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## Anticipatory Mourning in Caregivers With Children Who Die in the Hospital

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ANTICIPATORY MOURNING IN CAREGIVERS WITH CHILDREN  
WHO DIE IN THE HOSPITAL

by

Annie Rini

A thesis submitted to the Department of Nursing  
in partial fulfillment of the requirements for the degree of

Master of Science in Nursing

UNIVERSITY OF NORTH FLORIDA

COLLEGE OF HEALTH

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## Abstract

The death of a child has tremendous impact on a caregiver. Even when prognosis is poor and death appears imminent, care of the dying child typically focuses on achieving cure. Consequently, caregivers are often ill prepared to cope with the grief they experience as their child is dying. Anticipatory mourning allows caregivers time to begin grief work prior to the death of a loved one. Literature suggests that those who experience anticipatory mourning have a less complicated bereavement period. The purpose of this qualitative study is to (a) describe the presence (or absence) and role of anticipatory mourning in caregivers who recently experienced the death of a hospitalized child and to (b) determine if consistent themes exist that caregivers describe as helpful or detrimental to them during this process. An exploratory, descriptive design was used to answer questions in focused, guided, semi-structured, in-depth, tape-recorded interviews. Thematic content analysis derived themes from the interview transcripts of a sample of 11 caregivers who recently experienced the death of a hospitalized child. Caregivers' descriptions of their experiences surrounding the death of their child reveal an environment and health care team that is often ill prepared to deal with the impending death of a child. Also described are instances that reflect a compassionate process that positively affects the experience while facilitating appropriate grief work. Offered are recommendations for health care professionals that may assist caregivers in coping with the death of their child.

## Chapter One

### Introduction

The death of a child has profound impact on caregivers. Emotionally, physically, psychologically, and spiritually, caregivers feel an enormous toll as they experience such a loss. Researchers recognize that parental bereavement seems to be more intense than other forms of bereavement (Knapp, 1986). Often, the aim of treatment for dying children is one of aggressive care leading up to the time of death. Unlike the adult model, pediatric care tends to focus almost exclusively on cure rather than supportive or palliative care (Hilden, et al., 2001). Consequently, children and their caregivers often do not prepare or know how to prepare emotionally, psychologically, or spiritually for the impending death.

Health care providers often find it difficult to discuss end-of-life care with caregivers and their dying children. Advances in medical technology have resulted in prolonging lives; thus, many people in general, including children, are facing a longer period of their illness requiring palliative or supportive care. In an attempt to cure disease and prolong life, dying children often spend this period of time experiencing ongoing aggressive treatment. With cure as the primary focus and goal, even when death is imminent, frequently little time and effort is spent preparing for end-of-life tasks and reconciliation to the fact that a child is not expected to survive (Sahler, Frager, Levetown, Cohn, & Lipson, 2000).

Anticipatory mourning is the period of emotional preparatory experience leading up to the time of death. Formerly termed anticipatory grief, this term describes not only the process of grief but other processes as well. The phenomenon of anticipatory mourning encompasses seven operations according to Rando (2001). Grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death are components of the anticipatory mourning process. The majority of anticipatory mourning literature describes the process of anticipatory mourning in adults, but there is limited literature about children and the impact of successful anticipatory mourning on their caregivers. From an informal discussion with eight caregivers who experienced the death of a child, the researcher became aware of inconsistencies in how health care providers help caregivers prepare for the impending death of their child, thus limiting and perhaps impeding the mourning process.

Understanding and facilitating the process of anticipatory mourning before the death of a child is an important function of health care providers. Nurses who work closely and intensively with these caregivers and their children are in an important position to promote optimal grief work.

### Significance

Support to caregivers during the period leading up to the time of death of their child appears to be associated with less abnormal grief after the death (Rando, 1986a) and thus has tremendous practice implications for health care providers. This time can be used to begin and in some instances complete tasks associated with anticipatory mourning. Health care providers have the potential to facilitate and guide caregivers

through the beginning steps if not completion of this process, depending upon the amount of time one is aware that death is imminent. Primary prevention of abnormal grief reactions is key in helping caregivers cope with impending loss. Facilitating communication, encouraging and allowing expressions of grief, identifying and finishing unfinished business, preventing early detachment, and encouraging memorialization of the dying (Rando, 1986b) are important interventions in assisting caregivers in the period leading up to the death of their child. Being supportive to those caring for their child during this time and assisting them in steps necessary to process the tasks of anticipatory mourning is a tremendous contribution in assisting caregivers during a time of crisis. Waechter (1976) believes recognition of the process itself provides the potential for professional and personal growth of health care providers

#### Purpose

The purpose of this study was to describe the presence (or absence) and role of anticipatory mourning in caregivers who recently experienced the death of a hospitalized child and to determine if there are consistent factors that caregivers describe as helpful or detrimental to them during this process. By viewing the experience from the caregiver's perspective, health care professionals may gain insight into factors that may facilitate the anticipatory mourning process, thereby improving care to dying children and their caregivers. Additionally, this study seeks to determine whether caregivers that experienced anticipatory mourning felt the process positively or negatively affected the bereavement period following the death of their child. While the purpose of this study was not to explore bereavement, participants in this study described whether they felt the presence or absence of anticipatory mourning influenced the bereavement period.

## Research Questions

Literature suggests the process of anticipatory mourning is one that may facilitate a more positive bereavement period for survivors (Rando, 1986a). This study was designed to determine how caregivers who have had a hospitalized child die described the experience, whether caregivers were cognizant of their child's impending death, and to determine whether or not they experienced anticipatory mourning. If caregivers did describe experiencing anticipatory mourning, this study aimed to define which factors caregivers found beneficial or detrimental in helping them cope with this process and whether they felt the process influenced their bereavement period. Additionally, caregiver demographic data were collected and analyzed to determine if there were relationships between responses and demographic characteristics of the caregivers.

## Definition of Terms

### Anticipatory Grief

Anticipatory grief is defined as the process of acknowledging that there is an impending loss of a person, grieving for the impending loss of the person, detachment from the dying person without abandonment of that person, and memorialization of the person. This period of grieving is a finite period, ending with the death of the individual for whom one is grieving.

### Anticipatory Mourning

Anticipatory mourning defines the phenomenon encompassing seven generic operations: grief and mourning, coping, interaction, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death. Earlier

literature (prior to 2000) used the term anticipatory grief as described above. More recent literature uses the term anticipatory mourning to describe the time period and operations listed herein. For this reason, the use of the terms anticipatory grief and anticipatory mourning were used in this study.

### Bereavement

Bereavement defines the period of grief that occurs after the death of an individual. This period of grieving has no definite time period.

### Caregiver

A caregiver, for purposes of this study, is the person who is primarily responsible for the care of the dying child. The caregivers in this study were either the mother or father of the dying child.

### Primary prevention strategies and therapeutic interventions

Primary prevention strategies and therapeutic interventions are defined as those tasks that help a person face the reality of impending loss; complete tasks that a person defines as important to finish prior to the death of a loved one; and prepare for the impending death of a loved one.

### Overview of the Study

This qualitative study aimed to determine whether a selected group of 11 caregivers who experienced the recent (defined as two years prior to study initiation but no sooner than four months) death of a hospitalized child experienced anticipatory mourning. Caregivers described what factors they deemed helpful or detrimental in facilitating their progression through this process. Additionally, when caregivers stated they experienced anticipatory mourning, they described whether they felt this affected

their bereavement period. Focused, guided, semi-structured, in-depth interviews with study participants using open-ended questions written by the researcher (Appendix A), provided rich data. Face-to-face, tape-recorded interviews took place. Questions, based on a review of the literature as well as the researcher's personal experience in this field, comprised the Questionnaire Guide. Caregivers provided suggestions for continuing good practice as well improving end-of-life care. A Demographic Questionnaire (Appendix B) helped describe the sample so that the researcher could determine if relationships exist between demographics and interview responses. Data analysis was conducted by examining the transcribed interviews for thematic content, coding of themes, and tabulating the frequency of thematic occurrence. Relationships of demographic responses to thematic occurrence were examined to determine whether characteristics of the participants influenced the responses to questions or influenced how the participating caregivers perceived or described the events surrounding the death of their children.

### Conceptual Framework

Anticipatory mourning allows primary prevention strategies of dysfunctional grief and implementation of therapeutic interventions to facilitate appropriate grief work for a more positive bereavement for survivors-to-be. Anticipatory grief, henceforth termed anticipatory mourning, was first described and published in 1944 by a psychiatrist, Erich Lindemann (1944). More recently, Rando (1986b) reported that support to caregivers during the illness of a child appears to be associated with less abnormal grief after the death. She also suggested a failure in anticipatory mourning can be associated with poorer bereavement outcomes (Rando, 2001). These findings suggest that support to caregivers during the illness of their child help facilitate the process of anticipatory

mourning. Thus, support during the illness may be associated with less abnormal grief following the death of the child (1986b). According to Roach (1977), interventions made prior to the death of an individual can prevent problems with mourning after the individual's death.

Theoretical linkages between coping style and anticipatory mourning may lead to a more appropriate resolution of grief. Recent studies on quality of life leading up to the time of death, as reported by family members, also support that grief work done prior to the death of an adult loved one facilitates the bereavement process once death has occurred (Parkes, 1998).



## Chapter Two

### Review of Literature

A search of grief literature was conducted with a focus on anticipatory mourning. The literature review targeted studies that examined grief of parents. There is extensive research into the grief of those who have experienced the loss of an adult, be it a spouse or parent, but relatively little research for those who have experienced the loss of a child. The review of literature is organized into studies that examined grief associated with adult loss and those associated with parental loss of a child.

#### Background

Anticipatory mourning has been described in the literature for almost 60 years. Many of the original works are still relevant today and frequently are referenced in current literature. There is however, a paucity of literature, with the exception of Rando in the 1980s and more recently in 2001, that addresses anticipatory mourning in caregivers who have sustained the loss of a child. One could speculate that one reason few studies exist is a result of society's uneasiness in discussing the dying and death of children. It is this event, the death of a child, that is described as unnatural, as children are not meant to die before their parents (Rando, 1986b)

Over the past decade, the delivery of end-of-life care has brought about increased interest and scrutiny. Effort to change the culture of how dying and death is handled, particularly in the acute care setting, is occurring. Studies have shown that patients are

dying in significant pain, and end-of-life issues such as Living Wills and Do-Not-Resuscitate Orders are not routinely being discussed with dying patients and their loved ones (Connors, et al., 1995).

### Adult Literature

Lindemann (1944) first described the concept of anticipatory mourning in the 1940s. A soldier returned from war and discovered his wife thought he had been killed in battle. She displayed signs of not loving him anymore and found it difficult to reassimilate him into her life. She had already gone through the stage of anticipatory mourning, subsequent resolution of bereavement, and had in effect, detached herself from her spouse. She ultimately asked for a divorce. Lindemann described the loss sustained was not solely the loss of an actual person through the event of death, but a loss of one's hopes, dreams, and plans for the future. It is such loss that occurs with anticipatory mourning. The risk of premature detachment is further described in more recent studies done by Futterman, Hoffman, and Sabshin (1973). Futterman, et al. suggested the risk of premature detachment can result in emotional abandonment of the patient prior to death taking place. In this manner, inappropriate anticipatory mourning can actually have a deleterious effect on both the grieving survivor as well as the dying person. Recognizing inappropriate mourning and preventing premature detachment is an important task for those working with dying children and their caregivers.

Subsequent studies of anticipatory mourning have been done in the terminally ill setting, such as seen with adult patients dying of cancer (Sweeting, & Gilhooly, 1990). They suggested that families facing the potential loss of a loved one actually experience all the phases of normal grief as they attempt to cope with the impending loss and

separation, prior to the death of their family member. Suggested is that these family members experience less grief after the death actually occurs. A longitudinal study (Glick, Weiss, & Parkes, 1974) of 68 widows and widowers under age 45 found the presence of anticipatory mourning decreased the likelihood of psychological problems 13 months after the death of a spouse. In a study of 12 bereaved adults, Costello (1999) described anticipatory mourning as having a cumulative effect, one that allows for adaptation to the loss before the death of a spouse takes place.

It is such cumulative loss that Rando (1986a) described as occurring when facing an ongoing terminal illness of a loved one. Losses have already occurred, such as loss of previous lifestyle before the illness, as well as loss of opportunities for the future. In spite of the mourning that occurs during this time period, one does not necessarily disconnect from the dying person; a common fear of anticipatory mourning that is described as "premature". Often one is not even aware that the losses are present, yet Rando felt the mourning process is occurring nonetheless. Additionally, the experience of ongoing mourning takes place while actively dealing with a dying person, as losses continue to present themselves as progression of the disease or illness occurs.

#### Pediatric Literature

A study conducted by Binger, et al. (1969) of caregivers who experienced the death of a child revealed that those who experienced anticipatory mourning were more accepting of their loss. Fulton and Fulton (1971) believed that anticipatory mourning leads to a greater calm and acceptance of the impending death, thereby permitting the individual to regain effective functioning and resultant happiness more quickly.

Interviews with caregivers of dying children showed the optimal time for anticipatory mourning is 6 to 18 months before the death occurs. A shorter period of time did not allow caregivers to adequately prepare for their impending loss. A prolonged period often resulted in a debilitating effect (Rando, 1984). Premature detachment from the child can be detrimental for both the caregiver as well as the child, resulting in a sense of abandonment for the dying child. Lindemann (1944) and Futterman, et al. (1973) described similar findings as did Rando. Rando also found that support to caregivers during the illness of a child actually facilitated the anticipatory mourning process and appeared to be associated with less abnormal grief after the death of a child has occurred (Rando, 1986b).

Parental grief, as described by Miles (1984), consists of three overlapping phases: numbness and shock, intense grief, and reorganization. In her conceptual model of grief, Miles suggested a critical element of grief is “searching for meaning” in the death of a child. Through anticipatory mourning, caregivers may have the opportunity to explore and find meaning in their child's death.

Glick, et al. (1974), and Parkes and Weiss (1983) are among the proponents of the viewpoint that the phenomenon of anticipatory mourning does not exist, per se. They believe that anticipating the death of an individual allows time to complete tasks associated with preparation for an impending death, but do not see benefit in mourning prior to death occurring. Of importance in their stance is the notion that to have a period of loss, a death must occur, which they believe, does not take place with anticipatory mourning. Rando (1986a), on the other hand, believed that loss does not encompass only

the actual death, but rather the loss that has already occurred or the loss currently being experienced.

Futterman, et al. (1973) studied the grief experienced by caregivers during the time of a child's terminal illness as well as the time following their child's death. They saw a linkage between caring for a dying child and detachment, thus refuting the claim by Parkes and Weiss (1983) that anticipatory mourning could not occur while a person is still living.

Futterman, et al. (1973) described the stages of parental anticipatory mourning as:

(a) acknowledgment--a growing realization by caregivers that their child's death is inevitable; hope and despair alternate as this realization deepens; (b) grieving--beginning as intense undifferentiated responses and feeling, but these eventually become less acute; (c) reconciliation--the development of some perspective by caregivers about their child's impending death; recognition that the child's life has been worthwhile, and that life will continue after the child dies; (d) detachment--while still offering love and security to the dying child, caregivers begin to reinvest in relationships that will continue after the child dies; (e) memorialization--the development of a positive mental image of the child that will endure after the child's death; think of the child in generalities rather than in terms of specific behaviors (pp. 130-131).

Grossman (1998) described anger in parents of dying children and believed that health care professionals should make an effort to encourage parents to continue to be the primary caregivers of children throughout the dying process. Her belief was that this helps dispel anger in a situation when parents feel out of control and puts them back in the position of being the primary caretaker for the dying child. By "interacting" (Rando, 2001) or actively participating in the care of one's dying child, caregivers are performing one of the components described in the anticipatory mourning process.

Sudden death appears to be associated with greater problems for the survivors. Factors that may contribute to this include lack of support at the time of death and lack of time to grieve for the impending loss (Kalish, 1985). Nixon and Pearn (1977) described the psychological impact on families of 111 cases of childhood drowning in Brisbane, Australia. This study revealed two important findings. First, the lack of preparation for an accidental death left no time for anticipatory mourning or preparation, and second, the presence of guilt experienced by families over a potentially preventable death.

A recent qualitative study by Contro, Larson, Scofield, Sourkes, & Cohen (2002), examined family experiences with end-of-life care for their child. Sixty-eight family members of 44 deceased children described their experience while their child was hospitalized. Most questions could be answered yes or no with a Likert-type scale, and participants were encouraged to elaborate and bring up any issues or suggestions that were not directly addressed in the interview. Among the areas identified as problematic for families were confusing and inadequate information regarding treatment or prognosis, preventable oversights in procedures or policies, failure to include the needs of siblings, and inconsistent bereavement follow-up.

Unsatisfactory grief resolution that may contribute to acute problems later in life is preventable. Resolution of grief should be encouraged, and the process of anticipatory mourning and normal grief fosters this resolution (Schoenberg, Carr, Kutsher, Peretz, & Goldberg, 1974). According to Rando (2001), the experience of a loved one's life threatening illness or disease and subsequent death can have a profound impact upon the post death bereavement of survivors. Rather than attempting to remedy problems that

arise from post death mourning, efforts towards preventing these problems from occurring prior to the death of a loved one should occur.

## Chapter Three

### Methodology

#### Design

The study was designed to determine whether a selected group of 11 caregivers who recently sustained the death of a child (recent being one that occurred within the past two years but not sooner than four months prior to study initiation) experienced anticipatory mourning. If caregivers did experience anticipatory mourning, they described the experience, identified what factors they felt facilitated or impaired mourning, and whether or not they felt this experience facilitated bereavement.

The qualitative study design used was the ethnographic research tradition, a method of study that emerged from the field of anthropology. Focused, guided, semi-structured, in-depth interviews using open-ended questions were used to answer research questions. The researcher designed an Interview Guide for this study based on a review of anticipatory mourning literature and from the researcher's personal experience. The use of focused interviews allows an emic perspective, a view by which members of a group envision their world from an insider's view (Polit & Hungler, 1995). From focused interviews, the researcher was able to identify themes in content, leading to a descriptive picture of how this group of caregivers described their world prior to and including the time of death of their child. In addition, the researcher explored the relationship of responses to selected demographics of the participants.



## Recruitment and Sample

The sample recruited through purposive sampling technique consisted of 11 caregivers, comprising a homogenous subgroup. Medical records of children who died at a major pediatric hospital within the past two years, but no sooner than four months prior to study initiation, were reviewed. Selection of participants was based on whether or not the child's caregiver met this criterion. This time frame was chosen as it was felt this would add to data reliability, by reducing the problems associated with memory and perception when collecting data retrospectively (Grbich, 1999).

Caregivers of those children who died from terminal illness, unexpectedly from a previously diagnosed chronic condition or from an acute illness or trauma were invited to participate in the study. Not included in this study were caregivers of children whose death occurred in the Emergency Room or children whose cause of death was child abuse or suspected child abuse. Staff members assisted with identification of potential study participants. A professional health care provider involved with the care of the deceased child during hospitalization made initial contact to potential study participants. The provider asked for permission for the researcher to contact the caregiver. If permission was granted, the researcher gained verbal consent from caregivers before reviewing the deceased child's medical records. During record review, the researcher confirmed participant eligibility. Telephone contact to caregivers to introduce the study took place. An approved consent form was then mailed to the caregiver and a follow-up call placed within one week. The researcher answered questions about the study and obtained verbal consent for study participation. The researcher and the participant agreed upon a mutually

acceptable place for the interview. The researcher obtained written consent to participate before initiation of the interview process.

### Protection of Human Subjects

Institutional Review Board approval was obtained from the University of North Florida and the hospital where the children's deaths occurred prior to study initiation. Professional staff members involved in the care of the participant's child during the hospitalization made initial contact with prospective participants. In this manner, potential participants had the opportunity to decline participation without direct contact by a researcher with whom they were unfamiliar. Informed consent was obtained from each participant in the sample prior to initiating the interview process. All participants received a copy of the signed Informed Consent.

Prior to initiation of the interview process caregivers were informed that should they become emotionally distressed at any time during the interview they could stop the interview temporarily or altogether. Time for composure and/or time to speak about their feelings without being audiotaped were also offered. No caregiver chose to stop the process entirely but 10 of 11 did break for several minutes during the interview to compose themselves. These 10 participants were offered the opportunity to stop the process entirely but each chose to continue.

The researcher offered information to all caregivers about support groups for bereaved persons. Two caregivers were actively involved in such a support group at the time of the study. One caregiver had attempted to make contact with a support organization but stated no one returned her call, and stated she did not pursue further

contact. The remaining caregivers had either not heard of the availability of a support group or chose not to participate.

Audiotaped interviews took place privately between the researcher and each participant at a mutually agreed upon location. The audiotapes of the interview were available only to the researcher and a transcriptionist who assisted with transcribing the recorded interviews. The tapes were kept in a locked cabinet until data analysis was complete. Following transcription, the researcher assigned fictitious names to participants and deceased children to assure anonymity in reporting. Once data analysis was complete, the audiotapes were destroyed. Transcripts were made available only to the researcher and the researcher's thesis committee members. Transcripts were stored on computer diskettes and kept in a locked cabinet when not in use. Any report or publication associated with this study will protect the identity of the participants, their deceased children, or any other family members mentioned in the interview process.

### Setting

Monthly death report data, reported through the nursing office at the hospital, was obtained to search for deaths of hospitalized children that had occurred within the 4 to 24 months preceding study initiation. Participant interviews were conducted privately, face-to-face, between the researcher and the participant at a mutually agreed upon place. Most of the interviews took place in the participating caregivers' homes, the remainder at the researcher's place of employment in a private room. The duration of the interviews was approximately 1 to 1 1/2 hours.

## Research Questions and Procedure

Qualitative interviewing is a suitable approach for examining an individual's adaptation to critical life experiences (Benoliel, 1984). A descriptive design, using focused, guided, semi-structured, in-depth interviews, was used to collect data. A set of 10 questions was developed from a review of the literature to guide the interview (Vickers & Carlisle, 2000) as well as from the researcher's own personal experience in this field. Questions were open-ended to encourage caregivers to expand on their feelings and experiences. At the beginning of the interview session, the researcher explained the purpose of the study and the interview process. Natural conversation was allowed, although participants were encouraged to answer all questions outlined in the Interview Guide. Breaks were suggested and allowed when a participant became visibly emotional during the interview process. Additionally, offered to participating caregivers was the opportunity to stop the interview process when the researcher felt continuing the interview was too upsetting to the participant. No participant chose to discontinue the interview, although most of the participants wept at some point in the interview process. Specific questions are listed in the Interview Guide, shown in Appendix A.

The researcher developed a Demographic Questionnaire for this study, consisting of 12 questions. The researcher verbally administered the Questionnaire. Characteristics of the study sample could be described and relationships between responses and demographic characteristics examined through employing this tool. Basic demographics such as relationship to the deceased child, age of participant, age of child at time of death, level of education of participant, ethnicity and gender of participant, number of persons living in the home at the time of death of the child, cause of child's death, number of days

spent in the hospital preceding death, and whether the participating caregivers described themselves as spiritual beings were queried. This Questionnaire is found in Appendix B. Each participant completed the Questionnaire prior to beginning the interview.

### Data Collection and Analysis

The researcher used a Dictaphone recorder to audiotape individual interviews. Verbatim transcription of the interviews, performed by the researcher and a transcriptionist, yielded 336 pages of typed data. Handwritten notes taken during the interview describe any pertinent emotions of the participant observed by the researcher. The researcher then performed transcribed text analysis, followed by repetitive examination of transcripts for emergence of themes and subsequent coding of thematic content. After repeated analysis, collapsed themes encompassed broader categories. The researcher repeatedly referenced the original transcripts to ensure concepts and meanings were appropriately coded. Upon completion of coding, tabulation of thematic occurrence took place.

Demographic information was collected with the aid of a Questionnaire and was analyzed for relationships between themes and selected demographics. These data served to describe characteristics of the sample. Described in the Data Analysis section are associations between demographic characteristics and responses.

To assure trustworthiness, content analysis was performed by the researcher and a secondary reviewer (Creswell, 1998). The secondary reviewer possessed knowledge of the content area and was familiar with qualitative data analysis methodology. A sample of coded interviews was examined by the reviewer who re-coded the data and confirmed

thematic content. The secondary reviewer reported a 95% agreement with the researcher on both content analysis and thematic coding of transcripts.

Through the utilization of rich, thick, detailed descriptions, trustworthiness was achieved. This method was employed so that anyone interested in transferability would have a solid framework for comparison (Grbich, 1999). Several additional techniques were utilized to ensure and attain trustworthiness: a detailed account describing the focus of the study was provided, the researcher's role was described, the participant's basis for selection and role in the study sample defined, the sample size defined, and the context from which data were gathered was described. Display of text from interviews is available for review.

Data collection and analysis strategies are reported in detail to provide a clear and accurate description of the methods used in this study so that credibility and confirmability may be ensured. Consent forms were signed and filed, coded transcripts were stored on diskettes, printed reports of code frequency and demographics were kept on file, and comments of the secondary reviewer were typed and filed.

## Chapter Four

### Data Analysis

#### Participants

Eleven caregivers were recruited from a sample of 14 individuals contacted. Eight of the caregivers' children died in the Pediatric Intensive Care Unit, two in the Neonatal Intensive Care Unit, and one on a general pediatric floor. Provided in Table 1 are demographic descriptions of the study participants. Additional data were collected about the caregivers' deceased children and are summarized in Table 2.

Table 1  
Description of Caregivers

Relation to Child	Age Group	Marital Status	Education	# Persons in Home	Spiritual Being
Mother	18-25	Married	Some College	2	Yes
Mother	36-40	Married	College	5	Yes
Mother	36-40	Married	Some College	4	Yes
Mother	18-25	Married	Some HS	4	Yes
Mother	18-25	Single	Some HS	4	Yes
Mother	26-30	Married	HS	4	Yes
Mother	36-40	Married	Some College	3	Yes
Father	46-50	Married	College	4	No
Mother	41-45	Single	College	3	Yes
Father	31-35	Married	College	4	No
Mother	41-45	Married	Some College	2	Yes

Table 2  
Description of Deceased Hospitalized Children

Age of Child	Length of Illness	# Days in Hospital	Diagnosis
10 days	10 days	9 days	Prematurity
16 months	<24 hours	<24 hours	Drowning
10 1/2 months	birth	<24 hours	Polycystic Kidneys
4 weeks	4 weeks	10 days	Heart Disease
5 months	4 weeks	4 weeks	RSV
6 years	6 years	2 days	Neuroblastoma
12 years	10 years	3 weeks	Hunter's syndrome
12 1/2 years	10 years	4 days	Hunter's syndrome
17 1/2 years	19 months	2 weeks	Leukemia
4 days	4 days	4 days	Heart Failure
20 years*	20 years	2 days	Heart Disease

\*This young man was included in study as his illness extended throughout childhood and he received care and subsequently died at the hospital.

#### Difficulties With Recruitment

Of the 14 caregivers identified as potential participants who met inclusion criteria, three declined participation stating they felt they would be too emotional to discuss the events surrounding the death of their child. Of the three who declined participation, one prospective participant gave verbal consent but withdrew consent prior to being interviewed, stating she did not feel she could discuss her child's death without crying.

#### Findings, Analysis and Interpretation

Six main themes emerged from the data described by the caregivers, shown in Tables 3 through 8. Each major theme contains sub-categories that comprise the broader categories. The major themes that emerged as facilitating or impeding anticipatory mourning are: the giving of information to parents, the impact of attitudes and actions of health care professionals, physical presence with the dying child, the location of the child's death, and issues of hospital policy, procedures, process and rules. The final theme



was the existence of anticipatory mourning and its relationship with bereavement.

Verbatim accounts of caregivers are included as examples of each of the main themes.

Caregivers and their deceased children are identified only with fictitious names.

Theme One. Information, particularly detailed information explaining why a child is not expected to survive is crucial in helping caregivers prepare for the death of their child.

Table 3

Sub-categories of the Theme of Caregivers Desire for More Information, Particularly Detailed Information, Explaining why a Child is Not Expected to Survive

- 
- Medical staff does not give enough information or say child may die
  - Nobody wants to confront the fact that child is dying or may die
  - There is benefit in knowing that a child may die, helps families to prepare
  - Discussion regarding prognosis and suggestions for stopping treatment took place
  - Caregiver had to ask for information or it was not given
  - Health care staff should ask families how much information they desire
- 

Study participants felt that more information would be beneficial in helping them come to terms with the fact that their child was dying. Sixty-four percent of study participants felt they would have done things differently had they known the death of their child was imminent. One participant described the importance of timing:

Then at around 3 o'clock that afternoon, they called me and told me that they had put six chest tubes in her that day and they weren't expecting her to make it much longer. I think they should have called me earlier and told me that earlier. They waited until they had put all of them in {chest tubes} to call and tell me that she probably wasn't going to make it much longer, and that we needed to get there as quickly as we could...so it wasn't much time that we had with her.

Other participants describe what they perceived as lack of communication between the health care team and themselves:

Everything I pretty much had to ask for. And sometimes that was...maybe I hadn't asked the right question, so they didn't know how to answer. They should be able to tell you...at least little stuff, or stuff that maybe is not right. That way you can go ahead and prepare, because I honestly was not prepared. It was not faking anything bad...I just thought, well, she's in a slump...she's not going to die.

I think they knew more than they wanted to tell me. Like the last day, I think they knew, and they weren't...they just didn't want to I guess, maybe, expect that...I don't know if they didn't want me to prepare for that. But sometimes they need to prepare that person. I would have been able to deal with it better; I would have been more prepared, my husband would have been there.... He never would have left her side. You want family there, or the closest person to you, which would be your husband or your wife...you want all that. You don't want to be left in the dark.

Half of the study participants described getting some information about the status of their children but felt they would have benefited from having more in depth information about why their children were not expected to survive. In short, they expressed a need to have a clearer explanation of why their children were dying. Four participants in particular highlighted this concern:

I don't feel like I got enough, and I don't know if they felt like I couldn't handle it, or couldn't understand it...I'm not really sure. I know I could understand a lot of the medical lingo because I had taken courses in that as medical assistant. So, I think they could have told me more...so I don't really know what their reasons were...maybe I could have been more prepared, because it is pretty hard just knowing in one day...that this was it.

But we don't exactly know like, perhaps, why was he not oxygenating the way he was? Why wasn't he getting air? In that aspect, I wish that at the time I had asked, or we had had an explanation as to "well, this is what's going on".

...it might make it easier for them to understand that, yes--this is a real possibility; that there is a lot of good, and there is a potential for health and progression in recovery...but then there is also a real strong potential for death...this could happen, or that, depending on what the illness or injury is. To let them know what the possibilities are and what's available for them. I had no idea where to turn....

...but they didn't want to talk much. They didn't want to let me know how she was doing throughout the night. They just would tell me "Oh, she did good". You

know, that's not what I wanted to hear. I wanted to hear, you know, did she have any trouble, but I was scared to ask, you know? I didn't want to know...but then again I did, you know. You're scared to ask them questions.

Expressed by several participants is speculation on why information was not more forthcoming from the health care team. Most felt that giving bad news is difficult for health care professionals, that confronting the fact that a child is dying is extremely difficult and a topic that is often avoided by health care staff. Some of their explanations for this were:

And specifically information on her potential death or...nobody ever came out and said she could die...this is what you need to look at, you know, be prepared...because I guess that's hard to do. Nobody wants to say that; nobody wants to confront that.

They don't really tell you, point blank, "Mr. and Mrs. M., we think the time is close". Just something like that would have been somewhat helpful... No, nobody wants to talk about it...it's really kind of odd.

They have a very hard job because you sit down and you ask them questions and you want honest answers. And they do give you honest answers, but those answers are very hard because they don't want to tell you that. They don't want to tell you that "Okay, we've done these specific treatments and nothing is working and we're at that point where we can't do anything else".

I hadn't seen her {the pediatrician} in probably three or four years. I just sensed that she was frustrated with everything. Umm, she couldn't do much for us. So my husband and I, we were getting, we were getting desensitized over the past couple of years... {In terms of counseling or giving direction over decision-making and prognosis}...it probably would have been helpful.

It seemed to me that the doctors were more scared to tell you than was really happening. They would tell you some, but they wouldn't tell it all. And you could see it coming. It seemed to me that they were more scared to let you know what was really going to happen than trying to prepare you for the better.

Sufficient information about a child's illness was given to some of the participants interviewed. Length of illness did not appear to affect how the participating caregivers described the giving of information. Responses of participants with children who had

prolonged illness and hospitalization had similar responses as did participants whose children were sick for a short period. The examples below are from one study participant whose child died from an acute illness of short duration, followed by one whose child died from a progressive disease that lasted 10 years, demonstrating that neither duration of illness nor amount of time spent hospitalized appears to impact how participants felt about the experience:

It's got to be the choice of the parents. I got no sense that the doctors or the staff was trying to sway us in any way in our decision. They gave us all of the information that we needed, answered any questions we had, and didn't seem to keep anything back. So, I think that with answering the questions, the information was there for us to make our decision.

I will say that they never rushed anything and they couldn't. There was nothing to rush. They spent time...the ICU doctors spent whatever time was necessary, when he was there, and if we had a question he would come in and talk.

Participants described the failure to acknowledge that a child is dying as detrimental. Those appraised of the severity and imminent timeframe for death felt that this was quite beneficial in helping them come to terms with the event and afforded them an opportunity to prepare for their child's death. This timeframe, while in some instances only hours, allowed study participants time to conduct themselves in ways that made the experience meaningful to them and their dying child. Saying good-byes, gathering family members, being physically present, holding one's child prior to death, performing religious rituals, and having the time to begin acceptance for what is transpiring is made possible when participants were given an honest appraisal of their child's medical condition.

Theme Two. The attitudes and actions of health care professionals are pivotal in allowing the process of anticipatory mourning to not simply occur, but to actually

progress. The perceptions of how the health care staff treated the child and their caregiver had tremendous impact on how participating caregivers described the experience.

Table 4

Sub-categories of the Theme of Attitudes and Actions of Health Care Professionals Have Tremendous Impact On How Caregivers Describe the Experience of Death of a Child

- 
- Support of health care staff helps and was given
  - Caregivers describe staff as helpful during dying process
  - Caregivers describe staff as helpful after child has died
  - Lack of compassion is sensed by caregiver
  - Show of compassion is sensed by caregiver
- 

All participants described the attitudes and actions of staff members as having a profound and lasting effect on their experience with the loss of their child. When this experience was positive, when participants perceived staff as compassionate, sensitive and intuitive to the participant's needs, yet respectful of privacy, they recalled the experience in a favorable manner. Participants below expressed their feelings regarding staff whom they felt showed this compassion and concern:

And I saw every one of them very sad for a young man they didn't even know. They were very sad. But the sad part to me was the way they reacted because they felt so guilty. They felt so guilty not being able to bring him back. To be very honest with you there was not a dry eye. These nurses were crying. Me and the nurse were up there crying and it was just the most touching thing. It was the most wonderful thing for me. Like I said, it was...to see all these people who were so dedicated to what they were doing.

One of the nurses, the one that was encouraging us to take pictures...of course I was holding him and bawling...my nose was running constantly, and she just kept wiping it away for me, which is one of the things that...I mean, they were all so supportive.... These are the last memories, sometimes the only memories that we are going to have of our children.

One participating caregiver whose child was frequently hospitalized and who had become quite familiar with staff members expressed the following:

Like I said, we had been there so long that they knew us. It's hard for me to give you recommendations because they {staff} were like our extended family. We were on a first name basis...they just instinctively knew when we needed something. They could look at our face and know that this is when they need to offer some help...it's like they were kind of connected to us in a way, and they knew when to step in. When we got down to the 5<sup>th</sup> floor, if we had wanted anything done, they would have let us; I mean, they let us do whatever we wanted to when it came to that point.

The level of emotional involvement of health care professionals caring for sick children is also apparent in some instances. Displays of compassion were described as important to study participants as illustrated by the following excerpt:

He truthfully hurts as much as we when they die. We kept telling him...he kept saying, "I'm sorry that I couldn't do anything else". He's in a very tough spot, for him to come in and tell you, "there's nothing else" is a very hard thing for him to do...it's like he's driven, you know, to cure all of these children and he just can't. It's not his fault; there's not the knowledge, they don't know how to cure it. We could not have been referred to any better doctors or nurses, they are just wonderful; they really are.

She's on the 5<sup>th</sup> floor; she answers the phone and helps a little bit. She couldn't have been a better person. And when she {the caregiver's baby} came out of surgery, she was there, you know. You don't have very many people who would do that. She brought her in a bear that sang her a lullaby and had angel wings, because we all knew that she was going to be a little angel.

Conversely, descriptions of staff who lacked compassion and conducted themselves in manners that participants perceived as negative, routine, and callous, negatively affected the process of anticipatory mourning and were viewed as roadblocks to the mourning process, according to study participants. Reflecting back on the experience with negativity was viewed as detrimental. In 35% of participating caregivers,

visible agitation was observed as they recalled and described the way they or their children were treated.

The following statements describe situations that study participants considered detrimental to their mourning:

We really had a bad time in ICU. We just had some bad care from a couple of P. A.s and nurses, so our time in ICU wasn't good at all. Just for the fact of their attitude and kind of unwillingness to do anything for her because she was dying was the impression that we got from the way that they presented themselves to us....They were probably glad to see us go because I had had enough of them and I let it be known in front of one of them....They knew that I was not happy with the way they were treating Jenny. {Crying}

...I think they could have done a better job. They could have explained stuff better. They could have had a better attitude towards it. You're in a hospital with kids that, even after their surgery, if they are three or four years old, they want to see a smiling face and they want to see a good attitude. And that's how that parent looks at it too...the better your attitude the better you're going to take care of something. You wouldn't want someone to treat your child that way; don't treat this person's that way. That's the only thing that I felt was...it was someone acting like they didn't care, and if they don't care they don't need to be there. Or they need to change their outlook and think "How would I feel if I were in that person's shoes?" {Crying}

Interestingly, some participants rationalized why health care professionals lacked compassion. Several stated they believe in order for health care professionals to routinely work in the inpatient environment, these staff members cannot become emotionally involved or they would not be able to continue working in such a stressful and emotionally charged environment.

Compassion is lacking in the hospital, which is always kind of funny, you know. And I know they have to steel themselves because they see it. If they got so involved with each and every case they would probably have to get out of the profession.... I mean, he was a doctor. He was like a White Coat. You know, "This is the information, it's your decision"....They lower their voice; they speak softly; you know. But it's kind of like; it's a job. It's still a job. It's still business and you have to conduct business. I think that forms of compassion can represent themselves in things like helping with grieving.

One of the nurses said "Oh, you're gonna be one of the frequent fliers". And I looked and I said what are you talking about? "Oh yeah, {the nurse said} when you have a trach you're in and out of here all the time". Well, I was mad; cause I'm thinking no one ever presented that to me. I don't want to be here, he {caregiver's child} doesn't want to be here.

I had many times asked them to give him a sponge bath. What I found being there, and I was there day and night, night and day, they are very desensitized to the care of the patient. And, I know they can't help that, cause it's the line of work they're in...I really found that of the staff.

Several participants described having difficulty with how they were approached by health care professionals when request for autopsy occurred. Participants described what they felt was an insensitivity of staff regarding the timing or presentation of autopsy request. Two study participants stated they gave consent to participate in this study for the sole purpose of telling the researcher how this event affected them. While all participants recognized the importance of autopsy, a strong theme expressed by participating caregivers was the need for more empathy from the health care team when requesting permission for autopsy. Some specific examples are:

...the doctor came in very, very soon {after the child had expired}, and said,, "We would like to encourage you to allow us to autopsy your daughter". Which, at the time, seemed a little bit out of place, a little inappropriate on the timing. I know doctors seem to become a little numb at times, and to get used to it. I don't know if that's the cause of it. Not a sense that it is your loss. So it seemed like, to me, the most insane question at the time, when it came up, and I didn't know how to respond to that.

So yes, they need to have more consideration for the parents, when it comes down to ...you lose your child. But they were so into their job they didn't take into the fact that someone has just lost their child, and maybe to give them just that time...to take in the fact of what had just happened. You're not in the state of mind, at that very moment, even 20 minutes afterwards...you're still trying to absorb the fact that you just lost your child, not the fact that you need to be signing papers or any kind of legal documents...we were there, like I said, about two or three hours afterwards, you know, and we had all that time...I was aware enough to know what had actually happened and it had hit me. I took it in then. But they were trying to do their job and get everything done.



...have a little bit more heart. I know it's hard for them to do that...but it's not...you know, it's supposed to be part of their job...but they're not the one fixing to lose their child, you are. Just don't be so...I don't know, don't bring in all the legal stuff, and don't worry about all that...let them sit and do what they have to do, you know, mourn or whatever, at that point in time, until they can handle you talking to them, or you asking questions about what they want to do. Let them have that time before you start questioning or asking, or wanting them to sign anything. {Crying}

One participant angrily and tearfully described how she received the results of the autopsy on her child who had been buried several days prior. She claimed that she was unaware that her child's organs had not been placed back in the child's body before arrival at the funeral home. She claimed she would not have buried her child without first retrieving the organs from the hospital so they might be buried with the body. Her description of the event follows:

...I was so upset. I was just mad that he...because he just talked about it like it was casual, you know, "I have your child's heart and lungs laying here". And that's how it was, very crude more or less. Kind of heartless, you know. I was astonished. I was baffled...my mouth was wide open and tears were flowing. No, I think that that was something. I wouldn't have buried her had I known. {Sobbing}

While often there is little intervention that has the potential to change the outcome of a child's illness or disease, the framing of events for a caregiver experiencing such a loss certainly can. In giving bad news or administering care to a dying child, compassionate, honest, attentive staff members can tremendously influence the perception of the situation. Small acts of kindness that show empathy to the caregivers can have lasting effects, such as described in the wiping of tears of a mother holding her newborn baby as he was dying. The presentation of paperwork for legal or hospital policy purposes should be handled in as sensitive a manner as possible, with a focus on

appropriate timing. Additionally, the material should be presented in such a way that caregivers understand the purpose and meaning of the materials.

Theme Three. Physical presence is crucial for caregivers to experience anticipatory mourning, both leading up to and following the death of their child. Active participation allows for a sense of control and facilitates preparation for the event of death.

Table 5

Sub-categories of the Theme of Physical Presence is Paramount For Caregivers to Experience Anticipatory Mourning, Both Leading Up To and Following The Death of a Child

- 
- Being allowed to stay with child leading up to the time of death was allowed and is helpful
  - Not being allowed to stay with child is detrimental
  - Being asked if caregiver wants to be present; caregivers should have this choice
  - Holding child before death was allowed and is important
  - Holding child was not allowed and is detrimental
  - Caregiver held child or did not hold child before and/or after death occurred
  - Being allowed to participate in care of child is allowed and is felt to be helpful
- 

All study participants expressed the importance of participating in the care of their child, although only a few were given the opportunity to do so. In spite of the fact that most children were hospitalized for at least one week (n=6), half of the participants interviewed were not allowed to hold their child prior to death (n=5). Actively participating in the care of a dying child can help prepare a caregiver and also provide some sense of purpose, of control, in an otherwise desperate time for caregivers. The following illustrates the benefit of this experience for caregivers as described by two participants:

...they thought that the tube was clogged, or it was too small. It wasn't draining right. So the nurse let me actually get into and help her change that tube which

was like, you know, I was actually helping her get better.... Like I was a part of everything.

We got to talk to her even though she was, everybody told us that even though she was in a coma, she could hear what we were saying. So we had our time to talk to her, and tell her things that we needed to tell her, and just to sit there and I mean we even laid up on the bed with her. Her daddy fell asleep a few times...my thoughts at that point were that this is my child and if she is dying, I'm going to do what I want to and you need to get out of my way. I mean we never really got ugly, but that was the way we came across...don't tell me I can't sit on the bed, or I can't do this, or I can't hold her in that chair if I want to because it's my choice at this point.

Providing opportunities to participate in their children's care was described as beneficial by study participants. Instances where staff members created situations so that caregivers might assist in the dying child's care were described as helpful.

One of them had me take his temperature, which, thinking back now I'm very thankful that I did. My husband got to take it once also, and they gave us the thermometer.... Earlier that day, when we had the first scare, the nurse said that they wanted to try to let us have a positive holding, so that it wouldn't just be when they thought he was going to die.

I was always right there with everything that had gone on.... No one ever told me that I couldn't be with her or stay any point in time...so that was...that made it easier for me....They never shut me out and they never said "Can you step out of the room?" or they would tell me what they were going to do and asked me if it was okay if I stayed there or if I wanted to step out...which was great because it gave me that choice and I could stay there.

Physical presence at the time of death was extremely important for some participants interviewed. Missing the opportunity to be with the child during the last moments of life was described as very detrimental by several study participants, and resulted in regrets and negative memories of the experience. The following illustrates the importance of presence:

So I just stroked his head and I knew that this was the time and needed to tell him that it was okay to go and it was hard to tell him but I did. And I was right there. Everything I wanted it to be it was. I wanted to be there when he died. That was my prayer for him, God don't let me be in the shower, God don't let me be in the

bathroom, don't let me be home on a bath break or whatever. That was my prayer, to be with him. {Crying}

They let Sara {the child's mother} do some of the cleaning {after the death of the child} that she felt she wanted to do. And we were there talking...there was no rush or anything. We did anything that we needed to do, and they {staff} did their job.

Many participating caregivers (63%) expressed regret over not holding their child prior to death occurring, or being present at the actual time of death. Allowing caregivers to perform and participate in tasks during the dying process of their child may facilitate an improved mourning experience for caregivers. Additionally, being physically present and participating in the child's care appears to result in less regret following the child's death. The following examples describe how two participants felt about not having the chance to hold or be physically present with their child at the time of death:

Well, unfortunately no {did not hold child prior to death}, not before, because she was just hooked up to too many tubes at that point in time...all the different monitors and it made it difficult to hold her because she was on the ventilator, and that would have interfered with it too much.

They wouldn't let me in there...that way, I could tell her bye and that I loved her, right there at the end, before she actually died, so she could hear me.... Yeah, I would have liked to have had the chance. It would have been hard, yes. But just to be able to be there to say goodbye...or, no, to spend the last two or three seconds with her would have been excellent...but if you were trying for 45 minutes, and there's nothing else you can do, that parent needs to have the right to walk in there before the child completely goes....It was just like I didn't get her, in that little hole, right there before she did die...I just wish I could have that that one little chance, you know, just to be in there with her....I think every parent should have the chance, if they want to. But they wouldn't ever let me out of that little room. They just kept holding me in there. {Weeping}

Of the total caregivers interviewed, 45% were able to participate in the care of their child prior to his or her death and described this period of time as helpful to them in preparing for the death. Others looked back on this period with regret over not having

done more. One might speculate that these acts help caregivers feel a sense of control in a situation where they are essentially powerless.

Theme Four. Saying goodbye to a dying child and completing tasks described as important prior to death occurring are impacted by the physical place where dying and death occur. Having a health care professional who is trained in end-of-life care who can serve as a *coach* to caregivers experiencing the death of a child was described as both desired and helpful. Staff who are knowledgeable and competent in end-of-life care are an asset to caregivers, as often caregivers are uncertain of what is happening and are unsure what steps they should take to prepare for the events surrounding the death of their child.

Table 6

Sub-categories of the Theme of Separate Physical Space Impacts the Mourning Process and is Facilitated by Health Care Staff That is Trained in End-of-Life Care Who Can Coach Caregivers Through the Death of a Child

- 
- Separate room was available for death of child and was helpful
  - Separate room was not available but would have been helpful
  - Current physical space for child to die in hospital is problematic
  - Someone to serve as a coach through dying process was helpful or would have been helpful
  - Bereavement package was available and is helpful
- 

Participants described the setting and environment where their children's death occurred as influential in coping with, as well as remembering the event. For example, the Neonatal Intensive Care Unit has a room families use to "room in" with their baby before taking the baby home. The room is set up like a bedroom and has a bathroom, rocking chairs, a telephone, and a door. There is softer lighting than is found in the main part of the Unit and the room is decorated, as a home would be. Families can have total

privacy in this room. The dying infant and caregiver(s) can utilize the room if it is not in use for families who are rooming-in with their newborn. One participant whose infant died in the Neonatal Intensive Care Unit described how the setting was conducive to mourning at the time of her infant's death:

And I think there was a TV and a VCR. There were a couple of rocking chairs and a telephone. There was a day bed and there was a bathroom in there, which was good because whenever we'd get up to go to the bathroom, we wouldn't have to go and face people. I mean, we were pretty much in a cocoon. If we wanted to stay there all night we could have...which we ended up staying...we took him off the ventilator...I want to say around three or four...and we didn't leave there until like nine o'clock that night. I think it was great because I didn't even have to leave. I just started making the phone calls from there with my husband holding him. And we have a few pictures of my husband holding him....

Another study participant whose child died in the same Unit described the importance of privacy as well as separate space:

I know we were making a lot of noise, and sobbing pretty loudly. So at that point you know that you can't do this forever, but you don't know how to grieve...From that point I think that you can't describe how awkward it is, but eventually they have to move you out and get you into the small room right there at the Neonatal Intensive Care Unit. They had us go in there for awhile with Anna, so, to make phone calls, say our good-byes, and all that good stuff.

Eight of the participating caregivers experienced the death of their child in the Pediatric Intensive Care Unit. Unlike the Neonatal Intensive Care Unit, the Pediatric Unit has no so separate room for dying children. The rooms are all private rooms with glass doors and curtains, and the rooms surround the main workspace area. The general pediatric floor also has only private rooms and is equipped with a full bath and a couch/day bed for caregivers to use if desired. In contrast to participants who had a child in the Neonatal Unit, participants who had a child die in the Pediatric Intensive Care Unit expressed the following:

It would have been nice if there had been a bathroom in there and a shower...I was kind of surprised at that, because they have everything so nice at {the hospital} on the other floors, I guess...well, {the 5<sup>th</sup> floor} where you have a room with, like a bedroom with everything in there...I wouldn't hardly even want to leave the room to use the bathroom, or to take a shower or do anything...I would just stay with her whether I was dirty or not.

No. No rockers. We sat in a chair. I think I rocked because I do that when I get nervous, I rocked. No, it was in ICU so it was like dim lighting, gray walls, beds, curtains, the glass doors. Well, it certainly wasn't the birthing room. It didn't have the cozy colors and the nice furniture; it was very sterile. And the room that I was in was basically just a room with a sofa and a couple of chairs. There's no water, no pitcher of water or anything that I remember.

It's too, too sterile. I mean it was the same shiny floor with the same chair, and nowhere for me to really sit to be comfortable with him. Maybe like uh, something with a couch or something that other family members could be invited into.

When asked for suggestions on what would have been the preferred environment, participants described the following:

I don't know, kind of like a Hospice room, or something where you know, they're not going to live; that's more comforting, a place of dying would be a much better setting. A nice view, a nice room, and then the whole family can be in there, because this is a child who is not going to continue to breathe. He's going to let go of life.

You could have stuck us in Alaska somewhere and it wouldn't have been far enough away from people and everything else. So, it's all relative to how private you can make this for people, but I think it could have been more private. Yeah, rather than such a small room that's so close to the beeps of the unit...It would have to help, it would have to help our memories of it. But sure, anything that you can do to kind of remove you away from the whole hospital feel would certainly help. You are still aware of your surroundings to some extent and it's always easier to remove the stimulation around you...perhaps a little extra expense on the budget for the hospital to put a room, maybe a little farther away from the action.

Many of the caregivers had not had personal experience with the death of a loved one. The description of a coach or use of the word *coach* is a common theme in 27% of the interviews. The need to have someone describe, in detail, what the death experience

was going to be like, look like, and feel like was expressed by caregivers. For those who described having such a coach or guide, be it a health care professional or a family friend who had experience with the death of a loved one, study participants felt the experience was enriched. The following examples illustrate how a coach was of benefit:

We didn't know what to expect. We didn't want her dying in the first place, and I don't think that we would have gotten that *comfort* feeling had it not been for Nurse Mary. Even though she couldn't do anything either, she was just there and it kind of made everything feel a little bit calmer, you know...After Jenny died, we kind of sat in there, I don't know how long we sat with her, but she shut the door and made sure that nobody came in and gave us the time that we needed to sit with her.

And she was the one who came in and she prepared me. She said "Lila, this is what you're going to do. This isn't going to be easy; it's going to be really hard. You've got this one step to go. You're going to hold Chad and then they are going to disconnect him from the machine...and depending on him, he'll either stop breathing...he may breathe for a few minutes and then he'll stop breathing". And it was just like she said...that was exactly what happened.

When he did die, Nurse Dawn, I don't know if you know her, she was there when he died...She said "Why don't you sit down and I'll put him in your arms. So I got to hold him for like two hours, which I treasure. Never would I ever thought that, to do that, because he's big. I mean she kind of coached me in that respect. Yeah, that was wonderful.

And then there was the Respiratory Therapist Tom. He was my rock. They all turned around and left. And I said to Tom, "Don't you go anywhere cause I don't know what's about to happen". And I felt like I needed to be coached or something cause how many times is a lay person with a dying person, hopefully only once. So anyway, he stayed and told me what was happening.

The chaplain came down and was there, obviously. That certainly helped to have that point reference there, to help us through. The chaplain's staff was very nice and helping out with a little bit of information and offered support groups for grief counseling after the event.

Certainly, having staff trained to deal with end-of-life care is advantageous. Being skillful and comfortable with care that facilitates an improved death experience is an asset in the hospital setting. Caregivers are often so grief stricken and in shock that they



are unable to participate in rituals, say goodbye, hold their child, or come to terms with what is taking place around them. Study participants described simply not knowing how to grieve or what steps to take during the dying process and ultimate death of their child. Several expressed regret of not having done certain things that they now think would contribute to a better bereavement. Not participating in their child's care, not being present at the child's actual time of death, and not asking more questions regarding their child's status are described as causing caregivers regret after the fact. Regrets such as these might be minimized if staff were available to coach or guide families through this process. As coaches assist in the birth of a baby coming into the world, so too can coaches assist as a child departs the world.

Theme Five. Caregivers described the routine practices in the hospital setting such as following policy and procedures or issues of *process* as detrimental to mourning during the time of their child's hospitalization.

Table 7

Sub-categories of the Theme of Routine Hospital Policy, Procedures, Process, and Rules Are Detrimental to How Caregivers Perceive the Events Surrounding the Death of a Child

- 
- Caregiver describe routine hospital procedure, policy, process, and rules that are routine as problematic for mourning
  - Caregivers desire process of timing of autopsy and delay in autopsy results as problematic
  - Caregivers describe bereavement packages as helpful
- 

Forty-five percent of the participants had difficulty with routine procedures and rules followed during their child's hospitalization. Of this group, most feel that while institutional rules might be applicable in many instances, these rules should be relaxed

when a child is dying. On the occasion when staff made exception to certain rules, participants felt grateful:

That night my husband brought her {older daughter, Amy} up and he would go back and visit Beth and I would sit outside with Amy so she would get to see me too. And then he came out and before we left I begged, "Please, just let Amy go back"...she was crying. And they closed the glass door and let us take her back, just so she could see through the glass, her baby...it was her sister and it thrilled that child so much to see her baby lying there. It scared her but she was ready for it. And then she asked a million questions and the nurse was like, "Okay you need to go ahead and take her out now". But it was just enough...and the next day she died. So you know, it was like it was meant to be; it wasn't, it was a very good thing that she did, because she did get to see her and she did know she was sick...So it was a very good thing that the nurses did have a heart, you know, to let her go back, even if it was for two or three minutes, she did get to see what was going on...and understand, it helped her to understand a lot more.

One study participant described not wanting to leave her child under any circumstance, as she feared not being present if he died. Rather than eating in his hospital room, she was asked to leave to eat her meal away from her child's room, as visitors were not allowed to eat in a child's room. She described why this is problematic:

And I know that you just have to look on it on a case by case situation and they don't have time to be doing that all the time, but to just be rigid with all the rules and stuff like all of that. I think it's nice that you can go visit later in the night if someone gets sick. They're more open to that. That's good. But don't ask me to leave my son, who I wouldn't leave to go to the bathroom, to go eat because you're not allowed to bring food in the room, it's not hurting anyone, as long as it's not hurting any of the other kids.

Others describe not having bathroom facilities in their child's room as also problematic. Several participants stated they would opt to simply not use the bathroom for personal hygiene or would postpone bathroom breaks as long as they could possibly do, so as not to leave their child.

Several participants described the process surrounding obtaining consent for autopsy as well as the delay in receiving autopsy results as disruptive to their mourning

and bereavement process. While the need for autopsy of one's child was stated to be necessary and valued by caregivers, the timing of requesting permission for autopsy was described as important. The handling of autopsy was a particularly emotional topic for several participants during the interview process. Two openly wept while describing their experience. Several expressed anger and resentment over the timing of the request, as well as the attitude of the health care professional asking for consent. Additionally, 25% of participants stated feeling the delay in receiving autopsy results prevented them from achieving closure to the death of their child. Several described actively pursuing the results but felt the information was difficult to obtain. Participants described their experience:

And I think it was too soon when they brought it in for even them to be asking questions at that time, about legal work, you know, at that point in time you can't make the right decision at that time. I was so very upset, I was still trying to bring her back to life.

Like I said, if that was the surgeon in there and he had just lost his child, he wouldn't want me bringing in papers at that very time for them to sign, and you not understand, or be able to comprehend because you are so upset or torn about your child. To know what you signed or what you just said they could do. But I didn't know anything...I was just like, "Okay, just get away from me right now". I wasn't being rude, I was just doing whatever I could so they would leave me alone.

I think that probably one thing I'd change and everybody is guilty of this, I am particularly guilty of this, but I try my best now and that is follow-up after the fact. It was, I think, poorly handled by the hospital here and I will be the first to say it. We were approached 5, 10, 20 minutes after Anna's death and asked, "Will you let us do an autopsy on the child?" Yet we had to do everything in our power to extract the information back out, to find out if this is going to happen to our other kids. {Final autopsy results were not ready until one year after infant's death. Father refused to allow triplet sibling to have anesthesia for surgery until anesthesiologist obtained results to ensure that sibling would not have risk of sudden death as occurred with deceased infant.}

One study participant, following the recorded interview, asked if someone would call her with her son's autopsy results. His death occurred 11 months earlier and she had not yet received the final autopsy report. She stated she had not called to inquire but was now interested in knowing the outcome of the autopsy.

Three of the 11 participants described receiving a bereavement package at the time of their child's death. Two participants, one whose child died in the Neonatal Intensive Care Unit and the other in the Pediatric Intensive Care Unit, described how important this was and how they cherish the items today. Currently, both intensive care units have in place a procedure to give caregivers a personalized memento box for the deceased child. The box can contain a lock of hair taken from the child, hand or foot imprints of the child, articles of clothing, bracelet identification bands, and other items the family would like to keep. Health care team members mail decorative cards on the deceased child's birthday, anniversary of the child's death, and on holidays. The following are excerpts from study participants given a remembrance box of their child's belongings before leaving the hospital following their child's death:

We got a little special pillowcase that somebody had made to carry his belongings out with. It was wonderful. We got a little box with a ribbon and we put a lock of his hair in that. And she cut all his bracelets off and we put that in a bag, they have a special little bag they give you. So all of those things are just very near, just very near and dear to my heart. And that was nice.

But for the most part, they were all absolutely wonderful. One nurse made his imprints for the infant box for us.

At that point, my mother-in-law had arrived so we had her camera and my father-in-law's camera, and one of the nurses decided that we should take pictures, which at first I had said I didn't want to take pictures because of the tubes, and you couldn't see him and...I just would rather not. So we took a bunch of pictures and one of them is actually my favorite picture, because you get to see his legs, and you get to see his toes, and...I think it's probably the only full body shot that we have of him.

One participant suggested that the hospital have an information packet available to parents that would help them with the process of burial for their child. Knowing what to expect, who to call for burial information and services, what costs to expect, and how to make funeral plans was described as very important and something that was not available when her son died. Another mother suggested that grief counseling, particularly for siblings, would also be helpful.

Theme Six. Many study participants felt they knew their child was dying and had begun to mourn the loss. The majority felt that if they had begun the tasks associated with preparing for the death of their child that bereavement would have been impacted. Several expressed that nothing can prepare a caregiver for the loss of a child. These participants felt that participating in the care of their child, performing rituals, holding their child, being afforded separate physical space, and having time to grieve helped with bereavement after death had occurred.

Table 8

Sub-categories of the Theme of Caregivers Experiencing Anticipatory Mourning Which Impacts Bereavement

- 
- Caregiver was aware that child was dying and experienced anticipatory mourning
  - Caregiver was not aware that child was dying and did not mourn
  - Caregiver does or does not believe anticipatory mourning impacts bereavement
- 

Although some participants stated they were not aware that death was imminent, 64% felt they were aware that their child was dying and experienced anticipatory mourning. Of those who expressed awareness, all felt having this knowledge was helpful as it afforded time to complete tasks they deemed important. One participant best illustrated this awareness:

I think we always had that, though, from the time she was diagnosed we always were worried that we were going to lose her. The last couple of weeks, though, I had this little voice telling me that something was wrong, but I did not think it was that she was dying. In truth, if they had gotten the scans done before she died we would have known. But looking back, I don't know if it would have made it any easier knowing that at any time she was going to die...I don't think there was anything we could have done to prepare us for it.

Several participants stated they did not know death was imminent and felt they were unprepared for the event of death. As death occurred unexpectedly, they relate they did nothing to prepare for the death. This was described both in instances where the child had a progressive, terminal illness as well as in instances when the child had been previously healthy. Two participants stated nothing could prepare a person for the death of a child.

Even when anticipatory mourning was not experienced, the majority of study participants stated they felt bereavement could be positively impacted when anticipatory mourning occurred. This is illustrated by one study participant, who stated he knew his wife's pregnancy was high risk and thus was cognizant that their unborn child could potentially die prematurely. However, the death of his newborn daughter occurred quite unexpectedly. While very ill in the Neonatal Intensive Care Unit, she had shown signs of improvement. Presumably without warning her heart stopped and she was unable to be resuscitated. He stated:

Yes, {I think anticipatory mourning facilitates bereavement} umm, I think so. I think it would have. We lived through, went through that whole pregnancy thinking that we could lose them {triplets} at any time, so I think that if it had happened, we would still be grieving, but I think it would have been a little different, in that we certainly had to prepare ourselves....

### Demographics and Relationships to Themes

Examination of thematic occurrence frequency in relation to demographics took place. While there was occasional variation in response to sub-categories themes, in general participants' responses were uniform. Those participants who expressed experiencing a negative occurrence were asked for suggestions for change. Their responses described the experiences of those who felt the experience was positive.

No identified relationships between age, educational level, gender, or spirituality could be determined as affecting thematic response. It is noted that both male participants described themselves as not spiritual beings but it is unclear what, if any, impact this had on response to interview questions. Neither age of child, length of child's illness, nor amount of time spent in the hospital prior to death appeared to influence either type of response or response frequency for individual participants.

As the sample size was small, no statistical significance can be derived from the data comparing response and demographic characteristics. However, the fact that the majority of participants described very similar experiences, perceptions, and suggestions for practice, demonstrates the identified themes cross all demographic characteristics examined.

## Chapter Five

### Discussion

Families are often unprepared for the death of a child, even when the death is expected, such as with progressive illness or disease. In spite of such an expectation, people view the death of a child as unnatural and an event for which one does not prepare. As described by Rando, the loss of a child is an event for which caregivers are never prepared (1986b). Attempting to deal with such an overwhelming situation leaves most caregivers little reserve for trying to cope with the event. The majority of caregivers interviewed in this study considered themselves novices in terms of exposure to, and experience with, coping with a dying person. Additionally, typically many adults with children are in the second through fourth decade of life and consequently have not yet experienced the death of a loved one, particularly one of young age.

The impact that health care providers can have upon caregivers who sustain the death of a child while hospitalized is significant, as demonstrated by the themes identified in these 11 interviews. The findings in this study are similar to those of Contro, et al. (2002), which include families receiving inadequate information and inconsistent bereavement follow-up. Caregivers who sustained the death of a child described health care professionals as having a profound impact on the death experience. Often, health care professionals view the death of a child as an extremely personal event for families. However, the opportunity exists for health care professionals to influence the dying



process experience for caregivers, thereby influencing how the event is experienced and remembered by survivors.

The majority of caregivers interviewed felt they experienced anticipatory mourning surrounding the death of their hospitalized child and expressed that the health care teams' behaviors influenced their experience, as did the setting. This is similar to findings of Rando (1986a). Caregivers described the events leading up to and including the death of their child as affecting their memories of the experience as well as their bereavement following the death. Positive experiences surrounding the death of a child were recalled favorably and were described as somehow lessening the sorrow experienced in bereavement. While caregivers described the death of their children as the most heartbreaking event they had ever experienced, they described obtaining comfort in knowing that the events surrounding their children's deaths were handled compassionately and in a manner which was in concert to their individual preferences. Conversely, caregivers who recollect this time in a negative manner describe their grief as compounded. Several described not being able to obtain closure to their children's deaths as they found it difficult to move beyond anger over how the experience was handled.

Contrary to Rando's belief that a minimum time of six months was needed for appropriate mourning to occur (1984), 5 of the 11 caregivers interviewed had less than this period of time to anticipate their child's death, yet described experiencing anticipatory mourning. It is possible, as described by the participants in this study, that optimal mourning is not dependent upon length of preparation, as previously described by Rando. How participants in this study perceived the experience at the time, positively

or negatively, influenced their bereavement period and memories of the event. This is similar to studies done by Miles (1984), in that caregivers have a need to find meaning during the period leading up to their child's death.

Several themes emerged from these interviews that provide insight into what may be beneficial in assisting caregivers leading up to and including the time of their children's death. The first of these is the theme of desiring information, particularly detailed information, that would serve to assist caregivers in their attempts to grasp and understand the events that are occurring. Providing information that explains why a child is not expected to survive, not just simply the fact that he or she is dying, provides caregivers with information so they can begin to process what is occurring and attempt to come to terms with the event. Most caregivers interviewed in this study felt it beneficial to have as much information as possible as this allowed time to prepare for their child's death. While on the surface the giving of information seems rather straightforward, the participants interviewed felt that information was neither as forthcoming as they would have liked it to be nor as detailed. Study participants speculated that health care professionals choose to withhold information that they consider "bad news" or news that may cause added duress to caregivers already in crisis. This may be due, in part, to the hope of the health care professional that this may somehow serve as a protective barrier to families in grief. Others felt that the health care team was simply uncomfortable informing families that their children were not expected to survive. This is not however, a beneficial approach for those with dying children, according to caregivers in this study. Facing the facts and dealing honestly and empathetically is what caregivers suggested might be more helpful to them.

In a qualitative study done by Pierce (1999), family members gave suggestions on how to improve end-of-life care. Family members in Pierce's study made three suggestions that they considered would be helpful when caring for dying patients: facilitate improved interaction between the family and the dying patient; improve interactions between the health care team and the family and patient; and create an environment that is more conducive to allowing family members to be physically close to their dying loved one. Findings from this study reveal similar suggestions from caregivers.

The majority of participating caregivers interviewed in this study felt the health care team should be consistent in care, competent, truthful, and compassionate in their approach to dying children and their families. These findings are corroborated by Pierce's (1999) study results. While often the belief exists that caregivers want privacy and solitude with their dying child, the experience of the majority of the 11 caregivers in this study suggested otherwise. Support, by staff who are familiar with the child and caregiver, is both desired and appreciated, and is an expectation of care expressed by many of those interviewed. Grossman (1998) described similar findings in her case study on anger in parents of dying children. Consistent care by health care professionals seems to decrease anger and help minimize anxiety in parents who are facing a stressful and emotional event.

The need for a health care member to function in the role of coach, who can assist, describe, and guide caregivers through what is involved in the dying process is a strong theme expressed by many study participants. Interestingly, these caregivers did not want to be alone, but rather expressed a need and desire to be guided through the dying

process of their children. The importance of compassionate health care staff to provide such guidance cannot be underestimated. As in Pierce's study (1999), the impact of caring staff members on several caregivers interviewed in this study was profound. Equally profound, however, was the impact caused by uncaring, indifferent staff. Recalling experiences when staff seemed indifferent or lacking compassion for the dying child or the caregiver in this study, evoked considerable emotion, even when the child's death took place almost two years prior to the interview. Several study participants described single events that were so disturbing that they still experience continuing distress and anxiety. Caregivers described their grief was compounded when recollections of events surrounding their children's' deaths were perceived as lacking care and concern, either for the dying child or the caregiver. A recent study (Contro, et al., 2002) of 68 family members who experienced the death of a child corroborates this finding. Family members described as detrimental unsatisfactory staff behaviors and confusing or inadequate communication regarding prognosis or status.

Being physically present and participating in the care of the child leading up to and following the death, was desired and considered important for study participants. As described by one caregiver in this study, participating behaviors provided a sense of control. One might speculate that these final acts of parenting are beneficial in enabling caregivers to feel they had done everything possible in caring for their children, even in the dying and death process. Miles (1984) and Rando (1986b) described similar suggestions for parents who experienced the death of a child. According to caregivers in this study, physical presence and nurturing of a child are behaviors that should not be withheld simply because a child is dying.

The actual setting where death occurs appeared to influence the perception and experience for caregivers in this study. Clearly demonstrated was the need to be in a comfortable, soothing environment, where freedom to grieve and to complete tasks deemed important for caregivers, could occur as their children were dying. Participants desired a room similar to a Birthing Room that most health care facilities utilize with the birth of a baby. This type of room is more homelike; having soothing colors and décor. Ideally, this room would be away from the activity of the hospital ward, particularly the intensive care setting. Most caregivers in this study, while deeply appreciative of the maximization of medical efforts to prolong the life of their child, described the environment of the hospital as “too cold, sterile”, and not conducive for caring for a dying child. For the two caregivers who did have the benefit of such a separate birthing-type room, they recalled the experience in favorable terms. By the creation of such designated physical space with components similar to those found in a Birthing Room, anticipatory mourning is enhanced. For the caregivers in this study who were taken to such a room, the availability of health care staff competent in end-of-life care was also available. In these instances, nurses assisted caregivers in the dying process of their children and guided caregivers through tasks now described as beneficial to mourning.

While most participants felt their children were medically well cared for, many felt that emotionally they and their children were somehow neglected. Many described barriers that exist in the health care system that only serve to compound their struggle as they attempted to come to terms with the fact that their children were dying. Often barriers were simple routine or policy practices that perhaps are not applicable or necessary for circumstances surrounding a child's death. Directing efforts towards

removing these barriers while simultaneously concentrating on methods to facilitate anticipatory mourning is needed, as caregivers felt this positively influenced their bereavement period and influenced the memories they created. Families want and deserve care that is in concert with their belief systems, parenting styles, and individual preferences. Providing a system where the family unit is the focal point of the dying process, not merely the dying child, will facilitate such an experience. Having staff who are comfortable with, and competent in, end-of-life care, who can assist caregivers throughout the dying process of a child, is equally as important and necessary as having staff trained in providing life-saving care.

From data generated from this study, specific demographics examined do not appear to influence caregivers needs or desires surrounding the death of their child. Holistic programs can thus be designed and implemented for serving children and their families, while allowing for specific cultural and individual needs as individual situations arose. Providing a system in which the family becomes the focal point of the dying process, not merely the dying child, will facilitate anticipatory mourning. Programmatic design should focus on providing services that are holistic and available to all caregivers across all inpatient settings.

Children will die. The impact of their death will continue to be devastating for survivors. Caregivers want to know they have done all that is possible for their child. Assisting caregivers through the dying process of their child is an opportunity to ensure that everything has been done, even when the outcome is death. Recognizing the presence of and facilitating anticipatory mourning is one way to positively influence the experience for caregivers of dying children.

### Implications for Practice

The last decade has brought about the emergence of concentrated efforts to improve end-of-life care. Recognizing the lack of preparation of physician training in end-of-life care, in 2000 the American Association of Pediatrics released a position statement on the need for medical education about end-of-life care in the pediatric setting (Sahler, Frager, Levetown, Cohn, & Lipson, 2000). This awareness and move towards action has led to increased discussion about how children are treated with life-threatening or life-limiting illness and disease. This study emphasizes the need to garner input from the perspective of dying children's caregivers, as clearly this group of individuals has unique insight to how end-of-life care is experienced, and, of equal importance, perceived. Creating environments and programs that are sensitive not only to the needs of dying children but to the caregivers involved in children's deaths is recommended. Shifting control of care from the health care team back to the caregiver, under the guidance of staff who are competent and caring in their approach to end-of-life care, will allow the caregiver to experience anticipatory mourning. In this manner, feelings of control and a sense that the caregiver has done everything possible for their child may be facilitated. Living with decisions and actions made at the time of death of the child may be recalled by caregivers in a favorable manner, thus leading to a more appropriate bereavement and adjustment to life without one's child.

To accomplish this change in practice, changes in systems and approach to care of dying children will need to occur. Input of those who have experienced the loss of a child for suggestions on how to guide change in practice and process should be elicited. Health care professionals should receive consistent comments, both positive and negative to

reinforce the impact of their actions and attitudes on caregivers, both short term and long term. The focus on cure should be augmented with a concentrated effort towards palliative, or supportive care. Shifting the locus of control back to the caregiver from the health care team is necessary. Allowing caregivers to take a more active role, albeit a guided role, in the death of their children should be encouraged and allowed. Providing separate space that is comfortable and facilitating tasks that study participants have identified as important to them in the process of losing a child, is recommended. Resources, including the provision of time, should be offered and encouraged for end-of-life education and training of physicians, nurses, social workers, chaplains and all involved in caring for dying children and their families. Based on the information obtained from this study, programs should be designed that incorporate not just appropriate care for the dying child, but appropriate care of the child's caregiver as well. Recognizing the need for, and presence of, anticipatory mourning is necessary so that the process can be facilitated and encouraged for those experiencing the death of a child.

Affording caregivers the opportunity to participate in, and be supported through, the death of their children by caring and competent staff in an environment that is conducive to anticipatory mourning, is one way to promote optimal grief work, and hence a better bereavement period. Providing caregivers an opportunity to create positive lasting memories of time spent with their dying children is a valuable contribution of health care professionals to families. Ultimately, actions taken to promote anticipatory mourning result in less complicated grief reactions for survivors.

Further research to study the impact upon caregivers when changes suggested by these caregivers are implemented is warranted. Studies are recommended to examine the



influence of anticipatory mourning on bereavement of caregivers who experience the death of a hospitalized child, both in the short and long term. Further exploration is needed regarding how frequently support groups for the bereaved are utilized, how often bereaved persons miss days of work, and how frequently the bereaved visit primary care providers for complaints of depression, insomnia, and other physical ailments following the death of their children.

Studying the differences between caregivers who experience anticipatory mourning and were provided opportunities to create a more appropriate death experience and those who felt they could have done more or were unprepared for their child's death, is warranted. These studies could provide valuable information regarding how health care professionals should design and implement end-of-life programs. Studying the similarities or differences of anticipatory mourning in caregivers who have a child die in the home setting versus the inpatient setting would also be useful. Designing programs to suit the needs of the caregivers depending on the environment where their children die is suggested.

Additional exploration into what effect, if any, gender and spirituality have on anticipatory mourning, given a larger sample size, should be explored to determine if a correlation exists between these characteristics and how anticipatory mourning is experienced. Designing programs to incorporate findings into practice will benefit caregivers who experience such loss.

#### Limitations

There were several limitations of this study. While potential participants were identified and selected by location of death and time of death in an attempt to avoid

selection bias, unfortunately all study participants were Caucasian. Certainly, culture and racial background influence the perceptions of the experiences surrounding the death of one's child. Secondly, 2 of the 11 caregivers interviewed were fathers and the remainder mothers. This sample size was not large enough to determine the influence of gender on anticipatory mourning. The two fathers also stated they would not describe themselves as spiritual beings. This characteristic and relationship, if any, to response could not be examined more in depth due to the small sample size. The timing of the interval between the occurrence of death and the interviews may also limit the findings. It is unclear how long after a traumatic event memories fade or are altered. It is difficult to ascertain what, if any, affect timeframe had on recollection of events, particularly ones that were so emotionally charged.

How bereavement affects the recollection of events is not clearly understood. Those who experience bereavement appear to be influenced by numerous factors, only one of which is the anticipatory mourning experience. Attempting to link the presence or absence of anticipatory mourning to bereavement is just one piece of exploring the bereavement process. It is certainly possible that some caregivers will experience a complicated bereavement period regardless of how well the time leading up to and including the death of their child was handled or experienced. This study proposed to examine the presence and process of anticipatory mourning, by describing the experience through the perspective of caregivers who experienced the death of a child. It is hoped that with this information, discussion about how to expand and improve upon existing end-of-life practices can be encouraged by health care professionals.

### Conclusion

In spite of advances in medicine and technology, death remains inevitable. Those who experience the death of a child are particularly vulnerable, as often they have little or no prior experience in dealing with the death of a loved one. Additionally, caregivers of dying children have many life years ahead of them to live with memories of their child's illness and the experience surrounding the child's death. Most caregivers of dying children are aware that death is imminent, yet are ill prepared for the experience leading up to and following the death of their child. The link between anticipatory mourning and a more appropriate bereavement, or one with minimal complications, can be facilitated and influenced by several factors. Changes in hospital process that would eliminate burdensome and detrimental policy and routine practices should occur. Caregivers desire communication with detailed information about their dying child's status and prognosis, while simultaneously being administered compassionate and competent end-of-life care. Providing a milieu that is sensitive to the needs of both child and caregiver can facilitate anticipatory mourning, and hence a more appropriate bereavement period for caregivers.

By positively influencing the experience surrounding the death of a child, memories of the death experience can be recalled in a favorable manner, in spite of the devastation created by the loss of a child.

*To cure sometimes*

*To relieve often*

*To comfort always*

15<sup>th</sup> century French folk saying

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Appendix A  
Interview Guide

## Appendix A

Who was the primary caretaker of your child while he/she was in the hospital?

Were you aware that your child was dying?

How far in advance of your child's death were you aware that your child was dying?

How did you become aware that your child was dying?

Did you feel that you acknowledged your child's dying?

What are your perceptions about who was in control of your child's care?

What is your perception of your child's understanding of his/her condition?

What was your understanding of your child's condition?

What are your perceptions of what actually happened at the time of your child's death?

What fears and anxieties about your child's death did you experience?

Were you prepared for your child's death?

Did anyone help you prepare for your child's death?

Do you feel that you grieved for the loss of your child before your child/s death actually occurred?

Do you feel that you became detached from your child before he/she died? Did you find yourself visiting less frequently or did it become harder for you to visit your child in the hospital?

How would you describe how you thought of your child prior to his/her death?

(ex: present or past)

What happened after the death of your child?

How would you describe professional support leading up to the time of your child's



death?

How would you describe the communication between you and the professional staff?

What non-professional support did you receive prior to your child's death?

Do you have any thoughts about what you feel was helpful in terms of facilitating your coping with the impending death of your child?

Do you have any thoughts about what you feel was not helpful in terms of facilitating your coping with the impending death of your child?

Do you have any thoughts about whether you would have liked to have done anything differently?

Appendix B  
Demographic Survey

## Appendix B

### Demographic Information Collection Sheet Anticipatory Grief in Caregivers With Children Who Die in the Hospital

1. Relationship to child: \_\_\_\_\_
2. Age of caregiver: <18      18-25      26-30      31-35      36-40  
41-45      46-50      51-55      >55
3. Marital Status at time of child's death: \_\_\_\_\_
4. Age of spouse/significant other:  
<18      18-25      26-30      31-35      36-40  
41-45      46-50      51-55      >55
5. Highest level of completed education:  
Did not complete H.S.      Completed H.S.      Some college  
Completed college      Post-college
6. Number of persons living in household at time of child's death:  
\_\_\_\_\_
7. Ethnicity:  
White, not of Hispanic origin      American Indian or Alaskan Native  
Asian or Pacific Islander      Black, not of Hispanic origin  
Hispanic      Other or unknown
8. Does caregiver describe him/herself as a spiritual person?  
\_\_\_\_\_
9. Diagnosis of child: \_\_\_\_\_

10. Duration of your child's illness: \_\_\_\_\_

11. Age of child at time of child's death: \_\_\_\_\_

12. Number of days your child was in the hospital prior to his/her  
death: \_\_\_\_\_

## Appendix C

IRB Approval: University of North Florida

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Division of Sponsored Research and Training

**MEMORANDUM**

TO: Annie Rini  
Nursing Department

VIA: Dr. Li Loriz  
Nursing Department

FROM: James L. Collom, Institutional Review Board

**Signature  
Deleted**

DATE: October 9, 2000

RE: Review by the Institutional Review Board—  
"Anticipatory Grief in Caregivers With Children Who Die in the Hospital"

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This is to advise you that your project "Anticipatory Grief in Caregivers With Children Who Die in the Hospital" has been approved on behalf of the IRB and has been declared exempt from further IRB review. This status applies to your project in the form and content as submitted to the IRB for review. Any variations or modifications to the submitted protocol and/or informed consent forms as they relate to dealing with human subjects must be cleared with the IRB prior to implementing such changes.

If you have any questions or problems regarding your project or any other IRB issues, please contact this office at 620-2455.

dch

Attachments

c: Dr. Lucy B. Trice

## Appendix D

IRB Approval: Baptist Medical Center

October 12, 2001

Annie Rini, BSN, RN  
Nemours Children's Clinic  
307 Children's Way  
Jacksonville, FL 32207

RE: #00-111 "Anticipatory Grief in Caregivers with Children Who Die in the Hospital"

Dear Ms. Rini:

The Institutional Review Committee at Baptist Medical Center met on October 11, 2001, and the following action was taken. This IRC grants approval under the guidelines of the International Conference on Harmonization: Good Clinical Practice.

The annual protocol renewal report submitted for the above referenced protocol was reviewed and the annual renewal was approved.

The anniversary date for this protocol will be October 11, 2002. At that time, we will need an annual report of your experience with this protocol. In the meantime, please call immediately should any questions arise.

Sincerely,  
**Signature Deleted**

William Z. McLearn III, MD  
Chairman  
Institutional Review Committee

ZM/ts



Appendix E  
Informed Consent

## CONSENT TO PARTICIPATE IN A RESEARCH STUDY

**Title of Study: Anticipatory Grief in Caregivers With Children Who die in the Hospital**

**Principal Investigator: Annie Rini, BSN, RN**  
**University of North Florida**  
**Masters in Nursing Student**

**Telephone number: (904) 390-3761**

**Thesis committee Chairperson: Li Loriz, Ph.D., ARNP**

**Telephone number: (904) 620-2684**

I am a student in the Master of Science in Nursing/Primary Care Nurse Practitioner Program at the University of North Florida. I invite you,

\_\_\_\_\_ to participate in a research study about anticipatory grief in caregivers (parents, grandparents, etc. who were responsible for their child's care) who have had a child die while in the hospital. Anticipatory grief is being aware that a person is dying and preparing for the death of that person. I hope to learn whether or not caregivers experience this type of grief, and, if so, what factors they describe as being helpful or not helpful to them in this process.

You were selected for this study because you were a caregiver to a child who died while being hospitalized at Wolfson Children's Hospital within the past two years.

### INVESTIGATIONAL PROCEDURES

14 caregivers will be recruited for this study. Caregivers will be identified from a review of medical records of children who have died while a patient at Wolfson Children's Hospital. You will be contacted initially by a health care provider who was involved in the care of your child while he/she was hospitalized. If you are determined to be eligible, you will be offered the opportunity to participate in this study through a phone call by the investigator conducting this study. Informed consent will be obtained in writing prior to beginning the study. You will meet the investigator and she will answer any questions you might have about the study. You will meet at a place that is agreed upon by you and the investigator. An interview, lasting approximately 1-1/2 hours, will be conducted in which the investigator will ask you questions about the experiences which occurred during the time leading up to the death of your child. Questions will also be asked about whether you feel these experiences impacted your bereavement (time of mourning) experience after the death of your child. Demographic information (ethnicity, age, marital status, number of members living in your household, etc.) will also be collected about you. The interviews will be audiotaped and the transcripts typed and analyzed by the investigator and a secondary reviewer. The interviews will be analyzed to look for similarities and differences in how caregivers describe their experience at the time of their child's death. Once data analysis of the transcripts is final the audiotapes will be destroyed.

## RISKS AND BENEFITS

Research studies often involve some risks. The risks of this study involve potential psychological and emotional distress to you as you recount your experiences surrounding the death of your child. You will be counseled prior to the interview initiation that you will be able to stop the interview at any point should you so choose. Should you become emotionally distressed during the interview process, the interview will be stopped and you will be allowed to discuss your feelings if you so choose and/or given privacy to compose yourself. If you feel that you are unable to continue the interview this will also be offered as an option. You will have the option of either stopping altogether or continuing at a later date. Additionally, referral to a support group for caregivers who have had a child die will also be offered.

By participating in this study, you may not derive any direct benefit; however, the findings here may be of benefit to health care professionals who care for dying children and their caregivers. These findings may help these professionals find better ways to help caregivers cope with the impending death of their child. Additionally, other caregivers may also benefit from these findings. You may potentially gain some benefit by sharing your experience with the investigator, as some caregivers describe talking to others about their deceased child helps them better cope with their child's death.

## ALTERNATIVES TO PARTICIPATING IN THIS STUDY

Participation in the study is strictly voluntary. You may choose not to participate in this study. If you decide to participate, you may stop and withdraw from this study any time without prejudice. If you do choose to withdraw from this study, please notify the investigator, Annie Rini, BSN, RN promptly by calling (904) 390-3761

## PRIVACY OF RECORDS

The interview will be conducted privately between you and the investigator. The audiotapes will be transcribed (copied into writing, word-for-word) by the investigator only. During the transcription process, the investigator will change your name and your child's name to a fictitious (false) name so that neither you nor your child can be identified. The audiotapes, transcripts, and analysis documents will be kept locked in a file cabinet of the investigator. The audiotapes will be destroyed once data analysis is final.

The results of this study will be shared with you, if you choose. The results of this study will be summarized and presented to the investigator's thesis committee. Additionally, results of this study may be published in the nursing and/or medical literature, but no publication will contain any information that would identify neither you nor your child.

**PAYMENT**

You will receive no financial or other compensation for this study.

**CONCLUSION**

You are making a decision whether or not you will participate in this study. If you sign this form, you have agreed that you will participate based on reading and understanding this form. You will be given a copy of this consent form once signed. If you have any questions, please ask Annie Rini, BSN, RN by calling (904) 390-3761.

Any questions regarding your rights as a research subject should be directed to Dr. William McLearn, Chairman of the Institutional Review Committee, Baptist Medical Center at (904) 202-2000 or Dr. Warren Hodge, Chairperson of the Institutional Review committee at the University of North Florida at (904) 646-2455.

\_\_\_\_\_  
Subject

\_\_\_\_\_  
Principal Investigator

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

### Author Note

Annie Rini graduated from Florida Community College in 1981 with an Associate of Arts degree and an Associate of Science in Nursing. She received a Bachelor of Science in Nursing from the University of North Florida in 1998. In 1999 she enrolled in the Master of Science in Nursing/Primary Care Practitioner Program at the University of North Florida and anticipates graduation in May 2002.

Annie's nursing career has centered on the care of the child. She worked in the inpatient setting for many years before transitioning to an outpatient pediatric subspecialty clinic. For the past nine years she worked in endocrinology and research at the Nemours Children's Clinic. Most recently Annie accepted a position in the Hematology/Oncology Division at Nemours where she will practice as an ARNP upon graduation. She plans to incorporate findings from this study into assisting children and their families with a palliative approach to practice as they face life-limiting and life-threatening disease and illness. Annie's plans to concentrate her effort towards improving the path towards cure, as it is her belief that not infrequently the curative goal is either not attained or the experience leading towards cure often leaves children and families with permanent emotional and psychological scars. Perhaps by impacting the path the experience can be enhanced, regardless of whether cure is attained.

Annie is actively involved in several professional committees in Jacksonville that focus on bioethics and pain management. She has also been involved with the Parish Nurse Ministry at her church. She recently co-authored a White Paper on recommendations for addressing the needs of children living with life-limiting and life-threatening disease, along with members of the Children's International Project on Pediatric Palliative Care

and Hospice Services (ChIPPS), a subgroup of the National Hospice and Palliative Care Organization. She published several journal articles while working in endocrinology research. Her most recent publication was a paper co-authored with Kathy Bloom, Ph.D., ARNP, one of her nursing professors at the University of North Florida, on the current treatment strategies for oral mouth ulcers.