of the degree to which that response was felt or exhibited by the subject. The PBIRS allows subjects to rate intensity on one of four levels: 1 = none or negligible; 2 = low to moderate; 3 = high; 4 = extremely high.

10. The Compassionate Friends is an international self-help organization offering friendship and understanding to bereaved parents. The purposes are to promote and aid parents in the positive resolution of the grief experienced upon the death of their child, and to foster the physical and emotional health of bereaved parents and siblings. Subjects for this study were identified through TCF.

Basic Assumptions

The following assumptions are implicit within this study:

1. Subjects responded as completely and truthfully as possible to the items on the interview.
2. Experiences during the first two years of bereavement were recalled and described accurately by subjects, all of whom were interviewed two to five years after the child's death.
3. The breakdown of the bereavement period into three approximated segments (0-6 months, 7-24 months and 2-5 years) facilitates responses to some questionnaire items by allowing subjects to report changes in their experiences from the period of acute grief to the later stages of grief work.
4. The experience and insight of the researcher as a bereaved parent was an asset in generating items for the interview form and rating scales and in eliciting complete and accurate responses and ratings from interviewees.

Limitations of the Study

The following limitations are recognized:

1. This study is limited by the small sample size necessitated by the method (time-consuming and emotionally strenuous interview), the geographical distribution of subjects, the sensitivity of the

subject matter, and financial constraints.

2. The subject group is not a true, randomized sample, but a "sample of convenience." Participants were self-selected according to their willingness to examine and discuss their grief experiences. However, in the opinion of the researcher, there is nothing to indicate that this group is not representative of bereaved American parents in other parts of the country, or that the results are not generalizable to that larger population of parents bereaved under comparable circumstances.

3. This study may be limited by the inherent bias of the researcher stemming from her personal experience of parental bereavement. However, the fact that this researcher has chosen to study death and grief from her perspective as a professional counselor and researcher has likely facilitated and hastened her pursuit of objectivity. Parkes (1972) has noted that "the very act of thinking objectively about distress places us at one remove from the distress" (p. xi). Such has been the experience of the author: objectivity has largely replaced subjective considerations through the persistent, conscious application of professional knowledge and standards during the course of this investigation.

In addition, precautions have been taken to carefully structure the interview process, to adhere carefully to the PBIRS items as they are worded, and to allow subjects the opportunity to choose freely among the responses provided on the rating scales. A further check against interviewer bias is contained in the test-retest reliability study described elsewhere in this report.

4. This study is limited by the fact that the validity and reliability of the Parental Bereavement Interview and Rating Scale has not yet been thoroughly studied and determined. This task will be undertaken in later research with a larger subject group.

5. This study is limited by the amount of relevant resource literature available.

Summary

Though scientific interest in the study of death and bereavement has increased considerably in recent years, there is still little available information about the experiences of parents in the aftermath of a child's sudden and unexpected death. Because the consequences for survivors of such a loss may be so great and far-reaching, it is important for counselors and lay-persons alike to have a broader understanding and knowledge of what takes place during the processes of mourning and adjustment for these parents.

For the current study, an interview schedule and rating scale, the Parental Bereavement Interview and Rating Scale, was devised and, using that tool, the investigator developed a method for collecting data about parental bereavement that has not been previously available. This information and the PBIRS can be used by counselors, researchers, medical personnel, clergymen and concerned laity to begin to better understand and assist bereaved parents and to generate additional knowledge about the complex process of coping with the death of a child.

CHAPTER II

REVIEW OF THE LITERATURE

The review of the literature is organized around four major factors which have been important in the formulation of the Parental Bereavement Interview and Rating Scale and of the methodology used in the preliminary study: theories about the psychodynamics of grief, with special attention to Kübler-Ross' five stages and a critique of the methodology used to develop theories; the effect that death circumstances of youth and suddenness can have on survivors, including a discussion and comparison of the SIDS and anticipatory mourning situations; the variables of intensity and duration in grief work, emphasizing their significance in determining normal and atypical grief responses; the developmental stages of deceased children and bereaved parents as variables in the grief and adjustment processes; summary.

Theories About the Psychodynamics of Grief

Freud, Lindemann, Bowlby and Parkes

Freud formulated one of the earliest systematic explanations of grief (Glick, Weiss and Parkes, 1974). Freud believed that "grief is a process by which the individual progressively withdraws the energy that ties him or her to the object of his or her love" (Schulz, 1978, p. 137). This process requires that the bereaved person focus his thoughts on the lost person, mentally reliving the events leading to the death, and gradually setting free the energy he has bound up in the deceased. Freud also suggests that the mourner who confronts his loss in this way will achieve more complete and positive grief resolution than one who avoids thinking about it (Jones, 1959).

Lindemann's (1965) report on his clinical study of survivors after Chicago's historic Coconut Grove fire disaster is considered by most authorities to be the classic pioneering study in this field. Lindemann described bereavement as a process wherein survivors come to a recognition and acceptance of the pain and discomfort of their loss and make the adjustment necessary to go on living in an environment in which the deceased is missing. The primary task of the mourner is to verbalize and express the feeling of loss, sorrow, guilt, and hostility associated with the death, thereby extricating himself or herself from the bondage of the deceased and opening the way for new, rewarding interaction patterns.

English psychoanalyst, John Bowlby (1960, 1961), sees grief as a set of behavior patterns that attempt to restore physical and psychological closeness between the deceased and the survivor. These behaviors are gradually extinguished as the individual realizes that the longed-for reunion will not occur. Because Bowlby focuses his theory around grief situations where the loss is permanent, he views grieving behaviors as maladaptive because they are futile attempts to achieve something that is not possible under the circumstances. This is a departure from Freud's belief in the functional value of grieving to detach the mourner from the deceased.

A fourth perspective is advocated by C. Murray Parkes in his description of grief as a "process of realization whereby internal awareness is brought in line with external events" (Schulz, 1978, p. 138). Over the period of mourning, the individual encounters repeated discrepancies when he or she recalls the deceased in an environment where the deceased no longer exists. Frustration arises out of the awareness of these discrepancies. Since continual frustration is an aversive state, the grieving behaviors which produce the frustration are gradually extinguished and the process is ended (Parkes, 1972).

The Five-Stage Theory of Kübler-Ross

Many authorities in this field (Lindemann, 1944; Bowlby, 1960; Cattell, 1969; Blank, 1969; Pincus, 1974; Westberg, 1962; Tanner, 1976; Vanderpool, 1976) have attempted to conceptualize the bereavement process as a series of recognizable stages, ranging in number from three to eleven. Vanderpool (1976) labels his three stages (1) shock/denial, (2) recoil (anger, bargaining, depression), and (3) adjustment/acceptance; Cattell's (1969) three phases are (1) anger and anxiety, (2) pain and despair, and (3) new hope; Bowlby (1960) delineates (1) protest and denial, (2) despair and disorganization, and (3) reorganization.

Pincus (1974) outlines five stages: (1) shock and confusion, (2) controlled phase, (3) searching/realization of abandonment and loneliness, (4) regression, and (5) adaptation. Westberg's (1962) theory recognized ten stages in the grief process: (1) shock, (2) emotional release, (3) physical symptoms of distress, (4) isolation and depression, (5) guilt, (6) panic, (7) resentment/hostility, (8) inability to return to usual activities, (9) struggle to develop satisfactory new living patterns, and (10) re-affirmation of reality. Tanner's (1976) formulation of eleven stages is very similar to Westberg's, adding only the stage of "relief."

A comparison of these various "stages" theories reveals considerable overlap and repetition. However, the substance of the various processes which have been delineated in the literature appears to be embodied in the widely publicized and popular five-stage course of grief set forth by Kübler-Ross (1969, 1974, 1975, 1978). The sequence and duration of the stages may vary remarkably, depending on many factors, but the satisfactory resolution of grief will involve all five stages to some degree (Klein, 1978). Kübler-Ross' five stages of grief work are (1) denial, (2) anger, (3) bargaining or guilt, (4) depression, and (5)

acceptance. Her formulation has been adapted for use in the current research study and used as a basis for the PBIRS format.

The data and conclusions gathered by Kübler-Ross and her associates have been based almost entirely on interviews and observations of terminally ill patients. She concluded that these dying patients, if given sufficient time, pass through the five distinct stages from the time they learn of their condition to their deaths. However, she believes that the grief process is generally the same for family survivors of sudden death situations, "except the bargaining is often eliminated" and the process may last longer (Kübler-Ross, 1974, p. 71).

With two notable exceptions, the definitions of the five stages--Denial, Anger, Guilt, Depression, Adaptation--which appear in Chapter I, are inclusive of the definitions developed by Kübler-Ross. However, for the purpose of this research, each stage is expanded and described in less ambiguous terms, making possible the creation and practical use of the PBIRS as an assessment instrument. Each definition is, then, a composite of ideas and suggestions from many sources, both published and unpublished (see prior citations for proponents of stages theories).

The first major departure from the Kübler-Ross model is the deletion of the term "bargaining," leaving only the term "guilt." For the survivors of sudden deaths, as in the case of subjects for the current study, or even for those who grieve after the death of a terminally ill patient, there is no basis for bargaining with God or fate over the postponement or revocation of the death. In the post-death situation, guilt takes the place of bargaining. Guilt may take many forms, including regret, blame and scapegoating.

Inherent in the modern understanding of good parenting is the responsibility to protect one's child from harm, injury and death (Cutter, 1974). The failure of the bereaved parent in this regard

produces some form of guilt in virtually all situations, and it is especially pervasive in cases of accidental death (Friedman, 1974).

A second notable revision of Kübler-Ross' theory is the substitution of the term "adaptation" in place of "acceptance." Adaptation, as earlier defined, is a more inclusive term and reflects the lengthened adjustment process which Kübler-Ross suggests may be necessary for bereaved survivors as opposed to the terminally ill patients who supplied most of the information in her database. While acceptance of one's own impending demise is a highly significant accomplishment in the grief work of the dying patient, "adaptation" is perhaps the more appropriate term for the more complex social and emotional adjustment process that takes place in the ongoing life of the bereaved survivor (see definition of Adaptation, p. 11).

Ex Post Facto Research and the Study of Bereavement

Much of the criticism of the theories and hypotheses about bereavement formulated by Lindemann, Parkes, Kübler-Ross and others has centered on the weakness in methodology. Thousands of psychiatric interviews and case studies have been collected over the years, but no systematic process has been used to check the reliability and validity of the data. Such studies are subject to serious errors in terms of interviewers' observations or faulty or falsified accounts on the part of interviewees. With no standardized methodology, studies are not replicable and findings from the various investigations cannot be readily integrated to allow for a cumulation of knowledge in this field.

It has been argued that "the most important social scientific and educational research problems do not lend themselves to experimentation, although many of them do lend themselves to controlled inquiry of the ex post facto kind" (Kerlinger, 1973, p. 392). So

it is with the study of bereavement: the variables generally cannot be manipulated and subjects cannot be randomly assigned to treatments as in experimental research approaches. Nevertheless, ex post facto, or "retrospective," research can be used with intellectual profit in the social sciences. Perhaps the validity of such research methods and results is largely dependent on the degree to which the research process is systematized. Kerlinger gives the following definition of ex post facto research:

Ex post facto research is a systematic, empirical inquiry in which the scientist does not have direct control of independent variables because their manifestations have already occurred or because they are inherently not manipulable. Inferences about relations among variables are made, without direct intervention, from concomitant variation of independent and dependent variables (p. 379).

Examples of the widespread use of ex post-facto research in the behavioral sciences include Adorno's (1950) studies of the authoritarian personality, Pettigrew's (1949) study of anti-Negro prejudice, Rokeach's (1968) classic studies of beliefs and values, the retrospective analysis by Getzels and Jackson (1960) of occupational choice and cognitive functioning, and Sarnoff's (1958) cross-cultural study of anxiety among school children. The social problems on which these studies focused could not have been approached by experimental methods, yet ex post facto research yielded valuable knowledge from which could be developed sound hypotheses.

The methodology developed through the current research project on parental bereavement is an attempt to make controlled inquiry more possible. The PBIRS can facilitate the acquisition of quantitative data obtained through a systematic, replicable procedure. When a sufficient amount of data is obtained, common themes or elements may emerge to represent the average of the people being studied. Then firm hypotheses can be formulated and tested through

ex post facto methods. The PBIRS also has the potential of lending credence and validation to the theories of Kübler-Ross which, heretofore, have been based primarily on her own observation and intuition.

Youth and Suddenness: The Unanticipated Death of a Child

There are many factors which determine the intensity of despair and difficulty of recovery after the death of a loved one. Certainly two of the most prominent factors are the age of the deceased and the timeliness of the loss. "There is a great deal of difference between the quiet slipping away of an old man and the tragic cutting off of a young one 'in his prime'" (Parkes, 1972, p. 128). Several sources (Engel, 1964; Kutscher, 1969; Vanderpool, 1976) substantiate this observation that the magnitude of the grief reaction is generally increased when the deceased is a child and when there has been no opportunity for anticipatory preparation preceding the death.

In their controlled study of family survivors of sudden death situations, Williams and his associates (1976) determined that the more sudden, unexpected, tragic or violent the death, the greater the probability of a poor bereavement outcome. By contrast, when death occurs in an aged person or someone who has suffered a prolonged terminal illness, grief reactions are usually shorter because a certain amount of emotional detachment has already preceded the event in expectation of it. Pathological reactions--those of unusual intensity and duration--are more frequent when the death is sudden and untimely (Engel, 1964).

Fulton (1970) combines both the youth and suddenness factors in his definition and discussion of a "high grief death." He contrasts this with a "low grief death" which involves a prolonged illness of an old person. The greater probability of a positive

outcome in the low grief situation apparently occurs because the loss can be anticipated.

Children, Terminal Illness, and Anticipatory Mourning

The medical and psychological literature has devoted considerable attention to the issues related to fatal illness in children (Bozeman et al., 1955; Solnit and Green, 1959; Hamovitch, 1964; Wallace and Townes, 1969; Fulton and Fulton, 1971; McCollum and Schwartz, 1972; Gardner, 1976; Murray, 1976). Most parents and siblings of fatally ill children share many common feelings and experiences and there appears to be a characteristic pattern of psychological coping.

Wallace and Townes (1969) outline a triphasic process of anticipatory mourning which requires a minimum of four months between diagnosis and death for its completion. The first stage characteristically involves a denial of reality and attempts to screen it out or reverse it. There is shock, disbelief, hostility, guilt, anger and refusal to accept the diagnosis. The second phase or stage is acceptance of the diagnosis (child has the disease) but not the prognosis (child will die from the disease). There is a demand for information about the disease, concern over treatment, overprotection of the child, fear of separation, and expression of personal guilt. Finally, the mourner comes to accept both the prognosis and diagnosis. In phase three there is a redistribution of time and energy so that more time is devoted to the rest of the family, friendships are established with other such families, and there develops a wish for the suffering to end.

As can be seen, to the extent that anticipatory mourning is complete, much of the grief work described in Kübler-Ross' five stages can be accomplished prior to the child's death. Anticipatory grief enables the family to begin the tasks of adjustment while the dying person may be consulted about his ideas for the

family's future and can share in and facilitate the mourning of survivors (Goldberg, 1973). It makes the family's mourning a gradual, extended and less-intense process than is usually the case in the event of sudden, unexpected death.

McCollum and Schwartz (1972) identified several adaptive behaviors commonly available to parents during the time period preceding the fatal event. These include (1) information seeking (about the nature of the disease, the status of the child, and the "search for meaning"), (2) partialization, in which the grief experience is separated into component parts which can be more easily assimilated and the time perspective is narrowed to deal with only the immediate present, and (3) rehearsal of death, which "may dilute the intensity of emotions surrounding the final separation" (pp. 33-34). Since these adaptations are dependent on the time factor, they are not available to the suddenly bereaved.

Fulton (1970) writes:

Two decades of experimental, social-psychological research have taught us that stressful events are less aversive to the extent that they are predictable. This is partly due to the fact that organisms can brace themselves for predictable stressors; they can muster the appropriate coping mechanisms and thereby diminish the impact of the stressor (p. 141).

Rehearsal of the death and preparation for the post-death period give an element of control to grief work and should make the bereaved feel less helpless and victimized.

Levinson (1972) explains three reasons why the suddenness of death increases the pathogenic potential of grief work. First, time is required to fully perceive the loss and most people need a period of denial as a protective mechanism to avoid being overwhelmed by too much pain, anxiety and depression. Secondly, giving up the deceased person is, for most, a difficult and time-consuming task. Lastly, sudden death eliminates the chance for restitutive

efforts in the form of arranging affairs for the dying person, "securing his forgiveness, and effecting an actual or symbolic farewell" (p. 161). For many survivors, these restorative efforts are indispensable to a positive resolution of grief.

Finally, when death occurs without expectation or warning, as in circumstances of accident, murder or suicide, the survivors never really understand why the death occurred (see definition of Anger, p. 9, Chapter I). An anticipated death resulting from a specific disease with a predictable course is more easily understood and, therefore, less mysterious and frightening. Often steps can be taken to minimize the possibility of other children dying of the same cause. A sudden, unexpected death often makes parents more fearful that it could happen again and they could lose still another child without apparent reason, warning or opportunity to prevent it (Schulz, 1978).

Sudden Infant Death Syndrome (SIDS)

While the literature is seriously lacking in information about bereavement following the sudden death of young children, ages one to 20, a considerable amount of research and writing has been devoted to the study of SIDS, also called "crib death" (Bergman et al., 1969; Bergman, 1973; DeFrain and Ernst, 1978; Friedman, 1974; Halpern, 1972; Nakushian, 1976; Salk, 1971; Smialek, 1978). In SIDS cases, an active, apparently healthy infant under the age of one year dies in his sleep for no apparent reason. There are similarities between grief responses to SIDS and to other sudden deaths in childhood which make a brief discussion of SIDS appropriate here.

While SIDS is the number one killer of infants, accidents are the number one killer of children ages one to twenty, claiming 22,387 victims nationwide and 306 Oregonians in 1978 (U.S. Dept. of Health, Education and Welfare, 1978). An additional 37 Oregon children, ages one to twenty, died suddenly by homicide or suicide

in 1978. Similar statistics regarding acute fatal illnesses are not available. However, Green et al. (1969) have documented figures showing that ten percent of deaths among the general population occur abruptly, from nonaccidental causes, in patients who previously appeared to be in good health. The most obvious parallels between the two situations--(1) SIDS and (2) the accident/murder/suicide/acute illness grouping herein discussed--are factors of youth and suddenness. All these situations tend to trigger especially intense and complicated grief reactions among parents, two prominent features of which are anger and guilt.

In general, the parents who survive the death of a SIDS child evidence very intense and complicated grief reactions because the death is attributed to an unknown mechanism and feelings of condemnation and parental inadequacy are reinforced (Mandell and Belk, 1977). Each of the 32 parents studied by DeFrain and Ernst (1978) following a SIDS loss agreed that the death of their child was the most severe crisis ever encountered--greater than other deaths, divorces or illnesses they had experienced. They required an average of sixteen months to recover to a pre-crisis level of personal happiness. The severity and intensity of the grief reaction, as described by Bergman (1973), emphasized the factors of helplessness and a loss of meaning in one's life, fear of "losing one's mind," major disruptions of routine behavior, dreams of the dead child, and frequent expressions of hostile feelings toward close friends and relatives.

Friedman (1974) believes that all of Bergman's findings can be generalized to include expected sequelae for survivors of unexpected deaths from causes other than SIDS. Bereavement reactions may, in fact, be even more intense when the deceased child is older and has had more time to develop his personality and his role in the family unit (Cain and Cain, 1964; Vanderpool, 1976; Rees, 1969). To date, however, the research on SIDS survivors has had

no parallel in studies of parents surviving the deaths of older children. The present investigation seeks to provide some information about the latter group of bereaved parents.

The overwhelming anger and guilt often precipitated by the sudden, unreasonable and unexplainable loss of a child tends to increase the intensity and duration of grief reactions. When the death has been accidental, parents or other caretakers often experience debilitating amounts of guilt which can only be resolved by the survivor's acceptance of his own imperfections or denial of responsibility (Friedman, 1974). Because it is a greater task to reduce anger and guilt to manageable, non-debilitating limits, it is more difficult for these survivors to move on through their grief work to the final stage of Adaptation.

The Duration and Intensity of Grief

Most experts agree that the duration of mourning should not extend beyond two years. DeVaul and Zisook (1976) consider grief that lasts longer than six months to be "prolonged." Schmidt and Messner (1975) observed that the average grief reaction comes to a reasonable conclusion in six to twelve months. The findings of Lindemann (1944), Parkes (1972), and Glick et al. (1974) suggest that the recovery phase of bereavement is just beginning as the survivor embarks on the second year after the death.

Blank (1969) feels that grief is normally resolved in a minimum of one year, and the average duration lies somewhere between one and two years. It must be noted, however, that most estimates of duration are based on observations of widows in which cases the majority of deaths occurred in aged spouses and were not totally unanticipated. There are no similar estimates regarding the recovery time for suddenly bereaved parents of young children. According to Sanders (1980), the few existing studies (Gorer, 1966; Cain and Cain, 1965; Orbach, 1959) are poor in methodological

approach, limited in the variety of participants, and anecdotal in content.

There appears to be a near-total lack of systematic observation and measurement of the intensity of grief responses for any age group. One exception is the work of Faschingbauer and his colleagues (1977) who are in the process of developing an instrument to measure the extent of unresolved grief, the Texas Revised Inventory of Grief (TRIG) (Appendix A). At last report (correspondence with Dr. Faschingbauer, July 1980), the TRIG had been administered to 260 bereaved subjects throughout the U.S. It is a simple pencil-and-paper test which measures grief on two scales: (1) present level of unresolved grief, and (2) past level of life disruption. While this instrument shows promise as an effective clinical tool for identifying the extent of unresolved grief in the overall bereaved population, it does not satisfy the particular requirements of the current investigation.

Sanders (1980) compared intensities of grief across bereavement situations in the death of a parent, child or spouse. Her sample included 14 bereaved parents from a total sample of 102 bereaved persons and the children's ages at death ranged from six-and-one-half to forty-nine years. She concentrated on the early stages of grief, the period between the time of death and initial interview averaging 2.2 months. The primary research instrument was the Grief Experience Inventory (GEI) consisting of 135 True-False self-report items (Appendix B). Comparisons shows that the death of a child produces the highest intensities of bereavement as well as the widest range of reactions.

Beyond these two, systematic attempts to measure the quality and quantity of grief, the literature generally approaches the discussion by describing and comparing normal vs. atypical or morbid grief reactions. Schulz (1978) concludes that the two only differ in terms of intensity and duration. Pathology is recognized

when grief reactions are of unusual and incapacitating severity and duration. A variety of bizarre or strange behavior patterns are often seen when the mourning is arrested prior to the stage of Adaptation.

Descriptive information about atypical or morbid grief responses is derived primarily from bereaved individuals who have sought professional help for problems associated with the death. In his study of 35 bereaved males and females who underwent professional therapy, Parkes (1972) reported the following: the majority (26 of 35) sought help for depression, six had problems with alcoholism, five had hypochondriacal symptoms, and four had phobic symptoms. Other symptoms, on a smaller scale, included panic attacks, asthma, loss of hair, depersonalization, insomnia, fainting and headaches. Two persons in this group exhibited psychoses with hallucinations and delusions.

Krupp (1972) has identified five common, maladaptive reactions to the death of a family member: (1) exaggeration, wherein there is a prolonged and intense reaction leading to chronic depression; (2) complete ego breakdown, when anger leads to delusions and paranoia; (3) pathological identification, where the mourner assumes symptoms of the deceased; (4) arrested psychosocial development as the bereaved individual becomes fixated at the stage where he was at the time of the loss, completely denying occurrence of the death; and (5) absence of mourning behavior altogether.

Jackson (1972) observes that a bereaved person may react to unmanageable stress by a retreat from life and a reduction of social contacts. When the content of social life withers away, depression sets in. The processes of depression tend to be cumulative in that the more the person retreats the more reasons there seem to be for this backward action. He thus separates himself from meaningful social contacts at a time when this support system is most crucial.

Developmental Stages of Bereaved Parents
and Deceased Children

The variables that influence the process and outcome of bereavement are so numerous and complex (see Parkes, 1972, p. 121) as to have prohibited the development of firm hypotheses and theories about the nature of grief. It is probably impossible to clearly isolate one or two variables. Using a hypothetical example, evidence indicating that parents suffer more intensely over the loss of a son than a daughter could lead to no valid conclusions without first considering the effects of associated variables such as age, personality, ethnic background, secondary stressors, strength of attachment, and so on.

Nevertheless, an attempt will be made in the current study to look for some association between the bereavement data obtained by the PBIRS and the developmental stages of the bereaved parents and deceased children. This attempt will involve the development of a beginning methodology to facilitate future, more rigorous examination of this plausible relationship between the intensity and duration of parental grief and the ages/stages of the principal persons involved. This course of inquiry will also yield some indication as to whether or not the age range identified in this study as "young child" (ages 1-20) is too broad to permit useful generalizations about the characteristics of suddenly bereaved parents.

In recent years the study of human behavior has focused much attention on the characteristics of developmental stages. Stages are periods in a lifetime during which certain issues and tasks become predominant for the individual. Erikson (1963), Maddi (1976) and Havighurst (1972) have offered the most comprehensive theories of life-long growth and learnings, greatly expanding on Freud's early work and emphasizing the psychosocial significance rather than the biological nature of development. Several other researchers, including Sheehy (1974, 1976), Gould (1980) and Bischof (1976),

have expanded further on the stages comprising adulthood. Drawing from the combined efforts of these experts, several characteristics relevant to the analysis of parental bereavement emerge. Identification of these characteristics provides one interesting approach to the study of the data obtained through the PBIRS interviews.

The deceased children involved in this study ranged in age from one to eighteen years, covering three or four stages, depending on the theory. The bereaved parents serving as subjects range in age from twenty-eight to fifty-three years, divided variously into from two to five stages. A composite picture of the relevant characteristics of these "child" and "parent" stages can be usefully divided as follows:

Childhood Stages

- I Early Childhood, approximately 1-5 years
- II Middle Childhood, approximately 6-11 years
- III Late Childhood, approximately 12-18 years

Adult Stages

- A Early Adulthood, approximately 22-28 years
- B Thirties Transition, approximately 29-33 years
- C Mid-Adulthood I, approximately 34-39 years
- D Mid-Life Reexamination, approximately 40-43 years
- E Mid-Adulthood II, approximately 44-60 years

An analysis of the distribution of parent subjects and their deceased children through the stages perspective might allow for a comparison of the bereavement experiences of many parent-child combinations, e.g. parent, 28-child, 7; parent, 34-child, 1; parent, 39-child, 4; parent, 41-child, 16; parent, 53-child, 18. Through such an analysis one can begin to answer some questions about the common and unique features of the parental grief process.

It must be cautioned that the descriptions and characteristics of stages are generalizations, reflecting the average of considerable personality variation. It follows that any analyses based upon these stages can only be considered generalizations. Further, the

chronological ages assigned to these stages are only approximations, not discrete numerical parameters. Chapter IV will include an outline of the characteristics of each of the stages which have relevance for this study of parental bereavement behavior.

Summary

A survey of the literature reflects the current interest in understanding the psychodynamics of grief. Numerous authorities have described grief and developed theories or hypotheses about the course of grief work, frequently conceptualizing it as a process comprised of several stages. However, most studies to date have focused on widows and widowers bereft over the loss of an elderly spouse, or on adult patients during the final stages of their own terminal illnesses. In addition, prior studies have been generally unsystematic and unreplicable, overly reliant on the researcher's observation and intuition.

Though it has been assumed that the grief processes of widows and terminally ill adults will be mirrored by parents who survive the unanticipated death of a young child, there are few objective data to substantiate this assumption. Most reports agree that the youth and suddenness factors can be crucial to the process and outcome of bereavement. When the deceased is a young child and his or her death is totally unexpected, surviving parents appear to experience more intense and prolonged grief reactions which may be incapacitating and lead to pathology. Whether or not the developmental stages of the suddenly deceased child and his or her surviving parents can be identified as significant factors in the bereavement process is another interesting issue for consideration.

The existing literature indicates a need for more objective information about the mourning processes of suddenly bereaved parents, and for an instrument and methodology which might enable

counselors and researchers to obtain such information. The following chapter will describe the process whereby such an instrument was formulated. It will further describe the subjects, setting, procedure and treatment of data used in a preliminary field test of this instrument.

CHAPTER III

METHODOLOGY

Subjects

The 20 subjects who participated in this study were bereaved parents whose names were obtained from four chapters of The Compassionate Friends organization, which meet in Eugene, Albany, Salem and Portland, Oregon. These four cities lie within a span of approximately 100 miles along the major highway through the state, an area in which a significant percentage of Oregon's population is concentrated. The area, known as the Willamette Valley, is both urban and rural with a good deal of agricultural activity surrounding the cities. Each of the four cities is also in close proximity to a major state university.

Compassionate Friends, Inc. is an international organization founded in Coventry, England in 1969 by Rev. Simon Stephens. It is a non-denominational, self-help organization dedicated to serving the needs of families who have experienced the death of a child. The national headquarters in the U.S. is located in Oak Brook, Illinois. Groups at the local level are usually established by parents whose experience has lead them to determine a need in their community for a socio-emotional support group for bereaved parents. The four groups in this study have been formed within the last five years.

After gaining approval from the recognized leaders of each group, the researcher attended one of the monthly meetings to personally present her study to members in attendance. A request was made for volunteer subjects whose circumstances met the criteria of the study (i.e., parents of a child deceased between ages one and twenty, two to five years post-death event, death sudden and unexpected). Only five subjects were secured in this manner.

In addition to those present at each of the four meetings, the researcher obtained an address and phone list of other potential subjects associated with each group and solicited their participation by phone or mail (Appendix C). Of the 18 parents contacted in this manner, 12 agreed to become subjects, 5 did not respond to the written inquiries, and one declined to be involved for emotional reasons. A further appeal for subjects was made through the monthly newsletters of two groups, yielding four additional volunteers. All who volunteered were accepted and treated as subjects for the study. Though a total of 21 subjects were interviewed, one subject was eliminated because he was a step-parent and his responses indicated that he had had only a short and superficial relationship with his deceased stepson.

Instruments

The Parental Bereavement Interview and Rating Scale (PBIRS)

The PBIRS (Appendix D) represents a primary portion of the researcher's original contribution to this area of study. Items for the interview guide were developed from the author's process of listing and grouping, over the course of two years, all questions pertinent to parental bereavement derived from several sources including the literature, personal experience, and discussions with other bereaved parents. Autobiographical works by bereaved parents were particularly useful sources for interview items (Gunther, 1949; Lindbergh, 1973; Huffman, 1976; Schiff, 1977).

Over 200 questions were then combined and refined into 39 items which were rewritten and grouped into five categories, according to the grief stages they reflected: Denial (D), Anger (A), Guilt (G), Depression (DP), or Adaptation (AN) (see Definition of Terms, Chapter I). The PBIRS has content validity inasmuch as the items have been developed to directly reflect the constructs of the five stages assumed to comprise the parental grief process

(Sundberg and Tyler, 1962).

For items one through 35, the intensity of specific grief responses is measured by identifying their existence and magnitude on the four-point rating scales ("1" being the most adaptive and "4" being the least adaptive). In each case, the quality of the response is carefully described in the wording of the rating scales to identify the degree of intensity or severity. In general terms, a rating of one (1) indicates no, or negligible, intensity; two (2) indicates low to moderate intensity; three (3) indicates high intensity; and four (4) indicates an extremely high-intensity response.

The duration of each bereavement response is determined by asking respondents to recall changes and progressions which occurred from the onset of grief to the present, and to answer each item three times according to how they felt or behaved during three periods:

- I = 0-6 months after death occurred,
- II = 7-24 months after death occurred, and
- III = 2-5 years after death occurred.

During this preliminary study in which the PBIRS was being refined, subjects were asked the following question after completing the interview: "In general, did you feel comfortable with the breakdown of the grief process into these three time periods?" Responses to this question are reported in Chapter IV.

Items 36 through 39 are "time-specific." That is, they are designed to identify the duration of a particular bereavement experience by locating more specifically the time when the experience occurred or ended. These four items require only one rating rather than three.

To determine their placement order on the PBIRS, items were randomly selected from each of the five groups, alternating through

the groups in the order by which the five grief stages are most commonly arranged (D, A, G, DP, AN).

Space was provided following each item on the form for notations by the interviewer. Maccoby and Maccoby (1954) recommend the use of behavioral observation to help reduce errors of interpretation with interview data pertaining to sensitive subject areas. Space was also provided to the left of each item for the interviewer to record the numerical self-rating selected by the subject from the PBIRS rating scales.

The interview guide was constructed around a format suggested by Englehart (1972) and by Sears, Maccoby and Levin (1957) in their study of child-rearing. The main features of the format are: (1) Items suggest an interview method which is semi-structured--a list of open questions followed by one or more probes which may be used at the interviewer's discretion to facilitate more accurate and complete answers from interviewees; (2) Questions are carefully worded to avoid superficial, stereotyped answers based on the respondent's feeling about how one ought to feel or behave. Several devices for such wording are suggested and used by the Sears study and further described by Travers (1978); (3) Textbook language and psychological jargon have been avoided. An attempt was made to use the language of the bereaved whenever possible to facilitate communication between interviewer and interviewee. Such wording may help to better reflect the true experience of parental bereavement and increase the interviewer's ability to establish rapport.

Although the current investigation has defined the volunteer subjects by three criteria--(1) deceased child age one to twenty; (2) death sudden and unexpected; (3) two to five years post-death event--the PBIRS has been carefully constructed for clinical and research use with all bereaved parents. A few of the items may not be applicable for parents of stillborn babies or infants whose lives were very brief. In such cases, the inappropriate items

might be deleted. Otherwise, the PBIRS--particularly the revised form which was created following this study (Appendix E)--can be suitably adapted for use with bereaved parents whose children died at any age, due to any circumstances, and at any stage of the grief following the child's death.

The interview guide alone, without the rating scales, might be used by clinical practitioners in counseling with bereaved parents. But, for the purpose of this study and future research, a rating scale (Appendix D, Part 2) was also developed for use with the interview making the questions part of a psychometric instrument rather than merely a means for collecting information. Generally, it follows the format of a Likert Scale, though the gradations of each group of responses are highly variable and dependent upon the wording attached to each quantifier.

Demographic Data Sheet (DDS)

Objective data about the subjects and the circumstances that precipitated their bereavement experience were obtained through use of the Demographic Data Sheet (Appendix F), prepared especially for this study.

Method of Gathering Data

The investigator used the PBIRS and Demographic Data Sheet (DDS) to collect data through one-to-one, face-to-face interviews with each of the twenty-one volunteer subjects. The location and time for each interview was determined according to the convenience of the subject, and all but one were conducted in the subjects' homes. The length of the interview sessions ranged from one-and-one-half to five hours, including periodic breaks when needed. The average interview lasted about three-and-one-half hours.

The PBIRS was administered prior to the DDS with the expectation

that the personal nature of some of the demographic questions would be less threatening to subjects after they had had an opportunity to develop rapport with the investigator and judge the purposes and quality of the study. Subjects were encouraged to inspect the interview guide and answer sheet prior to commencing the interview, and the self-rating scales were made available to them on 3x5-inch cards throughout the course of the interview (see Appendix G).

Each subject was asked to sign a Participant Consent Form (Appendix H) prior to beginning the interview. Permission was requested to tape-record all sessions, and such recordings were made during fourteen interviews.

The research model used in the execution of this study is based on systematic retrospective techniques of data-gathering which will eventually allow for the formulation and testing of firm hypotheses through ex post facto methods. The problems associated with retrospective techniques include threats to validity and reliability of data due to faulty recall or falsified accounts. Several features were built in to the methodology of this preliminary study in an attempt to overcome these problems and make the research replicable:

1. Every subject was interviewed using the PBIRS and following a very specifically prescribed method of administration.
2. To minimize faulty recall and increase the likelihood of obtaining complete and honest responses,
 - a. the PBIRS format features semi-open-ended questions which encourage free discussion to enhance the respondent's ability to remember events accurately,
 - b. responses are divided into three time segments to allow for chronological ordering and comparison in a time frame, and
 - c. the interviewer can make use of "probe" questions to

encourage additional recollections and to check on the accuracy of recall.

3. The introduction to the interview (Appendix G) stresses the expected variability of responses to minimize the effect of social desirability responses.

Treatment of Data

Because the data collected and the research questions posed are of several different types, a variety of methods were employed in the analysis of the data. The discussion of the treatment of data has been organized according to the research questions each treatment addresses.

A. Methodological Considerations

1. Does the research instrument (PBIRS) have face validity as a measure of parental grief and adjustment? The PBIRS was subjected to the scrutiny of the professional and lay leadership of The Compassionate Friends at both the local and national levels. All five of these leaders are bereaved parents. Revisions suggested by these experts have been taken into consideration in the refinement of the instrument, and discussed in Chapter V.

2. What are the test-retest reliability estimates for the PBIRS? Each participating subject was asked to complete the interview/questionnaire a second time, independently, approximately two weeks after the initial interview. The two sets of responses were compared and estimates of test-retest reliability have been reported.

3. Can the parental grief and adjustment processes be usefully and comfortably divided into three time periods? The answer to this question has been derived from the opinions expressed by the

subjects after they completed the interview. These comments have been reported and discussed.

4. Is the designation of "young child" for children ranging from one to twenty years suitable and viable in terms of the characteristics of the parental grief process their deaths appear to precipitate? The significance of this age-range variable has been assessed by looking for gross, obvious differences in the bereavement experiences of parents who lose very young children as opposed to those who lose adolescent children. It must be kept in mind, however, that this variable cannot be clearly isolated from a great many other variables that also influence the grief process. Any answer must be considered tentative.

B. The Nature of Parental Grief and Adjustment

5. Does the intensity of parental grief responses decrease over time?

6. When do parents report negligible intensity for most grief responses?

7. When do parents complete the Denial stage and accept the finality of their child's death?

8. When do suddenly bereaved parents attain complete resolution of Anger?

9. When do suddenly bereaved parents attain complete resolution of Guilt?

10. When will most suddenly bereaved parents report a total or near-total level of Adaptation and grief resolution?

11. In what general ways is the grief process different or similar for parents with respect to the different ages and developmental stages of themselves and their deceased children?

Research questions 5 through 10 have been addressed in terms of the quantitative data from the rating scales. These data are presented by descriptive methods using the numerical quantifiers on the rating scales and simple percentages of responses to various items and categories. Tables and graphs have been developed to present the data grouped according to the five grief stages (Denial, Anger, Guilt, Depression, Adaptation). These tables and figures supply tentative answers to the research questions posed. The customary narrative discussion and explanation accompanies all tables and figures.

Question 11 has received additional attention in Chapters IV and V where the ages/stages characteristics of deceased children and bereaved parents have been presented in greater detail and some comparisons have been drawn.

C. Demographic Characteristics of Bereaved Parents/Subjects

12. What demographic features characterize the subjects in the present study? Information from the Demographic Data Sheet (DDS) has been charted and a descriptive profile of the subject group has been developed. Any additional information about the subjects which supplements the DDS, but was obtained through interviewer observations, has also been presented. Throughout the report, the anonymity of all subjects has been preserved by coding their names and omitting any information that would make their identities obvious.

13. How does this subject group compare demographically with other bereaved parents in the U.S. and Canada? The profile of the subject group has been compared with descriptive data about bereaved parents in the U.S. and Canada which was obtained in a study by researchers at the University of Chicago (Borman et al., 1979).

Rationale for Methodology

Pain and death are not themes comfortably encompassed by categories of methodological rigor and theoretical relevance. . . . Research on human behavior in extreme situations asks for a delicate balance of identification and intellectual detachment (Wallace, 1956, p. 14).

This attitude does not seem to have changed markedly during the past twenty-five years. Switzer noted in 1970 that the grief situation is not conducive to experimental manipulation or other commonly accepted forms of controlled observation, and that such methodology would likely serve to make the bereaved person's reactions more painful. Eysenck (1974) added that self-report measures are still more appropriate and accurate than either behavioral or physiological observations in the measurement of emotion.

Good science and good research have long been associated with complex statistics and numerical technology, so much so that more humanistic research is sometimes dismissed as invalid. When empathy and compassion are added to other research techniques and pure objectivity is lost, the value of the research is often discounted. But many social scientists have recognized the importance of insight in some situations and advocated the use of more humanistic approaches (Eliot, 1930; Jourard, 1964; Powdermaker, 1966; Frey, 1978). Such has been the method chosen for the project at hand. The value of both insight and objectivity is acknowledged, and a combination of both has been sought.

CHAPTER IV

PRESENTATION OF THE DATA

In this chapter the thirteen research questions will be addressed and relevant data from the interviews will be presented.

Methodological Considerations

- ♦ QUESTION 1: Does the PBIRS have face validity as a measure of parental grief and adjustment?

The PBIRS, in a questionnaire format, was subjected to the scrutiny of five leaders of The Compassionate Friends organization for their opinions regarding the face validity of the instrument. Each of these five experts critiqued the PBIRS in terms of the following questions:

- a) Does each of the 39 items clearly reflect an important aspect of the parental bereavement experience?
- b) Is each item stated in easily understood terms?
- c) Do the responses provided show a reasonable range of variation?

The general response was very positive, with a consensus that the three criteria for face validity had been met. There were, however, several suggestions about changes of format and terminology that might improve the instrument. These suggestions are discussed further in Chapter V, and some of the ideas are incorporated in the Revised PBIRS (Appendix E).

- ♦ QUESTION 2: What are the test-retest reliability estimates for the PBIRS?

Approximately two weeks following the initial interview,

subjects independently repeated the PBIRS using a questionnaire form very similar to the interview guide. Despite repeated reminders, four subjects chose not to participate in this retest portion of the study due to the added time and effort involved. Reliability coefficients for the test-retest self-ratings of the 16 (80 percent) participating subjects were computed by use of the Pearson product-moment correlation coefficient (Table 1).

Of the total 109 response pairs, 52 showed a high or very high degree of correlation, greater than .6994 (.001 one-tailed significance level). An additional 33 items showed estimates of positive correlations in the .50 - .69 range, described as moderate to high-moderate correlation. In a review of the literature reported by Sundberg and Tyler (1962), reliability coefficients of around .50 and .60 were found to be most common for the interview method of inquiry. The scores for two items, 5GII and 5GIII, were determined to be constants and the means not computable by the Pearson "r" statistic.

Two items, 4ANIII and 8DPIII, showed low and slight negative correlations (all of the other 105 computed estimates were found to be positive correlations). Some rationale for this reliability data is discussed in Chapter V, and revisions have been made in the PBIRS aimed at increasing the stability of the scales showing low test-retest correlations.

- ♦ QUESTION 3: Can the parental grief and adjustment processes be usefully and comfortably divided into three time periods?

Upon completion of the interviews, all subjects were asked the foregoing question. In the opinions of 16 subjects (80 percent), the three time periods (below) seemed appropriate and comfortable:

- I = 0-6 months after death occurred
- II = 7 - 24 months after death occurred
- III = 2 - 5 years after death occurred

TABLE 1. Pearson product-moment coefficients of correlation for test and re-test self-ratings on 109 PBIRS items.

Item number and time segment	Reliability estimate	Significance level	Item number and time segment	Reliability estimate	Significance level
10I	.7457	.001	30I	.7093	.001
10II	.7060	.001	30II	.6391	.004
10III	.8433	.001	30III	.5375	.016
1AI	.6417	.004	3AI	.5525	.013
1AII	.4364	.046	3AII	.5517	.013
1AIII	.3524	.090	3AIII	.5938	.008
1GI	.7735	.001	3GI	.7106	.001
1GII	.5811	.009	3GII	.9109	.001
1GIII	.6522	.003	3GIII	.8093	.001
1DPI	.7106	.001	3DPI	.6994	.001
1DP1I	.5212	.019	3DP1I	.7122	.001
1DP1II	.5728	.010	3DP1II	.8740	.001
1ANI	.6762	.002	3ANI	.6722	.002
1ANII	.7418	.001	3ANII	.6584	.003
1ANIII	.7614	.001	3ANIII	.4996	.024
20I	.6881	.002	40I	.3641	.083
20II	.8427	.001	40II	.9406	.001
20III	.4472	.041	40III	.9387	.001
2AI	.7125	.001	4AI	.6381	.004
2AII	.5008	.024	4AII	.5618	.012
2AIII	.6720	.002	4AIII	.4016	.062
2GI	.6564	.003	4GI	.9110	.001
2GII	.7065	.001	4GII	.8321	.001
2GIII	.5210	.019	4GIII	.7868	.001
2DPI	.3126	.119	4DPI	.3800	.073
2DP1I	.7684	.001	4DP1I	.5717	.010
2DP1II	.6784	.002	4DP1II	.8128	.001
2ANI	.8724	.001	4ANI	0	.500
2ANII	.8020	.001	4ANII	-.1578	.280
2ANIII	.7242	.001	4ANIII	.1407	.240

TABLE 1 (continued)

Item number and time segment	Reliability estimate	Significance level	Item number and time segment	Reliability estimate	Significance level
5D1	.8949	.001	7A1	.3490	.093
5D11	.7618	.001	7A11	.5589	.012
5D111	.6723	.002	7A111	.4045	.060
5A1	.9236	.001	7G1	.4286	.049
5A11	.7793	.001	7G11	.3026	.127
5A111	.7645	.001	7G111	.7868	.001
5G1	.6167	.005	7DP1	.4530	.039
5G11	99.0000		7DP11	.5019	.024
5G111	99.0000		7DP111	.5449	.015
5DP1	.6355	.004	8A1	.7048	.001
5DP11	.1627	.274	8A11	.6200	.005
5DP111	.7192	.001	8A111	.6000	.007
5AN1	.2308	.195	8DP1	.7494	.001
5AN11	.1068	.347	8DP11	.5661	.011
5AN111	.3896	.068	8DP111	-.2582	.167
6A1	.8050	.001	9DP1	.7708	.001
6A11	.9420	.001	9DP11	.8250	.001
6A111	.7701	.001	9DP111	.7800	.001
6G1	.8122	.001	10DP1	.5285	.018
6G11	.9110	.001	10DP11	.7632	.001
6G111	.7868	.001	10DP111	.6334	.004
6DP1	.7928	.001	6D	.9064	.001
6DP11	.7018	.001	6AN	.6580	.003
6DP111	.7201	.001	7AN	.8065	.001
			8AN	.9115	.001

Three subjects said they would have preferred a break at the one-year point, i.e., 0-6 months, 6-12 months, 1-2 years, 2-5 years. One subject felt that a break at the one-month point could have been useful in responding to a few of the items.

This research question is addressed further in Chapter V where PBIRS revisions are discussed.

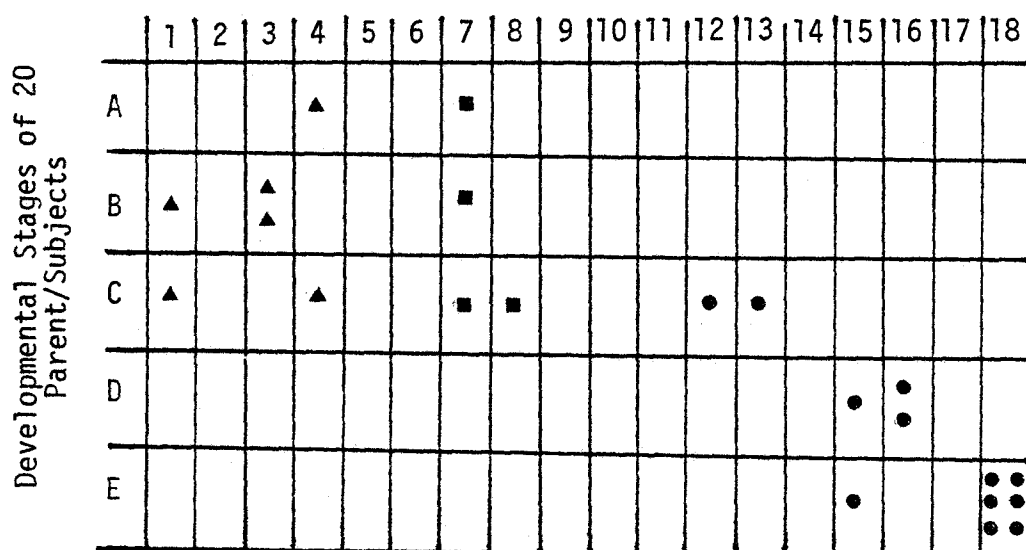
- ♦ QUESTION 4: Is the designation of "young child" for children ranging from one to twenty years suitable and viable in terms of the characteristics of the parental grief process their deaths appear to precipitate?

Figure 1, illustrating the distribution of subjects by their ages and the ages of their deceased children, presents data relevant to research questions 4 and 11. Question 4 has been addressed by comparing the mean response intensities of six parents of six younger children (ages 1-7) to the mean response intensities of ten parents who lost ten adolescents (ages 15-18).

Referring to Figure 1, the reader will observe that a group of six children, representing four parents in Stage C, has been omitted from this comparison. This has been done in the interest of clarity. In the two instances where sibling pairs died in the same mishaps, their paired ages were 7 and 12 and 8 and 13, so both "younger" and "adolescent" groups are represented. It is impossible to determine whether the two bereaved mothers interviewed were responding to the PBIRS items relevant to one deceased child or the other, or a combination of the two. Furthermore, by omitting the cases in Stage C, the extensive data in Table 2 are clearly germane to research question 11 as well as 4 and need not be presented a second time in this chapter.

Table 2 shows no appreciable difference between the mean response intensities of parents of younger children and those of parents of adolescent children. On the four-point scale of

Age of Children at Time of Death*

Child St/ages

- ▲ Early Childhood, 1-5 years (N=6)
- Middle Childhood, 6-11 years (N=4)
- Late Childhood, 12-18 years (N=12)

Adult St/ages

- A = Early Adulthood, 22-28 years (N=2)
- B = Thirties Transition, 29-33 years (N=4)
- C = Mid-Adulthood I, 34-39 years (N=4**)
- D = Mid-life Reexamination, 40-43 years (N=3)
- E = Mid-Adulthood II, 44-60 years (N=7)

* In actuality, only 16 fatalities occurred. There were six married couples among the parents interviewed.

** Two subjects in this age group each lost two children.

FIGURE 1. Scattergram depicting the distribution of subjects according to their ages and developmental stages and the ages and developmental stages of their deceased children.

TABLE 2. Mean response intensities of young parents (ages 28-33) who lost young children (ages 1-7) compared to means of older parents (ages 40-53) who lost adolescent children (ages 15-18). Grouped by grief stages: D, A, G, DP, AN.

PBIRS item number		Parent/Child Combination	
		Y/Y	O/A
1D	I	2.3	2.4
	II	1.5	1.7
	III	1.3	1.5
2D	I	1.5	2.3
	II	1.2	1.7
	III	1.2	1.2
3D	I	1.6	1.3
	II	1.6	1.3
	III	1.6	1.3
4D	I	2.3	2.8
	II	1.5	2.3
	III	1.3	1.8
5D	I	3.0	2.6
	II	2.1	2.1
	III	1.8	2.0
6D		1.8	2.7
Mean for all Denial responses		1.7	1.9

Key: Y/Y = Young Parent/Young Child (N=6)

O/A = Older Parent/Adolescent Child (N=10)

PBIRS item number		Parent/Child Combination	
		Y/Y	O/A
1A	I	2.8	2.6
	II	2.6	2.3
	III	2.0	1.8
2A	I	2.2	2.1
	II	1.8	2.2
	III	1.3	1.6
3A	I	2.3	1.9
	II	1.6	2.0
	III	1.5	1.7
4A	I	2.8	2.2
	II	1.8	1.9
	III	1.5	1.7
5A	I	2.3	2.6
	II	1.8	2.3
	III	1.5	2.0
6A	I	2.3	1.4
	II	2.0	1.2
	III	1.6	1.2
7A	I	1.5	1.7
	II	1.3	1.6
	III	1.3	1.5
8A	I	3.2	2.5
	II	2.5	1.9
	III	2.1	1.7
Mean for all Anger responses		2.0	1.9

TABLE 2 (continued)

PBIRS item number		Parent/Child Combination	
		Y/Y	O/A
1G	I	2.5	1.7
	II	1.8	1.6
	III	1.8	1.5
2G	I	1.6	2.3
	II	1.5	2.1
	III	1.5	1.9
3G	I	1.6	1.8
	II	1.1	1.9
	III	1.1	1.6
4G	I	1.0	1.4
	II	1.0	1.4
	III	1.0	1.2
5G	I	1.5	1.2
	II	1.0	1.0
	III	1.0	1.0
6G	I	1.8	1.1
	II	1.5	1.1
	III	1.3	1.1
7G	I	1.1	1.1
	II	1.0	1.2
	III	1.0	1.2
Mean for all Guilt responses		1.4	1.4

PBIRS item number		Parent/Child Combination	
		Y/Y	O/A
1AN	I	2.7	3.1
	II	1.8	2.6
	III	1.5	2.4
2AN	I	2.6	3.5
	II	1.6	2.4
	III	1.0	1.7
3AN	I	2.5	3.1
	II	2.0	2.3
	III	1.5	1.5
4AN	I	3.0	2.7
	II	2.1	2.2
	III	2.1	1.7
5AN	I	2.3	3.0
	II	2.3	2.4
	III	2.3	2.0
6AN		2.3	2.7
7AN		2.3	2.8
8AN		2.8	2.9
Mean for all Depression responses		2.2	2.5

TABLE 2 (continued)

PBIRS item number		Parent/Child Combination	
		Y/Y	O/A
1DP	I	3.0	3.3
	II	2.3	2.1
	III	1.7	1.5
2DP	I	3.0	3.1
	II	2.1	2.3
	III	1.5	1.6
3DP	I	1.8	2.3
	II	1.3	1.4
	III	1.3	1.3
4DP	I	2.3	3.1
	II	1.6	2.4
	III	1.1	1.5
5DP	I	2.5	2.2
	II	1.5	1.8
	III	1.1	1.4

PBIRS item number		Parent/Child Combination	
		Y/Y	O/A
6DP	I	2.6	2.9
	II	1.6	2.0
	III	1.3	1.5
7DP	I	2.5	2.5
	II	1.6	1.9
	III	1.0	1.3
8DP	I	2.3	2.1
	II	1.5	1.6
	III	1.1	1.2
9DP	I	2.0	1.8
	II	1.3	1.4
	III	1.0	1.1
10DP	I	2.1	2.1
	II	1.5	1.9
	III	1.3	1.5
Mean for all Adaptation responses		1.7	1.9

intensity, the parents of older children averaged only slightly higher on items related to Denial, Depression and Adaptation. The two groups rated the same on items related to Guilt, and parents of younger children scored themselves slightly higher on items related to Anger.

It appears, therefore, that the "young child" designation is a reasonable one and that parental grief responses are generally similar whether the deceased child was an adolescent or younger. (Note: This study does not include deceased infants under one year or adult children over 20. Therefore, it is not known whether their deaths might precipitate significantly different responses than those of the children reported here.) A few more striking comparisons emerge when individual PBIRS items are considered, and these will be reported in response to research question 11.

The Nature of Parental Grief and Adjustment

The answers to research questions 5 through 10 are based on data presented in Tables 3, 4, 5, 6, and 7 and Figures 2, 3, 4, 5 and 6. Individual quantitative responses to the PBIRS items are reported in detail, then converted to percentages and group data for graphic presentation. The reader will observe that three items, 9DP, 2AN, and 4AN, were answered by only 19 of the 20 subjects. In each of these cases the respondents simply felt that none of the four response choices reflected accurately enough his or her bereavement experience.

- ♦ QUESTION 5: Does the intensity of parental grief responses decrease over time?

Figures 2 through 6 illustrate clearly that the intensity of grief diminished over time for this subject group. In no instance

TABLE 3. Intensity of parents' Denial responses over three time segments. (Numbers in brackets represent percentages)

PBIRS item	Time segment	Intensity of Response				
		1	2	3	4	Total (2-4)
1D	I	3 (15)	8 (40)	7 (35)	2 (10)	17 (85)
	II	9 (45)	10 (50)	1 (5)	0	11 (55)
	III	12 (60)	8 (40)	0	0	8 (40)
2D	I	7 (35)	10 (50)	1 (5)	2 (10)	13 (65)
	II	13 (65)	6 (30)	1 (5)	0	7 (35)
	III	18 (90)	1 (5)	1 (5)	0	2 (10)
3D	I	16 (80)	1 (5)	3 (15)	0	4 (20)
	II	17 (85)	1 (5)	2 (10)	0	3 (15)
	III	17 (85)	1 (5)	2 (10)	0	3 (15)
4D	I	3 (15)	3 (15)	6 (30)	8 (40)	17 (85)
	II	5 (25)	9 (45)	3 (15)	3 (15)	15 (75)
	III	11 (55)	6 (30)	2 (10)	1 (5)	9 (45)
5D	I	2 (10)	7 (35)	6 (30)	5 (25)	18 (90)
	II	5 (25)	8 (40)	4 (20)	3 (15)	15 (75)
	III	7 (35)	7 (35)	4 (20)	2 (10)	13 (65)

Post-death Time Segments

I = 0-6 months
 II = 7-24 months
 III = 2-5 years

PBIRS Intensity Ratings

1 = none or negligible
 2 = low-to-moderate
 3 = high
 4 = extremely high

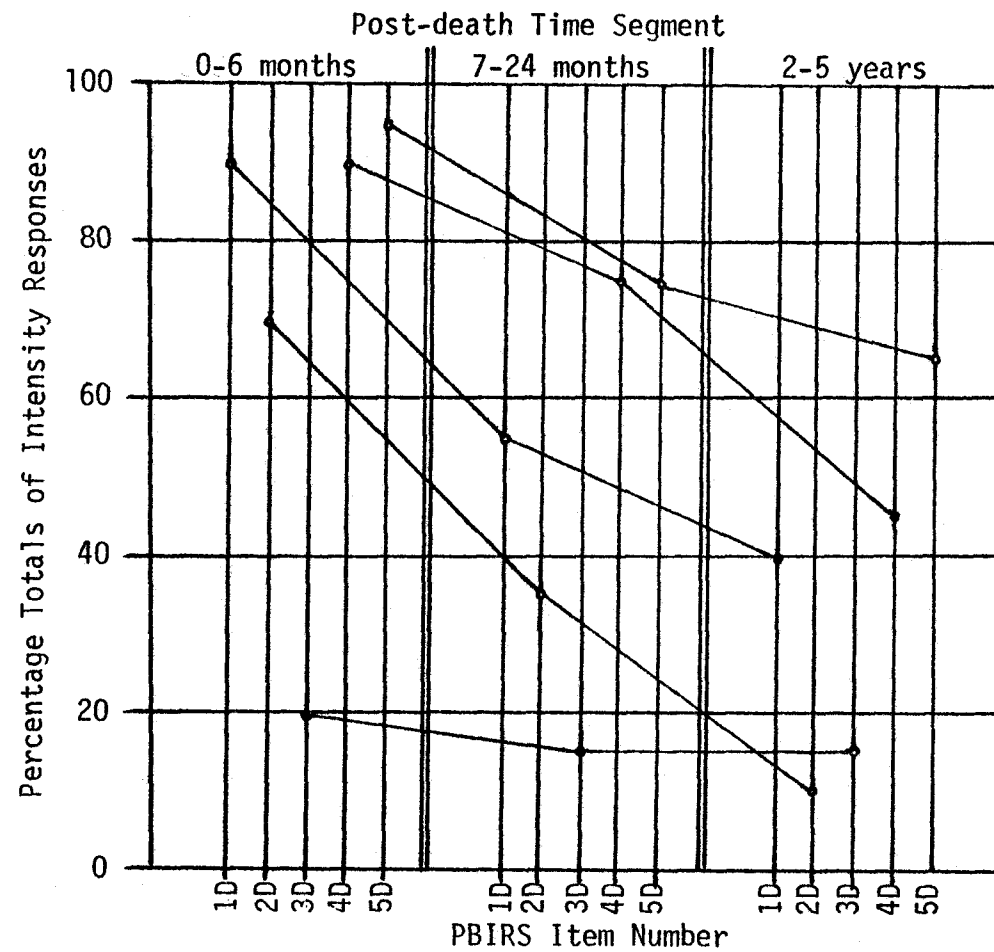


FIGURE 2. Graph illustrating variable intensity of total Denial responses over three time segments.

TABLE 4. Intensity of parents' Anger responses over three time segments. (Numbers in brackets represent percentages)

PBIRS item	Time segment	Intensity of Response				
		1	2	3	4	Total (2-4)
1A	I	1 (5)	8 (40)	5 (25)	6 (30)	19 (95)
	II	1 (5)	11 (55)	4 (20)	4 (20)	19 (95)
	III	2 (10)	16 (80)	1 (5)	1 (5)	18 (90)
2A	I	4 (20)	11 (55)	2 (10)	3 (15)	16 (80)
	II	4 (20)	12 (60)	3 (15)	1 (5)	16 (80)
	III	7 (35)	12 (60)	0	1 (5)	13 (65)
3A	I	5 (25)	7 (35)	3 (15)	5 (25)	15 (75)
	II	7 (35)	7 (35)	5 (25)	1 (5)	13 (65)
	III	11 (55)	7 (35)	1 (5)	1 (5)	9 (45)
4A	I	5 (25)	4 (20)	8 (40)	3 (15)	15 (75)
	II	5 (25)	11 (55)	4 (20)	0	15 (75)
	III	7 (35)	12 (60)	1 (5)	0	13 (65)
5A	I	6 (30)	4 (20)	7 (35)	3 (15)	14 (70)
	II	7 (35)	7 (35)	4 (20)	2 (10)	13 (65)
	III	10 (50)	5 (25)	4 (20)	1 (5)	10 (50)
6A	I	11 (55)	5 (25)	1 (5)	3 (15)	9 (45)
	II	12 (60)	3 (15)	3 (15)	2 (10)	8 (40)
	III	15 (75)	4 (20)	0	1 (5)	5 (25)
7A	I	10 (50)	8 (40)	2 (10)	0	10 (60)
	II	9 (45)	10 (50)	1 (5)	0	11 (55)
	III	11 (55)	9 (45)	0	0	9 (45)
8A	I	2 (10)	5 (25)	8 (40)	5 (25)	18 (90)
	II	3 (15)	12 (60)	4 (20)	1 (5)	17 (85)
	III	6 (30)	12 (60)	1 (5)	1 (5)	14 (70)

Post-death Time Segments

I = 0-6 months
 II = 7-24 months
 III = 2-5 years

PBIRS Intensity Ratings

1 = none or negligible
 2 = low-to-moderate
 3 = high
 4 = extremely high

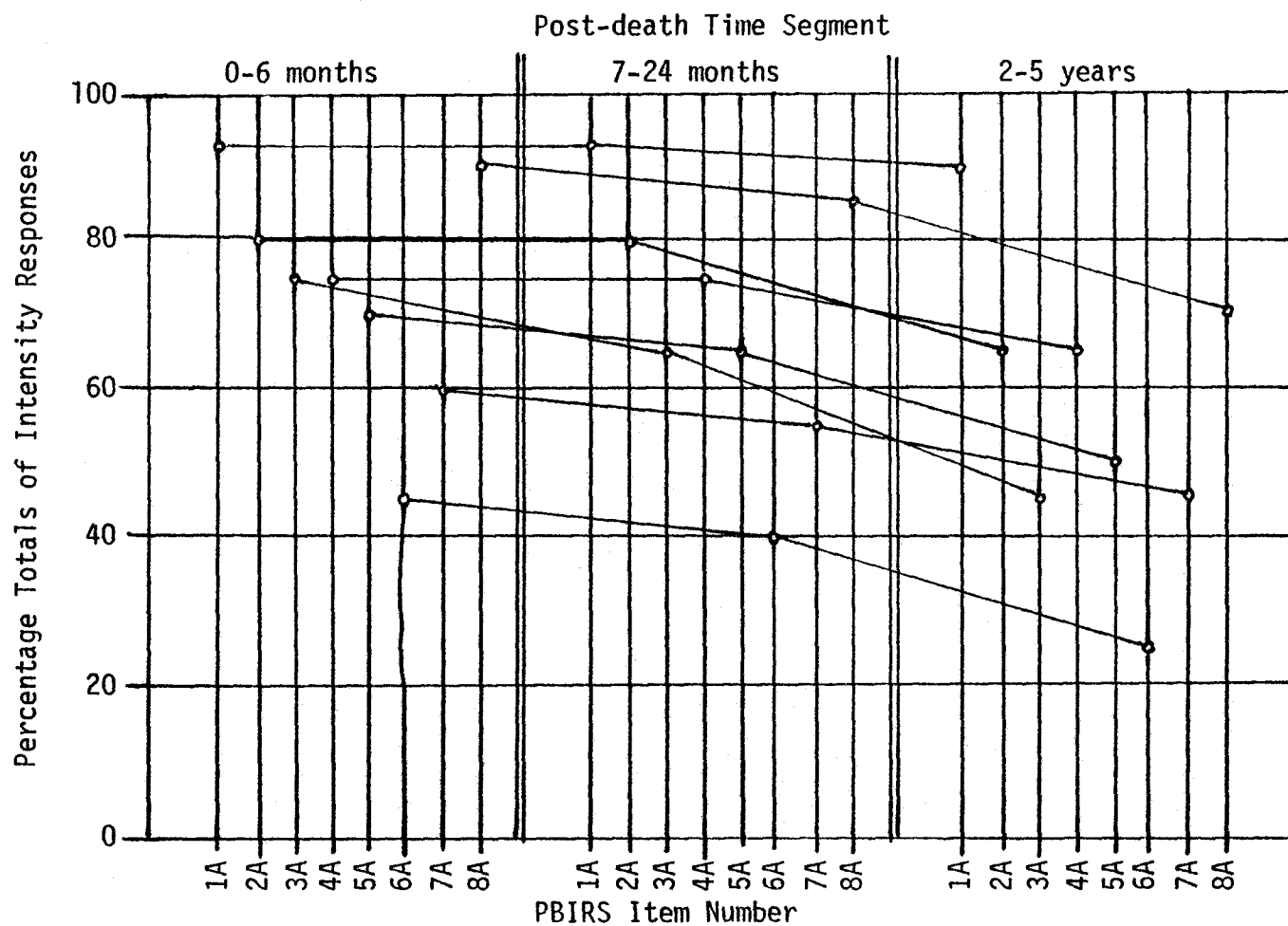


FIGURE 3. Graph illustrating variable intensity of total Anger responses over three time segments.

TABLE 5. Intensity of parents' Guilt responses over three time segments. (Numbers in brackets represent percentages)

PBIRS item	Time segment	Intensity of Response				
		1	2	3	4	Total (2-4)
1G	I	7 (35)	8 (40)	3 (15)	2 (10)	13 (65)
	II	11 (55)	6 (30)	3 (15)	0	9 (45)
	III	11 (55)	7 (35)	2 (10)	0	9 (45)
2G	I	6 (30)	8 (40)	4 (20)	2 (10)	14 (70)
	II	7 (35)	9 (45)	2 (10)	2 (10)	13 (65)
	III	7 (35)	12 (60)	0	1 (5)	13 (65)
3G	I	11 (55)	7 (35)	1 (5)	1 (5)	9 (45)
	II	12 (60)	6 (30)	1 (5)	1 (5)	8 (40)
	III	12 (60)	8 (40)	0	0	8 (40)
4G	I	17 (85)	2 (10)	1 (5)	0	3 (15)
	II	16 (80)	4 (20)	0	0	4 (20)
	III	18 (90)	2 (10)	0	0	2 (10)
5G	I	17 (85)	1 (5)	2 (10)	0	3 (15)
	II	19 (95)	1 (5)	0	0	1 (5)
	III	20 (100)	0	0	0	0
6G	I	14 (70)	2 (10)	3 (15)	1 (5)	6 (30)
	II	14 (70)	5 (25)	1 (5)	0	6 (30)
	III	16 (80)	4 (20)	0	0	4 (20)
7G	I	18 (90)	2 (10)	0	0	2 (10)
	II	18 (90)	2 (10)	0	0	2 (10)
	III	18 (90)	2 (10)	0	0	2 (10)

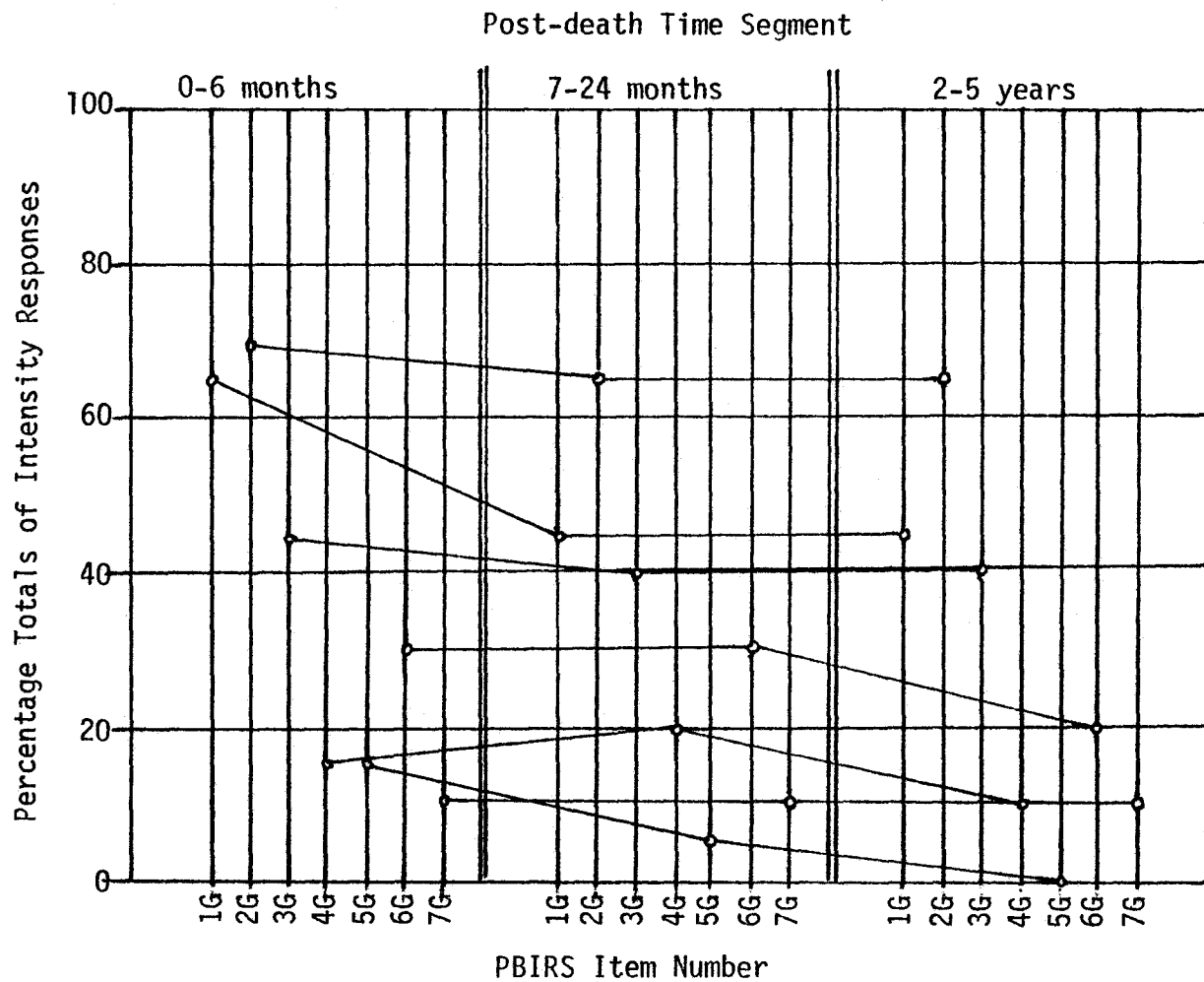


FIGURE 4. Graph illustrating variable intensity of total Guilt responses over three time segments.

TABLE 6. Intensity of parents' Depression responses over three time segments. (Numbers in brackets represent percentages)

PBIRS item	Time segment	Intensity of Response				
		1	2	3	4	Total (2-4)
1DP	I	1 (5)	4 (20)	5 (25)	10 (50)	19 (95)
	II	3 (15)	11 (55)	5 (25)	1 (5)	17 (85)
	III	10 (50)	7 (35)	3 (15)	0	10 (50)
2DP	I	2 (10)	4 (20)	4 (20)	10 (50)	18 (90)
	II	3 (15)	9 (45)	6 (30)	2 (10)	17 (85)
	III	8 (40)	10 (50)	1 (5)	1 (5)	12 (60)
3DP	I	7 (35)	4 (20)	5 (25)	4 (20)	13 (65)
	II	13 (65)	4 (20)	2 (10)	1 (5)	7 (35)
	III	14 (70)	3 (15)	3 (15)	0	6 (30)
4DP	I	6 (30)	10 (50)	4 (20)	0	14 (60)
	II	4 (20)	9 (45)	6 (30)	1 (5)	16 (80)
	III	11 (55)	7 (35)	2 (10)	0	9 (45)
5DP	I	6 (30)	4 (20)	7 (35)	3 (15)	14 (70)
	II	9 (45)	9 (45)	2 (10)	0	11 (55)
	III	14 (70)	4 (20)	2 (10)	0	6 (30)
6DP	I	1 (5)	6 (30)	6 (30)	7 (35)	19 (95)
	II	6 (30)	7 (35)	6 (30)	1 (5)	14 (70)
	III	12 (60)	6 (30)	1 (5)	1 (5)	8 (40)
7DP	I	4 (20)	7 (35)	5 (25)	4 (20)	16 (80)
	II	6 (30)	11 (55)	3 (15)	0	14 (70)
	III	16 (30)	4 (20)	0	0	4 (20)
8DP	I	6 (30)	6 (30)	5 (25)	3 (15)	14 (70)
	II	10 (50)	7 (35)	2 (10)	1 (5)	10 (50)
	III	16 (20)	3 (15)	1 (5)	0	4 (20)
9DP	I	6 (32)	6 (32)	6 (31)	1 (5)	13 (68)
	II	8 (42)	10 (53)	1 (5)	0	11 (58)
	III	13 (68)	6 (32)	0	0	6 (32)
10DP	I	7 (35)	6 (30)	6 (30)	1 (5)	13 (65)
	II	9 (45)	9 (45)	2 (10)	0	11 (55)
	III	12 (60)	7 (35)	1 (5)	0	8 (40)

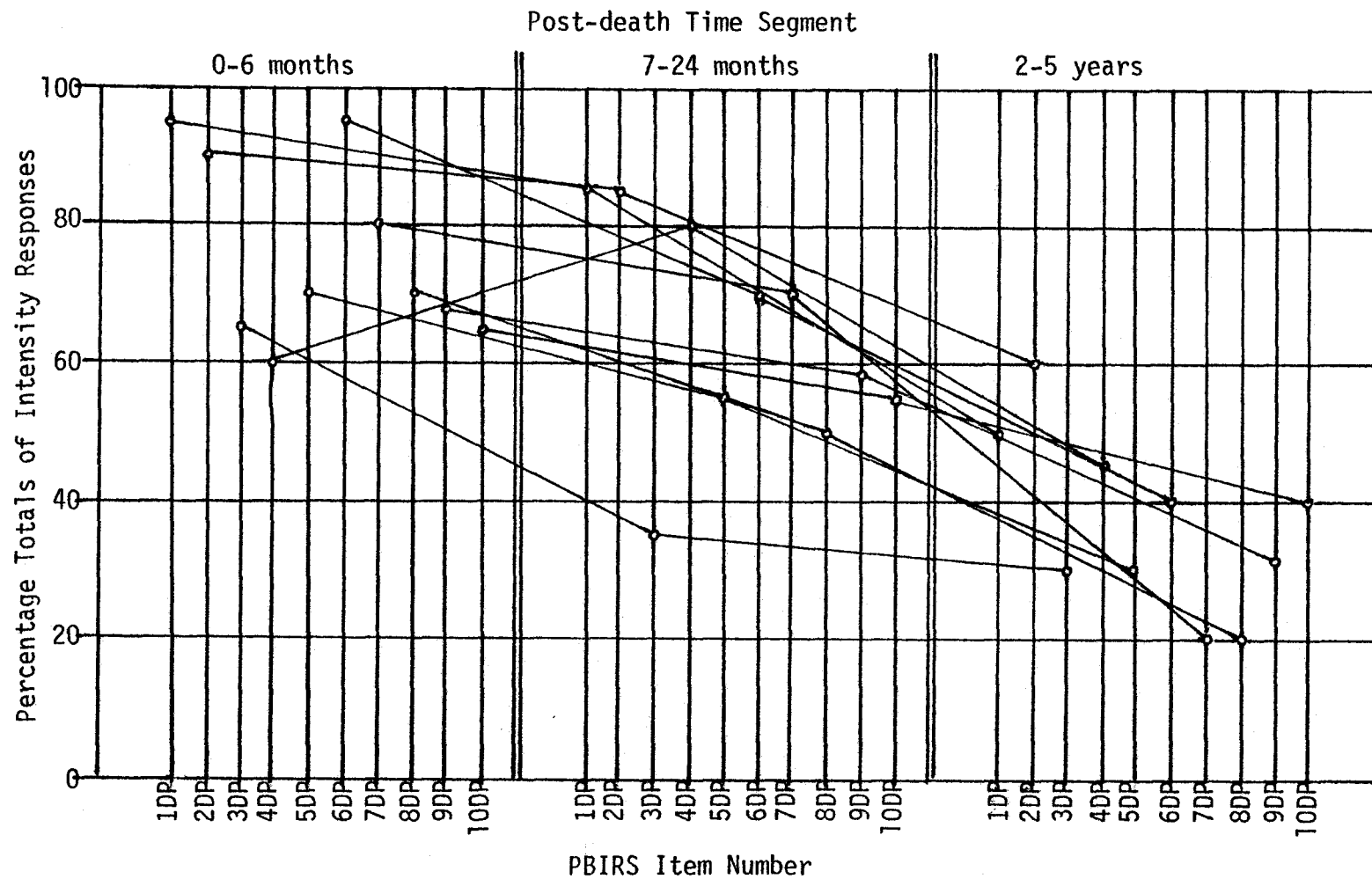


Figure 5. Graph illustrating variable intensity of total Depression responses over three time segments.

TABLE 7. Intensity of parents' Adaptation responses over three time segments. (Numbers in brackets represent percentages)

PBIRS item	Time segment	Intensity of Response				
		1	2	3	4	Total (2-4)
1AN	I	1 (5)	7 (35)	4 (20)	8 (40)	19 (95)
	II	4 (20)	8 (40)	4 (20)	4 (20)	16 (80)
	III	6 (30)	9 (45)	2 (10)	3 (15)	14 (70)
2AN	I	0	5 (25)	3 (16)	11 (58)	19 (100)
	II	4 (21)	9 (48)	5 (26)	1 (5)	15 (79)
	III	12 (63)	4 (21)	3 (16)	0	7 (37)
3AN	I	1 (5)	6 (30)	8 (40)	5 (25)	19 (95)
	II	3 (15)	10 (50)	7 (35)	0	17 (85)
	III	11 (55)	7 (35)	2 (10)	0	9 (45)
4AN	I	0	3 (16)	11 (58)	5 (26)	19 (100)
	II	2 (11)	6 (32)	10 (52)	1 (5)	17 (89)
	III	7 (37)	4 (21)	6 (32)	2 (10)	12 (63)
5AN	I	2 (10)	3 (15)	12 (60)	3 (15)	18 (90)
	II	2 (10)	8 (40)	9 (45)	1 (5)	18 (90)
	III	6 (30)	5 (25)	8 (40)	1 (5)	14 (70)

Post-death Time Segments

I = 0-6 months
 II = 7-24 months
 III = 2-5 years

PBIRS Intensity Ratings

1 = none or negligible
 2 = low-to-moderate
 3 = high
 4 = extremely high

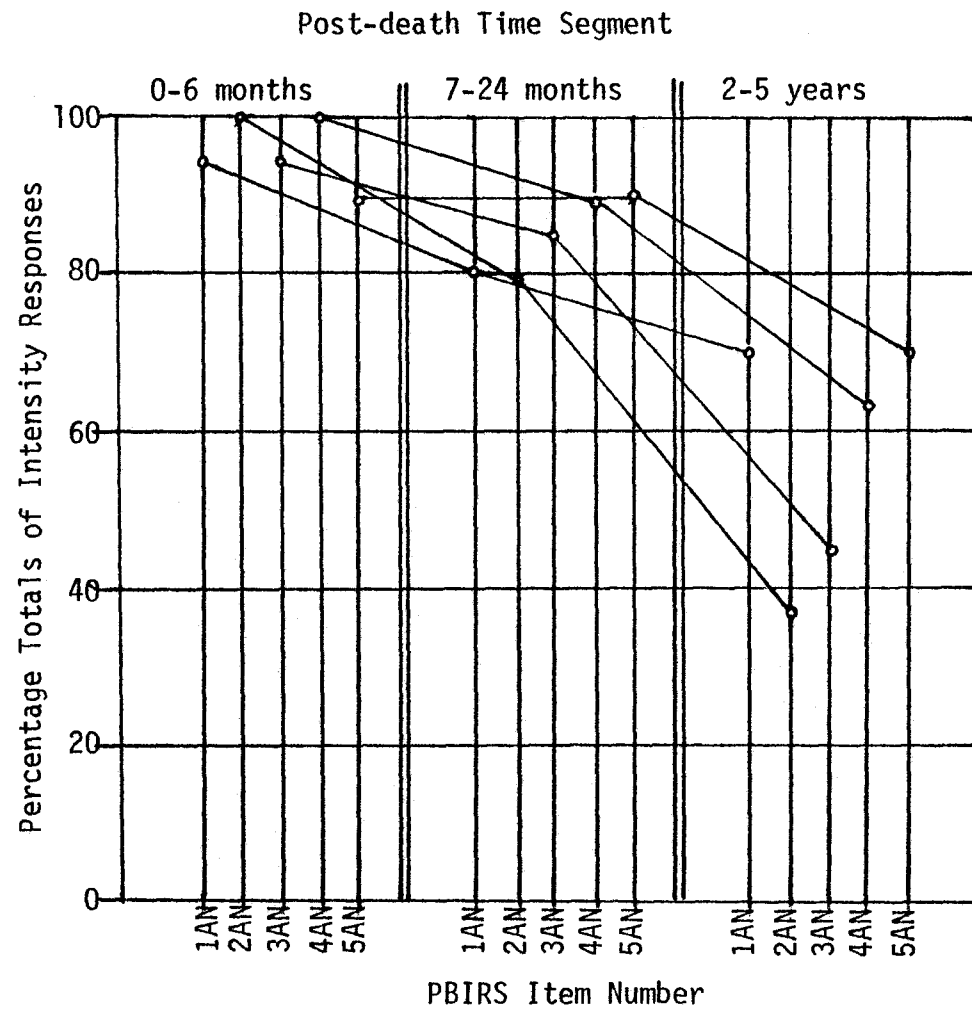


FIGURE 6. Graph illustrating variable intensity of total Adaptation responses over three time segments.

was the intensity reported at the 2-5 year, post-death time segment greater than that reported for the acute grief period of 0-6 months. Likewise, Tables 3 through 7 show that for all items except 7G, more subjects reported their response intensities as "none or negligible" in time segment III than in time segment I. Only item 7G pertaining to "scapegoating" behavior showed no downward trend over the course of grief work.

♦ QUESTION 6: When do parents report negligible intensity for most grief responses?

Because self-rating patterns showed considerable complexity and variation from subject to subject, this question has been approached by looking at majority responses. That is, at what point in their bereavement experiences do a majority (50 percent or more) of the subjects rate themselves "1" on the scale of intensity?

Table 8 shows that most parents achieved resolution of most Denial and Guilt responses within the five-year, post-death period. This was not the case in only two instances: 5D, in which parents claimed to have a continuing sense of the deceased child's closeness or presence, and 2G, in which they reported persistent feelings of regret for "unfinished business" in relationship to the child.

Few parents reported significant progress toward resolution of Anger and Depression responses prior to the two-year, post-death period. No Adaptation responses reached the "1" level in a majority of the cases prior to the second year of bereavement. As suggested by the definition of Anger (see Chapter I, p. 9), many Anger responses were slow to be resolved and often were likely to be "only reduced to within manageable limits." Eleven of the 35 responses had not been resolved to level "1" intensity for most parents at the time of their interviews (two-to-five years after child's death).

TABLE 8. Time period in which the majority of subjects reported "none or negligible" response intensities to the various PBIRS items.

Time period	Item number with grief-state abbreviation				
I 0-6 months	3D	6A	3G 4G 5G 6G 7G		
II 7-24 months	2D		1G	3DP 8DP	
III 2-5 years (or "now")	1D 4D	3A 5A 7A		1DP 4DP 5DP 6DP 9DP 10DP	2AN 3AN
Beyond III*	5D	1A 2A 4A 8A	2G	2DP 7DP	1AN 4AN 5AN
<p>* Subjects' proximity to the death event at the time of the interviews ranged from 2 years, 2 months to 4 years, 6 months, with a mean of 3 years, 2 months. The 11 items in the category "Beyond III" indicate that a majority of subjects did not rate their response intensities to these PBIRS items as "1" (none or negligible) at the time of their interviews.</p>					

For this group of 20, suddenly bereaved parents, grief resolution and adaptation, as measured by "1" ratings on the PBIRS, was generally a slow process lasting a minimum of two years, and frequently much longer. This is further substantiated by the group's responses to the final four PBIRS items--6D, 6AN, 7AN, and 8AN--which are "time-specific." Almost 50 percent of the parents reported high-intensity Denial of their child's death even after several months, and fewer than half of them felt that they regained hope and optimism, a present/future outlook, and general emotional calmness prior to six months after the child's death (Table 9).

TABLE 9. Self-ratings of 20 subjects on four "time-specific" PBIRS items.				
PBIRS item number	Response intensities in "Time-Specific" terms (see Rating Scales, Appendix D)			
	1	2	3	4
6D	6	5	5	4
6AN	1	8	7	4
7AN	1	5	12	2
8AN	1	3	10	6

- ♦ QUESTION 7: When do parents complete the Denial stage and accept the finality of their child's death?

Table 8 shows that a majority of subjects could report negligible intensity of Denial responses by the time of their PBIRS interviews in the 2-5 year period. Item 6D (Table 9) confirms that all but four subjects felt they had fully accepted the death within six months of its occurrence. As already reported, 13 (65%) continued to experience some Denial at the time of the interview,

as defined by their continuing sense of the deceased child's physical presence (5D).

Table 3 shows that the timeline for "completion" of the Denial stage is highly variable, and frequently it is not achieved prior to time period III when some of the Adaptation responses have begun to occur simultaneously. A review of the completed interview forms discloses that only three subjects gave themselves "1" ratings on all six Denial items, and all of these three subjects were at a minimum of three and one-half years beyond the death event.

- ♦ QUESTION 8: When do suddenly bereaved parents attain complete resolution of Anger?

Of all the grief responses, Anger appeared to be the least easily resolved for this group of parents. Table 4 and Figure 3 show that little anger resolution occurs within the first two years. The intensity of most Anger responses persists and ratings are, on the average, relatively stable.

Items in this category reflecting the least intensity throughout the grief period were 6A and 7A, showing that respondents were less apt to report intense anger toward God, and that they felt their anger was generally controllable and not surprising. After two years of bereavement, there appears to be a greater movement toward anger resolution, although none of the eight PBRIS measures of Anger approaches "complete resolution" ("1" rating).

- ♦ QUESTION 9: When do suddenly bereaved parents attain complete resolution of Guilt?

For the vast majority of subjects, feelings of guilt did not range above the low-to-moderate level of intensity during any of the time periods. Table 5 and Figure 4 illustrate that only item 2G remained a persistent problem for most of the parents. Reflecting on their regret for "unfinished business" with the deceased

child, the parent group reported slightly higher 2G intensities throughout their grief work and less progress toward resolution than for any of the other Guilt measures. Only seven subjects reported this regret to be "none or negligible" at the time of the interview, and six of these had given themselves the same "1" rating in post-death time segment I (0-6 months).

Complete resolution--100 percent of subjects rating themselves at the "1" level--was attained during the 2-5 year period on item 5G. Parent ratings on this item revealed that few had experienced any sense of relief that their child had died, and those who did had little trouble resolving guilt associated with that relief. Item 7G, on which only two subjects rated their responses as high as the "2" intensity level, demonstrated little "scapegoating" behavior in this subject group.

- ♦ QUESTION 10: When will most suddenly bereaved parents report a total or near-total level of Adaptation and grief resolution?

In addition to Table 7 and Figure 6, the reader is referred to Tables 8 and 9 for data regarding this question. These tabulations show that a majority of subjects felt that they were making considerable adaptive progress before the end of the second year. Sixteen (80 percent) had experienced a return of hope and optimism, 18 (90 percent) felt more oriented toward the present and future than the past, and 14 (70 percent) felt they had regained a sense of emotional calm. Between the second and fifth years after the loss, the majority of parents reported "none or negligible" intensities to items 2AN and 3AN, suggesting that their routines for daily living and their ability to experience pleasurable emotions had been largely restored.

Only six or seven parents (30-37 percent) reported negligible intensities to items 1AN, 4AN and 5AN by the time of their

interviews. Most parents still experienced more discontentment than pleasure in remembering the child and contemplating his/her lost potential. Most parents did not feel that they had made sufficient adaptive changes in their environments and their relationships so that life without the deceased child could be considered "comfortable" again. In summary, most of these parents appear to have begun the adaptation process sometime after the sixth month of bereavement and continued the work of grief resolution well beyond the second year.

- ♦ QUESTION 11: In what general ways is the grief process different or similar for parents with respect to the different ages and developmental stages of themselves and their deceased children?

Because of the relatively small sample size studied here, the ages/stages comparisons are drawn from two groups based on the distributions illustrated in Figure 1. Two paired groups emerge which are immediately relevant to this question: (1) Y/Y = young parents (28-33 years)/young children (1-7 years), and (2) O/A = older parents (40-53 years)/adolescent children (15-18 years).

Table 10 provides a composite picture of the developmental stages theories proposed by several different researchers (Erikson, 1963; Havighurst, 1972; Sheehy, 1974, 1976; Gould, 1980; Bischof, 1976). The stages and characteristics shown here do not fully describe lifespan, developmental-stages theory, but rather are inclusive of the ages and stages represented by subjects in the current study. Table 10 is arranged so that the Y/Y and O/A pairings are side-by-side and the characteristics easy to compare.

Table 2 identifies 22 of the 109 PBIRS responses on which the two groups' self-ratings showed a mean difference greater than .50 on the 4.0 scale. Three Denial responses--2DI, 4DII, and 6D--indicate that the parents who lost adolescent children took

TABLE 10. Characteristics of the ages and developmental stages of parents and children involved in this study.

Characteristics of Parent/Adult Stages		Characteristics of Child Stages	
Stage A Early adult-hood Age 22-28 (N=2)	<ol style="list-style-type: none"> 1. Firming of adult identity and identification with adult roles. 2. Selecting a mate, starting a family and establishing a home 3. Finding and becoming committed to a lifework in order to provide security and stability for the family 4. Often of the conviction that choices made are irrevocable 	Stage I Early child-hood Age 1-5 (N=4)	<ol style="list-style-type: none"> 1. Largely dependent on parents, though developing independence and a unique selfhood 2. Learning to make choices for him/herself 3. Learning right from wrong 4. Actively building emotional ties with significant others 5. Imitating adults and anticipating roles
Stage B Thirties Transition Age 29-33 (N=4)	A transition time in work and marriage: <ol style="list-style-type: none"> 1. Some questioning of goals and confusion about job and parental responsibilities 2. Development of new priorities and interests to overcome discontentment 3. More self-concern 	Stage II Middle child-hood Age 6-12 (N=2)	<ol style="list-style-type: none"> 1. Advancing basic skills (academic, social and physical) 2. Becoming a productive worker and potential provider 3. Developing morality, conscience and a scale of values

TABLE 10 (continued)

<p>Stage D Mid-life reexami- nation Age 40-43 (N=3)</p>	<ol style="list-style-type: none"> 1. Feeling of "time running out"--recognition of gulf between youthful dreams and actual fulfillment 2. Reexamination of purposes and resetting of priorities for one's time and energy: <ol style="list-style-type: none"> a) Frequent career or job changes b) Marital reappraisal and changes 3. Difficulty molding adolescent children, though success can provide considerable parental pride and pleasure 	<p>State III Late child- hood Age 12-20 (N=10)</p>	<ol style="list-style-type: none"> 1. Developing clear adult identity and achieving emotional independence from parents and other adults: <ol style="list-style-type: none"> a) Seeking and beginning to develop occupational identity and economic independence b) Mentally preparing for marriage and family c) Assuming social responsibility
<p>Stage E Mid- adulthood II Age 44-60 (N=7)</p>	<ol style="list-style-type: none"> 1. Reestablishment of position and status, leading to a new sense of stability: <ol style="list-style-type: none"> a) Renewed sense of selfhood and increased dependence on and affection for spouse b) Able to let go of both parents and children <p style="text-align: center;"><u>or</u></p> 2. Feelings of resignation, which may lead to stagnation and discontentment; fault-finding with aged parents and children 		<ol style="list-style-type: none"> 2. Strengthening relationships with age mates of both sexes (heavy emphasis on peer group) 3. Often confused and sometimes volatile--easily negative and ambivalent toward self

considerably longer to fully accept the death. More so than parents of younger children, they continued to act and plan as if the child were still alive, and they made greater efforts to maintain or regain feelings of physical closeness with the deceased.

This does not add credence to the suggestion made by developmental-stage theorists that parents over 40 are preparing or prepared to "let go" of their children. It may suggest the traumatic impact of a terminal end to "youthful dreams" and of facing the new impossibility of gaining fulfillment, pride and pleasure through raising one's children.

The younger parents who lost children under the age of seven appeared to have more intense Anger responses. Comparing the data on Table 2 for items 4AI and 6AI & II, the younger parents were initially more envious of other parents with intact families, and they admitted to more intense and prolonged anger toward God than did the older parents. Throughout the first two years of bereavement, the younger parents expressed greater dissatisfaction with the unanswered or unanswerable question, "Why did my child have to die?" (8AI & II).

This difference in Anger responses does not show any clear relevance to developmental-stages theory, unless to suggest that the younger parents feel more cheated out of the opportunity to parent the child for a significant number of years. Because the decision to start a family was a major commitment more recently undertaken, young parents may feel more thwarted in that effort.

Data from items 1GI and 6GI show that during the first six months the younger parents experienced a greater sense of responsibility and guilt for the child's death, and also more guilt for having survived the child. The older parents, however, expressed more regret for past behaviors toward the child or "unfinished business" in the relationship (2GI & II), and felt a greater sense of failure or inadequacy as parents (3GII).

These data regarding Guilt responses are somewhat more consistent with developmental-stages theory. The younger child, being more dependent on the parent, would likely engender a greater sense of parental responsibility for the child's welfare and guilt for not being able to preserve the child's life over one's own. The regret of older parents, on the other hand, may be reflective of the difficulty encountered in "molding adolescent children" and losing forever the chance to improve one's parenting with respect to that child.

With the exception of 4DPI & II, measures of Depression responses were highly similar for the two groups of subjects. The older parents were able to identify more physical and emotional problems in their behavior during the first two years of bereavement. The nature of those problems is further explored later in this chapter with the discussion of PBIRS item 4DP*.

The fact that older parents were aware of more physical and emotional problems during bereavement is likely a reflection of the realities of aging. Several of the over-40 parents stated their suspicion that some of their problems were as much related to aging as to mourning. Inasmuch as chronological ages are related to developmental stages, this PBIRS data regarding Depression is consistent with stages theory.

For all Adaptation measures showing a mean difference greater than .50 between the two groups, older parents who lost adolescent children reported grief responses of greater intensity and duration. They experienced more difficulty in focusing on the positive aspects and pleasant memories of the child's life, and were more frustrated and discontent in contemplating what or who the child might have become had s/he lived (1ANII & III).

Older parents reported consistently slower progress toward restoration of routine and order in their lives (2ANI, II & III). They were less able to experience pleasure and enjoyment during

the first six months (3ANI) and also slower initially to make adaptive changes in personal relationships and/or family structure (5ANI).

The characteristics of developmental stages (and advancing ages) appear consistent with the PBIRS data suggesting the younger parents' greater adaptability. The adolescent's death represents the total, irrevocable loss of one aspect of the parent's future in which he has made a considerable investment, both tangibly and intangibly. Because the lives of the older parent and child have been integrally involved for many more years, and the ability to have additional children is less likely, the sense of loss may be more intense and recovery more difficult. At a point in life when many of these parents feel that life should be becoming more stable and manageable, a major unexpected trauma creates upheaval and instability.

In addition to the Y/Y - O/A, paired group data, an attempt was made to examine and compare the self-ratings from some of the single cases to focus more attention on the st/ages variable. It soon became apparent, however, that each case had a unique set of complex variables that precluded any pairing which would effectively screen-out other highly significant factors. For example, a 26-year-old mother whose 4-year-old daughter was murdered by drowning might have been compared in terms of st/ages differences with a 43-year-old mother whose teenage girl was brutally assaulted and strangled. But many other variables confounded the data, i.e., one was a struggling single parent and the other had a sound marriage of 25 years duration; one had three, healthy adolescent children while the other had a sickly, six-year-old; one was interviewed two years and two months after the death; the other was at the four-and-one-half-year point. Attempts to pair other subjects were found to be similarly problematic, so this form of analysis was abandoned.

PBIRS Items 1A* & 4DP*

Before proceeding to the presentation of the demographic data in response to research questions 12 and 13, the results from PBIRS sub-items 1A* and 4DP* are summarized below, adding to this section describing the nature of parental grief. Both of the following questions were presented to the 20 subjects in a checklist format, and their responses are tallied here:

1A*. Where have your angry feelings been directed?

<u>11</u> yourself	<u>14</u> other person or circumstances responsible for the death
<u>6</u> spouse	
<u>9</u> other family member	Other categories added:
<u>7</u> friends	<u>6</u> police; law enforcement
<u>3</u> dead child	<u>3</u> justice system
<u>9</u> medical staff	<u>2</u> the media
<u>9</u> God	<u>4</u> parent of minor child responsible for the death
<u>8</u> fate	<u>1</u> child's incompetent counselor
	<u>1</u> employer/co-workers

4DP*. How many of the following have you experienced since your child's death?

- 18 inability to concentrate
- 13 loss of memory
- 16 loss of efficiency and/or organization
- 17 loss of initiative; laziness, inertia
- 14 being overwhelmed by everyday problems
- 14 fatigued, exhausted, aged (old) beyond your years
- 14 insomnia, sleep disturbance
- 10 sense of "going crazy"
- 6 increased physical illness or pain

Other categories added:

- 3 exacerbation or "flare-up" of a formerly existent problem (ulcers, psoriasis, cancer)
- 2 loss of interest in sexual intimacy
- 2 strange sounds or motion inside the head
- 2 increased use of alcohol or drugs
- 1 erratic eating patterns and weight loss or gain

The Revised PBIRS (Appendix E) reflects the data from new categories added by interviewees at the time of the interviews.

Demographic Characteristics of Bereaved Parents/Subjects

- ♦ QUESTION 12: What demographic features characterize the subjects in this study?

Demographic information is presented in the order it appears on the Demographic Data Sheet (Appendix F) which was completed by each subject immediately following the interview session.

I. The Deceased Child

The study focused on the parents of 16 deceased children in 14 families (in two instances, two siblings died in the same accident). There were nine sons and seven daughters, ranging in age from one to eighteen years (mean 10.4 years, mode 18 years). Their birth orders in the families were as follows: first child - 5; second child - 6; third child - 3; fourth child - 2. Causes of death were: acute illness - 1; suicide - 2; homicide - 2; accidents - 11 (8 automobile accidents, 1 fatal fall, 1 drowning, 1 surgical complications).

All of the deaths were sudden and unexpected, although a suicide-drowning victim had been missing from home for several weeks, and the child with spinal meningitis was gravely ill for four days before life-support systems were turned off. All 16 of

the children had lived with their parents consistently since birth.

II. Surviving or Subsequent Siblings

The numbers of children in the 14 families at the time of the interviews were: five families - 1 child; four families - 2 children; four families - 3 children; one family - 4 children. Six of the fourteen families had added one or more children since the loss, seven of whom were natural-born and two of whom were adopted. For three couples, the deceased had been their only child, but in each case the wife bore another child within one year of the death.

III. Parent/Subjects

All of the 20 subjects were the natural or "birth" parents of the deceased child(ren). There were six bereaved fathers, each of whom was married to one of the 14 mothers who served as subjects. Fathers ranged in age from 31-53 years, with a mean age of 42. Mothers were aged 28-51 years, with a mean of 38.9 years. Two of the female subjects had been divorced and remarried several years before the child's death, and another was separated prior to the death, divorced shortly afterward, and remained unmarried.

IV. Family

Subjects reported family incomes ranging from \$6,000-\$70,000, the average being \$29,000 and the mode \$18,000. All twenty subjects were Caucasian, and they listed their religious affiliations as Catholic - 5, Protestant - 13, and None - 2.

In a few cases there were persons living in the household who were not part of the "nuclear" family. Two households each had one foster child, one family had taken in a teenage classmate of one of their surviving children, and the unmarried subject lived in a communal arrangement with four additional adults and three children.

V. Adjustment

Nineteen subjects answered "yes" to the question, "Do you feel that you and your family are making a satisfactory adjustment to this tragedy?" One subject felt that her family was adjusting well but she herself was not. Sixteen subjects (80 percent) had used the services of what they considered to be a professional, therapeutic counselor: psychiatrist - 3, psychologist - 7, pastoral counselor - 3, and counselor - 3.

VI. Education and Employment

All subjects reported that they had completed high school, five had attended college, and one had six years of college education. Though the mode remained at 12 years, the average schooling for the 20 subjects was 13.2 years.

Fifteen of the 20 were employed at the time of the interview. Nine listed their occupations as either "white collar" or health para-professionals. Seven were in "blue collar" occupations such as auto mechanics or factory work, though three of these were unemployed. One husband and wife worked together in agribusiness (large-scale farming).

Finally, the group represented ten communities stretching from Vancouver, Washington to Cottage Grove, Oregon. They were on the mailing lists of The Compassionate Friends chapters in the following numbers: Albany - 2, Eugene - 4, Portland - 6, Salem - 8. Only six parents considered themselves to have ever been actively involved with the self-help group in their vicinity. Six claimed to be totally unassociated, and the remaining eight had attended a few meetings and/or read the chapter newsletter.

- ♦ QUESTION 13. How does this subject group compare demographically with other bereaved parents in the U.S. and Canada?

In 1978, a team of researchers at the University of Chicago

mailed a survey questionnaire to 2,356 bereaved parents in 18 locations in the U.S. and Canada (Borman et al., 1979). Responses were received from 663 persons (28 percent), about 50 percent of whom considered themselves to be members of The Compassionate Friends organization.

Because the set of criteria for subjects in the PBIRS/Oregon study was considerably narrower, fewer of those who heard about the study were qualified as potential subjects. Estimates gathered from local chapter leaders suggest that only about 15 percent of the bereaved parents who learned of the Oregon study were suddenly bereaved parents, lost children between ages 1 and 20 years, and were 2-5 years beyond the death event. Of 23 eligible persons contacted directly by the researcher (personal meetings, phone calls, personal letters), 17 (74 percent) volunteered to participate. An additional four parents responded to a newsletter article which was received by an estimated 115 parents who met the criteria for subjects. Including these indirect contacts, the overall response rate was roughly 16 percent.

Table 11 shows data comparing some of the basic descriptive characteristics of the two groups, including relevant information about the deceased children and their deaths.

Because the focus of the Chicago survey was to assess the effects of membership in a peer, self-help group such as The Compassionate Friends, most of the data obtained is not readily comparable with the PBIRS data gathered.

Comparison of the demographic features of the two samples had been presented to demonstrate that the PBIRS sample is not vastly different from a larger, national sampling gathered through similar channels. Therefore, the PBIRS subject group is likely to be fairly representative of other bereaved parents in North America--at least those who involve themselves voluntarily in research concerning their bereavement experience.

TABLE 11. Comparison of demographic characteristics for two groups of bereaved parents.

Characteristic	Chicago Survey Group (N=663)	PBIRS Study Group (N=20)
Females (mothers)	73%	70%
College graduates	28%	20%
Protestants	50%	65%
Employed at time of survey/ interview	66%	75%
Married	80%	95%
"White-collar" workers	34%	35%
Average age (in years)	43.1	39.8
Lost one child (rather than two or more)	89%	90%
Lost male child	67%	56%
Average age of deceased child (in years)	13	10.4
No warning before child's death	62%	100%
Cause of child's death:		
1) accident	46%	70%
2) medical disease or congeni- tal defect	43%	5%
3) murder or suicide	11%	25%

Summary: Results of the Investigation

This chapter has reported the data collected through a preliminary field test of the Parental Bereavement Interview and Rating Scale and the Demographic Data Sheet.

1. The PBIRS was judged by experts to have face validity as a measure of parental grief and adjustment.
2. Fifty-two of the 109 PBIRS items showed test-retest reliability coefficients greater than .6994 (.001 significance level). An additional 33 items had reliability estimates in the .50 - .69 range. Therefore, 78 percent of all the items were found, by use of the Pearson product-moment correlation statistic, to have moderate-to-very high reliability coefficients.
3. With few exceptions, subjects felt that the grief and adjustment processes of bereaved parents can be usefully and comfortably divided into three time periods: I = 0-6 months; II = 7-24 months; III = 2-5 years.
4. There appears to be little appreciable mean difference of intensity or duration between the grief-stage responses of parents of younger children (ages 1-7) and those of adolescent children (ages 15-18). On this basis, the designation of "young child" appears to be appropriate and useful for children in the 1-18-year age range.
5. The intensity of parental grief responses decreased over time for this group of subjects.
6. Most subjects reported that the majority of their grief responses did not drop to the "negligible" level of intensity until after the second year of bereavement.
7. The majority of subjects felt that they had completed the Denial stage by the time of their interviews (within two to

five years after the child's death).

8. The suddenly bereaved parents who constituted this subject group did not report complete resolution of Anger by the time of their interviews (two to five years post-death).
9. Complete resolution of Guilt was not attained by this subject group, although Guilt appeared to be far less a problem and far more easily resolved than Anger.
10. Most suddenly bereaved parents reported that the Adaptation process did not really begin prior to the second year of bereavement and that total Adaptation was not likely to be attained until well beyond that time.
11. As compared by grief stages, young parents who lose younger children (Y/Y) appear capable of overcoming Denial and accepting the child's death more readily than older parents of deceased adolescents (O/A). The younger parents reported more intense Anger responses, but these were largely resolved within the first two years. While the younger parents felt more Guilt in terms of responsibility for the child's dying, older parents' Guilt was reflected in regret for inadequacies in their relationships with their deceased offspring.

The measure of Depression responses were highly similar for the two groups of subjects, though older parents of adolescents felt that they suffered more physical and emotional problems during the first two years of bereavement. The group of older parents also reported more intense and long-lasting grief responses in terms of the items measuring Adaptation. Overall, the grief work of older parents seemed to be somewhat more difficult.

12. The small sample group involved in the PBIRS study was not markedly different demographically from the larger group of bereaved parents who volunteered to participate in a 1978 University of Chicago survey. The major differences were created by the narrower selection criteria of the PBIRS study, i.e., focusing on sudden death circumstances and causes.

CHAPTER V

SUMMARY, DISCUSSION, AND RECOMMENDATIONS

Chapter V begins with a brief summary of the investigation. Next, a discussion section deals with three areas of the study which require further comment:

1. The Revised PBIRS - Why and How,
2. Enlarging and Broadening the Sample, and
3. Developmental Stages as Variables.

Lastly, recommendations for further research and replication of the present study are presented.

Summary

The Problem

The major purpose of this investigation was to develop a methodology by which to objectively study and assess the grief and adjustment processes of bereaved parents. An original research and counseling instrument, the Parental Bereavement Interview and Rating Scale (PBIRS) was formulated, field-tested, and revised. The data from the field test were analyzed in terms of thirteen research questions related to methodology, the quantitative description of the parental grief and adjustment processes, and general information about the characteristics of the subject group as it compared with a national sample.

The Sample

The PBIRS was administered to 20 volunteer subjects in the area of northwestern Oregon. There were six fathers and fourteen mothers, ranging in age from 28 to 53 years ($\bar{x} = 39.8$). Each

subject met three criteria: (1) s/he was the parent of a child who died between the ages of one and twenty; (2) s/he was interviewed two to five years after the child's death, and (3) the child's death was sudden and unexpected.

The Instrument

The PBIRS (Appendix D) was developed to reflect the complex phenomenon of parental bereavement in a comprehensive way. Thirty-nine items, grouped according to grief stages (Denial, Anger, Guilt, Depression, Adaptation), were formulated to measure the existence and intensity of specific grief responses on a four-point, self-rating scale. The retrospective research format required that the subjects respond to most of the items three times, recalling their grief experiences during three specific time periods.

At the conclusion of the field study, the PBIRS was revised (Appendix E), reflecting the critical appraisal of experts and the observations of the subjects and the researcher regarding the interview experience. The Revised PBIRS is further described later in this chapter.

Research Methodology

The PBIRS was administered to each subject by the investigator in a one-to-one interview session. Each subject also completed a Demographic Data Sheet. Approximately two weeks following the interview, subjects completed the PBIRS a second time, independently, to supply data for estimating test-retest reliability of the instrument. Subsequently, the data were analyzed by various methods to determine the answers to the thirteen research questions and to serve as a basis for further developing and refining the research and counseling instrument.

Treatment of the Data

The Pearson product-moment correlation coefficient was computed to determine the test-retest reliability estimates for PBIRS items. The data were further presented in graphic and tabular forms to allow for comparison between various time periods in the grief process, and between different sub-groups of subjects.

Special attention was given to comparing the grief responses of parents according to developmental-stages theory. Finally, the demographic characteristics of the subject group were charted and compared with those of a much larger and more heterogeneous sample of bereaved parents surveyed in 1978.

Major Outcome of the Investigation

The research methodology and instrument were field-tested with satisfactory results. The preliminary reliability study showed 52 of 109 items to have test-retest coefficients of correlation in the high to very high range. Eighty-five percent of the items were significant at the .05 level.

The instrument and the protocol for its administration were well-received by subjects and by leaders of self-help groups for bereaved parents. There appear to be no reasons why this study cannot be replicated, although there are some indications that further studies would be improved, and validity and reliability of the PBIRS enhanced, by using the Revised PBIRS and a much larger subject group.

Discussion

The Revised PBIRS - Why and How

It became apparent in the early stages of field-testing that the efficacy and applicability of the PBIRS could be expanded through certain revisions in the instrument and its protocol for administration. The changes that appear in the revised form

(Appendix E) were indicated by general consensus of, or frequency of comment by, the 25 people who served as subjects and experts, all of whom were bereaved parents.

These parents showed a strong preference for the guided interview over the independent questionnaire format. The five experts, none of whom was interviewed, suggested that the independently completed questionnaire was too lengthy and might be easily abandoned without the presence of the interviewer and the opportunity to discuss the questions. Though the questions were deemed important and interesting, the involvement of the interviewer was judged to be a significant motivational factor.

Comparing their experiences with both interview and questionnaire formats, many subjects gave positive appraisals of the therapeutic nature of the interview. On the other hand, four subjects were not sufficiently motivated to complete the retest questionnaire, and several of those who did said it was a less interesting and less worthwhile experience than the initial interview. Therefore, in spite of the acknowledged danger of interviewer bias as a source of error, the interview, with self-rated responses, has been retained as the preferred form in this area of inquiry.

The Revised PBIRS has abandoned the three-answer, retrospective approach in favor of a one-answer-per-item format. This serves to simplify the instrument and shorten the time for administration (estimated 1-3 hours vs. 1½-5 hours). Though most subjects claimed to be comfortable with the I-II-III breakdown of the bereavement period, it was apparent that many had difficulty recalling their earlier responses and sorting out the overlap from one period to the next. Some response processes seemed to be clearly divisible by the three time periods, but others were not. In some cases, subjects were confused by the problem of having to determine an "average" intensity for a response over a time period covering six months or 18 months, when that response fluctuated from day to day or week to week. These findings under-

undermine the strength of Basic Assumption 2 (Chap. I, p. 12), set forth at the beginning of this investigation.

With regard to the task of increasing the reliability estimates for PBIRS items, the one-answer format is likely to have a positive influence. As illustrated by Table 1 (Chapter IV), the estimates of stability were consistently higher for the four items which required only one answer (6D, 6AN, 7AN, 8AN) than for the 35, three-answer items. If the Revised PBIRS can be administered to a sample of sufficient size to permit groupings of subjects by matched demographic characteristics, similar data about the progression through the grief and adjustment processes should be obtainable. In addition, the one-answer format makes the PBIRS more suitably adapted to longitudinal studies of bereaved parents.

Three other changes in format include the addition of the respondent's rating scales to the interviewer's guide, the placement of the optional probes after the rating-scale responses, and simplification of the numbering system. It was found that the interviewer needed to have easy access to the response scales during the interview in order to address the interviewee's questions regarding them. (The interviewee is given the scales on 3" x 5" cards to study after each item is discussed.) Moving the probe questions away from the primary question is intended to place greater emphasis on the main issue addressed by each item and to eliminate confusion. The items were renumbered sequentially, one through 39, at the suggestion of several experts who found the prior numbering system unnecessarily complex. The coding for grief stages--D, A, G, DP, AN--is retained and is sufficient to identify the appropriate groupings of responses according to the stages they are presumed to represent.

Finally, several changes have been made in the actual phrasing and ordering of items and rated responses. Most of these were minor revisions. For example, many parents felt that the terms "haunted" or "plagued" were too strong when referring to their

guilt feelings, so these were replaced or tempered by adding "bothered" or "troubled." Many subjects were unwilling or unable to admit that their anger approached "bitterness" and "outrage," but all had experienced at least "hurt" and "irritation" which are akin to anger. Many parents acknowledged their recovery to a life that was again "worthwhile" or "satisfying," but they seemed unable to report that they had adapted to being "quite comfortable" without the deceased child.

In some instances, probe questions that were never used during the field test were totally deleted from the PBIRS, or the ideas they conveyed were incorporated into the primary questions. Field testing also suggested the need for adding PROBES to four items--9DP, 29G, 24DP, and 38AN. Probes on the Revised PBIRS should improve the interviewer's ability to facilitate accurate and complete responses from those interviewed.

A few of the subjects felt very strongly that the PBIRS should address the problems of alcohol and drug abuse among the bereaved, and these ideas have been incorporated into items 24DP and 19DP*. Two of the original items (4AN and 5AN), which dealt with adaptive changes in the bereaved's environment and personal relationships, were found to be too similar and, thereby, confusing. They were combined into one item, 20AN, followed by a new sub-item, 20AN*, which helps subjects to identify their adaptive changes more specifically.

Only one, totally new item has been added, 32G, relating to parent's guilt for thinking or wishing one of the siblings had died instead of the deceased. This question of the "favorite child" was identified as a significant problem for seven of the 20 subjects.

In summary, the Revised PBIRS should prove to be a superior research and counseling instrument in many important respects. It features a less-complex answering system which increases clarity

and shortens administration time. Changes in wording and re-arrangement of the format are expected to be more appealing and acceptable to interviewees. It is quite probable that the improved instrument will yield better reliability and validity data. And, the Revised PBIRS is more appropriate for use with a less-restricted sample of bereaved parents, including those who lose infants or adult children or whose children die deaths that can be anticipated due to chronic illness or physical defect.

Enlarging and Broadening the Sample

In the interest of controlling the variables and making the data more manageable, this preliminary PBIRS study used a sample selected according to age of the deceased child, circumstances of the death, and the length of time that had transpired since the death. This focus also provided a means by which to study a group of bereaved parents who have generally been less-accessible than those who frequent hospitals and clinics in the course of their child's treatment for a terminal disease or physical defect. The results reported here reflect the grief and adjustment processes of only a portion of the bereaved parent population.

It would be advantageous for future studies to enlarge and broaden the sample in several respects. Scientific, reliable information about all types of parental bereavement is unavailable and needed. Future studies would profit by removing the criteria for subjects imposed by the current investigation. This would allow inclusion of parents who lose infants and adult children, whose children's deaths have been anticipated, and who can be interviewed at any point in their post-death, bereavement processes. Further, it would be desirable to include a greater variation in terms of racial, ethnic, marital and social class characteristics. Wherever possible, interview data from therapeutic, mental health settings might be included to diversify the volunteer, non-clinical sample.

Continued development of the PBIRS in terms of reliability, validity and norms is dependent on enlarging the sample. Most statistical formulas, including the Pearson product-moment correlation coefficient, are recommended for use with random samples of 30 cases or more. With a larger, more representative subject group, more sophisticated statistics can be applied and the value of the instrument as a research and clinical tool can be determined through the development of norms and predictive capability. With regard to future test-retest reliability studies, it should be noted that the Revised PBIRS is in a form that can be used interchangeably as an interview guide or a self-administered questionnaire.

A second reason for enlarging the sample was demonstrated by the difficulty encountered in trying to analyze the data in terms of developmental-stages theory. With only 20 subjects from which to choose, it was impossible to find pairs sufficiently matched to isolate variables and make their grief experiences comparable. Each of these subjects had one or more highly unique features to their situations which became confounding variables. These were such things as the mutilation and non-viewability of the child's body, one or more pregnancies within two years of the death, incompetence of medical personnel, sensationalized coverage by the news media, and prolonged, unsatisfying legal proceedings. A larger sample increases the potential for matching and contrasting individual subjects and groups of subjects so that hypotheses can be formulated and tested.

The sample for the preliminary study was primarily White, middle-class and Protestant. The literature suggests that social class influences attitudes toward death, with families of low socio-economic position being more likely to experience many births and deaths, violence, exploitation, hopelessness and despair (Glick, 1978). It would be useful to broaden the sample to gain insights regarding the variability of coping strategies and grief experiences between ethnic groups, those with divergent religious orientations, different social strata, etc.

Because studies (Parkes, 1972; Vollman et al., 1971; Benoliel,

(1971) show that bereaved families from the lower socio-economic levels are at "high risk" of getting into difficulty, it is important to understand the basis for their greater vulnerability and the possibilities for providing appropriate services to facilitate positive grief resolution. Since lower-class bereaved parents appear less likely to volunteer for studies through the usual contact channels, efforts to locate them might focus on clinics and health departments, churches, and social welfare programs.

Finally, there were four items on the PBIRS field test which might have yielded significantly different responses from a less-restricted sample. The available literature suggests that these factors are considerably more problematic than indicated by the outcome of the current study. Item 3D, for example, questioned the subject's ability to discuss the child's death. Because all 20 subjects readily volunteered to be interviewed, it is obvious that they would be willing and able to talk about their experiences of child loss--perhaps moreso than most bereaved parents.

In general, guilt was far less troublesome than suggested by previous research and observation. Only two subjects admitted to any "scapegoating" behavior (7G), though it is mentioned with relative frequency in the literature (Cain and Cain, 1964; DeVaul and Zisook, 1976; Schiff, 1977). Few of the parents interviewed reported negative feelings toward the deceased child (4G), though this has been identified as a common problem for bereaved parents in clinical settings. Though Kübler-Ross' work (1974, 1975) suggests that relief over a child's death is a common source of guilt, these parents of suddenly deceased children could not recall having felt relief or the attendant guilt (5G). If samples of parents representing both sudden and anticipated death situations could be compared, one might learn if this "relief/guilt" factor is, indeed, a significant one for either group.

Pending further study, these four items--3D, 7G, 5G, and 4G--have been retained as a part of the Revised PBIRS, even though they failed during the preliminary field test to show the expected

intensity or variation over time. It is possible that these factors are more significant in the broader population of bereaved parents. In particular, ratings for Guilt responses may be higher among those who do not volunteer for studies, i.e., those experiencing intense guilt might be less willing and able to talk about their grief experiences.

Developmental Stages as Variables

Close scrutiny of the subjects and their circumstances has revealed the uniqueness and complexity of each of the twenty bereavement experiences. The special attributes of participants in this small-sample study prevented a thorough, definitive analysis of the data in terms of developmental-stages theory. In all cases, there appeared to be one or more personal or situational characteristics which likely influenced PBIRS responses far more than the ages or developmental stages of the subjects or their deceased children.

For example, in the paired groups labeled "Y/Y" (Young parents ages 28-33 years who lost Young children ages 1-7 years), five of the six mothers became pregnant within a few months of their loss and had one or two additional children within three years. All of these subjects (and their spouses) indicated that this ability to quickly begin reconstituting their family size was a very positive factor in reviving hope and facilitating grief work. On the basis of this sample, and inasmuch as younger parents in earlier developmental stages are usually more capable of having additional children, one might surmise that their grief would generally be less intense and prolonged. It is unlikely, however, that the early pregnancy and childbirth rate approaches 83 percent among the larger population of younger bereaved parents, and the PBIRS responses of these mothers and fathers may not be representative of others in the same st/ages categories.

It is important to note here the highly positive value these subjects placed on their ability to have another baby shortly after losing a child. Contrary to what the literature reports about the dangers of the "replacement child" syndrome (Cain and Cain, 1964; Poznanski, 1972), these parents felt that the new baby was crucial to the success and rapidity of the healing process. None seemed to have unusual expectations for the subsequent child(ren) in terms of being a "carbon copy" of the deceased or of dying a similar, young death. All of the women indicated that the knowledge of their pregnancies caused them to be more aware and careful to maintain their physical and emotional health during bereavement. In light of these findings, it may be of value for physicians to re-examine the generally accepted practice of advising bereaved parents against having more children in the early years after child loss.

Another seemingly important factor--this one cutting across the lines of developmental stages--was the problem of mutilation and non-viewability of the corpse. The murdered four-year-old whose body was decomposed after drowning, the suicide-by-shotgun victim, the accident victims who were badly burned or crushed--in all cases where the dead child was not viewable, parents had more difficulty coping with the reality of the death and seemed more obsessed by horrible nightmares and images of the child. This was reflected in their Denial and Depression responses.

Looking again at the subjects of the ages/stages comparisons drawn in Chapter IV, it is quite probable that the causes of death were more critical than developmental stages in determining PBIRS responses. In the group of ten adolescents, five died by either murder or suicide, and the other five deaths resulted from the careless driving of other teenagers. Among the six younger children, only one was murdered, though two others died as a direct result of unintentional parental negligence. The implications

for different Anger and Guilt responses are obvious. Considering the lack of similarity between the two groups of subjects in terms of death circumstances, it is impossible to isolate the developmental stages as significant variables in determining grief responses.

In this group of only 20 subjects, it is also important to note that there were no very young or elderly parents. The age range at the time of loss was 26-49 years, rising to 28-53 years at the time of the interviews. Also, the group of six younger children were quite young, only two having entered into the early stages of Mid-Childhood (refer to Figure 1 and Table 10 in Chapter IV). In summary, all the data suggest the need for a larger sample in which variables can be better matched and controlled and the various developmental stages can be better represented. Until more extensive data are available, it appears that any discussion related to developmental stages is purely conjecture. The complexity of both the grief processes and developmental stages--because both are descriptive measures of human behavior--makes the problem of studying them together a formidable challenge.

Recommendations

The following recommendations are made on the basis of the present investigation:

1. The PBIRS has been field-tested on a limited population. It is recommended that similar studies, preferably using the Revised PBIRS, be carried out in other locations with larger, more heterogeneous populations to support and/or supplement the findings and procedures of the present investigation.
2. The reliability of the instrument should be further studied. Many items have been rewritten on the Revised PBIRS in an

effort to improve their clarity and stability in the test-retest situation. The split-half technique might also be applied for items judged sufficiently homogeneous to be matched.

3. Further research is recommended to determine the validity of the PBIRS. One might look at the consistency of ratings among items related to specific grief stages (Denial, Anger, etc.) to see if correlations suggest these items are measuring what they purport to measure. Ratings on the PBIRS might also be indirectly validated by studying their correlation to the subject's responses on other grief measures such as the Texas Revised Inventory of Grief or the Grief Experience Inventory (Appendices A and B).
4. All data gathered through future use of the PBIRS should be pooled in an effort to increase the normative sample and to improve the precision, generalizability and predictive capability of the instrument.
5. As the data pool is increased, the grief processes of parents should be studied and hypotheses developed by comparing the impact of a wide range of specific variables, including:
 - a) sudden vs. anticipated death circumstances
 - b) mothers' responses vs. fathers' responses
 - c) different socio-economic strata
 - d) religious vs. non-religious orientations
 - e) baby's death vs. loss of older child
 - f) loss of dependent child vs. loss of older, independent child
 - g) different developmental-stage pairings of parents and deceased children
 - h) variable strengths of social support systems
 - i) different racial and ethnic backgrounds
 - j) married vs. single parents
 - k) loss of one child vs. loss of two or more

- 1) different causes of death (i.e., illness, suicide, accident, murder)
6. It is recommended that a longitudinal approach, using the Revised PBIRS, replace the retrospective approach for studying the progression through grief work to adaptation.
7. It is strongly recommended by the researcher that the Revised PBIRS be used by counselors in the clinical setting to facilitate information gathering and therapeutic intervention. The instrument has been devised (a) to guide counselor and client through a thorough evaluation of the grief process, (b) to help bereaved clients overcome anxiety and reticence to discuss particularly difficult aspects of their grief work (i.e., guilt, shame, rage) by validating these feelings, and (c) to facilitate the counseling techniques of "operational mourning" or "regriefing therapy" (Cutter, 1974; Krupp, 1972; Paul and Grosser, 1965).
8. It is recommended that the grief and adjustment processes of those parents who begin reconstituting their family size immediately after the child's death--either by pregnancy or adoption--be studied in greater detail to determine the short- and long-range effects and advisability of this action.
9. Further investigation should be undertaken to determine why Guilt, as measured by the PBIRS with suddenly-bereaved parents, was judged to be a significantly less problematic factor than is indicated by the available bereavement literature.
10. It is recommended that the information about parental bereavement, gathered through more extensive use of the PBIRS in research and clinical settings, be used in attempts to identify families and individuals at-risk for pathological grief reactions so that appropriate interventions can be made to assist them in coping with the death of a child.

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APPENDICES

APPENDIX A

Texas Revised Inventory of Grief (TRIG)

(Reproduced by permission of
T. Faschingbauer, Ph.D.)

TEXAS REVISED INVENTORY OF GRIEF

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Name or #: _____ Age: _____ Sex: _____ Race: ☐ White ☐ Black ☐ Lat. Am. ☐ Oriental ☐ Other (list)

Circle Last Year of Formal Schooling Completed: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 or more.

Religion: ☐ Protestant ☐ Catholic ☐ Jewish ☐ Other (list)

The person who died was my (check only one): Father-☐ Mother-☐ Brother-☐ Sister-☐ Husband-☐ Wife-☐ Son-☐
Daughter-☐ Friend-☐ Other (list)-☐

LOOKING BACK I WOULD GUESS THAT MY RELATIONSHIP WITH THIS PERSON WAS (check only one):

- ☐ Closer than any relationship I've ever had before or since. ☐ Closer than most relationships I've had with other people.
☐ About as close as most of my relationships with others. ☐ Not as close as most of my relationships. ☐ Not very close at all.

PLEASE COMPLETE A SEPARATE FORM FOR EACH PERSON WHO DIED.

HOW OLD WAS THIS PERSON WHEN THEY DIED? _____

THIS PERSON DIED (check only one box):

- ☐ Within the past 3 months ☐ 9-12 months ago ☐ 5-10 years ago
☐ 3-6 months ago ☐ 1-2 years ago ☐ 10-20 years ago
☐ 6-9 months ago ☐ 2-5 years ago ☐ More than 20 years ago

THIS PERSON'S DEATH WAS: ☐ Expected ☐ Unexpected ☐ Slow ☐ Sudden

Do Not
Write
In Box

PART I: PAST BEHAVIOR

Think back to the time this person died and answer all of these items about your feelings and actions at that time by indicating whether each item is Completely True, Mostly True, Both True and False, Mostly False, or Completely False as it applied to you after this person died. Check the best answer.

	COMPL. TRUE	MOSTLY TRUE	TRUE & FALSE	MOSTLY FALSE	COMPL. FALSE
1. After this person died I found it hard to get along with certain people.					
2. I found it hard to work well after this person died					
3. After this person's death I lost interest in my family, friends, and outside activities.					
4. I felt a need to do things that the deceased had wanted to do					
5. I was unusually irritable after this person died					
6. I couldn't keep up with my normal activities for the first 3 months after this person died.					
7. I was angry that the person who died left me					
8. I found it hard to sleep after this person died.					

OVER

PART II: PRESENT FEELINGS

Now answer all of the following items by checking how you presently feel about this person's death. Do not look back at Part I.

Do Not
Write
In Box

	COMPL. TRUE	MOSTLY TRUE	TRUE & FALSE	MOSTLY FALSE	COMPL. FALSE
1. I still cry when I think of the person who died					
2. I still get upset when I think about the person who died					
3. I cannot accept this person's death					
4. Sometimes I very much miss the person who died					
5. Even now it's painful to recall memories of the person who died					
6. I am preoccupied with thoughts (often think) about the person who died					
7. I hide my tears when I think about the person who died					
8. No one will ever take the place in my life of the person who died					
9. I can't avoid thinking about the person who died					
10. I feel it's unfair that this person died					
11. Things and people around me still remind me of the person who died					
12. I am unable to accept the death of the person who died					
13. At times I still feel the need to cry for the person who died					

PART III: RELATED FACTS

Now please answer the following items by circling either True or False

1. I attended the funeral of the person who died.	True	False
2. I feel that I have really grieved for the person who died.	True	False
3. I feel that I am now functioning about as well as I was before the death.	True	False
4. I seem to get upset each year at about the same time as the person died.	True	False
5. Sometimes I feel that I have the same illness as the person who died.	True	False

THANK YOU FOR ANSWERING ALL OF THESE QUESTIONS. WE ARE ALSO VERY INTERESTED IN YOUR SPECIAL THOUGHTS AND COMMENTS. PLEASE USE THE REST OF THIS SIDE TO TELL US ABOUT ANY THOUGHTS AND FEELING YOU HAVE.

APPENDIX B

Grief Experience Inventory (GEI)

(Reproduced by permission of
C. M. Sanders, Ph.D.)

GRIEF EXPERIENCE INVENTORY

Catherine M. Sanders, Paul A. Mauger,
and Paschal N. Strong, Jr.

INSTRUCTIONS

This questionnaire is concerned with the experience of grief. The statements which are included represent various thoughts and feelings commonly expressed by people who have suffered the loss of a relative or close friend through death. Read each statement and then try to determine how well it describes you during your period of bereavement. If you are still experiencing some of these thoughts or feelings, please respond in the same manner as you would a past experience. If the statement is true or mostly true as applied to you, blacken the space under true on your answer sheet. If the statement is mostly false, blacken the space under false on your answer sheet. If a statement does not apply to you leave it blank.

Please mark your answers on the sheet provided. In marking your answers, be sure that the number of the statement agrees with the number on the answer sheet. Write only on the answer sheet. Do not make any marks on the mimeographed booklet.

GRIEF EXPERIENCE INVENTORY

Catherine M. Sanders, Paul A. Mauger,
and Paschal N. Strong, Jr.

- | | |
|---|--|
| 1. Immediately after the death I felt exhausted. | 17. I often experience confusion. |
| 2. I tend to be more irritable with others. | 18. I feel lost and helpless. |
| 3. I am strong preoccupied with the image of the deceased. | 19. I am comforted by believing that the deceased is in heaven. |
| 4. I frequently experience angry feelings. | 20. I have had frequent headaches since the death. |
| 5. It is not difficult to maintain social relationships with friends. | 21. It was difficult to part with the clothing and personal articles of the deceased. |
| 6. My arms and legs feel very heavy. | 22. It was necessary to take sleeping pills after the death. |
| 7. I am unusually aware of things related to death. | 23. The yearning for the deceased is so intense that I sometimes feel physical pain in my chest. |
| 8. It seems to me that more could have been done for the deceased | 24. I cry easily. |
| 9. I showed little emotion at the funeral. | 25. I have taken tranquilizers since the death. |
| 10. I felt a strong necessity for maintaining the morale of others after the death. | 26. I experience a dryness of the mouth and throat. |
| 11. I feel cut-off and isolated. | 27. I feel restless. |
| 12. I rarely take aspirins. | 28. Upon first learning of the death I had a dazed feeling. |
| 13. I feel reluctant to attend social gatherings. | 29. Concentrating upon things is difficult. |
| 14. I was unable to cry at the announcement of the death. | 30. I have feelings of apathy. |
| 15. I have feelings of guilt because I was spared and the deceased was taken. | 31. I experienced a feeling when the death occurred that "something died within me." |
| 16. I have a special need to be near others. | 32. Aches and pains seldom bother me. |
| | 33. I find I am often irritated with others. |

34. I could not cry until after the funeral.
35. I feel that I may in some way have contributed to the death.
36. I find myself performing certain acts which are similar to ones performed by the deceased.
37. I made the funeral arrangements.
38. I lack the energy to enjoy physical exercise.
39. I rarely feel enthusiastic about anything.
40. I feel that grief has aged me.
41. I have never dreamed of the deceased as still being alive.
42. I find myself frequently asking "why did the death have to happen in this way?"
43. I sometimes have difficulty believing the death has actually occurred.
44. I feel a strong desire to complete certain unfinished tasks the deceased had begun.
45. I have often dreamed of times when the deceased was living.
46. I am often irritable.
47. I have dreamed of the deceased as being dead.
48. I feel extremely anxious and unsettled.
49. I feel tenseness in my neck and shoulders.
50. Sometimes I have a strong desire to scream.
51. I am so busy that I hardly have time to mourn.
52. I feel anger toward God.
53. I have the urge to curl up in a small ball when I have attacks of crying.
54. I feel the need to be alone a great deal.
55. I rarely think of my own death.
56. I find it difficult to cry.
57. Looking at photographs of the deceased is too painful.
58. Life has lost its meaning for me.
59. I have no difficulty with digestion.
60. I have had brief moments when I actually felt anger at having been left.
61. I have no trouble sleeping since the death.
62. I have a hearty appetite.
63. I feel healthy.
64. It comforts me to talk with others who have had a similar loss.
65. I yearn for the deceased.
66. I seldom feel depressed.
67. I have the feeling that I am watching myself go through the motions of living.
68. Life seems empty and barren.
69. There are times when I have the feeling that the deceased is present.
70. I often take sedatives.

71. I have frequent mood changes.
72. The actions of some people make me resentful.
73. My feelings are not easily hurt.
74. I am losing weight.
75. Small problems seem overwhelming.
76. I sometimes feel guilty at being able to enjoy myself.
77. I frequently have diarrhea.
78. I often wish that I could have been the one to die instead.
79. I have lost my appetite.
80. I sometimes talk with the picture of the deceased.
81. I am not interested in sexual activities.
82. At times I wish I were dead.
83. It is hard to maintain my religious faith in light of all the pain and suffering caused by the death.
84. I seem to have lost my energy.
85. I dread viewing a body at the funeral home.
86. I find myself idealizing the deceased.
87. I have problems with constipation.
88. I frequently take long walks by myself.
89. I avoid meeting old friends.
90. I have a special need for someone to talk to.
91. It often feels like I have a lump in my throat.
92. I sometimes find myself unconsciously looking for the deceased in a crowd.
93. I seem to have lost my self-confidence.
94. I drink more alcohol now than before the death.
95. After the announcement of the death I thought, "this could not be happening to me."
96. I have nightmares.
97. The thought of death seldom enters my mind.
98. I have never worried about having a painful disease.
99. funerals sometimes upset me.
100. I would not feel uneasy visiting someone who is dying.
101. I often worry over the way time flies by so rapidly.
102. I have no fear of failure.
103. I am close with only a few persons
104. The sight of a dead person is horrifying to me.
105. I always know what to say to a grieving person.
106. I often seek advice from others.
107. It does not bother me when people talk about death.
108. I cannot remember a time when my parents were angry with me.
109. I do not think people in today's society know how to react to a person who is grieving.

- | | |
|--|--|
| 110. I never have an emotional reaction at funerals. | 122. I spent a great deal of time with the deceased before the death. |
| 111. I often think about how short life is. | 123. It helps me to comfort others. |
| 112. I am not afraid of dying from cancer. | 124. My family seems close to me. |
| 113. I do not mind going to the doctor for check-ups. | 125. I feel that I did all that could have been done for the deceased. |
| 114. I shudder at the thought of nuclear war. | 126. My religious faith is a source of inner strength and comfort. |
| 115. The idea of dying holds no fears for me. | 127. I am smoking more these days. |
| 116. I never lose my temper. | 128. I am not a realistic person. |
| 117. I have always been completely sure I would be successful when I tried something for the first time. | 129. I am awake most of the night. |
| 118. I am not usually happy. | 130. I feel exhausted when I go to bed but lie awake for several hours. |
| 119. I feel that the future holds little for me to fear. | 131. I lose sleep over worry. |
| 120. I cannot ever remember feeling ill at ease in a social situation. | 132. I often wake in the middle of the night and cannot get back to sleep. |
| 121. I find myself sighing more now than before the death. | 133. I sleep well most nights. |
| | 134. Things seem blackest when I am awake in the middle of the night. |
| | 135. I can sleep during the day but not at night. |

APPENDIX C

Letter of Request to Participate

LETTER OF REQUEST TO PARTICIPATE

Dear

I am writing to you today as one bereaved parent to another, with interest and concern about the tragic experience we have shared. I believe I can understand the pain and loneliness you have felt because I have known the sorrow and despair of losing my own young son in 1977. If you're like me, you've found the healing process is very slow, and you have realized that the sources of comfort are hard to find.

During my bereavement I became very dedicated to trying to help other parents whose child has died. One way of doing so is through the Compassionate Friends group. I got your name and address from them.

I am a professional counselor, and right now I am working on a research project aimed at helping all of us, especially counselors, to better understand the experiences and problems that arise during the adjustment period of parents after losing a child. I am working under the guidance of the counseling department at Oregon State University. I would like to ask your help with this project. It will not require a great deal of your time, but the time you spend may be of great value in helping others.

Your participation would be in the form of a personal, confidential interview with me, scheduled at a place and time convenient for you. We will discuss and share your recollections of the bereavement experience. Such information gathered from many different individuals like yourself will be combined to help us draw some clearer pictures of what it takes to survive the tragedy of child-loss.

I think you will find the interview itself a very positive experience--a chance to share, to learn, to grow and to help others in the process. If you are interested in participating with me in this study, please call me collect at 399-7966 (Salem), afternoons or evenings.

Your cooperation is deeply appreciated. Best wishes.

Sincerely,

Cheron J. Mayhall, M.A.
Doctoral Student
Oregon State University

APPENDIX D

Parental Bereavement Interview
and Rating Scale (PBIRS)

Initials of Interviewee_____

First Name of Deceased Child

Cause of Death_____

How long since death?_____

PARENTAL BEREAVEMENT INTERVIEW AND RATING SCALE (PBIRS)

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Interview Guide and Answer Sheet

Key: I = 0-6 months after death occurred
II = 7-24 months after death occurred
III = 2-5 years after death occurred

- I_____ 1D. Bereaved parents want desperately to believe that their
II_____ child's death is only a nightmare--a mistake--that it
III_____ didn't really happen. To what extent have you
experienced this sense of unreality?
PROBE: Have you ever said, "It can't be true," "I don't
believe it," "It's impossible"?

I _____ 1A. To what extent have you experienced anger or outrage
 II _____ over _____'s death?

III _____ PROBES: Do you feel you and your family have been
 unfairly victimized? (asked, "Why me?")

Have you felt frustrated and angry about your power-
 lessness (inability) to change the situation?

1A* Where have your angry feelings been directed?

_____yourself	_____God
_____spouse	_____fate
_____other family	_____other person or
member	circumstances
_____friends	responsible
_____your dead child	for the death
_____medical staff	_____other _____

I _____ 1G. Bereaved parents seem to struggle with feelings of guilt.
 II _____ Some guilt may be realistic, but usually it is magnified
 III _____ far beyond reality during the period of grief work.

Have you been haunted by feelings of responsibility for
 _____'s death?

PROBES: Do you realistically believe that you might
 have been able to prevent the death?

How frequently have you thought, "If only I had . . .
 (kept him home, locked up the medicine, not given her
 that toy, gotten him to the hospital sooner, etc.), my
 child would still be alive"?

- I _____ 1DP. Now I'd like to talk with you about your feelings and
II _____ actions after the shock and anger had worn off and you
III _____ realized that there was nothing you could do to get
_____ back.

Did you ever feel that life had lost its meaning and value--that everything else seemed unimportant and meaningless compared to your tragedy?

- I _____ 1AN. When you think of _____, have they been pleasant
II _____ memories of what was, rather than painful, frustra-
III _____ ting thoughts of what might have been?
PROBE: Have you mourned greatly over your lost dreams for _____ (first step, mastery of a bicycle, first day of school, musical interest and achievement, first love, etc.)?

- I _____ 2D. In thinking and talking about _____, to what extent
II _____ has s/he still seemed a part of your present and future?
III _____ PROBE: Did you find yourself still acting/planning as if s/he were alive, i.e. setting _____'s place at the table, calling for _____, including _____ in vacation plans, etc.?

- I _____ 2A. Have you felt or acted with hostility toward the people
II _____ around you, even though they usually tried to be
III _____ helpful?

PROBE: Were there well-intentioned but insensitive comments or gestures to which you responded with anger, i.e. "Be grateful you have other children", "You're still young--have another child!", "Here's a book with religious answers that will make it all okay". . . .

- I _____ 2G. Even parents who clearly were not responsible in any way
II _____ for their child's death are plagued by guilt in the form
III _____ of regret for past behaviors toward the child which are now unchangeable. Have you had this sense of "unfinished business"---a desire to change something that you did to _____, or to do for him/her something you'd neglected to do or put off while s/he was alive?

PROBES: Did _____'s death leave an unresolved disagreement?

Do you regret any instances of punishment or discipline you imposed?

Had you neglected to do something for or with the child (fishing trip, birthday party, purchase special toy or gift, etc.) which s/he'd really wanted?

- I _____ 2DP. Have you experienced a sense of utter powerlessness
II _____ and futility with regard to _____'s death---like
III _____ nothing you might do could make any difference
whatsoever?

- I _____ 2AN. To what extent has your routine or schedule for daily
II _____ living been restored to the prior level of activity
III _____ and orderliness?
PROBE: What parts of your routine have you changed, and
what parts have you kept the same? (job, mealtimes,
social or civic activities, etc.)

- I _____ 3D. Were you, and are you now, willing and able to talk
II _____ about _____'s death with a sympathetic listener?
III _____ PROBE: Were there periods when you absolutely could
not discuss your child's death?

- I____ 3A. Have you felt irritated and bitter about how easily most
II____ people have seemed to accept _____'s death?
III____ PROBE: Did you ever ask, "How can everyone go on with
their daily living routines as if my child never lived
or died?"

(Interviewer may suggest five minute break at this time, if necessary.)

- I____ 3G. Consider your general relationship with _____ during
II____ his/her lifetime. Because your time together was cut
III____ short, you have probably thought a great deal about how
good a parent you were to _____ in the too-short
span of his/her life. Have you been haunted by your own
shortcomings or a sense of failure or inadequacy as a
parent?
PROBE: Have you thought, "If only I had, in some way,
loved my child more."

- I____ 3DP. Have you ever thought you'd rather be dead than live
II____ with your pain and anguish over _____'s death?
III____ PROBE: Have you felt that life is a trap from which
you wanted to escape but couldn't?

PBIRS - 7

- I _____ 3AN. Let's talk a few minutes about how feelings of happiness
II _____ and pleasure re-entered your life after _____'s
III _____ death. Namely, to what extent have you been able to
have fun and experience pleasurable emotions like joy
and happiness?

PROBES: Have you treated yourself to many more pleasurable or exciting activities in an effort to ease the pain and quicken the healing?

Has having fun sometimes been a bittersweet experience because returning to the reality of your loss and sadness is intensified by comparison to the fun?

Did it ever seem that enjoying life again is disrespectful---a betrayal or abandonment of your dead child?

- I _____ 4D. To what extent have you tried to maintain or regain a
II _____ feeling of physical closeness with _____?
III _____ PROBES: What have you done with _____'s belongings,
pictures, bedroom, etc.?

How frequently have you visited the cemetery, mausoleum, or other burial site?

- I _____ 4A. Have you felt jealous of other parents whose children
II _____ are all still living?
III _____ PROBE: Have you questioned, "Why my child instead of
theirs', when they have 'more to spare,' 'care for them
less well,' etc.?"

- I _____ 4G. Even the most loving parents get irritated by their
II _____ children from time to time. Most children live to
III _____ outgrow or otherwise reconcile annoying behaviors or
qualities so they are forgotten or dismissed by the
parent. But your child died young, and may have left
you "hanging" with some negative feelings which now make
you feel guilty. Have you had difficulty coping with
negative feelings toward _____?
PROBES: Were you ever disappointed or angry about his/
her 1) choice of friends, 2) academic ability or
performance, 3) social behavior, 4) general health and
development, etc.?
Have you been angry regarding _____'s carelessness
which may have contributed to his/her death?

- I _____ 4DP. To what extent have you experienced increased physical
II _____ and/or emotional problems since _____'s death?
III _____ 4DP* PROBE: How many of the following have you experienced
since _____'s death?

___ inability to concentrate
___ loss of memory
___ loss of efficiency and/or organization
___ loss of initiative; laziness, inertia
___ being overwhelmed by everyday problems
___ fatigued, exhausted, aged (old) beyond your years
___ insomnia, sleep disturbance
___ sense of "going crazy"
___ increased physical illness or pain
___ other _____

- I _____ 4AN. Have you chosen to make some changes in your environment
II _____ so it is more compatible to life without _____?
III _____ PROBES: Have you taken up new activities and hobbies to
help fill the void in your life?
Have you taken a new job or changed your line of work?
Have you increased or decreased your involvement in
church or secular interest groups?
Have you changed your residence to a new home or
community?
If you did not move, have you rearranged your home or
yard in any way?

- I _____ 5D. Have you sensed a continued close relationship with
II _____ even without making a conscious effort at it?
III _____ PROBES: Have you dreamed about _____ a great deal?
Have you sometimes sensed the child was still close
by, so much so that you could still talk with him/her?

- I _____ 5A. Have you had a strong need to blame or to know that
II _____ someone feels or is responsible, or, have you felt any
III _____ need to punish or avenge for _____'s death (to see
that someone pays for it)?
PROBE: Have you considered or taken any sort of
punitive action toward yourself, other family member(s),
doctor, hospital, other caretaker, etc.?

PBIRS -10

- I _____ 5G. Frequently a parent will have a sense of relief that his
II _____ or her child has died, and then feel guilty for being
III _____ relieved! Have you had any trouble coping with this
dual sense of relief and guilt?

PROBES: Have you ever felt that your child is better
dead than seriously ill, crippled, paralyzed, brain-
injured, etc.?

Have you ever felt gladly relieved of the responsi-
bility for raising _____ in this troubled and
troublesome world?

- I _____ 5DP. Have you needed or wanted to sleep a good deal more
II _____ since _____'s death?

III _____ PROBE: Have there been days when you retired much
earlier, slept later in the morning, taken more naps
during the day?

- I _____ 5AN. Have you made changes in your relationships with other
II _____ people so that life without _____ is more
III _____ comfortable?

PROBES: Have you changed the composition of your family
in any way---divorced, married, added a child, etc.?

Have you strengthened your relationships with friends
or relatives, or have you formed new relationships?

Have you associated with people more attuned to your
changed role as a bereaved parent, i.e. others who have
lost a child or other close family member?

(Interviewer may suggest five minute break at this time, if necessary.)

- I____ 6A. Have you felt angry toward God for allowing _____
II____ to die?
III____ PROBE: Do you feel betrayed or punished by God, or do
you believe _____ died for some purpose ordained by
God?

- I____ 6G. Have you felt guilty for having survived your child and
II____ living to enjoy life when s/he has been deprived of this
III____ opportunity?

- I____ 6DP. During the course of your grief work, have you ever felt
II____ detached or somehow unrelated to the people and events
III____ around you?
PROBE: Did it seem strange that everything and everyone
around you seemed to go on functioning much as if
_____ had never died?

- I _____ 7A. While working through your grief, have angry feelings
II _____ taken you by surprise and been difficult to control?
III _____

- I _____ 7G. The sense of personal guilt which some bereaved parents
II _____ experience is so intense that they may need to share
III _____ part of the burden with someone else. In this process,
it is usually the spouse or one of the other children
who is called upon to carry or share the blame. Have
you, at any point, needed to share your guilt with
another person close to you?

- I _____ 7DP. Did you lose, to any degree, a sense of alertness and
II _____ personal awareness? That is, did you feel a vague
III _____ strangeness in relation to your own self?
PROBE: Did you get through days and weeks seemingly not
thinking about or directing your own behavior?

- I _____ 8A. To the question, "Why did my child have to die?", have
II _____ you found any satisfactory answer?
III _____ PROBES: Are you still looking for an answer?
Can you be content if there is no answer to be found?

- I _____ 8DP. Have there been times when you somehow felt no emotion,
II _____ even though you know that _____ had died?
III _____ PROBE: Were you unable to feel sad or cry or to respond
with any sort of emotion to the people and events
around you?

- I _____ 9DP. How much time did you want or need to be alone and to
II _____ what extent did you isolate yourself from others?
III _____ PROBE: Did you ever reject attempts of others to help,
especially those who had not lost a child and therefore
could not really understand your grief?

- I _____ 10DP. Did you ever feel rejected or otherwise isolated
II _____ from the sources of support and comfort you wanted
III _____ or needed?

PROBES: How soon after _____'s death did
friends and relatives stop visiting or calling?

Have you felt deserted or ostracized, as if
grief and child-loss might be contagious?

Have you had to bear the greatest part of the
burden for maintaining relationships?

- _____ 6D. At what point were you able to fully accept _____'s
death--to say, "My child is DEAD and I must go on
living without him/her"--and really believe it?

- _____ 6AN. In most instances, the helplessness which bereaved
parents feel is accompanied also by feelings of
hopelessness---a severe loss of optimism. Can you
recall the point at which you really began to feel
optimistic and hopeful again?

7AN. There is usually a point in the healing process at which the mourning parent's focus of interest and activity shifts from the past to the present and future. Can you remember when you made this shift, i.e. could concentrate the majority of your thought and effort on the activities of your daily life and could plan and work toward future goals and activities without thinking of how might have fit into them?

 8AN. At what point in your bereavement did you regain a sense of emotional calm? That is, when did you begin to feel consistently composed and in control of your emotions rather than experiencing erratic waves of great sadness, fearfulness, joy, anger, etc.?

PARENTAL BEREAVEMENT INTERVIEW AND RATING SCALE (PBIRS)

Respondent's Rating Scales

(to be affixed to 3 x 5 cards)

1D. To what extent have you experienced a sense of unreality regarding your child's death?

- 1 Never doubted or questioned the reality of the death
- 2 Sometimes seemed impossible or unreal
- 3 Frequently seemed impossible, unreal
- 4 Totally unable to believe child really dead

1A. To what extent have you experienced anger or outrage over your child's death?

- 4 Have felt intense anger and frustration
- 3 Considerable anger and frustration; sometimes not controllable
- 2 Some anger and frustration, but not debilitating
- 1 No feelings of anger and frustration

(See reverse side of card, 1A*, for additional information)

1A*: Where have you directed your angry feelings?

- Yourself
- Your spouse
- Other family members
- Friends
- Your dead child
- Medical personnel
- God
- Fate
- Other person(s) or circumstance(s) responsible for the death _____
- Other _____

1G. Have you been haunted by feelings of responsibility for your child's death?

- 1 No guilt; have not blamed myself at all for child's death
- 2 Feel somewhat responsible/guilty
- 3 Feel considerable responsibility and guilt
- 4 Overwhelmed by feelings of responsibility/guilt for child's death

PBIRS Rating Scales - 2

1DP. Did you feel that life had lost its meaning and value?

4 Life lost all meaning and value for me

3 Meaning and value of life greatly decreased

2 Meaning and value of life somewhat decreased

1 Never lost a sense of the meaning and value of life

1AN. When you think of your child, have they been pleasant memories of what was rather than painful, frustrating thoughts of what might have been?

1 All memories pleasant; remembering brings contentment

2 Remembering is generally pleasant, although I sometimes feel sad for my child's unrealized potential

3 Remembering frequently leaves me discontented when I think of all the things s/he missed out on

4 Deep sense of loss for what might have been if s/he had not died; remembering always brings discontentment

2D. In thinking and talking about your dead child, to what extent has s/he still seemed a part of your present and future?

4 I consistently continued to act as if s/he were alive

3 I frequently found myself acting or planning as if s/he were still alive

2 Now and then I found myself "forgetting"

1 Always fully aware of my child's being gone forever and have acted accordingly

2A. Have you felt or acted with hostility toward the people around you?

1 No hostile feelings or behavior

2 Some hostility felt and/or expressed

3 Considerable hostility felt and/or expressed

4 Intense hostility felt and/or expressed

PBIRS Rating Scales - 3

2G. Have you had a sense of "unfinished business;" a desire to change something you did or did not do with or for your child?

- 4 Intense feelings of regret for past behaviors/unfinished business
- 3 Considerable regret over past behaviors toward the child; many things I wish I could change
- 2 Somewhat regretful; there are a few past behaviors toward the child I wish I could change
- 1 No regret for unfinished business or past behavior

2AN. To what extent has your routine or schedule for daily living been restored to the prior level of activity and orderliness?

- 4 Routine largely unrestored; far fewer activities and considerable disorganization
- 3 Activity level reduced about 50%; definitely less orderly and organized than before child's death
- 2 Routine and schedule nearly as full and organized as before
- 1 Fully restored; same or greater levels of activity and orderliness

2DP. Have you experienced a sense of utter powerlessness and futility?

- 1 Never sensed a loss of power or ability
- 2 Some sense of decreased power and ability to make a difference
- 3 Considerable sense of decreased power and ability to make a difference
- 4 Intense feelings of powerlessness and futility

3D. Were you, and are you now, willing and able to talk about your child's death with a sympathetic listener?

- 1 Always open to discussion; willing to talk about it
- 2 Usually able to talk about it
- 3 Usually unable to talk about it
- 4 Totally unable to discuss child's death

PBIRS Rating Scales - 4

3A. Have you felt irritated and bitter about how easily most people have seemed to accept your child's death?

- 4 Extremely irritated and bitter about others' easy acceptance
- 3 Considerable bitterness and irritability
- 2 Some bitterness and irritability about others' easy acceptance
- 1 No bitterness or irritability about others' acceptance

3DP. Have you ever thought you'd rather be dead than live with your pain and anguish over the child's death?

- 4 Death would definitely be preferable
- 3 Frequently think or thought death would be preferable
- 2 Sometimes think/thought I might rather be dead
- 1 Never felt that death would be better than enduring the pain and living

3G. Have you been haunted by your own shortcomings or a sense of inadequacy or failure as a parent?

- 1 No sense of failure or inadequacy; my relationship with my child was the best it could be
- 2 Some sense of failure or inadequacy; some aspects of the relationship could have been better or stronger
- 3 Considerable sense of failure and/or inadequacy; many aspects of the relationship could have been better
- 4 Intense sense of inadequacy and failure in my relationship to the child

3AN. To what extent have you been able to have fun and experience pleasurable emotions like joy and happiness?

- 1 No significant decrease in my ability to feel joy, happiness, pleasure
- 2 Somewhat less capable of having fun or experiencing pleasurable emotions
- 3 Seldom have/had fun or experience pleasurable emotions
- 4 No experience of joy, fun, happiness, pleasure

PBIRS Rating Scales - 5

4D. To what extent have you tried to maintain or regain a feeling of physical closeness with your dead child?

- 4 Tried desperately to maintain feelings of closeness--to hold on to the relationship as it had been before death
- 3 Frequently tried to regain closeness
- 2 Now and then tried to regain feelings of closeness
- 1 Accepted fully the distance between my child (death) and myself (life)

4G. Have you had difficulty coping with negative feelings toward your dead child?

- 4 Extreme difficulty coping with negative thoughts and feelings toward child
- 3 Considerable difficulty dealing with negative thoughts and feelings toward child
- 2 Some difficulty dealing with negative feelings and thoughts toward child
- 1 No problems with regard to negative thoughts or feelings toward child

4A. Have you felt jealous of other parents whose children are all still living?

- 1 No envy or jealousy
- 2 Some envy or jealousy
- 3 Much envy and jealousy
- 4 Extremely jealous and envious

4DP. To what extent have you experienced increased physical and/or emotional problems since the child's death?

- 1 No decrease in physical or emotional well-being
- 2 Some decrease in physical health and/or emotional well-being
- 3 Marked negative change in physical and/or emotional functioning
- 4 Extreme negative change in physical and/or emotional functioning
(See reverse side of card, 4DP*, for additional information)

PBIRS Rating Scales - 6

4DP*: How many of the following have you experienced since your child died:

- Inability to concentrate
- Loss of memory
- Loss of efficiency and/or organization
- Loss of initiative; laziness, inertia
- Being overwhelmed by everyday problems
- Fatigued, exhausted, aged beyond your years
- Insomnia; sleep disturbance
- Sense of "going crazy"
- Increased physical illness or pain
- Other _____

5D. Have you sensed a continued close relationship with your child even without making a conscious effort at it?

- 1 No sensation of closeness or presence
- 2 Rarely or briefly sense a continued presence or closeness
- 3 Frequent sense of child's presence or closeness
- 4 Continuous sense of child's presence in dreams and/or waking hours

4AN. Have you chosen to make some changes in your environment so it is more compatible to life without your child?

- 4 No positive, adaptive changes in my environment
- 3 A few adaptive changes which make life without the child somewhat more tolerable
- 2 Several adaptive changes; life, for the most part, is comfortable, even though s/he is gone
- 1 Sufficient adaptive changes to live quite comfortably without my deceased child

5A. Have you had a strong need to blame or to know that someone feels or is responsible, or, have you felt any need to punish or avenge for your child's death?

- 4 Absolute necessity to blame and/or punish
- 3 Considerable need to blame and/or punish
- 2 Some need to blame and/or punish
- 1 No need to blame or punish

PBIRS Rating Scales - 7

5G. Have you had trouble coping with a dual sense of relief and guilt?

- 1 No problem dealing with guilt arising from any sort of relief
- 2 Some difficulty dealing with guilt for feeling relieved
- 3 Considerable difficulty dealing with guilt for feeling relieved
- 4 Extreme difficulty coping with guilt for feeling relief

5AN. Have you made changes in your relationships with other people so that life without your child is more comfortable?

- 1 Sufficient adaptive changes to live quite comfortably without child
- 2 Several adaptive changes; life is, for the most part, comfortable, even though my child is dead
- 3 A few adaptive changes which make life without child somewhat more tolerable
- 4 No positive, adaptive changes in relationships with others

5DP. Have you needed or wanted to sleep a good deal more since your child's death?

- 4 Enormous increase in need or desire for sleep
- 3 Considerable increase in need or desire for sleep
- 2 Some increased need and/or desire for sleep
- 1 No need or desire for more sleep

6A. Have you felt angry toward God for allowing your child to die?

- 4 Intensely angry that God let child die without apparent reason or purpose
- 3 Considerable anger toward God
- 2 Some anger toward God
- 1 No anger toward God

PBIRS Rating Scales - 8

6G. Have you felt guilty for having survived your child and living to enjoy life when s/he has been deprived of this opportunity?

- 1 No feelings of guilt for having survived my child
- 2 Somewhat guilty for having survived my child
- 3 Considerable guilt for having survived my child
- 4 Intense guilt for having survived my child

7A. Have angry feelings taken you by surprise and been difficult to control?

- 1 Never surprising or uncontrollable
- 2 Sometimes surprising and uncontrollable
- 3 Usually surprising and uncontrollable
- 4 Always unexpected and impossible to control

6DP. During the course of your grief work, have you ever felt detached or somehow unrelated to the people and events around you?

- 4 Felt totally unrelated to people and events around me
- 3 Felt greatly detached, unrelated and uninvolved
- 2 Felt somewhat detached, unrelated and uninvolved
- 1 Felt the usual, appropriate level of involvement with surrounding people and events

7G. Have you needed to share your guilt with another person close to you?

- 4 Intense need to blame and share my sense of guilt; absolutely could not handle it alone
- 3 Considerable need to ease my feelings of guilt by blaming another person
- 2 Some need to ease my feelings of guilt by blaming another person
- 1 No need to blame or place my guilt on anyone else

PBIRS Rating Scales - 9

7DP. Did you lose, to any degree, a sense of alertness and personal awareness?

- 1 Totally aware and in command of mental and physical functioning
- 2 Sometimes felt out of touch with my own self
- 3 Frequently felt out of touch with my own self
- 4 Felt totally out of touch with my own mind and/or body

8DP. Have there been times when you somehow felt no emotion, even though you knew that your child had died?

- 1 No decrease in emotional responsiveness
- 2 Some decrease in emotional responsiveness
- 3 Marked decrease in emotional responsiveness
- 4 Completely unable to feel and express emotion

8A. To the question, "Why did my child have to die?", have you found any satisfactory answer?

- 4 Totally dissatisfied with unanswered "Why?"; intense, desperate search for meaning in child's death
- 3 Bothered a good deal; looking for reasons and explanations
- 2 Not completely satisfied, but able to live with ambiguity; not actively searching for answers
- 1 Satisfied; no need to ask "Why?"

9DP. How much time did you want or need to be alone and to what extent did you isolate yourself from other people?

- 4 Needed and sought total isolation
- 3 Considerable need for self-isolation (to be alone)
- 2 Some decrease in social contacts; increased need or desire to be alone
- 1 No need or desire to decrease social contact and involvement

PBIRS Rating Scales - 10

10DP. Did you ever feel rejected or otherwise isolated from the sources of support and comfort you wanted or needed?

- 1 Felt no lack of support and comfort
- 2 Felt somewhat isolated and lacking for support and comfort from others
- 3 Felt substantially more isolated and rejected by others
- 4 Felt totally isolated and rejected by others

6AN. At what point did you really begin to feel optimistic and hopeful again?

- 4 Still haven't really regained my former level of hope and optimism
- 3 Regained hope and optimism within first two years after child's death
- 2 Regained hope and optimism within six months after child's death
- 1 Never really lost hope and optimism about the future

6D. At what point were you able to fully accept your child's death--- to say, "My child is DEAD and I must go on living without him/her?"

- 1 Within the first week after death
- 2 Within the first month
- 3 After several months
- 4 Six months or more after child's death

7AN. When did your interest in the present and the future become more important than your memories of the past?

- 1 Never became more absorbed or interested in the past than in the present or future
- 2 Changed focus from past to present and future within six months after child's death
- 3 Changed focus from past to present and future within first two years after child's death
- 4 Still spend more time thinking about the past and my dead child than about my present and future activities

PBIRS Rating Scales - 11

8AN. At what point in your bereavement did you regain a sense of emotional calm?

4 Still struggle with unexpected waves of emotion which are very disquieting

3 Regained a sense of general emotional calm within two years

2 Regained a sense of calm and composure within six months

1 In general, my child's death was not disquieting; I did not experience strong waves of emotion

APPENDIX E

Parental Bereavement Interview and
Rating Scale/PBIRS (Revised)

Parent/Interviewee _____

Name of deceased child _____ Age _____

Cause of death _____ How long since death? _____

Did you know/suspect in advance? _____ How long? _____

PARENTAL BEREAVEMENT INTERVIEW AND RATING SCALE/PBIRS (Revised)

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Part A: Interviewer's Guide

Counselor/
Interviewer
Notations

- 1D. Bereaved parents want desperately to believe that their child's death is only a nightmare--a mistake--that it didn't really happen. To what extent have you experienced this confusing sense of unreality?

Responses (circle one):

- 1 Never felt unsure about the reality of the death
- 2 Sometimes seemed impossible or unreal
- 3 Frequently seemed impossible; unreal
- 4 Totally unable to believe child really dead

PROBE: Have you ever said or thought, "It can't be true," "I don't believe it," "It's impossible"?

- 2A. To what extent have you experienced anger and/or frustration over _____'s death?

Responses (circle one):

- 4 Have felt intense anger and/or frustration
- 3 Considerable anger and/or frustration; sometimes out of control
- 2 Some anger and/or frustration
- 1 No feelings of anger or frustration

PROBES: Do you feel you and your family have been unfairly victimized? (asked, "Why me?")
Have you felt frustrated and angry about your powerlessness (inability to change the situation)?

(2A* may be used as a PROBE to facilitate responses to 2A.)

2A*. Where have your angry feelings been directed?

- | | |
|---|--|
| <input type="checkbox"/> yourself | <input type="checkbox"/> justice system |
| <input type="checkbox"/> spouse, child's
other parent | <input type="checkbox"/> God, religion,
church, clergy |
| <input type="checkbox"/> other family member | <input type="checkbox"/> fate |
| <input type="checkbox"/> friends, neighbors,
acquaintances | <input type="checkbox"/> other person(s) or
circumstances con-
tributing to the
death--Explain: |
| <input type="checkbox"/> your dead child | <input type="checkbox"/> _____ |
| <input type="checkbox"/> medical personnel
or facility | <input type="checkbox"/> _____ |
| <input type="checkbox"/> media coverage | <input type="checkbox"/> _____ |
| <input type="checkbox"/> law enforcement | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> _____ |

- 3G. Bereaved parents seem to struggle with feelings of guilt. Some guilt may be realistic, but usually it is magnified far beyond reality during the period of grief work. Have you been bothered by feelings of responsibility for _____'s death?

Responses (circle one):

- 1 No guilt; have not blamed myself at all for child's death
- 2 Have felt somewhat responsible/guilty
- 3 Have felt considerable responsibility/guilt
- 4 Overwhelmed by feelings of responsibility/guilt

PROBES: *Do you realistically believe that you might have been able to prevent the death?
How frequently have you thought, "If only I had ... (kept him home, locked up the medicine, not given her that toy, gotten him to the hospital sooner, etc.), my child would still be alive"?*

- 4DP. Now I'd like to talk with you about your feelings and actions after the shock and anger had worn off and you realized there was nothing you could do to get back. Did you ever feel that life had lost its meaning and value--that everything else seemed unimportant and meaningless compared to your tragedy?

Responses (circle one):

- 4 Life lost all meaning and value for me
- 3 Meaning and value of life greatly decreased
- 2 Meaning and value of life somewhat decreased
- 1 Appreciation for the meaning and value of life the same or greater than before tragedy

5AN. When you think of _____, have they been pleasant memories of what was, rather than painful, frustrating thoughts of what might have been?

- 1 All memories pleasant; remembering brings contentment
- 2 Remembering is generally pleasant, although I sometimes feel sad for my child's unrealized potential
- 3 Remembering frequently leaves me discontented when I think of all the things s/he missed
- 4 Remembering always brings discontentment; deep sense of loss for what might have been if s/he had not died

PROBE: Have you mourned greatly over your lost dreams for _____ (first step, mastery of a bicycle, first day of school, musical interest and achievement, first love, etc.)?

6D. In thinking and talking about _____, to what extent has s/he still seemed a part of your present and future?

- 4 Consistently continued to act as if s/he were alive
- 3 Frequently found myself acting or planning as if s/he were still alive
- 2 Now and then found myself "forgetting"
- 1 Always fully aware of my child's being gone forever, and have acted accordingly

PROBE: Did you find yourself still acting/planning as if s/he were alive, i.e., setting _____'s place at the table, calling for _____, including _____ in vacation plans, etc.?

7A. Sometimes people will approach bereaved parents with well-intentioned but insensitive comments like, "Be grateful you have other children," "You're still young--have another child!", "Here's a book with religious answers that will make it all okay" ... Have you either felt or reacted out of anger and annoyance toward such people and their comments?

- 1 No angry feelings and/or behavior
- 2 Some anger felt and/or expressed
- 3 Considerable anger felt and/or expressed
- 4 Intense anger felt and/or expressed

8G. Even parents who clearly were not responsible in any way for their child's death are bothered by guilt in the form of regret for past behaviors toward the child which are now unchangeable. Have you had this sense of "unfinished business"--a desire to change something that you did to _____, or to do for him/her something you'd neglected to do or put off while s/he was alive?

- 4 Intense feelings of regret for past behaviors/ unfinished business
- 3 Considerable regret over past behaviors toward child; many things I wish I could change
- 2 Somewhat regretful; there are a few past behaviors toward the child I wish I could change
- 1 No regret for unfinished business or past behavior

PROBES: Did _____'s death leave an unresolved disagreement?
Do you regret any instances of punishment or discipline you imposed?
Had you neglected to do something for or with the child (fishing trip, birthday party, purchase special toy or gift, etc.) which s/he'd really wanted?

9DP. Have you experienced a generalized sense of powerlessness and futility in the course of your grieving?

- 1 No sense of lost power or ability
- 2 Some sense of decreased power and/or ability to make a difference
- 3 Considerable sense of decreased power and ability to make a difference
- 4 Intense feelings of powerlessness/futility

PROBE: Since your child's death, have you ever felt that what you do, or do not do, has little significance?

10AN. A child's death often leaves the parent's own schedule or routine in a state of confusion or disorganization for awhile. To what extent has your routine for daily living been restored to its prior level of functioning?

- 4 Routine largely unrestored; life seems chaotic
- 3 Routine restored only about 50%; definitely more disorganized than before child's death
- 2 Sense of order/routine largely restored (although activities/priorities may be different)
- 1 No sense of disorganization; routine functioning at same or higher level (although activities/priorities may be different)

PROBE: *What parts of your routine have you changed, and what parts have you kept the same? (job, mealtimes, social or civic activities, etc.).*

11D. Were you, and are you now, willing and able to talk about _____'s death with a sympathetic listener?

- 1 Always open to discussion; willing or eager to talk about it
- 2 Usually able to talk about it
- 3 Usually unable to talk about it
- 4 Totally unable to discuss child's death

PROBE: *Have there been periods when you absolutely could not discuss your child's death?*

12A. Have you felt irritated or hurt or bitter about how easily most people have seemed to accept _____'s death?

- 4 Extremely irritated, hurt or bitter about others' easy acceptance
- 3 Considerable hurt, bitterness or irritation
- 2 Some hurt, bitterness or irritation about others' easy acceptance
- 1 No bitterness or irritability; reactions of others seemed appropriate to me

PROBE: *Did you ever ask, "How can everyone go on with their daily living routines as if my child never lived or died?"*

13G. Consider your general relationship with _____ during his/her lifetime. Because your time together was cut short, you have probably thought a great deal about how good a parent you were to _____ in the too-short span of his/her life. Have you been troubled about your own shortcomings or a sense of failure or inadequacy as a parent?

- 1 No sense of failure or inadequacy; my relationship with my child was the best it could be
- 2 Some sense of failure or inadequacy; some aspects of the relationship could have been better or stronger
- 3 Considerable sense of failure and/or inadequacy; many aspects of the relationship could have been better
- 4 Intense sense of inadequacy and/or failure in my relationship to the child

PROBE: *Have you thought, "If only I had, in some way, loved my child more."*

14DP. Have you ever thought you'd rather be dead than live with your pain and anguish over _____'s death?

- 4 Death would definitely be preferable
- 3 Frequently think or thought death would be preferable
- 2 Sometimes think/thought I might rather be dead
- 1 No feeling that death would be better than enduring the pain; or, it never occurred to me that I had a choice

15AN. Let's talk a few minutes about how feelings of happiness and pleasure re-entered your life after _____'s death. Namely, to what extent have you been able to have fun and experience pleasurable emotions like joy and happiness?

- 1 Same or greater ability to feel joy, happiness, pleasure
- 2 Somewhat less capable of having fun or experiencing pleasurable emotions
- 3 Seldom have/had fun or experience(d) pleasurable emotions
- 4 No experience of joy, fun, happiness, pleasure

PROBES: *Have you treated yourself to many more pleasurable or exciting activities in an effort to ease the pain and quicken the healing? Has having fun sometimes been a bittersweet experience because returning to the reality*

*of your loss and sadness is intensified by comparison to the fun?
Did it ever seem that enjoying life again is disrespectful--a betrayal or abandonment of your dead child?*

160. To what extent have you tried to maintain or regain a feeling of physical closeness with _____?

- 4 Have tried desperately to maintain/regain feelings of physical closeness
- 3 Frequently try/tried to experience physical closeness
- 2 Now and then I try to experience feelings of physical closeness
- 1 Fully accept(ed) the physical distance between myself (life) and my child (death)

*PROBES: What have you done with _____'s belongings, pictures, bedroom, etc.?
How frequently have you visited the cemetery, mausoleum, or other burial site?*

17A. Have you felt jealous of other parents whose children are all still living?

- 1 No envy or jealousy
- 2 Some envy or jealousy
- 3 Much envy or jealousy
- 4 Extremely jealous or envious

PROBE: Have you questioned, "Why my child instead of theirs", when they have 'more to spare,' 'care for them less well,' etc.?"

18G. Even the most loving parents get irritated by their children from time to time. Most children live to outgrow or otherwise reconcile annoying behaviors or qualities so they are forgotten or dismissed by the parent. But your child did not live a full lifetime, and may have left you "hanging" with some negative feelings which now make you feel guilty. Have you had difficulty coping with negative feelings toward _____?

- 4 Extreme difficulty coping with negative thoughts/feelings toward child
- 3 Considerable difficulty dealing with negative thoughts/feelings toward child
- 2 Some difficulty dealing with negative thoughts/feelings toward child
- 1 No problems with regard to negative thoughts/feelings toward child

PROBES: Were you ever disappointed or angry about his/her (1) choice of friends, (2) academic ability or performance, (3) social behavior, (4) general health and development, etc.?

Have you been angry regarding _____'s carelessness which may have contributed to his/her death?

19DP. To what extent have you experienced increased physical and/or emotional problems since _____'s death?

- 1 No decrease in physical or emotional well-being
- 2 Some decrease in physical health and/or emotional well-being
- 3 Marked negative change in physical and/or emotional functioning
- 4 Extreme negative change in physical and/or emotional functioning

(19DP* may be used as a PROBE to facilitate response to 19DP.)

19DP*. How many of the following have you experienced since _____'s death?

- | | |
|---|---|
| ___ inability to concentrate | ___ sense of "going crazy" |
| ___ loss of memory | ___ anxiety over loss of other children/loved ones |
| ___ loss of efficiency and/or organization | ___ anxiety over loss of your own life/health |
| ___ loss of initiative; laziness, inertia | ___ decreased interest and/or energy for intimacy with spouse/partner |
| ___ being overwhelmed by everyday problems | ___ increased use or abuse of alcohol or other drugs |
| ___ fatigued, exhausted, aged (old) beyond your years | ___ other _____ |
| ___ insomnia, sleep disturbance | |
| ___ increased physical illness or pain | |

20AN. We know that the death of a child leaves a great void and can drastically change a parent's environment and his/her relationship with others. Adapting to the loss usually requires that the parent respond by making some additional adjustments (see 20AN*). Are you satisfied by the changes you have chosen to make in adjusting to life without _____?

- 4 Insufficient adaptive change(s) to lessen the pain of loss
- 3 Some adaptive change(s); life without child is becoming more tolerable
- 2 Enough adaptive change(s) so that life, for the most part, seems worthwhile
- 1 Sufficient adaptive change(s) so that life without child is, nevertheless, quite satisfying

(20AN* may be used as a PROBE.)

20AN*. What adaptive changes have you made in your environment and/or personal relationships?

- ☐ moved to different home or community
- ☐ rearranged home or yard
- ☐ changed job/occupation/career
- ☐ changed, increased or decreased hobbies/activities
- ☐ changed, increased or decreased involvement in church and/or civic groups
- ☐ changed family structure (divorced, married, added a member, etc.)
- ☐ strengthened relationships with family or friends, or formed new relationships
- ☐ other changes _____

21D. Have you sensed a continued close relationship with _____, even without making a conscious effort to do so?

- 1 No sensation of closeness or presence
- 2 Rarely or briefly sense child's presence or closeness
- 3 Frequent sense of child's presence or closeness
- 4 Continuous sense of child's presence in dreams and/or waking hours

PROBES: Have you dreamed about _____ a great deal? Have you sometimes sensed the child was still close by, so much so that you could still see or talk with him/her?

22A. Have you had a strong need to blame or to know that someone feels or is responsible, or, have you felt any need to punish or avenge for _____'s death (to see that someone pays for it)?

- 4 Absolute necessity to blame and/or punish
- 3 Considerable need to blame and/or punish
- 2 Some need to blame and/or punish
- 1 No need to blame or punish

PROBE: *Have you considered or taken any sort of punitive action toward yourself, other family member(s), doctor, hospital, other caretaker, etc.?*

23G. Frequently a parent will have a sense of relief that his or her child has died, and then feel guilty for being relieved! Have you had any trouble coping with this dual sense of relief and guilt?

- 1 No problem dealing with guilt arising from any sort of relief
- 2 Some difficulty dealing with guilt for feeling relieved
- 3 Considerable difficulty dealing with guilt for feeling relieved
- 4 Extreme difficulty coping with guilt for feeling relieved

PROBES: *Have you ever felt that your child is better dead than seriously ill, crippled, paralyzed, brain-injured, etc.?*
Have you ever felt gladly relieved of the responsibility for raising _____ in this troubled and troublesome world?

24DP. Have you needed or wanted to sleep a good deal more since _____'s death (regardless of whether or not you could sleep)?

- 4 Enormous increase in need or desire for sleep
- 3 Considerable increase in need or desire for sleep
- 2 Some increased need or desire for sleep
- 1 No need or desire for more sleep

PROBES: *Have there been days when you retired much earlier, slept later in the morning, took more naps during the day?*
Have you used sleeping pills or other medication to help you sleep?

25A. Have you felt angry toward God for allowing _____ to die?

- 4 Intensely angry that God allowed child to die
- 3 Considerable anger toward God
- 2 Some anger toward God
- 1 No anger toward God (or, No belief in God)

PROBE: *Do you feel betrayed or punished by God, or do you believe _____ died for some purpose ordained by God?*

26G. Have you felt guilty for having survived your child and living to enjoy life when s/he has been deprived of this opportunity?

- 1 No feelings of guilt for having survived my child
- 2 Feel somewhat guilty for having survived my child
- 3 Feel considerable guilt for having survived my child
- 4 Feel intense guilt for having survived my child

27DP. During the course of your grief work, have you ever felt detached or somehow unrelated to the people and events around you--like you were isolated or out of touch with reality?

- 4 Have felt totally unrelated to people and events around me
- 3 Felt greatly detached, unrelated, uninvolved
- 2 Felt somewhat detached, unrelated, uninvolved
- 1 Felt the usual, appropriate level of involvement with surrounding people and events

PROBE: *Did it seem strange that everything and everyone around you seemed to go on functioning much as if _____ had never died?*

28A. While working through your grief, have angry feelings taken you by surprise and/or been difficult to control?

- 1 Never surprising or uncontrollable
- 2 Sometimes surprising or uncontrollable
- 3 Usually surprising or uncontrollable
- 4 Always unexpected and impossible to control

29G. The sense of personal guilt which some bereaved parents experience is so intense that they may need to share part of the burden with someone else. In this process, it is usually the spouse or one of the other children who is called upon to carry or share the blame. Have you, at any point, needed to share your guilt with another person close to you?

- 4 Intense need to blame and share my sense of guilt; absolutely could not handle it alone
- 3 Considerable need to ease my feelings of guilt by blaming another person
- 2 Some need to ease my feelings of guilt by blaming another person
- 1 No need to blame or place my guilty feelings on anyone else

PROBE: *Have you wanted another person to feel some of the guilt you feel in hopes they might better understand and/or ease your pain?*

30DP. Did you lose, to any degree, a sense of alertness and personal awareness? That is, did you feel a vague strangeness in relation to your own self (zombie-like)?

- 1 Totally aware and in command of mental and physical functioning
- 2 Sometimes have felt out of touch with my own self
- 3 Frequently felt out of touch with my own self
- 4 Felt totally out of touch with my own mind and/or body

PROBE: *Did you get through days and weeks seemingly not thinking about or directing your own behavior, as if you were functioning on "automatic pilot"?*

31A. To the question, "Why did my child have to die?", have you found any satisfactory answer?

- 4 Totally dissatisfied with unanswered "Why?"; intense, desperate need to find meaning in child's death
- 3 Bothered a good deal; looking for reasons and explanations
- 2 Not completely satisfied, but able to live with ambiguity; not actively searching for answers
- 1 Satisfied; no need to ask "Why?"

PROBE: *Are you still looking for an answer? Can you be content if there is no answer to be found?*

32G. It is not uncommon for parents to have a "favorite" child. If that child dies, the parent might find him-/herself wishing it had been one of his/her other children instead. Have you felt guilty for wondering why this particular child has died instead of a sibling whose loss might be less painful or less significant?

- 1 No guilt related to wishing that a sibling had died instead
- 2 Some guilt for wishing that children might exchange places
- 3 Considerable guilt for wishing that children might exchange places
- 4 Extreme guilt for wishing to trade a surviving or subsequent sibling for the dead child

33DP. Have there been times when you somehow felt no emotion, even when thinking about _____'s death?

- 1 Same or greater ability to respond with appropriate emotion
- 2 Some decrease in emotional responsiveness
- 3 Marked decrease in emotional responsiveness
- 4 Completely unable to feel and express emotion

PROBE: Have you sometimes been unable to feel sad or cry or respond with any sort of emotion to the people and events around you?

34DP. How much time did you want or need to be alone and to what extent did you isolate yourself from others?

- 4 Needed and sought total isolation
- 3 Considerable need and/or desire for self-isolation (to be alone)
- 2 Some increased need and/or desire to be alone
- 1 No need or desire to decrease social contact and involvement

PROBE: Did you ever reject attempts of others to help, especially those who had not lost a child and therefore could not really understand your grief?

35DP. Did you ever feel rejected or otherwise isolated from the sources of support and comfort you wanted or needed?

- 1 Have felt no lack of support and comfort
- 2 Have felt somewhat isolated and/or lacking for support and comfort from others
- 3 Have felt substantially more isolated and/or rejected by others
- 4 Have felt totally isolated and/or rejected by others

PROBES: *How soon after _____'s death did friends and relatives stop visiting or calling?
Have you felt deserted or ostracized, as if grief and child-loss might be contagious?
Have you had to bear the greatest part of the burden for maintaining relationships?*

The final four questions are "time-specific." That is, they are designed to identify the duration of a particular bereavement experience by locating more specifically the time when the experience occurred or ended. They are most appropriate with parents whose children have been dead two or more years.

36D. Have you been able to fully accept _____'s death, both emotionally and intellectually--to say "My child is DEAD and my life must go on without him/her"--and really believe it?

- 1 Accepted the death fully within the first week
- 2 Within the first month
- 3 After several months
- 4 Six months or more after the death

37AN. Frequently the helplessness which bereaved parents feel is accompanied also by feelings of hopelessness--a severe loss of optimism. At what point did you really begin to feel optimistic and hopeful again?

- 4 Regained, or am hoping to regain, optimism somewhere beyond the two-year point
- 3 Regained hope and optimism within first two years after child's death
- 2 Regained hope and optimism within 6 months after death
- 1 Never really lost hope and optimism about the future

38AN. There is usually a point in the healing process at which the mourning parent's focus of interest and activity shifts from the past to the present and future. When did your interest in the present and the future become more important than your memories of the past?

- 1 Never became more absorbed or interested in the past than in the present and future
- 2 Changed focus from past to present/future within six months after child's death
- 3 Changed focus from past to present/future within two years
- 4 Until sometime beyond two-year point, I continue(d) to spend more time thinking about the past and my dead child than about present and future activities

PROBE: *Did you ever feel that your emotions seemed to be "stuck in reverse gear?" When did you "shift," so that the majority of your effort became focused on the activities of your daily life and future goals?*

39AN. At what point in your bereavement did you regain a sense of general emotional calm? That is, when did you begin to feel consistently composed and in control of your emotions rather than experiencing erratic waves of great sadness, fearfulness, anger, etc.?

- 4 Even after two years, the waves of sad emotions continue(d) to be very strong and frequent
- 3 Regained a sense of general emotional calm within two years
- 2 Regained a sense of general calm and composure within six months
- 1 In general, my child's death was not disquieting; I have not experienced strong waves of emotion

INTERVIEWER: _____

LOCATION OF INTERVIEW: _____

DATE: _____

COMMENTS: _____

PARENTAL BEREAVEMENT INTERVIEW AND RATING
SCALE/PBIRS (Revised)

Part B: Respondent's Rating Scales

- (to be affixed to 3 x 5 cards)

1D.

To what extent have you experienced a confusing sense of unreality regarding your child's death?

- 1 Never felt unsure about the reality of the death
- 2 Sometimes seemed impossible or unreal
- 3 Frequently seemed impossible, unreal
- 4 Totally unable to believe child really dead

2A.

To what extent have you experienced anger and/or frustration over your child's death?

- 4 Have felt intense anger and/or frustration
- 3 Considerable anger and/or frustration; sometimes out of control
- 2 Some anger and/or frustration
- 1 No feelings of anger and frustration

(See subsequent card, 2A, for additional information.)*

2A*.

Where have you directed your angry feelings?

- ☐ Yourself
- ☐ Your spouse/child's other parent
- ☐ Other family members
- ☐ Friends, neighbors, acquaintances
- ☐ Your dead child
- ☐ Medical personnel or facility
- ☐ Media coverage
- ☐ Law enforcement
- ☐ Justice system
- ☐ God, religion, church, clergy
- ☐ Fate
- ☐ Other person(s) or circumstances contributing to the death
Explain _____
- ☐ Other _____

3G.

Have you been bothered by feelings of responsibility for your child's death?

- 1 No guilt; have not blamed myself at all for child's death
- 2 Have felt somewhat responsible/guilty
- 3 Have felt considerable responsibility/guilt
- 4 Overwhelmed by feelings of responsibility/guilt

4DP.

Did you ever feel that life had lost its meaning and value?

- 4 Life lost all meaning and value for me
- 3 Meaning and value of life greatly decreased
- 2 Meaning and value of life somewhat decreased
- 1 Appreciation for the meaning and value of life the same or greater than before tragedy

6D.

In thinking and talking about your dead child, to what extent has s/he still seemed a part of your present and future?

- 4 Consistently continued to act as if s/he were alive
- 3 Frequently found myself acting or planning as if s/he were still alive
- 2 Now and then found myself "forgetting"
- 1 Always fully aware of my child's being gone forever, and have acted accordingly

5AN.

When you think of your child, have they been pleasant memories of what was rather than painful, frustrating thoughts of what might have been?

- 1 All memories pleasant; remembering brings contentment
- 2 Remembering is generally pleasant, although I sometimes feel sad for my child's unrealized potential
- 3 Remembering frequently leaves me discontented when I think of all the things s/he missed
- 4 Remembering always brings discontentment; deep sense of loss for what might have been if s/he had not died

7A.

Have you either felt or reacted out of anger and annoyance toward such people and their comments?

- 1 No angry feelings and/or behavior
- 2 Some anger felt and/or expressed
- 3 Considerable anger felt and/or expressed
- 4 Intense anger felt and/or expressed

8G.

Have you had a sense of "unfinished business"; a desire to change something you did or did not do with or for your child?

- 4 Intense feelings of regret for past behaviors/unfinished business
- 3 Considerable regret over past behaviors toward child; many things I wish I could change
- 2 Somewhat regretful; there are a few past behaviors toward the child I wish I could change
- 1 No regret for unfinished business or past behavior

10AN.

To what extent has your routine for daily living been restored to its prior level of functioning?

- 4 Routine largely unrestored; life seems chaotic
- 3 Routine restored only about 50%; definitely more disorganized
- 2 Sense of order/routine largely restored (although activities/priorities may be different)
- 1 No sense of disorganization; routine functioning at same or higher level (although activities/priorities may be different)

9DP.

Have you experienced a generalized sense of powerlessness and futility in the course of your grieving?

- 1 No sense of lost power or ability
- 2 Some sense of decreased power and ability to make a difference
- 3 Considerable sense of decreased power and ability to make a difference
- 4 Intense feelings of powerlessness and futility

11D.

Were you, and are you now, willing and able to talk about your child's death with a sympathetic listener?

- 1 Always open to discussion; willing or eager to talk about it
- 2 Usually able to talk about it
- 3 Usually unable to talk about it
- 4 Totally unable to discuss child's death

12A.

Have you felt irritated or hurt or bitter about how easily most people have seemed to accept your child's death?

- 4 Extremely irritated, hurt or bitter about others' easy acceptance
- 3 Considerable hurt, bitterness or irritability
- 2 Some hurt, bitterness and irritability about others' easy acceptance
- 1 No bitterness or irritability; reactions of others seemed appropriate to me

14DP.

Have you ever thought you'd rather be dead than live with your pain and anguish over the child's death?

- 4 Death would definitely be preferable
- 3 Frequently think or thought death would be preferable
- 2 Sometimes think/thought I might rather be dead
- 1 No feeling that death would be better than enduring the pain and living; or, it never occurred to me that I had a choice

13G.

Have you been troubled about your own shortcomings or a sense of inadequacy or failure as a parent?

- 1 No sense of failure or inadequacy; my relationship with my child was the best it could be
- 2 Some sense of failure or inadequacy; some aspects of the relationship could have been better or stronger
- 3 Considerable sense of failure and/or inadequacy; many aspects of the relationship could have been better
- 4 Intense sense of inadequacy and failure in my relationship to the child

15AN.

To what extent have you been able to have fun and experience pleasurable emotions like joy and happiness?

- 1 Same or greater ability to feel joy, happiness, pleasure
- 2 Somewhat less capable of having fun or experiencing pleasurable emotions
- 3 Seldom have/had fun or experience pleasurable emotions
- 4 No experience of joy, fun, happiness, pleasure

16D.

To what extent have you tried to maintain or regain a feeling of physical closeness with your dead child?

- 4 Tried desperately to maintain/regain feelings of physical closeness
- 3 Frequently tried to experience physical closeness
- 2 Now and then tried to experience feelings of physical closeness
- 1 Fully accept(ed) the physical distance between my child (death) and myself (life)

18G.

Have you had difficulty coping with negative feelings toward your dead child?

- 4 Extreme difficulty coping with negative thoughts and feelings toward child
- 3 Considerable difficulty dealing with negative thoughts and feelings toward child
- 2 Some difficulty dealing with negative feelings and thoughts toward child
- 1 No problems with regard to negative thoughts or feelings toward child

17A.

Have you felt envious of other parents whose children are all still living?

- 1 No envy or jealousy
- 2 Some envy or jealousy
- 3 Much envy or jealousy
- 4 Extremely jealous or envious

19DP.

To what extent have you experienced increased physical and/or emotional problems since the child's death?

- 1 No decrease in physical or emotional well-being
- 2 Some decrease in physical health and/or emotional well-being
- 3 Marked negative change in physical and/or emotional functioning
- 4 Extreme negative change in physical and/or emotional functioning

(See subsequent card, 19DP*, for additional information.)

19DP*.

How many of the following have you experienced since your child died:

- ☐ Inability to concentrate
- ☐ Loss of memory
- ☐ Loss of efficiency and/or organization
- ☐ Loss of initiative; laziness, inertia
- ☐ Being overwhelmed by everyday problems
- ☐ Fatigued, exhausted, aged beyond your years
- ☐ Insomnia; sleep disturbance
- ☐ Sense of "going crazy"
- ☐ Anxiety over loss of other children/loved ones
- ☐ Anxiety over loss of your own life/health

19DP*. (continued)

- ☐ Decreased interest and/or energy for intimacy with spouse/partner
- ☐ Increased use or abuse of alcohol or other drugs
- ☐ Increased physical illness or pain
- ☐ Other _____

20AN.

Are you satisfied by the adaptive changes you have chosen to make?

- 4 Insufficient adaptive change(s) to lessen the pain of loss
- 3 Some adaptive change(s); life without child is becoming more tolerable
- 2 Enough adaptive change(s) so that life, for the most part, is worthwhile
- 1 Sufficient adaptive change(s) so that life without child is, nevertheless, quite satisfying

(See subsequent card, 20AN*, for additional information.)

20AN*.

What adaptive changes have you made in your environment and/or personal relationships?

- ☐ Moved to different home or community
- ☐ Rearranged home or yard
- ☐ Changed job/occupation/career
- ☐ Changed, increased or decreased hobbies/activities
- ☐ Changed involvement in church and/or civic groups
- ☐ Changed family structure
- ☐ Strengthened relationships, or formed new ones
- ☐ Other changes _____

21D.

Have you sensed a continued close relationship with your child even without making a conscious effort to do so?

- 1 No sensation of closeness or presence
- 2 Rarely or briefly sense a presence or closeness
- 3 Frequent sense of child's presence or closeness
- 4 Continuous sense of child's presence in dreams and/or waking hours

22A.

Have you had a strong need to blame or to know that someone feels or is responsible, or, have you felt any need to punish or avenge for your child's death?

- 4 Absolute necessity to blame and/or punish
- 3 Considerable need to blame and/or punish
- 2 Some need to blame and/or punish
- 1 No need to blame or punish

23G.

Have you had trouble coping with a dual sense of relief and guilt?

- 1 No problem dealing with guilt arising from any sort of relief
- 2 Some difficulty dealing with guilt for feeling relieved
- 3 Considerable difficulty dealing with guilt for feeling relieved
- 4 Extreme difficulty coping with guilt for feeling relief

24DP.

Have you needed or wanted to sleep a good deal more since your child's death?

- 4 Enormous increase in need or desire for sleep
- 3 Considerable increase in need or desire for sleep
- 2 Some increased need and/or desire for sleep
- 1 No need or desire for more sleep

25A.

Have you felt angry toward God for allowing your child to die?

- 4 Intensely angry that God let child die
- 3 Considerable anger toward God
- 2 Some anger toward God
- 1 No anger toward God (or, No belief in God)

26G.

Have you felt guilty for having survived your child and living to enjoy life when s/he has been deprived of this opportunity?

- 1 No feelings of guilt
- 2 Feel somewhat guilty for having survived my child
- 3 Feel considerable guilt for having survived my child
- 4 Feel intense guilt for having survived my child

27DP.

During the course of your grief work, have you ever felt detached or somehow unrelated to the people and events around you?

- 4 Have felt totally unrelated to people and events around me
- 3 Felt greatly detached, unrelated and uninvolved
- 2 Felt somewhat detached, unrelated and uninvolved
- 1 Felt the usual, appropriate level of involvement with surrounding people and events

28A.

Have angry feelings taken you by surprise and/or been difficult to control?

- 1 Never surprising or uncontrollable
- 2 Sometimes surprising and uncontrollable
- 3 Usually surprising and uncontrollable
- 4 Always unexpected and impossible to control

29G.

Have you needed to share your guilt with another person close to you?

- 4 Intense need to blame and share my sense of guilt; absolutely could not handle it alone
- 3 Considerable need to ease my feelings of guilt by blaming another person
- 2 Some need to ease my feelings of guilt by blaming another person
- 1 No need to blame or place my guilty feelings on anyone else

30DP.

Did you lose, to any degree, a sense of alertness and personal awareness?

- 1 Totally aware and in command of mental and physical functioning
- 2 Sometimes felt out of touch with my own self
- 3 Frequently felt out of touch with my own self
- 4 Felt totally out of touch with my own mind and/or body

31A.

To the question, "Why did my child have to die?", have you found any satisfactory answer?

- 4 Totally dissatisfied with unanswered "Why?"; intense, desperate need to find meaning in child's death
- 3 Bothered a good deal; looking for reasons and explanations
- 2 Not completely satisfied, but able to live with ambiguity; not actively searching for answers
- 1 Satisfied; no need to ask "Why?"

32G.

Have you felt guilty for wondering why this particular child has died instead of a sibling?

- 1 No guilt related to wishing that a sibling had died instead
- 2 Some guilt for wishing that children might exchange places
- 3 Considerable guilt for wishing that children might exchange places
- 4 Extreme guilt for wishing to trade a surviving or subsequent sibling for the dead child

33DP.

Have there been times when you somehow felt no emotion, even when thinking about _____'s death?

- 1 Same or greater ability to respond with appropriate emotion
- 2 Some decrease in emotional responsiveness
- 3 Marked decrease in emotional responsiveness
- 4 Completely unable to feel and express emotion

34DP.

How much time did you want or need to be alone and to what extent did you isolate yourself from other people?

- 4 Needed and sought total isolation
- 3 Considerable need and/or desire for self-isolation (to be alone)
- 2 Some increased need and/or desire to be alone
- 1 No need or desire to decrease social contact and involvement

35DP.

Did you ever feel rejected or otherwise isolated from the sources of support and comfort you wanted or needed?

- 1 Felt no lack of support and comfort
- 2 Felt somewhat isolated and lacking for support and comfort from others
- 3 Felt substantially more isolated and rejected by others
- 4 Felt totally isolated and rejected by others

36D.

Have you been able to fully accept your child's death, both emotionally and intellectually?

- 1 Accepted the death fully within the first week after death
- 2 Within the first month
- 3 After several months
- 4 Six months or more after child's death

37AN.

At what point did you really begin to feel optimistic and hopeful again?

- 4 Regained, or am hoping to regain, hope/optimism somewhere beyond the two-year point
- 3 Regained hope and optimism within first two years after child's death
- 2 Regained hope and optimism within six months after child's death
- 1 Never really lost hope and optimism about the future

38AN.

When did your interest in the present and the future become more important than your memories of the past?

- 1 Never became more absorbed or interested in the past than in the present or future
- 2 Changed focus from past to present and future within six months after child's death
- 3 Changed focus from past to present and future within first two years after child's death
- 4 Until sometime beyond the two-year point, I continue(d) to spend more time thinking about the past and my dead child than about present and future activities

39AN.

At what point in your bereavement did you regain a sense of general emotional calm?

- 4 Even after two years, the waves of sad emotions continue(d) to be very strong and frequent
- 3 Regained a sense of general emotional calm within two years
- 2 Regained a sense of general calm and composure within six months
- 1 In general, my child's death was not disquieting; I have not experienced strong waves of emotion

APPENDIX F

Demographic Data Sheet

DEMOGRAPHIC DATA SHEET

Please complete the following confidential questionnaire.

I. The Deceased Child

Name _____ Sex _____
 Birthdate _____ Date of Death _____ Age _____
 Birth order in family (1st child, 2nd, 3rd, etc.) _____
 Circumstances of the death (Cause? Where it occurred?, etc.) _____

Did you have any warning? _____ How long? _____
 Did the child live with you consistently throughout his or her
 lifetime? _____ If not, explain: _____

II. Other Children in the Family (list from oldest to youngest):

Name _____	Age now _____	Sex _____
_____	_____	_____
_____	_____	_____
_____	_____	_____

III. Parents, including yourself (also include step-parents or adoptive parents, as well as natural parents:

Name _____	Age now _____	Relationship _____
_____	_____	_____
_____	_____	_____

Please put an X in front of the name(s) of parent(s) now living in this household.

Have parents been married, divorced, separated or reunited since the child's death? _____ Explain: _____

IV. Family

Current, annual family income (approx.) _____
 Nationality/Race _____

Religion: Catholic ☐ Protestant ☐ Jewish ☐ Other ☐ None ☐

Are there people other than those already listed living in your home?

Age Relationship How long with you

V. Do you feel that you and your family are making a satisfactory adjustment to this tragedy?

Have you or any family member sought professional counseling or treatment to help you through your sorrow?

If so, who? Psychiatrist ☐ Psychologist ☐ Pastoral Counselor ☐
Other

VI. Who completed this questionnaire?

Name or initials

Highest level of education years schooling

Employed? ☐ If so, occupation:

Compassionate Friends group (circle one)

Eugene Albany Salem Portland

How would you describe your association with TCF (circle one)

Inactive

Attended a few meetings

Attend(ed) regularly

Very actively involved

Comments:

Thank you. Your cooperation is greatly appreciated. Be assured that this information will be kept strictly confidential.

APPENDIX G

Interviewer's Introduction and
Explanation of the PBIRS

INTERVIEWER'S INTRODUCTION AND EXPLANATION
OF THE PBIRS

_____(name)_____, I appreciate your willingness to make a contribution to this study by allowing me to interview you today. I understand the child you lost was named _____, and was _____ years old. My son who died was named Scotty and he was four. I'm sure as we talk we will find a lot of similarities between our experiences as bereaved parents. But the course of grief work is also unique and different for each of us who loses a child. Hopefully, through your help and that of others parents, we can get a clearer picture of the bereavement experience, and this information can be used to help others who are confronted with the pain of child loss.

Be assured that our conversation will be kept strictly confidential. No names or other such identification will be used in reporting the results of these interviews. If you would like, I will send you a summary of my findings when the study is completed.

Today's interview will probably last between two and four hours, with two scheduled breaks if needed. But, please don't feel rushed. I want it to be a good experience for you--an opportunity to share and learn and grow.

(Show interviewer's PBIRS form and fill in blanks at the top.)

There are 39 questions in all. However, most of them will require three answers from you. First, I will ask a question and we will discuss your response for a few minutes. Then I will supply you with a set of responses from which you should choose the one that best describes your experience. This will be clearer as soon as we have completed the first interview item.

One more thing--I want you to try to recall your bereavement experience during three periods: (refer to key on interview form)

1. during the first six months after _____'s death
2. between the sixth month and the two-year anniversary of the death, and
3. how you feel now (2-5 years post-death).

Again, this routine for answering my questions will become clear soon after we begin.

Now, do you have any questions before we get started?

Will you please read and sign this consent form?

(Start tape recorder if permission has been granted.)

APPENDIX H

Participant Consent Form

PARTICIPANT CONSENT FORM

PBIRS Preliminary Study

Thank you for agreeing to participate in this study. Please read the following material and sign this form below. The Human Subjects Board at Oregon State University requires this signature to protect you by insuring you are properly informed about the study.

My participation in this study will entail a very complete interview and self-rating procedure, plus the completion of a general information questionnaire about my family. I agree to allow from two to four hours for these purposes.

I understand that all the information I give will be strictly confidential and the data will not be identified by my name or any other identifying system. I understand that I may ask questions about the study, that my participation is voluntary, and I am free to withdraw at any time or refuse to answer any question if I choose.

I have read the above material and I agree to participate in the study.

Signature _____

Date _____

Do you agree to permit the interviewer to make an audio tape-recording of the interview? _____

APPENDIX I

Application for Approval of
the Human Subjects Board

and

Information for Human Subjects Board

OREGON STATE UNIVERSITY

APPLICATION FOR APPROVAL OF THE HUMAN SUBJECTS BOARD

Principal Investigator* Mary Jane WallDepartment Education/ Guidance & Counseling Phone 754-4317Project Title The Development of a Beginning Methodology to Study the Grief and Adjustment Processes of Parents Following the Sudden and Unexpected Death of a Young ChildPresent or Proposed Source of Funding Grad. Student ResearcherType of Project Faculty Research ProjectX Graduate Student Thesis Project*(Student's name Cheron J. Mayhall)

The following information should be attached to this form. All material, including this cover sheet, should be submitted IN DUPLICATE to the Office of the Dean of Research, AdS A312. Feel free to call extension 3437 if you have questions.

1. A brief description of the methods and procedures to be used during this research project.
2. A list of the risks and/or benefits (if any) to the subjects involved in this research.
3. A copy of the informed consent document and a description of the methods by which informed consent will be obtained. (Information concerning the "Basic Elements of Informed Consent" is reproduced for your information on the back of this form.)
4. A description of the method by which anonymity of the subjects will be maintained.
5. A copy of any questionnaire, survey, testing instrument, etc. (if any) to be used in this project.
6. If this is part of a proposal to an outside funding agency, attach a copy of the proposal.

Signed _____ Date _____
Principal Investigator

*Note: Graduate Student Thesis projects should be submitted by the major professor as Principal Investigator.

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INFORMATION FOR HUMAN SUBJECTS BOARD

1. Description of Methods and Procedures

Volunteer subjects will participate with the researcher in an interview and self-rating procedure using the Parental Bereavement Interview and Rating Scale, PBIRS (attached). Following discussion of each interview item, subjects will select one of the four available responses from the corresponding rating scale. Each scale will be affixed to a 3x5 card to facilitate the subject's rating response. The data collected will be analyzed and presented in terms of a group response, thereby keeping individual subject's responses anonymous.

A Demographic Data Sheet (DDS) will be completed by each subject after termination of the interview. This information will be used to develop a descriptive profile of the subject group.

2. Risks and/or Benefits

While it is possible that some of the interview questions might evoke feelings of sadness and grief, it is equally possible that the opportunity to discuss grief experiences will offer the positive therapeutic benefits of catharsis. If the data suggest that any subject has not made satisfactory progress in his or her grief work, a referral for assistance will be recommended.

3. See Attached Participant Consent Form

Informed consent will be obtained by securing the subject's signature on the consent form prior to the interview. Time will be allowed for the researcher to respond to any questions related to this document.

4. Anonymity of Subjects

An initial code, rather than names, will be used to identify subjects throughout the research. The majority of reporting will focus on group data, obviating any necessity for identification of individual subjects. Any tape recordings of interview sessions will not be used for other purposes without the permission of the subject involved.

5. Attached are copies of the research instruments (PBIRS and DDS).

6. Not applicable.