

CRITICAL NURSING BEHAVIORS IN THE CARE OF
DYING CHILDREN IN THE HOSPITAL SETTING

by

LOIS E. HAWKINS

85

A Thesis

Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements for the Degree of

MASTER OF NURSING

Faculty of Nursing
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CHILDREN IN THE HOSPITAL SETTING**

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LOIS E. HAWKINS

**A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba
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The author thanks the eleven pediatric nurses who consented to participate in this investigation. These nurses willingly gave of their time and shared their knowledge and experience even though the memories were sometimes painful. Their interest in advancing the knowledge of expert nursing practice in the care of dying children has made this investigation possible. This study is dedicated to these nurses.

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CRITICAL NURSING BEHAVIORS IN THE CARE OF DYING CHILDREN IN THE
HOSPITAL SETTING

Abstract

A child's death is no longer considered to be a natural part of life. Rather, advances in medical science and technology have fostered society's expectation of treatment and cure. Pediatric nurses are required to provide terminal care in a curative environment and are required to help children and families cope with death even though they often feel poorly prepared to do so.

Quint (1967) applied the theoretical sociological model of symbolic interactionism to describe and understand, in general terms, the actions of nurses providing terminal care. More recently, Benner (1984) adapted the Dreyfus Model of Skill Acquisition to discover the nature of expert practice of nursing "experts." Quint's theory and Benner's adaptation of the Dreyfus Model of Skill Acquisition provided the theoretical perspectives for this qualitative descriptive study.

Eleven pediatric nurses deemed "expert" in the care of dying children by their peers were asked to describe both positive and negative behaviors in the care of dying children that they had either experienced or observed in students or colleagues. Content analysis revealed ten critical nursing behaviors in the care of dying children: connecting, responding to the family, providing comfort, enhancing the quality of life during dying, responding to anger, facilitating the transition to palliative care, responding during the death scene, responding after death has occurred, enhancing personal growth and responding to colleagues. Based on the findings of this study, implications for nursing education, practice and research have been addressed.

TABLE OF CONTENTS:

Acknowledgments.....	ii
Abstract	iii
Table of Contents.....	iv
CHAPTER I.....	1
Statement of the Problem.....	1
Introduction.....	1
Nursing Care of the Dying.....	1
Nursing Care of Dying Children.....	4
Purpose of the Study	6
Assumptions Underlying the Study.....	7
Conclusion.....	7
CHAPTER II.....	9
Review of the Literature.....	9
Introduction.....	9
Healthy Children's Developing Understanding of Death.....	9
1. Children's Intellectual Understanding of Death.....	9
2. Environmental Conditions Influencing Children's Understanding of Death.....	11
3. Children's Anxieties and Attitudes Toward Death.....	12
Hospitalized and Dying Children's Understanding of Death.....	13
Dying Children's Growing Awareness of Impending Death.....	14
<u>Figure 1.</u> Dying Children's Stages of Acquisition of Information.....	15
<u>Figure 2.</u> Dying Children's Changing Self-Concept.....	15
Dying Children and Family Relationships.....	17
1. Parental Adjustment To A Dying Child.....	18
2. Sibling Responses To A Dying Child.....	20
Nursing Care of the Dying Child and Family.....	21
Specific Nursing Behaviors in the Care of Dying Children and their Families.....	23
1. Comfort Care.....	23
2. Patient Feelings.....	24
3. Nurses Feelings.....	25
4. Supporting Colleagues.....	25
5. Patient Rights.....	26
6. Family Care.....	26
7. Manipulation of Environment.....	27
Conclusion.....	28

CHAPTER III.....	30
Conceptual Framework.....	30
Introduction.....	30
Theoretical Perspectives.....	30
1. Quint's Perspective	31
<u>Figure 3. Quint's Theoretical Model</u>	32
<u>Figure 4. Adaptation of Quint's Theoretical Model to Pediatric Nursing</u>	33
2. Benner's Adaptation of The Dreyfus Model of Skill Acquisition.....	34
<u>Figure 5. Benner's Adaptation of the Dreyfus Model to Nursing Practice</u>	35
Application of Theoretical Perspectives	36
CHAPTER IV	38
Methodology	38
Research Design.....	38
Population, Sample and Sample Selection.....	38
Identification of Pediatric Nursing Experts.....	39
Data Collection Methods.....	39
Procedures.....	41
Ethical Considerations.....	45
Data Analysis.....	47
Issues of Reliability and Validity.....	48
Strengths and Limitations of the Study.....	49
Conclusion.....	52
CHAPTER V.....	53
Research Findings.....	53
Introduction.....	53
Sample Characteristics.....	53
<u>Figure 6. Children's Hospital Death Statistics</u>	55
<u>Critical Nursing Behaviors in the Care of Dying Children</u>	55
1. Connecting.....	56
1.1. Behaviors that Promoted a Mutual Closeness.....	56
1.2. Behaviors that Embraced the Child and Family.....	58
2. Responding to the Family	60
2.1. Behaviors that Supported the Family, Including or Relieving Them of the Responsibility for Care According to What Was Best for the Family.....	60
2.2. Behaviors that Brought Families Together	64
2.3. Behaviors that Fostered a Homelike Environment	70

2.4. Behaviors that Responded to the Family's Need for Information	71
2.5. Behaviors that Decreased the Potential for Future Regret.....	74
2.6. Behaviors that Supported the Child and Family's Cultural and Religious Beliefs and Practices.....	76
3. Providing Comfort.....	78
3.1. Behaviors that Reduced Physical Pain and Discomfort.....	78
3.2. Behaviors that Satisfied the Child's Psychological and Emotional Needs.....	80
4. Enhancing the Quality of Life During Dying.....	82
4.1. Behaviors that Responded to the Child's Need for Information.....	82
4.2. Behaviors That Helped Dying Children Do Things That Were Important to Them.....	85
4.3. Behaviors that Made Dying Children Feel Special.....	89
5. Responding to Anger.....	90
5.1. Behaviors that Demonstrated Respect and Empathy, Even When Anger was Directed at the Health Care Team.....	91
5.2. Behaviors that Promoted Resolution When Anger Occurred Within the Health Care Team.....	93
6. Facilitating the Transition to Palliative Care.....	95
7. Responding During the Death Scene	97
7.1. Behaviors that Acknowledged the Child's Dying.....	98
7.2. Behaviors that Supported the Child and Family as Death Approached.....	99
7.3. Behaviors that Maintained a Sense of Calm	102
8. Responding After Death Has Occurred.....	105
8.1. Behaviors that Demonstrated Respect, and Supported Families Through the Realization of Death.....	105
8.2. Behaviors that Demonstrated Respect for the Body During Post- Mortem Care	107
8.3. Behaviors that Supported Families Beyond the Death of Their Child.....	109
9. Enhancing Personal Growth.....	114
10. Responding to Colleagues.....	117
Conclusion.....	119
CHAPTER VI	120
Discussion and Recommendations.....	120
The Sample.....	120
Paradigm Cases.....	121

<u>Nursing Behaviors</u>	123
1. Connecting.....	124
2. Responding to the Family.....	125
3. Providing Comfort.....	128
4. Enhancing Quality of Life During Dying.....	128
5. Responding to Anger.....	129
6. Facilitating the Transition to Palliative Care.....	130
7. Responding During the Death Scene.....	132
8. Responding After Death has Occurred.....	133
9. & 10. Enhancing Personal Growth and Supporting Colleagues.....	134
Relation of the Research Findings to the Conceptual Framework.....	135
Relationship of the Research Findings to the Proposed Research Questions.....	137
Recommendations for the Integration of Nursing Research Findings.....	138
Limitations of this Study.....	139
Nursing Implications.....	139
References.....	144
Appendices.....	155
<u>A.</u> Definition of Terms.....	156
<u>B.</u> Piaget's System of Cognitive Development.....	157
<u>C.</u> Nursing Behaviors Described in the Literature.....	158
1. Comfort Care.....	158
2. Patients Feelings.....	159
3. Nurses Feelings.....	161
4. Supporting colleagues.....	162
5. Patient Rights.....	162
6. Family Care.....	164
7. Manipulation of Environment.....	167
<u>D.</u> Critical Nursing Behaviors in the Care of Dying Children.....	168
<u>E.</u> Introduction to the Study.....	171
<u>F.</u> Background to the Educational Influential Tool.....	172
<u>G.</u> Educational Influential Instrument.....	173
<u>H.</u> Invitation to Participate in The Research Study.....	175
<u>I.</u> Semi-Structured Interview Guide.....	176
<u>J.</u> Structured Data Collection Tool.....	177
<u>K.</u> Consent to Participate in a Nursing Research Study.....	178

CHAPTER I

Statement of the Problem

Introduction

Society has seen a transformation in the fundamental commitment of hospitals from care of the poor and dying toward healing and cure (Benoliel, 1988; Mauksch, 1975). The developing expectation for state-of-the-art treatment and cure has resulted in a shift toward the hospital as the accepted place to die (Degner & Gow, 1988). It is not uncommon for aggressive treatment to continue until close to the time of death (Benoliel, 1988). Dramatic advances in medicine and technology have forever changed the nature of dying (Flood, 1989).

The process of institutionalizing dying has removed death and dying from daily life. Nevertheless, death and the dying process continue to be matters of concern to most people (Brockopp, King & Hamilton, 1991). Death and dying often represent a new experience for which families are poorly prepared even though the effects on families may be profound (Kristjanson, 1989; Kübler-Ross, 1969; Martinson, 1983; Strauss & Glaser, 1970). In particular, the death of a child has been described as one of life's most stressful events (Back, 1991).

Nursing Care of the Dying

Although the provision of care for the dying has been identified as one of their responsibilities nurses report that they often feel ill-equipped to deal with the human experience of dying (Coty & Tamlyn, 1984; Corner, 1991; Degner & Gow, 1988; Faulkner, Webb & Maguire, 1991; Quint, 1967; Wilkinson, 1991). Nurses are faced with the juxtaposed expectation of providing terminal care in the curative environment (Degner & Gow, 1988; Quint, 1967). As the number of terminally ill patients in hospitals

increases, health professionals whose focus has been on improving life continue to describe difficulties in dealing effectively with the dying (Degner & Gow, 1988; Faulkner, Webb & Maguire, 1991; White *et al.*, 1983; Wilkinson, 1991).

In her pioneering nursing research, Quint (1967) focused on the sources of nurses' difficulties in providing skilled and sensitive terminal care. She found that not only were caregivers faced with the difficult challenge of providing excellent care, they also were expected to provide emotional support to patients and loved ones throughout the dying process. Yet during their training, their education focused on the preventive/curative aspects of care and their clinical experiences exposed them to curative-oriented care rather than comfort-oriented care. Quint concluded that nursing education did not adequately prepare nurses for the care of the dying. Although Quint's work helped nursing educators to recognize the importance of death education in nursing curricula, nurses continue to report their professional education to be less than adequate in preparing them for the care of the dying (Corner, 1991; Degner & Gow, 1988; Faulkner, Webb & Maguire, 1991; Wilkinson, 1991, Davies & Eng, 1993).

Degner and Gow (1988) found that consideration of nurses' attitudes toward their dying patients provided additional insight into the feelings of inadequacy that nurses experience in the care of the dying. Nurses' attitudes can influence their professional role in death and dying situations and can be a strong predictor of clinical behaviors (Campbell, Abernethy & Waterhouse, 1983; Caty, Downe-Wamboldt & Tamlyn, 1982; Corner, 1991; Faulkner, Webb & Maguire, 1991; Lockard, 1989; Milton, 1984; Quint, 1967; Wilkinson, 1991). Martinson, Palta and Rude (1978) found that nurses who seldom dealt with death were more likely to become discouraged and depressed when they cared for dying patients. Caty, Downe-Wamboldt and Tamlyn (1982) found that older nurses were better able to cope with a patient's death, but the age of the patient also had a strong effect. The younger the patient the more difficulty the nurses had in dealing

with their feelings about death. To deal with death anxiety health professionals have been known to employ such defensive behaviors as denial, avoidance, and distancing tactics (Campbell, Abernethy & Waterhouse, 1983; Hunt & Meerabeau, 1993; Lockard, 1989; Maguire, 1985; Maguire & Faulkner, 1988; Quint, 1967; Strauss & Glaser, 1970).

In a review of death education programs in nursing, Degner and Gow (1988) found that although death education has been included in some curricula few such programs have been systematically evaluated. Of those that were, most failed to link the intended effect of nursing education to practice. To address this gap, Degner and Gow (1988) conducted a longitudinal study to evaluate the effectiveness of two alternative death education approaches. Students in the control group received an integrated approach to death education in nursing. The experimental group received a required course in palliative care during their junior year. One year after graduation, nurses from the experimental group felt more adequate in caring for the dying and judged their undergraduate program to have been more adequate in preparing them for care of the dying.

Many questions arise when considering nursing behaviors in the care of the dying. Despite professional agreement that nurses should and do provide supportive care to the terminally ill, there are few descriptions of what supportive care is, or of how nurses provide such care (Davies & O'Berle, 1990; Degner & Gow, 1988; Davies & Eng, 1993). To address this issue, Degner, Gow and Thompson (1991) generated an initial list of critical nursing behaviors in the care of the dying. Knowledge of behaviors central to the care of the dying would not only provide a basis for future nursing education in the care of the dying, but could also contribute toward the development of a model of expert nursing practice in the care of the dying.

Nursing Care of Dying Children

In their investigation, Degner, Gow and Thompson (1991) acknowledged that their population of care recipients was restricted to adults. They queried whether pediatric nurses would identify different behaviors as central to the care of dying children. It is conceivable that pediatric nurses would identify different behaviors as critical to the care of dying children. Wilson (1982) identified some major differences in emphasis in the care of dying children. Support of the family suffering the death of a child is especially important because their grief can be devastating and long lasting, and the number of family members affected is often large. Home care options become even more pressing because of the recognized benefits of home care for both child and family. Finally, there is an ongoing need for both professional and public education in caring for terminally ill children and their families, and in coping with childhood death.

Advances in medical science have fostered the belief that children need not die (Adams, 1985; Bearison, 1991; Dufour, 1989; Peace & O'Keeffe, 1993). Childhood death has become the ultimate contradiction (Gyulay, 1989). In reality, although almost half of the children with newly diagnosed cancer will be cured, cancer remains one of the leading causes of childhood death (Bearison, 1991; Dufour, 1989). The death of a child continues to be one of the most stressful and poignant experiences that a family can encounter (Ross-Alaolmolki, 1985).

The care of a dying child can be particularly arduous. The dying child may represent the family's first experience with death and dying. Understanding the child's view of death and the parent's reaction to their child's imminent death necessitates an understanding of child and family development and knowledge of how parents understand, relate to, and cope at each particular stage (Gartner, 1976). The child and family have different backgrounds of experience and different abilities to cope with the demands of the situation (Adams, 1985; Benoliel, 1985; Martinson, 1983; Peace & O'Keeffe, 1993).

Hospital staff must discern the child and family's experience with death in order to provide appropriate support and education to both (Adams, 1985; Peace & O'Keeffe, 1993).

Nurses must also recognize the importance of experience in shaping their own attitudes and behaviors. Martinson, Palta and Rude (1978) have suggested that pediatric nurses working in a terminal care environment would be more care- and comfort-oriented, less likely to apply life-saving measures, and would report less difficulty caring for dying children and their families. In reality, caring for a dying child is known to evoke significant emotional stress among caregivers (Peace & O'Keeffe, 1993; Vachon & Pakes, 1985; Davies & Eng, 1993). Nurses who assume responsibility for helping children and families cope with death continue to report difficulty in making the transition to palliative care, with recurring sentiments of overwhelming panic and fear, and feeling of inadequacy and uncertainty (Bull, 1985; Gronseth *et al.*, 1981; Martinson, Palta & Rude, 1978; Peace & O'Keeffe, 1993). Adams (1985) contended that there is nothing more challenging than caring for a dying child.

Davies and Eng (1993) identified a scarcity of literature relating to the experiences of nurses caring for dying children. They noted that dying children cause the greatest anguish, that the nurse-patient relationship involves a long-term investment in time, energy and emotional involvement, that the nature of the child's illness requires the establishment of relationships on both personal and professional levels. A significant gap remains in the existing knowledge base with regard to specific knowledge and skills that are essential to the care of dying children and their families. Pediatric nurses do not feel adequately prepared to meet the challenge.

The development of knowledge in an applied discipline such as nursing requires the documentation of existent knowledge (the "know-how") and an extension of this practical knowledge through theory-based scientific investigations (Benner, 1984). The

generation of such research based knowledge is necessary for future developments in nursing research and education. Although reports in the literature have identified dying children's need for supportive care (Bearison, 1991; Carlson *et al.*, 1985; Coody, 1985; Flood, 1989; Gyulay, 1989; Martinson, 1983, 1979; Martinson *et al.*, 1978), few provide detailed descriptions of specific nursing behaviors that are relevant to the care of the dying child (Davies and Eng, 1993). Davies and Eng (1993) determined the need for systematic investigation of the experience of nurses who are actively engaged in providing care to children who are dying.

Purpose of the Study

The overall purpose of this study was to describe the nursing behaviors that "expert" pediatric nurses described as critical to the care of the dying child in the hospital setting. The following research questions were addressed:

1. What are the behaviors that pediatric nurses, deemed "expert" in the care of the dying by their colleagues, describe as having a positive influence on care of the dying child in a pediatric hospital setting?
2. What are the behaviors that pediatric nurses, deemed "expert" in the care of the dying by their colleagues, describe as having a negative influence on the care of the dying child in a pediatric hospital setting?
3. How do the behaviors identified by the pediatric nurses in this study compare with those identified in Degner, Gow and Thompson's (1991) qualitative study of palliative care nurses and nurse educators?

Assumptions Underlying the Study

1. Emotional support and proficient nursing skills are essential components of supportive care (Benoliel, 1985; Martinson *et al.*, 1978; Davies & Eng, 1993).
2. Emotional factors influence the reactions of the dying child, parents and siblings to death, dying and grieving (Freyer, 1992; Gray, 1989; Martinson, 1983, 1979).
3. Sound intellectual, emotional and philosophical skills are required if the pediatric nurse's work with dying children and their families is going to be effective (Coody, 1985; Papadatou, 1989; Petix, 1987; Davies & Eng, 1993).
4. Dying children should be active participants in the dying process (Carlson, Simacek, Henry & Martinson, 1985; Freyer, 1992; Gyulay, 1989).
5. The requirements of nursing practice include basic nursing skills, communication skills, and awareness of psychosocial and spiritual dimensions of dying (Dobratz, 1990; Flood, 1989; Davies & Eng, 1993).
6. Children deserve full disclosure of information about their fatal illness (Bearison, 1991; Freyer, 1992).

(N.B. Definitions of terms that have been used in this study can be found in Appendix A.)

Conclusion

Degner, Gow and Thompson (1991) have reaffirmed nursing's critical need to define the nature of expert practice in the care of the dying. Systematic documentation of the nature of expert practice in the care of dying children as described by pediatric nurses deemed "expert" in the care of dying children, could enhance this developing field of clinical knowledge (Benner, 1984).

The realization that specific behaviors could be employed when caring for a dying child could help to diminish pediatric nurses' feelings of helplessness and inadequacy and could help to guide pediatric nurses in the provision of skilled and compassionate terminal care for dying children and their families. The results of this investigation will contribute toward the development of a model of expert nursing practice in the care of dying children and their families. Knowledge generated would guide nurse educators in the development of education programs regarding the nursing care of dying children and their families.

CHAPTER II

Review of the Literature

Introduction

Following a detailed search of the literature, specific issues were identified concerning dying children and their families: healthy children's developing understanding of death, hospitalized and dying children's understanding of death, hospitalized and dying children's growing awareness of impending death, dying children's patterns of coping, dying children and family relationships, and nursing care of the dying child and family, including hospital, hospice and home care literature. Each of these issues will be critically reviewed.

Healthy Children's Developing Understanding of Death

Two main approaches to children's understanding of death are discussed in the literature. The first considers children's understanding from the perspective of Piaget's (1973, 1965, 1930, 1926) theory of cognitive development. The second, an environmental approach, considers the individual's emotional development and maturation within their distinctive personal circumstance (Florian, 1985; Katsenbaum, 1991, 1967). Children's death attitudes and death anxieties have also been considered, since anxiety and fear have been found to interfere with children's comprehension of death (Rochlin, 1967; Wass & Cason, 1985).

1. Children's Intellectual Understanding of Death

Jean Piaget, the Swiss developmental psychologist, is well-recognized for his comprehensive theory of children's cognitive development (Wass, 1985). Piaget described children's thinking and their conceptions of the world through three major

periods of intellectual development, from birth to approximately fifteen years of age (Piaget, 1973, 1965, 1930, 1926). Each period represents the usual cognitive and developmental characteristics of that life stage (see Appendix B).

The first period begins at birth with sensory and motor actions that become established as behavioral sequences and form the basis for later intellectual development (Piaget, 1973). The second period follows children through the stage of egocentric and animistic thinking to a developing awareness of such concepts as conservation, space and time. The final period, during which the adolescent learns to deal with the abstract, represents the integration and culmination of intellectual development to mature adult levels. Piaget once described death as the greatest mystery for children to understand, but he predicted that children's definitions of life and death would follow his cognitive developmental model, moving in an orderly sequence toward a more mature understanding of the finality of death (Piaget, 1965; Zeligs, 1974).

Piaget's theory and findings have provided the foundation for an abundance of research into the development of children's concept of death. Similar research protocols were applied by investigators with American children (Koocher, 1973; Schilder & Wechsler, 1934; Swain, 1979; Wass *et al.*, 1983), Hungarian children (Nagy, 1948), English children (Anthony, 1940), Canadian children (Weininger, 1979), Swedish children (Wenestam, 1984), and Israeli children (Florian, 1985). In all of these investigations, large numbers of healthy children of various ages were observed at play, and their drawings and stories about death, interviews and/or intelligence tests were analyzed. Results consistently supported Piaget's contention that children's concepts develop in an orderly sequence. Three distinct levels have been found to represent children's developing understanding of the meaning of death: no concept of death, a limited or erroneous concept of death, and a biological and logical understanding of the essentials of death. Researchers have found that although the sequence is the same, the

rate of development may vary. Knowledge of this kind provides a basic background and serves as a frame of reference and general guide about children's concepts of death (Wass, 1985).

2. Environmental Conditions Influencing Children's Understanding of Death

Piaget's model provides a cognitive formula for children's understanding of death. However, it fails to address changing environmental conditions. Although children have many attributes in common, they also have characteristics or circumstances that make them unique. Rose Zeligs, a clinical psychologist, chose to relate children's understanding of death to their physical, mental and emotional development, suggesting that children's understanding advances with age, education, and personal experience with death such that it becomes a part of their total personality (1974). Katsenbaum (1991, 1967) has also emphasized the need to attend to the full complexity of each individual's maturation within their particular environment.

Wass *et al.*'s (1983) study of one hundred and forty one young children's death concepts and two environmental variables (their parents' marital status and socio-economic backgrounds) failed to reveal any relationship between marital status and death concept and demonstrated similarities rather than differences in death concepts of children from various socio-economic backgrounds. Cognitive processes were found to be more influential than environmental factors in Florian's (1985) investigation into the developing concept of death of one hundred and eleven young kibbutzim children aged four to six. Further study with other ages of children was recommended, since environmental influences may be more important when the concept of death reaches a more mature development.

McCown (1988), a pediatric nurse practitioner, incorporated both the cognitive and the environmental approach in her clinical practice with children facing a death in a

family. She explained that children's understanding of and their reaction to death are influenced by their cognitive understanding and their emotional experience with death.

There is a need for further research to validate these initial findings. More sensitive tools may be required to better understand environmental effects on children's developing death concept.

3. Children's Anxieties and Attitudes Toward Death

Early researchers assumed that fear of death was a singular psychological phenomenon characterized by death anxiety. Fear of death and resulting death anxiety were felt to interfere with children's comprehension of death through a variety of defense mechanisms (Rochlin, 1967). Multidimensional measures were only adopted when the psychological approach to death was recognized to be especially complex (Katsenbaum, 1967).

Florian and Har-Ever (1983) adopted a multidimensional approach in their study of the interaction between sex, religion and fear of personal death among two hundred and twenty five Jewish high school students. Significant differences were identified that related to religious upbringing and sex-role socialization. Although this study demonstrates the merits of a multidimensional approach, further research is needed to clarify relationships between personal, emotional and environmental variables and people's feelings toward mortality.

Wass and Cason (1985) reviewed four perspectives of children's feelings, perceptions and behaviors concerning death, including Freud's psychoanalytic view, Piaget's cognitive view, Bandura's social learning view, and humanistic psychology. Although each perspective provided different explanations and interpretations of fear and anxiety about death, and each cited numerous studies supporting their point of view, common sources for death fear and anxiety were identified. Personal experience with

death represents the most direct, immediate and powerful threat to a child and is therefore the most frightening (Wass & Cason, 1985). Cotton and Range (1990) found that fear of death could also interfere with children's development of an accurate understanding of death. Their investigation involved children being asked to complete cognitive function testing, a death questionnaire, a fear of death scale and a hopelessness scale, but conclusions are viewed with caution due to the small number of subjects (n=42) and the limited scope of death concept considered.

Contradictory or inconclusive findings continue to appear in the literature, thus conclusions regarding how various life factors affect death attitudes cannot be made at this time (Franke & Durlak, 1990). Further study is required to learn more about the impact of life factors on the development of death attitudes.

Hospitalized and Dying Children's Understanding of Death

Research with hospitalized and dying children appears to dispute research findings that propose an age-specific relationship between death experience and an accurate death concept (Bluebond-Langner, 1978; Schilder & Wechsler, 1934; Waechter, 1985, 1971). Schilder and Wechsler's (1934) study was the one of the first to consider hospitalized children's understanding of death. They found that even young children could accept the possibility of their own death and did not appear to demonstrate concern about it. Richmond and Waisman (1955) concurred, reporting that children reacted to illness with an air of passive resignation and acceptance, rarely manifesting overt concern about death.

Natterson and Knudson (1960) disagreed with the above conclusions, suggesting that these previous studies misinterpreted the subtle behaviors of hospitalized children. In their investigation, they found that children under six exhibited extreme reactions to separation from their mother. Children between six and ten were especially fearful of

physical injury and/or mutilation, demonstrating their most intense reactions to treatments and procedures. Older children reacted most strongly to the death of another child. They concluded that behavior changes resulted from separation fear, mutilation fear or death fear, depending on the age of the child.

Waechter's (1971) study of sixty four hospitalized children found that not only were dying children aware that they were dying, they were also able to express their awareness using words related to death. Dying children scored higher on the anxiety scale, told substantially more stories related to threat to body integrity, and discussed loneliness, separation and death much more frequently in their fantasy stories. Zeligs, a child psychologist, also noted that dying children could also express their awareness of impending death in non-verbal ways (1974). Spinetta's (1974) review of the literature identified a lack of objective data regarding what hospitalized and dying children actually know about their illness, and their psychological reactions to it. This shortcoming was soon addressed by Myra Bluebond-Langner (1978).

Bluebond-Langner's (1978) landmark study of children with terminal cancer viewed life and death through the eyes of dying children. She considered dying as a biological, social and cultural phenomenon in order to better understand how terminally ill children became aware of the fact that they were dying.

Dying Children's Growing Awareness of Impending Death

Bluebond-Langner (1978) found that children faced death with a great deal of understanding regardless of age. She detected a socialization process through which hospitalized children acquired information about the hospital, their disease, their treatment and prognosis, other children with cancer, their parents and themselves (see Figure 1). Hospitalized and dying children adopt new social rules and roles in order to maintain relations with those around them.

Figure 1. Dying Children's Stages of Acquisition of Information

(Bluebond-Langner, 1978)

<u>Diagnosis....</u>	<u>==> 1</u>	<u>==> 2</u>	<u>==> 3</u>	<u>==> 4</u>	<u>==> 5</u>
	" <u>I</u> " is a serious illness.	Names of drugs and side-effects.	Purposes of treatments and procedures.	Disease as a series of relapses and remissions. (- death)	Disease as a series of relapses and remissions. (+ death)

Children acquire information in an orderly manner. Information in any one stage is necessary for interpreting information in the next stage. Certain experiences are also a prerequisite to passing on to the next stage. By the fourth stage, children are able to view treatments, procedures and symptoms from a grander perspective, but it is not until the fifth stage that children learn that the cycle ends in death (Bluebond-Langner, 1978).

Dying children experience a sequence of changes in self-concept as they pass through the five stages of information acquisition (see Figure 2). The role of experience in this self-concept model provides a plausible explanation for why age and intellectual ability do not appear to be related to the speed or completeness with which children pass through stages.

Figure 2. Dying Children's Changing Self-Concept

(Bluebond-Langner, 1978)

<u>Diagnosis....</u>	<u>==> 1</u>	<u>==> 2</u>	<u>==> 3</u>	<u>==> 4</u>	<u>==> 5</u>
Well.	Seriously ill.	Seriously ill, but will get better.	Always ill, but will get better.	Always ill, and will never get better.	Dying. (<i>Terminally ill.</i>)

Bluebond-Langner's research supported the developing opinion that children sense what is happening to them and come to recognize and understand dying (Gartner, 1976; Green-Epner, 1976). Kübler-Ross's (1983) narratives of her experiences with dying children support the opinion that children are aware of impending death and are able to communicate this inner knowledge through symbolic language. Her first story told of a small child whose grandmother was constantly at her bedside, attending to her every need. Initially, the child was full of questions but as time went on the questions became few. On the day of her death, the child simply asked if her Granny would "visit her soon." In another example, Kübler-Ross (1983) recounted a poem written by a sixteen year old girl on the day of her death. The poem expressed the girl's concern that her mother be assured of her love even though she must leave her. The girl went on to describe her life's end as "a cry, a scream.....a jump before a fall." Hours later, she died following a tragic fall from a horse.

Children as young as two years of age have been reported to say "good-bye" rather than "good night" when their death is imminent (Kübler-Ross, 1983). By four years of age, children have been known to communicate their concerns about their diagnosis, the severity of their illness, and their awareness of their impending death verbally and/or through their behavior (Bearison, 1991; Bluebond-Langner, 1978; Gray, 1989; Graham-Pole *et al.*, 1989; Hockenberry-Eaton & Minick, 1994; Waechter, 1985).

Dying Children's Patterns of Coping

Zeligs (1974) recognized the importance of learning and understanding how dying children think and feel about death and dying. Terminally ill children's patterns of coping are influenced by their personal encounters with death and how those around them are seen to cope (Wass & Cason, 1985). Even though most children are aware that they are dying, their environment may not invite an open sharing of this knowledge

(Bluebond-Langner, 1978; Hockenberry-Eaton & Minick, 1994; Waechter, 1985). If one considers the dying child's locus of control, in most instances parents and caregivers represent absolute authority over the child's life. If parents and caregivers fail to communicate their awareness of a child's imminent death, the child may not feel welcome to express personal thoughts and feelings, even though they are aware of the illness and undesirable changes in their daily lives (Hockenberry-Eaton & Minick, 1994). The resulting silence may lead to denial, rejection and feelings of isolation (Carpenter, 1992; Hockenberry-Eaton & Minick, 1994).

Preschoolers rarely ask "why." Instead, they tend to assign causation to some aspect of their own behavior. They believe that the illness and hospitalization are a punishment for bad behavior. Their convictions support their feelings of blame, guilt and withdrawal. Death represents the final punishment (Waechter, 1985). School-aged children are better able to communicate their awareness and concern about the future and may demonstrate assertive or manipulative behavior in an effort to exert control over their situation (Waechter, 1985). Adolescents may demonstrate increasing vulnerability as they come to realize the loss of their envisioned future. Instead, they face the cumulative loss of life's goals, their independence and their bodily integrity (Adams & Deveau, 1986). Feelings of uncertainty, sadness, anger, confusion, fear, frustration and depression can compound feelings of loneliness and isolation from family members, separation from their peer group, and may result in further withdrawal from both peers and loved ones (Hockenberry-Eaton & Minick, 1994; Waechter, 1985).

Dying Children and Family Relationships

A child's death and dying represents one of the potentially most stressful and poignant experiences that a family can encounter (Ross-Alaolmolki, 1985; Siever, 1994; Yoder, 1994). Each family member can be affected and changes in family functioning

can be long lasting (Thoma *et al.*, 1993). Some of the changes are developmental in nature, requiring adjustment of relationships between family members. Others, which can be directly attributed to the terminal illness and death of the child, reflect changes in family perceptions and their responses to these changes (Martinson *et al.*, 1994).

Therefore, analysis of family relationships requires consideration from the perspective of each family member, including parents and healthy siblings.

A family's ability to mobilize and maintain their resources in response to repeated stressful life events will determine the family's survival and growth during treatment and life-threatening childhood illness (Thoma *et al.*, 1993). The following discussion will consider parental adjustment to the dying child, and the response of healthy siblings to living with a dying child.

1. Parental Adjustment To A Dying Child

Friedman *et al.* (1963) sought to understand parental stress and suffering in response to childhood cancer and impending death through observations and clinical impressions gathered over a two year period. Parents were found to face similar problems inherent in their situation and their adjustment tended to occur in a predictably characteristic manner. Three distinct phases of parental response to impending childhood death were identified. Early emotional responses included guilt, blame and a need for information as parents searched for meaning. As parents mastered their emotions, they developed strategies to meet the psychological needs of their child. Defense patterns and coping mechanisms were employed to assimilate and deal with their new reality. Near the time of death, grief work accelerated as hope diminished and emotional expression became more frequent. Grief reactions at the time of death were seen as a step toward final closure. Parents in this study viewed death as an anticipated loss at the end of a long sequence of events.

Observations by Futterman, Hoffman and Sabshin (1972) led to their conceptualization of anticipatory mourning as a series of functionally related processes. Parents of twenty three children were regularly interviewed over the course of their child's illness. Content analysis revealed a series of adaptive processes that parents experienced when coping with their child's fatal illness. First was the cognitive action of acknowledging the impending death. Then parents dealt with the emotional impact of grieving and the psychic process of reconciliation. Finally, parents faced the psychological process of detachment, developing a mental representation or memorialization of their child. These findings support the earlier findings of Friedman *et al.* (1963).

One striking finding in Waechter's (1971) study of dying children's awareness of impending death was the dichotomy between the child's degree of awareness and the parent's belief about their child's awareness. Parents failed to perceive their child's knowing and rarely offered their child an opportunity to discuss fears about prognosis and impending death. This was especially true when the illness ran a rapid course. Such denial or protectiveness on the part of the parents did not shelter the child or prevent their child from experiencing death anxiety. Nor did it protect the parents. Ross-Alaolmolki's (1985) literature review supported these early findings of Waechter (1971). She found that parents attempted to regulate and monitor their emotions by modifying their behavior according to their experience with the life situation confronting them. Ross-Alaolmolki (1985) concluded that such attempts rarely conceal the parents' pain and anguish and seldom shield others from feelings of pain and loss.

Birenbaum and Robinson's (1991) literature review detected conflicting reports about family relationships during a child's terminal illness. Some authors recounted closer marital relationships, new adaptive capacities, improved family cohesiveness, and better family coping. Others reported increased family dysfunction and diminished

family effectiveness, noting multiple problems affecting the family's normal functioning and closeness. Birenbaum and Robinson's (1991) investigation of parents' perceptions followed family relationships through the child's terminal illness and the first year following death. This longitudinal study concluded that the perceptions of dying children's parents differed from those of normal families. However, family cohesion and expression only rated higher following the child's death, not before, suggesting that the grief reaction after the death was a necessary developmental crisis that preceded the emotional growth of bereaved family members.

2. Sibling Responses To A Dying Child

Coleman and Coleman (1985) employed a systems theory framework to develop a series of vignettes that reflected the complex world of siblings of dying children.

Vignettes were based upon experiences drawn from their clinical practice. Sibling difficulties arose from a number of factors: the sibling's definition of the sick role, dying and death, the sibling's internal world (including feelings of responsibility, guilt, anger and anxiety), the need for clarification of changing family roles and communication, the sibling's role in treatment, the type of illness (chronic/acute, disease/trauma), and the reactions of peers other than siblings. The authors noted that particular children and families could present with different etiologies requiring different interventions.

Bendor's (1989) literature review concluded that healthy children have difficulty coping with a sibling's illness and death. Serious behavioral problems, including guilt reactions, may be influenced by the healthy child's stage of development and the family's response/adaptation. Crucial factors that influence healthy children's responses to sibling death include age, sex and attributes of the dying child, sibling involvement in the death, the pre-existing relationship with the dying child, parent and community reactions, the impact of the death on the family structure, and concurrent stressors (Bendor, 1989).

Bluebond-Langner (1989) studied the impact of illness and death on the lives of healthy children and their dying siblings. She found that these children lived in homes of chronic sorrow, surrounded by signs of anguish, illness and death, whether spoken of or not. Although they wanted to know the truth, many found it too painful to hear it from their parents. Nevertheless, siblings acquired information in a manner similar to dying children.

Well siblings experienced changes in both status and their role in the family, had difficulty receiving care and attention, and missed the support and nurturing they once knew. Well siblings often felt alone, neglected, and confused by their parents' shifting emotions. They seldom chose to express their feelings to their parents because they did not wish to upset them. Instead, they attempted to protect their parents from further distress (Faulkner, Peace & O'Keeffe, 1993; Martinson *et al.*, 1990). Two of the most common ways that well children expressed their feelings were through sleep disorders and acting out. Children experienced emotional reactions in response to diagnosis and hospitalization, prognosis and mortality, ongoing effects of the disease, their understanding of cancer, and their hopes and desires for the future (Martinson *et al.*, 1990).

The loss of a child requires individual reorganization and adjustments within the entire family system (Dufour, 1989; Martinson *et al.*, 1994). Regardless of how it is approached, a child's death is perceived as a significant event, a reference point to which all subsequent events can be related (Martinson *et al.*, 1994).

Nursing Care of the Dying Child and Family

A significant body of palliative care literature has investigated the desirability of home care for the dying. Recognizing the importance of family relationships surrounding the dying child and the impact of a child's death on the family, home care and hospice

literature were included in the literature review to ensure that all aspects of child and family care were considered.

The family-centered focus of pediatric nursing, in general, and pediatric terminal care, in particular, have proven particularly successful in the home environment (Carlson, Simacek, Henry & Martinson, 1985; Connolly, 1994; Dufour, 1989; Levy *et al.*, 1990; Martinson *et al.*, 1994, 1985, 1983, 1979, 1978). Ongoing evaluation of Martinson *et al.*'s (1978) home care model of care for dying children has shown that home care allows families to experience their sorrow fully, and their participation in their child's care can dispel feelings of total helplessness. Dufour's (1989) investigation stressed the need for open communication to reassure families regarding their feelings and to help them develop an appropriate balance between hope and anticipatory grief. A successful home care program requires that nurses be available whenever requested to provide direct nursing care and emotional support to child and family (Dufour, 1989; Duffy *et al.*, 1990; Martinson *et al.*, 1986).

Birenbaum and Robinson's (1991) investigation did not fully support the above findings. Their study found that home care did not necessarily result in a more positive long-term outcome for families. They identified the need to consider each family's unique needs and recommended evaluating the care needs of the dying child and family before undertaking any decisions regarding home care. Duffy *et al.*'s (1990) evaluation of a home care program found that parent satisfaction was closely related to their ability to control their child's symptoms and the availability of supportive health care resources.

Recent hospice literature has also explored the needs of the dying child and family (Corr & Corr, 1985; Dominica, 1987; Duffy *et al.*, 1990; Lauer *et al.*, 1986; Levy *et al.*, 1990). Since the philosophy of hospice care encompasses the family as the unit of care, it can be readily adapted to situations involving dying children, grieving children and grieving adults in the hospital or at home (Dominica, 1987).

Specific Nursing Behaviors in the Care of Dying Children and their Families

Research-based death and dying literature was reviewed to ascertain and describe nursing care measures that were deemed important in the care of the dying, in general, and dying children, in particular. Whether or not the child was dying at home, the needs of dying children and their families were found to be the same.

Following the technique described by Degner, Gow and Thompson (1991) and McClement (1993), specific nursing behaviors that were identified in the literature were written onto cue cards. Then, for purposes of analysis, cards describing similar nursing behaviors were clustered and cataloged.

Seven major categories of nursing behaviors were identified. The following seven descriptions depict the categories of behaviors that were deemed relevant to the care of the dying child and family: providing comfort care, responding to patients' feelings, acknowledging nurses' feelings, supporting colleagues, acknowledging patients' rights, and providing family care (see Appendix C). The remainder of the chapter will provide a critical analysis of each category.

1. Comfort Care

Comfort care behaviors included such aspects of care as symptom management, pain control, and those basic and technical nursing care measures that attend to routine bodily requirements (Benoliel, 1972; Brockopp, 1987; Corless, 1994; Davies & O'Berle, 1990; Dawson, 1991; Heslin & Bramwell, 1989; O'Berle & Davies, 1992; Kristjanson, 1989).

The pediatric literature expands the concept of comfort to include the psychological, developmental and emotional needs of the dying child. These additional behaviors include the provision of compassion, love and reassurance beyond physical needs (Adams, 1985; Bluebond-Langner, 1978; Martinson, 1983; Flood, 1989). Age-

appropriate interventions include recognition of parents as essential in identifying and providing for their child's comfort, distraction strategies, and coaching children through difficult situations (Cahill *et al.*, 1990; Corless, 1994; Hockenberry-Eaton & Benner, 1990; Siever, 1994).

2. Patient Feelings

This category reflects a nurse's ability to talk with patients about dying and the supportive relationship that results. Open and honest communication requires ongoing assessment of patient needs, including information needs and the provision of time for talking and listening (Dobratz, 1990; Kristjanson, 1989; O'Berle & Davies, 1992; Reimer *et al.*, 1991; Reissetter & Thomas, 1986; Ryan, 1992).

Pediatric authors expanded the discussion of communication skills to include assessment of the child's locus of control (Carpenter, 1992), recognition of the need for age-appropriate communication (Coody, 1985; Flood, 1989; Hockenberry-Eaton & Minick, 1994; Kuykendall, 1989; Waechter, 1985), and consideration of the child's need to integrate thoughts and feelings and to express self-awareness and understanding through play (Cahill *et al.*, 1990; Gray, 1989; Green-Epner, 1976; Kuykendall, 1989).

Nurses work to develop a helping/trusting relationship with their dying patients, providing emotional support as dying patients confront their burden of suffering (Benoliel, 1972; Brockopp, 1987; Friedman & Huls, 1991; Heslin & Bramwell, 1989; Kincade & Powers, 1984; Kristjanson, 1989; Ryan, 1992; Reimer *et al.*, 1991). Papadatou (1989), Davies and Eng (1993) describe a deeper relationship that develops when the dying patient is a child or adolescent, that demonstrates the nurse's willingness to meaningfully share in the remainder of the child's life and their death.

3. Nurses Feelings

Nurses must come to terms with their own thoughts and feelings about death and dying. Self exploration, including one's own feelings about life, illness, dying, death and bereavement, can improve a nurse's ability to provide insight, sensitivity and openness while providing comfort, support and care (Benoliel, 1985; Conrad, 1985; Hare & Pratt, 1989; Petix, 1987).

In the pediatric literature, nurses are encouraged to come to terms with their thoughts and feelings about childhood death (Davies & Eng, 1993; Siever, 1994). Assessment of one's emotional abilities and limitations can enable the nurse to identify areas in which their ability to provide care may be affected (Adams, 1985; Coody, 1985; Davies & Eng, 1993; Flood, 1985; Petix, 1987). This category reflects the need to acknowledge one's stresses and difficulties related to exposure to the dying (Benoliel, 1988, 1985; Conrad, 1985; Hare & Pratt, 1989).

4. Supporting Colleagues

Providing emotional support to colleagues requires that nurses acknowledge that exposure to death and dying is stressful (Benoliel, 1988, 1985). Colleagues require regular and systematic support, including recognition of the difficulties and stresses they face in caring for the dying (Benoliel, 1988).

Pediatric authors expand the description of supporting colleagues to include the need for a good external support network (Flood, 1989; Vachon & Pakes, 1985), acknowledgment of the conflicting expectations between acute and palliative care (Adams, 1985; Davies & Eng, 1993), and recognition of the need to find relief and solace away from the strain of caring for the dying child (Adams, 1985).

5. Patient Rights

Patient Rights require respect for the patient as an individual, including the right to self-determination (Davies & O'Berle, 1990), the need for advocacy (Kincade & Powers, 1984), the right to be fully informed (High, 1989) and respect for confidentiality (High, 1989). Pediatric authors have expanded this category to include: maintenance of dignity and self worth (Adams, 1985; Martinson, 1983), respect for the child as a willful, purposeful individual (Bluebond-Langner, 1978; Hockenberry-Eaton & Minick, 1994), understanding of the child's desire to live (deHennezel, 1989; Hockenberry-Eaton & Minick, 1994), and giving the child permission to die (Gray, 1989). In addition, the child's right to be informed, to be able to communicate, and to share in decisions were acknowledged (Adams, 1985; Adams & Deveau, 1986; Bearison, 1991; Gray, 1989; Hockenberry-Eaton & Minick, 1994; Kuykendall, 1989).

Freyer (1992) debated the unique ethical issues of life and death decision-making that arise when the patient is a child. Dying children lack a legal claim to personal competence and autonomy even though they may have acquired substantial personal experience and practical meaning through the course of a terminal illness. Treatment decisions require consideration of the child's well-being and the parents' wishes. Dialogue between clinicians, children, and parents can facilitate decisions in the child's best interests (Freyer, 1992). The American Academy of Pediatrics has since published guidelines on forgoing life-sustaining medical treatment when caring for children (1994) and a pediatric patient self-determination act has been developed (Sahler & Greenlaw, 1992).

6. Family Care

The Family Care category reflects the family's need for care and support while adjusting to the death and dying of a loved one (Davies, Chekryn Reimer & Martens,

1994; Corless, 1994). Family participation is encouraged, as is preparing the family for the death event (Benoliel, 1983; Chekryn, 1985; Reimer *et al.*, 1991).

A growing body of pediatric literature is devoted to families as they come to acknowledge their child's dying during the terminal period, at the moment of death and during the period of bereavement. Essential caring behaviors include: establishing effective relationships with families (Martinson, 1983, 1979; Thoma *et al.*, 1993), providing education and guidance (Gyulay, 1989; Neidig and Dalgas-Pelish, 1991; Whyte, 1992), supporting parental adjustment and decision-making (Adams, 1985; Dufour, 1989; Gyulay, 1989; Martinson, 1979), facilitating access and supporting parents' need to care for their child (Adams & Deveau, 1985; Gyulay, 1989; Neidig & Dalgas-Pelish, 1991), and supporting them through their grief experience (Neidig & Dalgas-Pelish, 1991; Whyte, 1992; Yoder, 1994).

Pediatric nurses must also recognize siblings' need for age-appropriate, factual information and emotional support (Adams & Deveau, 1987, 1986; Bendor, 1989; Bluebond-Langner *et al.*, 1989; Graham-Pole *et al.*, 1989; Kuykendall, 1989; Martinson *et al.*, 1990), and their need to be involved (Coleman & Coleman, 1985; Graham-Pole *et al.*, 1989; Yoder, 1994).

7. Manipulation of Environment

The preceding categories has been previously described by Degner, Gow and Thompson (1991). This last category was first described by McClement (1993) in her review of adult critical care literature. Manipulation of Environment was also found in the pediatric literature. Environmental factors that are important to dying children include the provision of: safe, familiar surroundings (Bluebond-Langner, 1978; Martinson, 1983), a warm, loving environment (Adams, 1985; Hockenberry-Eaton & Minick, 1994), an environment that encourages play (Adams, 1985; Green-Epner, 1976),

a climate conducive to open and honest communication (Bearison, 1991), and a nurturing environment that treats them as normal, yet allows them to feel special and loved (Gyulay, 1989; Hockenberry-Eaton, 1994).

Conclusion

Nursing's growing body of pediatric death and dying literature has begun to identify central issues that encompass the death of a child and the impact of a child's death and dying upon the family. Researchers have identified the need to learn how children comprehend death and dying, and those environmental factors that can influence their understanding. Death anxiety and death attitudes have also been found to influence children's comprehension of death.

Dying children and their siblings have been found to comprehend information about death and dying in a sequential manner, regardless of age. Personal experience and socialization in a death and dying environment can influence their death concepts and their patterns of coping -- changes in family functioning can be profound and long-lasting. Researchers have recognized the importance of family-centered care in pediatric palliative care.

Nursing behaviors that were deemed important in the care of the dying, in general, and the care of the dying child and family, in particular, have been catalogued. Appendix C represents a comprehensive list of recommended nursing actions when caring for the dying adult, child and family. Although each pediatric nursing behavior was readily placed within previously described adult categories, many offered a unique pediatric perspective that has not been previously described in adult palliative care (Degner, Gow & Thompson, 1991) or in adult intensive care (McClement, 1993). This method of classification proved to be beneficial since no one author has described them all.

This literature review reflects the current state of knowledge regarding nursing care of dying children and their families. Degner, Gow and Thompson (1991), and Davies and Eng (1993) have identified a significant gap with regard to specific knowledge, skills and behaviors that are essential when caring for dying children and their families. Further research is required. This can be accomplished through systematic investigation of the experiences of nurses who are actively engaged in such care.

CHAPTER III

Conceptual Framework

Introduction

The conceptual framework has been adapted from the work of Degner, Gow and Thompson (1991) and McClement (1993).

Two theoretical orientations have been applied:

1. Quint's (1967) Model of Nursing Care of the Dying, and
2. Benner's (1984) adaptation of the Dreyfus Model of Skill Acquisition.

Theoretical Perspectives

Quint's (1967) landmark study of how nurses learn to care for the dying resulted in recommendations for significant changes in nursing education. She maintained that nurses exposed to the care of the dying without accompanying educational support would adopt the behaviors they observed in professionals around them and would limit their involvement in death-related situations. She suggested that if nurses were to receive systematic death education with planned clinical assignments, they would be less likely to withdraw from care of the dying. This research based model provided the theoretical orientation for Degner and Gow's (1988) longitudinal evaluation of death education in nursing. Degner and Gow's findings supported those proposed by Quint more than twenty years ago and upheld a their revised theoretical model of nursing care of the dying.

Degner and Gow's (1988) revised model proposes that education and exposure to care of the dying could diminish death anxiety and foster positive attitudes toward care of the dying with resultant increased approach behaviors in the care of the dying. This revised theoretical model recognizes the need for research-based knowledge to guide

nursing practice. Further development and investigation of a model of expert nursing practice in the care of the dying requires research-based descriptions of critical nursing behaviors in the care of the dying (Degner & Gow, 1988). Studies undertaken by Degner, Gow and Thompson (1991), and McClement (1993), reported critical nursing behaviors in the palliative care setting and in the Intensive Care setting. This investigation focused specifically upon descriptions of critical nursing behaviors in the pediatric setting.

The Dreyfus Model of Skill Acquisition posits that in the acquisition and development of a skill, a student passes through five levels of proficiency, from novice to expert (Benner, 1984). Benner has applied this model to the discipline of nursing in order to identify nursing experts and to uncover common meanings acquired in the art and science of nursing. This investigation applied Benner's model to discover the knowledge embedded in the practice of nurses deemed "expert" in the care of dying children through recording and description of critical incidents. Descriptions of behaviorally based, care-related variables will contribute to the body of research-based knowledge in the care of dying children and their families that can then be tested using Quint's revised theoretical perspective.

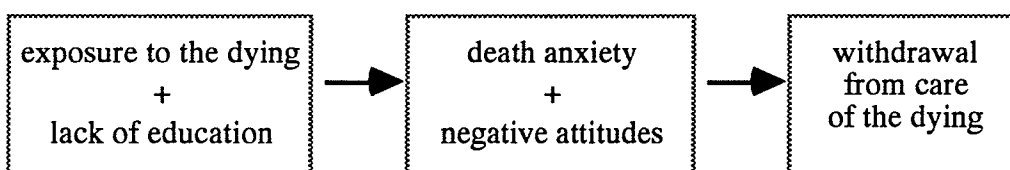
1. Quint's Perspective

Quint used the theoretical sociological model of symbolic interactionism to describe and understand, in general terms, the actions of human groups (Spencer, 1985). Symbolic interactionism supposes that social relationships are built up through social interactions on a symbolic level. The model's subjective approach to the understanding human conduct is based upon an understanding that far from responding automatically to events, people have to interpret those events, define the situations facing them, and anticipate the outcomes of various possible responses (Spencer, 1985, 18).

This approach to social life is mediated by the interpretation that individuals place on events. To understand what people are doing requires an understanding of the meaning that they bring to a situation, and the meaning of the event within the context that surrounds it (Spencer, 1985, p. 142). Symbolic interaction stresses the importance of communication through language and gestures so that persons participating in a social situation can share their experiences and develop common meanings. People strive to fit their actions together.

Quint (1967) claimed that nurses would adopt behaviors they observed in other health professionals, and maintained that nurses who were exposed to care of the dying without accompanying educational support would limit their involvement in death-related situations (see Figure 3). Quint (1967) postulated that if nurses were to receive systematic death education with planned assignments, they would be less likely to withdraw from care of the dying.

Figure 3. Quint's Theoretical Model

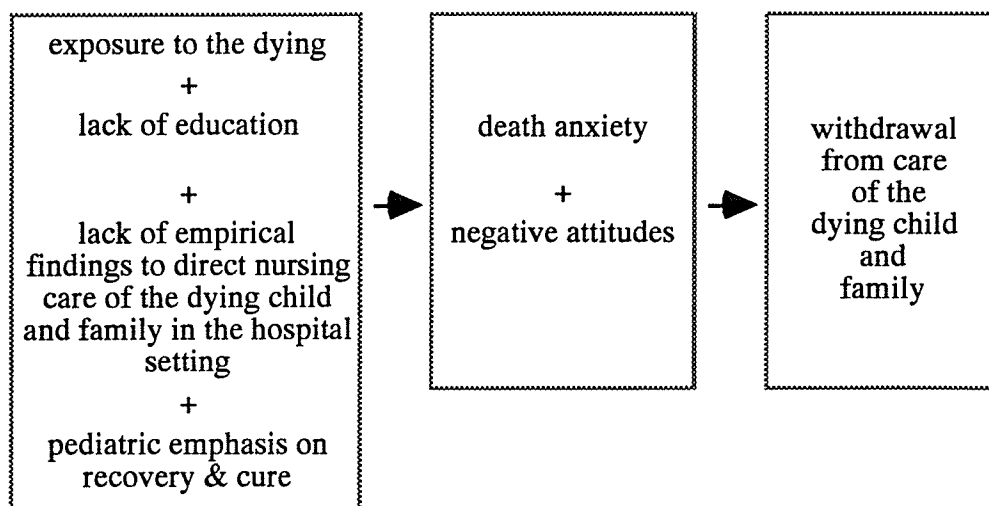


Although Quint's orientation has not been systematically tested (Degner & Gow, 1988), empirical reports appear to support her perspective (Degner & Gow, 1988; Milton, 1984; Pearlman, Stotsky, & Dominick, 1974; Shusterman & Sechrest, 1973). Pearlman, Stotsky and Dominick (1974) reported that less experienced nurses demonstrated a more open and direct approach in caring for the dying than did their more experienced

colleagues. Shusterman and Sechrest (1973) found that more experienced nurses tended to be more satisfied with traditional means of managing the dying, including isolating the dying from other patients and not informing them of their prognosis. Degner and Gow (1988) detected an initial decrease in death anxiety and more positive attitudes toward the dying among nurses who had received death education. Analysis of one year posttest results revealed that the experimental group continued to feel more adequate in caring for the dying.

Applications of the Quint Model were not found in the pediatric death and dying literature but most authors acknowledged Quint's contributions toward nursing care of the dying. Based on the review of the literature and previous work by Quint (1967), Degner and Gow (1988), Quint's original model has been adapted by the author to reflect the additional factors that could be considered problematic in the care of dying children and their families (see Figure 4). This adaptation of Quint's model reflects the lack of empirical findings to direct the nursing care of dying children and their families in the hospital setting.

Figure 4. Adaptation of Quint's Theoretical Model to Pediatric Nursing



2. Benner's Adaptation of The Dreyfus Model of Skill Acquisition

Benner (1984) adapted a model of skill acquisition that was developed by professors Stuart Dreyfus (a mathematician and systems analyst) and Hubert Dreyfus (a philosopher), based upon their study of chess players and airline pilots. The model proposes that students pass through five levels of proficiency in the acquisition of a skill. These levels are novice, advanced beginner, competent, proficient, and expert (Benner, 1984). The different levels reflect changes in three general aspects of skilled performance. The first is a movement from abstract concepts to concrete experiences as paradigms. The second is a change in perceptions toward a more complete whole, with recognition that only certain parts may be relevant. The third level represents a passage from *detached* observer to *involved* performer, reflecting an ability to engage *in* the situation (see Figure 5).

Figure 5. Benner's Adaptation of the Dreyfus Model to Nursing Practice

<u>Stage 1</u>	<u>Stage 2</u>	<u>Stage 3</u>	<u>Stage 4</u>	<u>Stage 5</u>
Novice	Advanced Beginner →	Competent →	Proficient →	Expert
reliance on abstract principles	use of past concrete experience; situations compiled from relevant bits of information	situations considered a complete whole with many relevant parts	detached observer	involved performer

The Dreyfus Model is a model of skill acquisition rather than a trait or talent model. Performance, or skill level, is determined through general agreement of experts and through ongoing assessment of situational outcomes. Reliability is determined by inter-rater agreement between experts and by repeated assessments (Benner, 1984, p. 293).

Benner's adaptation assumes that with experience and mastery, nursing skill is transformed, bringing about improvement in performance. Expert nurses perceive situations as a whole, employ past situations as paradigms, and promptly and accurately focus on the region of a problem (Benner, 1984, p. 3). This expertise reflects the clinician's ability to test and refine hypotheses and interpret actual practice situations. Experience results when preconceived notions are challenged and refined by actual situations (Benner, 1984). These aspects of clinical "know-how" can be captured through descriptions of intentions, expectations, meanings and outcomes of expert nursing practice. The profession of nursing would benefit from descriptions of excellence from expert nurse clinicians.

When expert nurses described clinical situations in which their interventions had made a difference, Benner (1984) was able to uncover portions of the knowledge embedded in their practice. Systematic documentation of such expert clinical performance represents a first step in clinical knowledge development. The documentation of areas of clinical knowledge broadens the scope of practice of nurses who wish to and are capable of achieving excellence, and provides opportunities for further investigation (Benner, 1984).

Benner (1984) described the practical experiences of expert nurses. Degner, Gow, and Thompson (1991) employed Benner's techniques to define the nature of expert practice in the care of the dying through interviews with a experienced nurse educators and palliative care nurses. McClement (1993) addressed critical nursing behaviors in the care of the dying adult in the Intensive Care setting from the perspective of expert

Intensive Care nurses. An alternative approach was employed when Davies and O'Berle (1990) interviewed one nurse "expert" in the care of the dying a number of times.

Detailed descriptions of supportive care behaviors from the perspective of this nursing expert led to the development of a model of supportive care.

Application of Theoretical Perspectives

Benner (1984) estimated that proficient performance could usually be found in nurses who had worked with similar patient populations for approximately three to five years. She selected nurses with at least five years of clinical experience currently engaged in direct patient care who were recognized as being highly skilled clinicians (p. 15).

Benner suggested that expert clinicians would not be difficult to identify. The expert nurse is an individual with considerable experience who can intuitively grasp a situation and accurately focus on a problem without wasteful consideration of ineffective alternatives.

Benner's criteria were put to use to identify "pediatric nursing experts" in this investigation (see Appendix F). Vignettes were developed that provided the context of a situation, a description of particular nursing behaviors, and personal attributes of nursing experts in the care of dying children and their families (see Appendix G). The vignettes enabled their colleagues to identify the pediatric nursing experts with whom they worked. All participants in this study were recognized by their peers to be "expert" in care of dying children and their families in the hospital setting.

This study was undertaken to identify nursing behaviors that expert pediatric nurses deemed as critical in the care of dying children and their families in the hospital setting. Benner's adaptation of the Dreyfus Model (1984) has provided the means to examine the knowledge imbedded in the practice of "expert" pediatric nurses who care

for dying children and their families. Interviews with these expert nurses provided systematic descriptions of what these nurses have learned from their clinical experience.

Quint's (1967) research suggested that if nurses were to receive systematic death education with planned assignments, they would be less likely to withdraw from care of the dying. Research-based descriptions of nursing practice in the care of the dying, such as those reported in this investigation, will advance the systematic testing that Quint's Model requires, and will contribute towards the research-based body of knowledge that should direct nursing education in the care of dying children and their families.

CHAPTER IV

Methodology

Research Design

Part of developing the knowledge base for any science is the detailed description and classification of relevant phenomena (Brink & Wood, 1989). Since literature addressing nursing behaviors that are critical in the care of dying children is limited, there is a need to discover, or enrich existing knowledge.

A descriptive design was selected to answer the questions posed by this study. This factor-naming, or factor-searching research aimed to describe, name and further characterize those nursing behaviors that expert pediatric nurses deemed critical, or essential, in the care of the dying child (Wilson, 1987). Since the main objective was the accurate portrayal of the characteristics of persons, situations and groups, the descriptive design offered the best opportunity to answer the level of questions posed in this investigation (Polit & Hungler, 1991).

Population, Sample and Sample Selection

The population consisted of pediatric nurses identified by their colleagues as experts in the care of dying children who had worked in the pediatric setting for at least five years. The finite population is unknown.

Purposive sampling is appropriate when the researcher wants a panel of experts (Polit & Hungler, 1991). Accordingly, purposive sampling was selected because the intent of the study was to identify those behaviors that expert nurses described as critical in the care of dying children. The sample was deliberately drawn from a population of pediatric nurses at a tertiary care facility who were deemed expert by their colleagues. This deliberate sampling provided data from the desired perspective, according to the needs of

the study (Benner, 1984; Morse, 1989). Previous research has shown a sample size of ten subjects per contrasting group to be adequate when conducting qualitative studies, since data usually become redundant and new categories of behavior are not discovered by collecting data from additional subjects (Munhall & Oiler, 1986).

Identification of Pediatric Nursing Experts

The method employed to identify nurse experts was adapted from Benner's (1984) work (see Appendix F). A one page sociometric tool, the Educational Influential Instrument, was then developed to assist pediatric nurses in the identification of those nursing colleagues whom they considered to be expert in care of dying children in the hospital setting (see Appendix G). This tool consisted of three one-paragraph vignettes which described the key attributes of a peer with expertise in terminal care in the pediatric setting. These attributes were drawn from Benner's (1984) descriptions of expert nursing practice, from the descriptions of optimal nursing care behaviors that have been described in the death and dying literature (see Appendix C), and from vignettes developed by McClement (1993).

Data Collection Methods

Benner's (1984) original guidelines for the recording of critical incidents included descriptions of both positive and negative situations as experienced by respondents. Degner, Gow and Thompson (1991) adapted Benner's guidelines to include descriptions of observed behaviors that nurse educators and palliative care nurses associated with both positive and negative attitudes in the care of the dying. Their investigation identified seven categories of nursing behaviors. Degner, Gow and Thompson's (1991) interviewing technique was adapted to reflect the selected focus of this investigation -- the dying child and family. McClement's (1993) semi-structured interview guide was adapted to extract

descriptions of pediatric nursing experts regarding behaviors they associated with positive and negative attitudes in care of dying children (see Appendix I).

Benner (1984) first described the ability of experienced nurses to readily bring to mind clinical situations that have altered their approach to patient care. Systematic recording and investigation of such paradigm cases provided an opportunity to extend the knowledge embedded there (p. 10). Accordingly, expert pediatric nurse were asked to describe the most recent incident they could remember in which a student or a colleague demonstrated a positive attitude in caring for a dying child and family: Was it something the student or colleague said or did? What were the consequences of the identified behaviors? Why did this incident stand out in their memory? What lesson was learned? This same approach was repeated a second time, but participants were asked to describe an incident in which a student or colleague displayed a negative attitude in the care of the dying child and family. Participants were also encouraged to identify any behaviors that were vivid to them, or that did not fit within the described typology. The deliberate seeking out of atypical experiences sought to ensure that data was not distorted (Polit & Hungler, 1989). This method of gathering information allowed the examination of nursing care behaviors in the care of dying children and their families in order to understand why and under what circumstances nurses act the way they do.

Participants completed a Structured Data Collection Tool that was adapted from the work of Benner (1984) and McClement (1993; see Appendix J). At the beginning of each interview, participants were invited to expand upon this general biographical data that included age, level of education completed, and years of work experience. This descriptive information facilitated the investigator's portrayal of the sample of nursing expert in this investigation.

Procedures

Following ethical approval from the University of Manitoba Faculty of Nursing Ethical Review Committee, the researcher approached the Director of Nursing at the Children's Hospital and explained the nature of the project in detail.

Following a brief presentation of the proposed investigation at the pediatric head nurses' monthly meeting, the researcher met with each head nurse to describe the study in greater detail (see Appendix E), to address any specific questions or concerns, and to introduce the Educational Influential Instrument (see Appendix F). Each head nurse reviewed her staff roster and invited the researcher to present this first phase of the study to nursing staff following morning report or nursing rounds. The Educational Influential Instrument was presented to as many nurses as possible (see Appendix G).

Seventeen presentations occurred over a three week period of time. At each meeting, the pediatric nurses were given: 1) a brief written explanation of the study that included the researcher's name and phone number (see Appendix E), 2) the Educational Influential Tool (Appendix G), and 3) an envelope. The voluntary nature of participation in this phase of the study was emphasized. Staff nurses were not required to sign a consent form. Rather, a written disclaimer appeared on the tool. The disclaimer was explained by the researcher and pediatric nurses were invited to complete the ballot, seal it in the envelope, and place the envelope in the clearly marked ballot box that was placed at each nursing station.

Those who wished to participate were invited to list the name and nursing unit of one to three peers whom they felt best suited each vignette and who had a minimum of five years of pediatric nursing experience. They were invited to list their own name, if they felt it was appropriate.

Additional packets containing the background information guide (Appendix E), the ballot (Appendix G), and an envelope, were left near the ballot box for any nurses who

had not been present for the researcher's presentations. Staff nurses were invited to tell their colleagues about the study, and all were invited to contact the researcher if they had any questions before completing the ballot. The investigator collected the ballot boxes one week after the final presentation on each unit.

A total of twenty-eight nomination forms were returned. Nominations were tabulated by the researcher in consultation with the advisor. The nurses who were mentioned most often became the population of nursing experts that were invited to participate in the next phase of the study. Fourteen pediatric nurses received a minimum of five nominations, with one receiving seventeen nominations. The sample for the second phase of the study was drawn from this group of fourteen expert pediatric nurses.

The top ten expert nurses were sent an Invitation to Participate in this research study (see Appendix H). Invitations were placed in a sealed confidential envelope, addressed to each nurse's workplace, and routed through the inter-departmental mail system. The invitations asked nominees if they would be willing to participate in the second part of the study. The nominees were asked to respond by phone or through inter-departmental mail. In the case of a tie between two or more candidates, names were randomly chosen. If a candidate declined to participate, the name of another expert nurse was randomly selected from the pool. Altogether, each of the fourteen candidates was invited to participate in the study. Three candidates declined. The eleven who consented provided the researcher with either their home and/or work phone numbers. Each was contacted by telephone, and a mutually convenient date and time were selected for the tape-recorded interview. Participants were informed that the interview would take approximately two to three hours to complete.

Interviews were conducted in person, at a mutually convenient location. Three interviews were conducted in a private location within the Children's Hospital, and one interview was conducted in the conference room on the participant's nursing unit at her

request. A “do not disturb” sign was placed on the door to bar interruptions. The remainder were conducted in the living room or kitchen of participants’ homes. In one instance, a toddler was present for the interview, and in two instances, family pets were present.

To begin, each subject was given two copies of the Consent to Participate in a Research Study (see Appendix K). This form provided a detailed description of the study, informing participants that participation in the study was voluntary and that data would remain confidential. Since respondents were known to the researcher their participation could not be considered anonymous. One copy of the signed and dated consent form was retained by the researcher and one copy was retained by the participant.

Next, the participants completed the Structured Data Collection Tool (Appendix J). The Semi-Structured Interview Guide (see Appendix I) was reviewed with the participants to familiarize them with the types of questions they would be asked, the dimensions of death and dying that they were asked to consider, and the details that would help to place their answers in the context of their lived experience. Each participant was given a copy of the interview guide that could be referred to at any time during the interview. The researcher briefly recounted examples of Degner, Gow and Thompson’s (1991) original categories, and some of the variations that were identified by McClement (1993).

For many, this was their first experience as a participant in a research study, and a number voiced their discomfort at the thought of the tape recorder being turned on. Participants were instructed that the interview could be interrupted at any time, and to facilitate their discussion about their caring experiences with dying children, as the tape recorder was turned on, participants were first asked to talk about the place that they work, in general terms, and to describe their working experience with dying children.

The first phase of this study had stimulated discussion among the staff nurses on some wards and many nurses had already begun to recall their death and dying

experiences before they were contacted about the second phase of the study. In some instances, the participants were prepared to begin their narrative before any questions were asked. These individuals had specific stories they needed to tell, and often, it was a first pediatric death experience that they felt had shaped their future attitudes and behaviors. The semi-structured interview format proved to be appropriately flexible while allowing the exploration of areas of commonality and difference.

In interviews with the first subjects, the participants were encouraged to talk in depth about their particular perspective. In later interviews with subsequent participants, questions were drawn from preliminary interviews and the interview guide. Focused questions allowed the participants to compare themselves and their stories to the researcher's analysis of others, and helped to place the participant's story in a meaningful context (Morse, 1989). Such questions were helpful in validating the researcher's assumptions about the participants' range of shared experiences, or indicated that an assumption was invalid.

It was recognized that excessive control of an interview would run the risk that a preconceived idea or other investigator bias would shape the data. Occasionally, participants presented a challenge: to allow enough flexibility while also gathering information with enough consistency for comparison among subjects. Often a redirected question about the meaningfulness of a situation helped to draw the participant back to the topic of interest and helped the researcher to see the problem through the participant's eyes.

The researcher recognized that the success of the interview process was dependent upon her interpersonal communication skills. Skillful interviewing has been characterized by the extent to which the investigator can establish rapport, elicit information without excessive control, and accurately record information (Morse, 1989). To facilitate communication, the researcher maintained eye contact with the participant and arranged

seating so as to not threaten or intimidate the participant. In one instance where a room was particularly large, the researcher chose to sit on the floor near the participant, to ensure that facial expressions and body language could also be observed. Formal notes were not taken, but participants were informed that if they made reference to another case or described a concept that they had not previously mentioned, the researcher would make note these key words or concepts and ask the participant to talk further about them.

One hundred and fifty minutes of recording tape were brought to each interview. On three occasions, the participants filled the tape, but all of the questions on the semi-structured interview guide were discussed within the hundred and fifty minutes of tape. The researcher was impressed that these nurses had so many stories to tell, and on one occasion, additional verbatim notes were taken as the participant narrated her final story.

The final step involved a comparison of the research findings to those previously identified in the review of the literature.

Ethical Considerations

Ethical approval to carry out this study was obtained from the Faculty of Nursing's Ethical Review Committee at the University of Manitoba. Site approval was obtained from the Director of Nursing at the Children's Hospital.

All nominees were informed that participation was completely voluntary and written consent to participate in the study was obtained (see Appendix K). The researcher provided a brief verbal summary of the consent form and the participants were given time to read the form in its entirety. Participants then were asked if they understood what was read and were given the opportunity to ask any questions they had about what they had read, or the study as a whole. Before they were asked to sign the consent form, their right to withdraw from the study at any time was restated. Each participant was invited to retain the second copy of the consent form for their personal reference. The researcher's name

and phone number had been recorded on the form to enable participants to contact the researcher at any time if any questions or concerns arose following the interview. Consent forms were stored in a locked drawer in the researcher's office, separate from the transcribed interview data.

Anonymity was not possible since the participants were known to the researcher but confidentiality was strictly maintained. In the first phase of the investigation, pediatric nurses who participated in the nomination process were asked not to mark the form as their own. In the second phase of the study, each participant was assigned a code letter which was the only identifier affixed to the tape recordings and the Structured Data Collection Tool. For any particular illustrations that have been cited by the author, pseudonyms have been assigned to patients, and nursing colleagues have only been referenced in general terms, such as "the nurse." The researcher will not divulge the identities of the participants. Only the investigator and her Faculty Advisors have had access to the transcripts, and both tape recordings and transcripts are stored in a locked drawer in the researcher's office. This data will be retained for a period of seven years. Tapes will then be destroyed and transcripts will be shredded.

There were no known benefits to subjects participating in the study. However, nurses who agreed to participate may have gained satisfaction from the realization that they may be helping to improve the future nursing care of dying children. Enhancing knowledge and education for nurses in this area should help to improve the care of dying children in the future.

Due to the fact that the death of a child can be associated with strong emotional responses, such as anger, guilt, and frustration, there was a slight risk that the recollection of vivid events surrounding the terminal care of a dying child could cause a degree of psychological discomfort for the subjects. The investigator made it known that she was available to the participants, and if a participant became upset the investigator

had planned, in advance, to spend additional time with them or to seek out the support person of the participant's choice. The investigator was also prepared to ask the participant if she wished to withdraw from the study or continue the interview at a suitable later date.

Three participants did become tearful as they recalled particularly difficult death and dying events. In each case, the interview was interrupted for a period of time until the participant felt she was able to continue. At no time did a participant ask to terminate an interview. In fact, one commented that she had not cried about a certain patient for a long time, and she felt it was cathartic to have a good cry. Another commented that some of the situations she was discussing were so heart-breaking that she could not help but cry. None of the participants required additional care following the interview.

The tape-recorded interviews ranged from fifty to one hundred and fifty minutes in length. All interviews were transcribed verbatim by the researcher.

Data Analysis

Analysis, in qualitative research, refers to the organization, interpretation, and categorization of *non*-numerical data to discover patterns, themes, and qualities; to make sense of the data and to write a final report that is true and accurate (Morse, 1989; Wilson, 1987). A modified version of the constant comparative method of content analysis was used to analyze the interview data and determine commonalties and variations. Using this method, each section of the interview was coded as having a particular meaning and was compared with other previously-coded sections to derive themes from the data. In this way, the investigator was able to determine whether an incident in question was the same as, or different from, other incidents in a category (Degner, Gow & Thompson, 1991). Whenever possible, the names of emerging categories were abstracted from the language

used by the participants. Categories that did not lend themselves to such characterization were assigned titles by the investigator.

The researcher reviewed the transcripts independently to extract all critical behaviors. The behaviors from each interview were noted, examined and compared to ensure consensus in meaning and wording. The same approach was used with each subsequent interview. Next, all of the behaviors were compared and clustered into categories that appeared to provide the best explanation of the data, and operational definitions were written for these categories. All of the coded data was then extracted from the original interviews and organized under each of the final categories that emerged.

Descriptions of the critical nursing behaviors identified from the interview data, and the inferences drawn, were then checked against the original data by the researcher's thesis advisor, and a preliminary draft of the results was issued to each study participant for their comments and critique.

The final product documented the nursing behaviors that the respondents identified as being critical in the care of dying children in the hospital setting. Both positive and negative operational definitions were developed for each behavior identified and the information was summarized (see Appendix D).

Issues of Reliability and Validity

Reliability is concerned with the consistency, stability and repeatability of the informant's accounts as well as the investigator's ability to collect and record information accurately (Morse, 1989, p. 161). Stability was tested by asking participants similar questions of the same content to evaluate the consistency of their answers. Internal consistency was judged by the explanatory rationale of ideas about the same topic within each interview. Equivalence was tested by asking different kinds of questions within the

interview, or a particular question in a variety of ways, to establish the congruence of the data regardless of the form of the question.

The collected information was intended to depict a truthful representation of the desired content. To ensure the reliability of the collected data, all interviews were tape recorded and transcribed verbatim by the researcher. The researcher checked all transcripts against the original tape recordings to ensure their accuracy. This confirmation of research findings by the actual participants served as a control for investigator bias and validated the accuracy of the researcher's interpretation of all dimensions of the interview data (Degner, Gow & Thompson, 1991).

Since this qualitative research project was based upon a single semi-structured interview with each participant, it was important to establish the validity of the investigation. Theoretical sampling criteria provided the rationale for selection of the study's purposive sample. The researcher relied upon practicing pediatric nurses for the identification of key informants for this investigation. Pragmatic validation was achieved through repeated collection of data on the same content from recognized expert informants. What was learned from one participant was verified by asking the other participants about the same content. This form of concurrent validation represents the most crucial validation procedure in qualitative research, since it establishes the standards against which the data are verified as being true or accurate (Morse, 1989). Validity and reliability were further provided for by the use of the constant comparative method and the search for negative cases to ensure that developing categories were representative.

Strengths and Limitations of the Study

Although there was no power relationship between researcher and participants, the researcher was an employee of the same institution. There was a need for clarity in the explanation of the voluntary nature of the study, and the researcher reiterated the fact that

participants were free to choose whether or not they chose to participate and that their choice would in no way affect their position or their employment.

The researcher was familiar with the patient population, the institutional language, the roles and the functions of her pediatric nursing colleagues. The fact that the researcher was familiar with the pediatric environment and the nursing care of dying children could have facilitated her ability to “ask the right questions” when interviewing participants. However, there was a greater risk of investigator bias because of the researcher’s own experiences with dying children and their families. This risk was minimized by inviting the participants to critique the findings of the investigation.

Since the researcher was an inexperienced interviewer, there was a need to become as familiar as possible with recommendations regarding the interviewing process and to formulate a consistent approach for each interview. The researcher recognized the need to establish rapport and elicit information without excessively controlling the nature or flow of information. The fact that the researcher was familiar with a number of participants relieved the researcher’s initial anxiety and could have had a similar effect on the participants.

For most of the participants, this interview marked their first experience as an informant in a research study. The participants felt particularly vulnerable and unsure of what was expected of them. Many stated that they rarely had taken an opportunity to stop and think about what they do. Participants were encouraged to choose the date, time, and location of the interview. It was hoped that by allowing the participants to choose an environment that they were comfortable in, they would feel less constrained at the time of the interview. A brief introduction to the interview was given, and participants were allowed to familiarize themselves with the interview guide before the tape-recording began in an effort to set them at ease. When the tape recorder was turned on, the investigator began with a grand tour question, “Can you tell me, in general terms, about

the place in which you work,” that allowed the participants to place themselves in the cultural scene, and set the pace for the interview. Subsequent questions were constructed in a manner that avoided any “correct” answer to decrease the risk of such errors as social desirability and acquiescent response set.

It was a challenge for the researcher to balance flexibility and consistency in her investigation. Individual stories were extremely interesting, but some were so unique that it was difficult to formulate follow-up questions. The emotional content of certain stories also made it difficult for the researcher to consider the more factual aspects of the situation. Interruptions were necessary in certain cases because of the emotional impact of the story on the participant. Participants were asked if they wished to “talk about it” anymore, and in some cases, a change of topic was necessary. If the participant was able to talk about it, a more general question such as “What was the important part of that story?” allowed an opportunity for them to describe their emotional response and to place the story in a meaningful context. A number of participants were particularly articulate and insightful.

The researcher was able to identify several paradigm cases in which a number of participants described similar behaviors and attitudes in relation to the same patient. This consensus between participants likely represented the specialized knowledge and expertise of pediatric nurses who are experts in the nursing care of dying children. However, the researcher can not rule out the influence of their working culture and environment on their common experiences.

Qualitative designs are based upon known populations from which to sample. The researcher selected a purposive sample from a single institution. This sample cannot be considered representative of the population of pediatric nurses in that institution and is not representative of the entire population of pediatric nurses. The homogenous characteristics of the sample represent a further limitation.

One weakness of this design is its lack of replicability. No single researcher can return to the same participants, ask the same questions, and receive the same answers. Many participants themselves identified that they learn from each experience and adopt new approaches based upon these new experiences. Nor can any other researcher enter this field and find the same individuals, or receive the same results. No two humans see the same phenomenon in the same way, unless trained to do so. Nor do they record and report identical sorts of things (Brink & Wood, 1989). The process of caring for dying children may remain the same, but individuals and their environment change over time. It may be necessary to conduct this type of investigation periodically. Continued documentation of nurses' detailed descriptions would add to nursing's body of knowledge about the care of dying children and their families.

Conclusion

The findings of this study are not generalizable to other pediatric nurses, nor was this the intent of the investigation. The researcher sought to describe and explain the behaviors of caring for dying children and their families in the hospital setting. This objective was achieved. Eleven pediatric nurses who were nominated by their colleagues as experts in the care of dying children and their families participated in this investigation. The collection of demographic information about the participants allowed the researcher to provide an accurate characterization of the sample. During tape recorded interviews, the participants were invited to share their experiences and their observations of positive and negative attitudes of students or colleagues in the care of dying children and their families. The following chapter presents the findings of this investigation.

CHAPTER V

Research Findings

Introduction

The Structured Data Collection Tool (see Appendix J) was used to collect descriptive data about the participants. Description of the characteristics of the sample will be followed by an in-depth discussion of each of the ten critical nursing behaviors that were identified in the study. Specific nursing behaviors were drawn from the transcribed interviews to preserve the language and intended meaning of the participants. Pseudonyms have been used to protect the identities of participants, their nursing colleagues, the children, and their families.

Sample Characteristics

The purposive sample for this investigation consisted of eleven pediatric nurses who had been identified by their colleagues as experts in the care of dying children in the hospital setting. The participants ranged in age from twenty-eight to sixty-one years, with an average age of thirty-nine years. All were female. Ten were diploma-prepared registered nurses, and the eleventh had recently completed her post-diploma baccalaureate degree in nursing. One participant had completed a post-basic pediatric nursing course (a Neonatal / Pediatric Critical Care Nursing Program).

Total years of nursing experience ranged from seven to twenty-five years, with an average of fifteen years. Years of pediatric nursing experience ranged from seven to twenty years, with an average of over thirteen years. Only three participants have worked outside the pediatric setting.

Four participants worked on an adolescent medical floor, and a fifth had previously worked on the same adolescent unit prior to her transfer to a specialty clinic in

the Children's Hospital. This twenty two bed acute-care medical unit was also the designated isolation ward. The nurses explained that although they usually cared for older children ages eleven to sixteen, they did, at times, care for infants as young as ten days old. Children on this unit suffered from a variety of conditions, such as cancer (including bone marrow transplants), renal problems (including kidney transplants), cystic fibrosis, asthma, neurologic problems such as seizure disorders, and eating disorders. However, the nurses agreed that they primarily cared for children with cancer.

Four participants worked on a twenty-two bed medical ward that provided care for infants and young children ranging in age from newborn to eleven years of age, but the patient population was predominantly under the age of three. This acute-care medical unit provided care for a variety of patients with cancer, renal problems, cystic fibrosis, asthma, heart problems, and acute illnesses such as respiratory infections and meningitis.

One participant worked on the orthopedic ward. At the time of the study, care for dying children was rarely provided on this unit but palliative care had been provided there in the past. The final participant worked within a subspecialty program. She cared for patients in both the clinic and hospital setting, and her work with dying children extended to all areas of the Children's Hospital and the children's homes.

At the beginning of each interview, the participants were asked to describe their experience in caring for dying children. One supposed that she had cared for more than one hundred dying children over the past twelve years. She estimated that eight to twelve children died from cancer each year, with almost half of these deaths occurring in the hospital and half occurring at home. The hospital deaths were often related to an inter-current illness such as a secondary infection.

Another participant estimated that she had cared for ten to fifteen dying children over a seven year period. Her estimate only included those children whose deaths had occurred while she was their assigned nurse. Other participants found it difficult to

estimate the number of dying children they cared for. In many instances, the participants were not on duty at the time of death even though they had known and cared for the child for an extended period of time. Instead, these nurses were asked to approximate the number of children that died on their ward each year. The nurses consistently estimated between three and six deaths, on average. Their perceptions were confirmed by information obtained through the nursing department. In a review of the hospital's patient care statistics, six ward-deaths were reported in the year preceding this study (see Figure 6).

Figure 6. Children's Hospital Death Statistics: April 1991-March 1992

(Children's Hospital Nursing Office, I Boyle, 1993).

<u>Emergency</u>	<u>Pediatric Intensive Care Unit</u>	<u>Neonatal Intensive Care Unit</u>	<u>Wards</u>
12	28	29	6

Critical Nursing Behaviors in the Care of Dying Children

The preliminary data analysis revealed twelve categories of nursing behaviors. Descriptions of these behaviors were based on the coded interview data. These initial descriptions were checked against the original data, and operational definitions were written. This preliminary work was reviewed with the thesis advisor. A further check against the interview data resulted in the revision of certain interpretations, and resulted in ten final categories of critical nursing behaviors. The preliminary draft of this chapter

was distributed to all study participants as a final check on the validity of inferences drawn from the data.

The remainder of this chapter will provide a detailed description of the data. In addition, the categories and their operational definitions have been summarized (see Appendix D).

1. Connecting

Participants explained that long-standing relationships were not uncommon in the pediatric setting. In some cases, the children may have been hospitalized for three to six months at a time. In other cases, their stays in hospital were shorter, but much more frequent, and the nurses had known them for a number of years. In particular cases, for example children with cystic fibrosis, or rare conditions diagnosed in infancy, the nurses had known the children for their lifetime.

Pediatric nurses came to know dying children and their families in an especially intimate way. Connecting represents those nursing behaviors that acknowledged and incorporated this close emotional relationship. Two major themes were identified: 1) behaviors that promoted a mutual closeness, and 2) behaviors that embraced the child and family.

1.1. Behaviors that Promoted a Mutual Closeness

Some participants described the relationship that developed between nurses and dying children as a special friendship. This level of relationship involved a mutual closeness, characterized by demonstrations of affection, concern, and caring. Getting along, or being comfortable together, was essential. The children shared themselves with the nurses, and came to know the nurses personally. The participants considered this tie to be a precious, special bond.

There are certain kids that I think were special to everybody. Aleck was special to everybody. Bonnie was special to everybody. Because she was a wonderful kid. We knew her for a long time. She was funny. She was animated. She talked a lot, about herself, her life, and what she wanted to do, and things like that, so she participated in our lives. It wasn't just us being nurses taking care of her. Bonnie's personality came back.... I don't expect patients to do that, but sometimes it happens. And it's a wonderful thing. And so you end up developing relationships with these people. (N)

Pediatric nurses developed comparable relationships with the families of dying children. They described really getting to know a family, in order to understand their needs and wants, and to respect their feelings. The development of a close, comfortable relationship required that the nurse be willing to extend herself and share herself with the family. Feelings of friendship, trust, and closeness evolved. The nurse "kept in touch" with the family, and became a significant support person for them. The nurse was someone they could lean on. The nurse was seen as a person who cared for the family and was there for them.

If one of the children you were really close with died and you weren't there that particular day, it's almost like you missed sharing that with the family. You'd kind of been through so much with them that... the ultimate ending of your relationship was being able to provide that, at the end, for the family. And if you missed doing that, it was like your job wasn't finished. (M)

In certain cases, participants described how a nurse and a particular child and family could "click just right." In these instances, that nurse got along with the child better than her colleagues, and became "hooked in" with that particular family. She intuitively knew what to do for them better than other people.

Most of the kids end up having a favorite. And I think that it's really important, if a child has a particular favorite nurse, not to say that one nurse is better than the other, but if you just happen to be that special person in that child's life, I think that it's really important that *that* person be assigned to that child. On our ward, we tend to know who is special to who. And we do. We change assignments on a

continual basis, so that nurse is with that child and family, because it makes the family feel better and it makes the child feel better. (E)

In contrast, all participants were able to describe instances in which nursing colleagues maintained their distance and behaved in a reserved, controlled manner. They suggested that some nurses did not allow themselves to become close to the dying children or their families. This behavior was described in personal terms, that a particular nurse had never allowed herself to become close to dying children, in general, or that at that particular time, in that particular situation, the nurse could not be close.

You really develop such a close relationship with the family and child that it does become hard. And there's been times, I can personally say, that I have just got to the point, at certain times in my career, when I've thought, "I don't want to be close to another family right now. I don't think I can be close to another family now." And that's happened to me several times. (F)

In other instances, the children had not been hospitalized long enough, or the children and their families did not allow the nurses to get to know them. The participants expressed regret that they did not get to know these people very well. They would have felt better if they had been somewhat closer.

That's one family I could never really get close to, and also either to the girl. They did not talk a lot. You never had a real sense of knowing whether they really understood what was going on, whether they really had all the information that they wanted.... They really sort of pushed us away, and they didn't want to hear the bad news, that their daughter was dying. (A)

1.2. Behaviors that Embraced the Child and Family

Many participants described a more profound relationship with the dying child. These nurses "crossed that boundary" and let the child into their lives. The nurse and child bonded in such a way that the child "got right into her heart." The child became a

part of her and was almost as close to the nurse as her own family. These nurses loved the children and in many instances became an extension of the child's family.

Parents aren't there 24-hours a day. And because they are children who need parents, that's what you become for them, is their parent, or a sibling. If it's an older child, like an adolescent, sometimes you will almost appear to them, it's, you know, you're the grandfather, if you need to be the grandfather. You're the aunt who isn't there, if it's the child who's really attached to an aunt. I guess you have to play that role for the child. They just need parents in their lives, and that's what you become for them. (M)

Some you feel you're closer to than the parents are. (K)

Participants described a similar emotional attachment to the families of dying children. Pediatric nurses recognized the important part they came to play in the lives of the families and recognized that an incredible bonding could take place. They came to share into each other's families.

I feel that I become a part of their family, because most times, with the kids, there's, you know, one or two parents, the brothers and sisters, sometimes, you know, even a more peripheral family: aunts, uncles, grandparents. Like, all of those people. And depending on the family, you meet all or most of these people. And so I think that they take us into their family. They see us as a member of their family. (N)

A number of participants identified situations in which they felt a colleague had become too involved. Over-involvement was characterized by the loss of one's professional identity. The nurse's personal involvement limited her ability to provide comfort and support to the family.

If you become so involved you can become ineffective, because you always must still be the stronger person, and you cannot become that. You know, I think it's okay to cry with the parents, but you still must always be the caregiver. You know, you must still be the stronger person. (K)

2. Responding to the Family

The participants reported that pediatric nurses considered the wishes of the dying child to be of primary importance and view themselves as secondary to the family in the care of the dying child. They reported that pediatric nurses were challenged to respond to the many unique demands that were placed upon families when their child was dying and depicted the components of family care that were required. Six major themes were identified within this category: 1) behaviors that supported the family, including or relieving them of the responsibility for care according to what was best for the family, 2) behaviors that brought families together, 3) behaviors that fostered a homelike environment, 4) behaviors that responded to the family's need for information, 5) behaviors that reduced the potential for future regret, and 6) behaviors that supported the child and family's religious beliefs and practices.

2.1. Behaviors that Supported the Family, Including or Relieving Them of the Responsibility for Care According to What Was Best for the Family

The participants identified the need to get to know a family, to understand their life circumstance, their expectations of the nurses and for their child, and to clearly communicate about these expectations. This "getting in touch with the family" involved being available to the family and taking time to get to know them so that the nurses could support parental choices and maintain the family's sense of control. When nurses were attuned to the parents in this way, they could better respond to them and look after their needs. Participants explained that parents saw the nurses as persons who knew what was happening, could answer their questions and allay their concerns. Parents came to depend on the nurses to respond to their needs and to help them interpret the needs of their child. The nurses responded by "being there," providing support and encouragement, reassurance and positive feedback.

Remember what's the priority. That family and the child of the family, and nothing else. And what do they need from you the most?.... So, I think if I was to tell you the best thing to do, it's to find out what the parents need from you. And that's not hard to do, because they will usually tell you. It doesn't take much. (F)

Most of the participants reported that given the choice, almost all dying children would choose to die at home. Pediatric nurses recognized that parents were faced with the difficult choice of whether to take their child home or not, and the additional challenge of providing adequate care for their child at home. Pediatric nurses were sensitive to the dilemmas facing these families.

Rhonda's dad was quite worried, I think, about managing her pain . He didn't want her to be in any pain. And so she stayed at home for as long as they both felt comfortable. But then, he brought her into hospital. And Rhonda agreed. (N)

Whatever the ultimate decision, whether the parents took their child home or whether the child remained or returned to hospital, participants related that the concerns of families were essentially the same.

I don't think it's any different in hospital or out of hospital. I think, basically, the concerns are the same. They don't want their child to suffer. Nobody wants to have their child in pain. And they want to feel that people are seriously interested in that. The difference that people find between home and hospital is that at home, if the person is having pain they will move the medication up right away, and they know they have the latitude to do that. (A)

Pediatric nurses appreciated that dying children were concerned about their care and their caregivers, and recognized that a particular nurse's caring and support could make a difference for both the child and the family. Participants described numerous examples of pediatric nurses willingly providing care beyond their scheduled shift and beyond the institution. Many pediatric nurses made themselves available to dying children and their families at home, in both urban and rural settings.

I was going to go back to work, and then come back later, but Abbie said to me, "Don't leave. I want you to stay." I said I was going to go, that I'd come back later, but Abbie said, "No. You have to stay, because I'm going to die today." And she did. She died that day. (A)

Gestures of caring and thoughtfulness were common. The participants identified that families of dying children are especially vulnerable and that pediatric nurses must get to know them and win their trust in order to help them through the difficult times.

Thoughtful and caring behaviors included being there for them, recognizing who was important to them, and making them comfortable. The participants stressed that knowing a family enhanced this component of care.

One particular nurse took a great amount of time and effort to try and develop a relationship with Amber's mom so we could understand what she wanted for her daughter's death. And it was difficult because there was a language barrier, and the mother was aboriginal, so she had some different ideas about what she wanted for her daughter's death. But this particular nurse did a lot of things surrounding that death. She got the Native Services interpreter to come, spent a lot of time with her, and the three of them talked a lot about what it meant for her to have a dying child, and how she wanted Amber to die. (H)

The participant also recognized the need to relieve families of the responsibility of caring for their child. Pediatric nurses provided support and encouragement, and reassured parents that their child would be cared for and that the family would be notified if their child needed them, or if their condition changed.

That's what I encourage the parents. Now, I'm not talking about when the child is actually dying, but I've told them many times, you know, "If you can get yourself to do it, please leave for the night. You'll do your child a favor. You'll do yourself an enormous favor, because now maybe you'll get a decent sleep. But also, we have a chance to get close to your child." And that is, I think, what makes the children become very precious to the nurses. When a child can put her arms out to a nurse, and not say, "I don't want you." (K)

Not all parents were able to leave their child. Pediatric nurses recognized their need to be there, day and night, but did not translate this to mean that the parents wished to assume the sole responsibility for care. The nurses supported these families and provide relief from the responsibility of care.

You're a pediatric nurse. You take care of children, but 50% is family. Very much so. You must handle the family just as well. So, sometimes, it's some coffee. And I know that you hear from other parents how much they have appreciated that little gesture. If they couldn't leave the child alone, and you said, "Well, aren't you having lunch, or supper, or breakfast?" "No, no, no." And so you just made some toast, and brought in a glass of juice, and it made a difference. Just a little, little caring, you know. (K)

The participants were able to provide descriptions of negative behaviors towards the families of dying children. Certain families did not demonstrate caring behaviors or loving relationships with the dying child. Pediatric nurses sometimes avoided these families rather than becoming involved with them, to sidestep potential conflicts that could have had a further negative impact on the dying child. Other families refused to listen, or had unrealistic expectations of their child and of the child's caregivers. The participants related that pediatric nurses felt they never really got to know, understand or support such families, and identified an increased potential for miscommunication and misunderstanding.

Parents can sometimes be unrealistic about the outcome of their child. You know that it is just very obvious that this child is going to die, and the parents are just "this child is just going to wake up tomorrow and start walking." I think the staff tend to become really negative about dealing with that family. That is pretty hard. You certainly can't feel very supportive towards a parent who feels that way. You actually don't like them. You don't want to deal with them. (F)

Other examples of negative behaviors were felt to arise among the nurses themselves. Negative nursing behaviors included an inability to listen to the family, passing judgment on decisions made by the family, or avoiding contact with the family.

I can think of one little girl, Nicole, who was in for palliative care. Her mom had a really hard time dealing with the fact that she was dying.... She began to distance herself, and I know lots of the nurses got really angry about that... Her visits just got more and more infrequent, and people had a hard time dealing with that. I remember hearing on the phone someone actually almost to the point of being rude, blaming her for not showing up, and not coming to visit Nicole. (E)

Some participants voiced an additional concern, that too much pressure could be placed on parents to take their dying child home. The participants explained that the preference of pediatric nurses and doctors was readily apparent. Families were encouraged to take their child home. They were told that it was better for them, better for their child, and better for the children at home. However, in imparting the message, it was felt that families could feel obliged to make the 'right' decision. Only two participants mentioned that families were always offered the option of bringing their child back to the hospital at any time.

I think that we may coerce the families in taking the kids home, when they might not really want to take them home.... The family might not want to take the patient home, and we kind of have negative feelings towards that. We think that the children should be dying at home, that it's better for them.... And I think we almost put a guilty feeling on the parents if they don't want to take their child home. (C)

2.2. Behaviors that Brought Families Together

Family assessment is an integral part of pediatric nursing. As the following descriptions suggest, complex family circumstances are not uncommon in the pediatric setting. Participants provided numerous examples of complicated and dynamic family situations, many of which were further compounded by distance.

The family situation becomes so strained that many families break up. And this family initially were together, and I don't know how much trouble there was, but then the family just broke down, and dad had a girlfriend. (K)

Some families were committed to being together throughout their child's death and dying. These families participated until the end, and the parents worked as a team. However, the more likely scenario was that of the mother as the constant companion throughout the child's death and dying, while the father worked to support his family, and often assumed sole responsibility for parenting other children at home. The father's contact with his wife and hospitalized child could become extremely limited. In some instances, roles were reversed, and fathers demonstrated their ability to love and nurture their dying child in the hospital, while the mother worked and provided for her family.

The nurses working with these families recognized that relationships between these couples suffered as a result of prolonged separation. Family situations could become so strained that families fell apart and relationships dissolved in response to the stress of parenting a dying child.

All participants recognized the burden that the dying child placed upon the family. They described efforts of their colleagues to promote family togetherness because pediatric nurses recognized the need for everyone to be there, both for the parents' sake and for the sake of their child. Examples were provided of nurses facilitating communication and seeking additional help, including financial assistance, to assist families. The participants also noted the need for nurses to be advocates for all family members.

We don't just deal with the child. It is very, very much the parents, too. And maybe it is "You come out for a little while, and I'll sit here for half an hour," so they know the child's not alone, and so they can go out together and maybe talk about the things that they can't talk about in front of the child, and maybe just cry. (K)

Negative nursing behaviors that were not felt to be helpful in bringing families together included judgmental, controlling behaviors that either limited or demanded that families spend time together with their dying child. Pediatric nurses have been known to judge a family based upon their own values and expectations rather than those of the family. The most extreme example of this kind of behavior, "going overboard," was depicted by a nurse actually instituting a plan of care that met the nurse's personal need rather than the needs of the family.

Austin is dying right now at home. He's never really talked a lot, and his family had never really talked with him, so there were a lot of things that were not said.... Austin needed a nurse to go in every day, and the nurse decided to make this a project, to try and get Austin's family together, but it kind of went overboard. The nurse even decided to get a minister, and this minister came last week and said, "So what would you like for your funeral?" Austin got so upset. "You guys are talking like I'm dead already." Austin didn't want to talk about it. He didn't want it brought up. (A)

One last scenario involved those families whose constant contact with their child had dissolved. In some instances, an infant had been apprehended, or the mother had given the baby up for adoption in the newborn period. In others, the family lost touch because the child had been separated from them for weeks, or months, or years. Although participants had difficulty understanding it, they were able to provide many examples of parents who were not there for their child "for the long haul." Pediatric nurses responded by assuming a dual role: caregiver and surrogate family.

Danny had no parents that were involved with him.... There wasn't much more they could do for him. He became like our little baby, on the ward.... All of us just loved this little guy. (M)

All participants recognized the need to incorporate siblings in their descriptions of bringing families together. They reported that in most cases, siblings had grown up knowing about their sick and dying sibling and had learned to deal with it.

I went back to the family's house after Amy's funeral. And the girls dragged me all around the house and they showed me their bedroom. They each had their own room, but for quite a long time before Amy had died the sisters had insisted on moving their beds into her room. So, even though they each had their own bedroom, with their own dresser and their own clothes in the closet, they all slept in the same room. They had this little bedroom with three little single beds in it, bing, bing, bing, in a row. And they all had their names above their beds. When Amy was home, her sisters were happy to be in the room with her. When she was in the hospital, they missed her, and they often slept in her bed, the two of them, together. And in fact, since Amy's death, they had been sleeping in her bed. (M)

The participants described that in the beginning, parents hoped to protect their other children from their pain and suffering, by "acting like nothing was going on." Rather than being reassured, siblings often felt left out and alone. Siblings realized that their parents were not able to spend time with them because their time was devoted to the dying child. However, feelings of jealousy, sibling rivalry and guilt could still surface. In addition, siblings relied on their parents for transportation to the hospital for visits, and were not usually allowed to be at the hospital for extended periods of time. Prolonged physical separation could intensify sibling feelings of isolation from their dying sibling and parents. Well siblings could feel unimportant, neglected, and insecure.

The worst thing is for the siblings to know that a brother or sister isn't coming home, and they don't understand what's going on, and sometimes, their imagination can be far worse (than the truth). But parents really try to hide their feelings from the children. They don't let them see that they are hurting. They try to carry on. (F)

Participants described the need to include siblings. Siblings were encouraged to express their interest in their sibling's care, and were allowed to participate in care giving

if they so chose. Examples were provided of nurses communicating with parents, helping them understand that their well children were experiencing similar thoughts and feelings to the parents.

Gabe's two brothers stayed overnight with him.... It was so nice that they were able to do that, and it was nice for Gabe. It was important for them, and they were given the option, but they wanted to stay. They wanted to be there, and so they spent Gabe's last two nights with him, crashed out there, in his room. (N)

The participants also reported that well siblings could have vivid imaginations. It was not uncommon for siblings to blame themselves for the illness, believing that "it was all their fault," because, in a moment of anger, they wished that something bad would happen to their sibling. Siblings could also imagine that the same thing would happen to them, that they would get sick and die. The participants told of nurses spending time with siblings and listening to their concerns. Nurses talked with them, reassured them, and helped them to understand their sibling's illness. Siblings wanted open, honest communication, and needed continuous emotional support. Pediatric nurses often became role models for parents, demonstrating how to meet these sibling needs.

Anne's older sister Becky came in infrequently, but she did come in, and one of the nurses got really close to her. And one day, Becky just said to the nurse, "Do you think that I'm going to die like Dana?" And she just started crying. I don't know. This makes me cry..... But the nurse comforted her, and reassured Becky that it was not her fault, and that she was not going to die. (H)

The participants identified some particularly challenging incidents. In one example, the parents had not told a child that he was dying and would not permit anyone to talk with him about it. The nurses recognized the additional strain this placed on the siblings and were sensitive to their distress. They provided support for the siblings.

He had two older brothers who had to go along with this as well. They knew. And they would stand outside the room when they came to visit. It was like, "I have to wait a few minutes and kind of get up my nerve to go in," because they'd meet the same questions, and they couldn't support him either. We gave them moral support. (M)

A number of participants recalled a particular incident in which a sibling was not allowed to be a part of his brother's hospitalization, death and dying. They had difficulty understanding the parents' decision, and although they disagreed with the parents' choice, they acknowledged the parents had a right to make such a decision. The nurses stated that they had to respect the parents' choice.

His younger brother Harry, who was about twelve, unfortunately was left at home, which I think was not a good thing to do, but that was their decision. So, Harry never really was involved in his brother's death, and never saw his brother for the last number of weeks of his life.... He was excluded from being at the hospital the whole time. Not only did he not see his brother, he didn't see his parents. It was a long time to not see your mom and dad. And twelve-year olds can have very active imaginations. I can just imagine what Harry was thinking was going on. When people aren't there, and they're just talking to you on the phone, you start imagining all kinds of things. I think that was an unfortunate decision....It's perfectly within their rights as his parents, but I think that it probably wasn't the best for Harry. He should have been there, I think, or had the choice, at least. (H)

The participants made brief references to additional support services that were available to the siblings of dying children. Social workers were often involved with the family as a whole and Child Life therapists worked with the ill child and siblings. The nurses came to rely on these additional services and expressed their appreciation that such services were available to them.

We try to keep the siblings involved. If they're older, like in their teens, they like to stay there and act as a second mother or a second father you know. If they're younger, they still have their own needs.... We try to get other services involved for them, like Child Life will do a lot of therapeutics with the siblings. (J)

2.3. Behaviors that Fostered a Homelike Environment

Two participants talked about the stress and tension that were being experienced in their working environment at the time of this investigation. They described feelings of anger and frustration at staffing cutbacks and the reported dissension among staff nurses. Other participants described a very supportive collegial environment. Despite this marked contrast, all participants reported that the environment they created for dying children and their families was of utmost importance, and each was able to provide a graphic description of the setting their unit was able to provide.

All of the participants described their aversion to a rigid hospital feeling. Their vivid descriptions of a negative environment included such things as a stark room, with harsh fluorescent lighting, and the child, alone, in a large, cold bed. In contrast, a homelike environment was felt to create a positive milieu. Participants provided very similar descriptions of the room that they create around dying children and their families. They described a set of household furnishings that includes a sofa-bed, dresser and bedside lamp, which pediatric nurses make available to dying children and their families. The participants were unanimous in their opinion that the furnishings were effective, and very much appreciated by both children and their families.

I think to provide an environment for the child and family is really good. We have private rooms. In fact, a couple are quite big. And what we've done, we've brought in a big cot. Like, it's a hide-a-bed. It's a nice double-sized bed. And Todd died right in his mom's arms, lying in that bed. And we tucked them both in at night. Like we cared for them both, so they could be as close as they could be to a home situation, yet they've got us there. And that made all the difference in the world to both of them, just to have that closeness. (F)

The furnishings created a standard environment. When the children and families "set up shop," the room also became filled with many personal things. At this point, the room was seen to belong to that child and family, and became their home away from

home. Children and families were encouraged to “bring everything they could possibly want to bring,” to surround themselves with treasured personal belongings, and to invite their favorite people to visit them.

When Dale was coming into hospital, he was usually coming in for a fairly lengthy stay. You always prepare for an admission, but in Dale’s case, the ghetto-blaster would go in there, and we would always get a nice quilt for his bed. And we would try to spiff it up a bit. And then, of course, when Dale actually came in, he would bring quite a few things with him. He brought his own TV, and his own VCR, and all that sort of stuff. So, when he would come, Dale was moving in, in a serious way. (N)

When talking about the environment, one participant described a home environment that she felt represented the ideal circumstance.

I got to Wanda’s home, and there Wanda was, propped up in the living room on the couch.... And her mom and dad were there, and all her siblings were there, and her boyfriend was there, and the next door neighbors were there, and the dog was bouncing around the living room, and I thought, “This is where you should be. As far as I’m concerned, if this is what you want, this is where you should be.” (N)

Participants described their satisfaction at being able to provide an environment in which the children felt secure and comfortable. One participant suggested that it was one of the few things that nurses could really do to help them.

I’ll bring in some tapes that I have from home. Some really quiet, relaxing tapes. And I’ll play them most of the night long for them, just quietly. And I think as well as caring for them, in the background they’ve got this nice soothing music, and I find they just stay really more comfortable. And I feel really good about that. It’s a very simple thing, but it makes me feel good. (F)

2.4. Behaviors that Responded to the Family’s Need for Information

To begin, the participants identified the need to establish good communication with the family, to understand how much information they wanted, or needed to have, and

to determine what their expectations were. One participant suggested that families should be thought of as knowledgeable and sophisticated consumers. All participants indicated that regular, consistent information was important to the families of dying children.

When asked what information was important to families, participants did not refer to any standard script. Instead, they spoke about "the intangible things." The nurses recognized that families looked to them for answers, and stressed the need for honesty when dealing with them. They recommended answering only what people asked, providing families with what they wanted using everyday language that they understood.

They want to feel that people are seriously interested.... I spend a lot of my job talking to families about their child, you know, things that the child did that were funny, and things like that. And sometimes, talk about the diagnosis and things like that, but also talk about very philosophical issues, existential types of issues, like why this has happened, you know, how they feel about it. I think they really need to have people sit down and talk to them about those things. They really appreciate that, and they really appreciate the nursing staff who will do that. (A)

Once again, the participants reported that pediatric nurses acted as role models, helping families understand what their well children perceived, and demonstrating how families could approach these children with relevant information. The nurses talked to families about the information needs of their well children and encouraged them to provide them with the information they wanted. Parents were taught that their children needed someone to talk to and wanted to be kept informed.

We usually always encourage siblings to come in to hospital. And then explain everything. Explain everything they want to know. Absolutely everything. And answer just what they ask. "What's that tube for? What's that? What are you doing now? Why is she crying? Why are you doing that to her? Why are you giving her a needle?" And I think that's really good. (F)

Most of the participants stated that it was not their place to tell families that their child was dying. They considered this to be the physician's responsibility. Then, the

nursing role could be more clearly defined. The nurse should reinforce what the physician had said, make known the child's current condition, provide information about the future, and assess the family's need to speak with their child's physicians or other health professionals. Repeated conversations with families were recommended to ensure that what was said had been understood.

The participants were able to identify a number of negative behaviors associated with the relaying of information. Difficulties could originate with the families. For example, not all families were able to accept the message that their child was dying. Some "shut out" the nurses, making it difficult for the nurses to evaluate their level of knowing. Other families received the message, but chose to withhold this information from their children.

It was obvious to me. They really sort of pushed us away. They didn't want to hear the bad news, that their daughter was dying.... I never had a real sense of knowing whether they had all the information they wanted, or whether they really understood. (A)

The message itself could also be problematic. In some cases, pediatric nurses were placed in an awkward position because a family had not been given a clear and honest message. When families heard mixed messages, they often looked to the nurses to help them interpret conflicting information. Conversely, certain families could be so well informed that nurses felt threatened by their knowledge, because the family knew as much or more about their child's condition than the nurses.

Some of the interviews that physicians had with nurses present, they just didn't want to come right out and say, "We're sorry. We can't do any more for your baby. This is what's going to be happen." And what's very frustrating, as nurses, is that the medical staff keep doing things that give the parents hope. You know, we'll all of a sudden start some sort of more heroic measures, and the parents go, "Maybe they'll be okay." That's a problem we all have to deal with. (F)

A final comment by one participant suggested that many pediatric nurses felt uncomfortable sitting down and talking with families even though they had valuable information and experience that they could impart.

A lot of nurses, I think, have trouble doing that. They're not used to it, just sitting down and actually talking with families about those kinds of things, or about some of their experiences that they've had with other children who have died, or their own life experience about somebody who has died in the family. (A)

2.5. Behaviors that Decreased the Potential for Future Regret

The participants recognized the importance of their role in caring for dying children and their families. One participant described it as “customer satisfaction guaranteed, or your money refunded.” They spoke about particular nursing colleagues who had demonstrated their willingness to extend themselves, to overcome obstacles, to make the situation “the best that it could be” for dying child and family. In this component of family care, they recommended that pediatric nurses strive to heal rifts, apologize for misunderstandings, and work to achieve total agreement with the child and family about the terminal care of the dying child.

The best situations are those where communication is at a degree where everybody is in total agreement and understanding of exactly what the plan of care is for this child and family; where there can be disagreements, but everybody has a basic understanding and you know exactly what you're going to do; where the communication with the parents is at the level where you can provide excellent care, like good emotional and physical support for the child, and where everybody has the same goal in mind, you know? The goal being that you want the child to die in dignity, without pain, and in a good environment, and the parents have a good experience, if you could ever have a good experience, but when they remember back, years from now, and know that their child died in a situation that pleases them, that is warming to their heart, rather than something that is harsh and painful. (H)

Participants also provided examples of behaviors that they felt would not reduce the potential for future regret. In some instances, the caregivers and the parents had never

reached a consensus about what was best for the child or the staff minimized the concerns of the family. In other cases, the family had not accepted that their child was dying, or the child had not been told. The participants described that in these situations, their work seemed incomplete. They were left with feelings of frustration and sadness, and they regretted that things were not different. They predicted such families would inevitably have future regrets.

It took too long to get all that stuff done.... That's what parents complain about, and they will complain about that every time when their child is dying--those kinds of things that get screwed up, when they know they shouldn't. There's not enough attention paid to detail, to the importance of something.... And I can tell you that if Kelly had become septic, that family would have gone back, over and over, "this didn't happen, that didn't happen." They get angry about that. And once their child dies, they will think about that for a long time. And no matter what you do to try and say, "Well, maybe it might not have made a difference," it does make a difference. There's no question about that. (A)

Problems also arose if the nurses failed to initiate a discussion about death and dying with the family. In some instances, the nurses also had difficulty accepting the fact that the child was dying. If nurses were unable to face the reality of the situation, their ability to properly support the dying child and family was compromised.

Nina was still deteriorating. We had put her into a tent, and she was slipping into comas, but the whole problem was that I was totally blind to that. My personal relationship with Nina was just covering up for her impending death.... It just went right over my head.... I lost the opportunity to talk with Nina and her family about death and dying, and not only helping her along with it, but also helping me accept the fact that she was dying. (J)

2.6. Behaviors that Supported the Child and Family's Cultural and Religious Beliefs and Practices

Participants identified the need to demonstrate respect and sensitivity towards the cultural orientation of the family, to achieve that "total agreement" about the child's terminal care. They provided numerous examples of nurses supporting and including traditional native rites and rituals that were important to aboriginal families.

The medicine man and all the elders from the band had come in to do their blessing for Lana, because they did that while she was alive so that she could enter into that world, you know, and have her prayers, and also, to give Lana strength. And they needed another person to come in, to make the circle complete. I was her nurse, so I went. We had the smoke sensor shut off, and everything, because they had to burn their leaves. And we got the okay for that, which I thought was very good. That was a wonderful experience. It was so enlightening to be a part of that. (J)

Discussions of faith were also common. Participants recognized that many families relied upon their deep inner faith to deal with the situation. Whether it be the "Coming to Jesus" talk with the dying child and family, or the use of prayers to help families through the hard times, faith was recognized to represent a significant component of family care. Additional religious support services were made available to families, including their own minister (or holy man), prayer groups, and hospital chaplains.

Paige asked for a minister to come in, and she actually talked to the clergyman about opting not to start treatment again. And it was very difficult for me, because I didn't think that it was fair that Paige had to make the decision about whether to start treatment or not. A sixteen-year old should be deciding what she's going to wear to the prom, not whether she's going to stop treatment. (C)

Most participants reflected about their own faith and personal beliefs. They acknowledged that their religious beliefs and practices had influenced their nursing

practice. A number couldn't imagine how they would ever cope if they did not believe in God.

That's where a lot of faith came into it. Where you questioned, "Why? Why, when there's so many rotten people walking the face of this earth, and you see a boy like Nathan, who has so much to give, and is such a positive person, and you can't tell him why, and you can't tell yourself why. And it happens, and you accept it, and you go on. (M)

One participant described herself as a devout Christian, who incorporated her faith into her nursing practice. She explained that she always remembered that "it was all in God's hands." Her life was committed to "doing God's work." She had an talent for praying with dying children and their families, and was able to talk with them about God.

Zack was a bad boy really, but he crawled right into your heart.... And he actually had the horrible, horrible task of saying "It's enough," because he was on a ventilator, and he did not ever want to be, for the rest of his days, on a ventilator. But Zack was so scared.... He was extremely scared. His eyes were just so fearful.... He was sitting in a chair, so I had to kneel by him. We talked softly. He could not answer me, but he did say, "Yes, I am so scared...." Zack felt his life had been too bad for God to forgive him. And so I told him what I believe, that Christ came to take our sins away, and so I said, "Never mind how sinful your life was. In God's eyes, no more sinful than mine." And I said, "Zack, do you want me to pray with you?" And he said "Yes," and took my hands in his. And at that moment, I really feel, not that the fear was totally gone, but that he knew things were going to be all right, when he took my face in his hands, and said "I love you." (K)

One participant, in contrast, stated that she was an atheist. Although she was a non-believer, she clarified that she always supported the beliefs of her patients and their families.

I'm not a religious person. Not at *all*. Like, don't tell me that they've gone to a better place, please, or that, you know, I do agree, hopefully, that when children die that their pain is over. I mean, I do believe in that. But like, don't tell me that they've gone to see the Creator, or they've gone to a better place. I have a great deal of difficulty with that..... However, I'll support anyone's belief, whatever it is, how ever I can. (N)

References were also made to what the participants felt was the inappropriate use of faith and religion. In one case, the mother and nurses opposed the child's religious practices. In other cases, the family's religious practices were felt to interfere with the child's terminal care.

Rita clicked in with a bible-reader who would come for hours. Nobody ever found out what went on behind that closed door. He had his own thoughts, and unfortunately, because it's unknown, all of the hairs on our backs were standing yea-high. We were angry because we didn't think that he was good for Rita. Now, that's our judgment, isn't it? ...Our staff felt he had too much control, and in retrospect, why did we do that? Maybe that's all Rita needed.... We interfered. We really did. We just didn't like him. His attitude was not nice. He was very secretive, and Rita's mom didn't like him seeing her, either.... But Rita was obviously comfortable enough with the situation, and if that's how she found her solace, who were we to say no? (L)

3. Providing Comfort

The need to provide comfort was deemed a priority by all participants. Two themes represent the range of caring measures that pediatric nurses were able to provide: 1) behaviors that reduced physical pain and discomfort, and 2) behaviors that satisfied the child's psychological and emotional needs.

3.1. Behaviors that Reduced Physical Pain and Discomfort

The participants reported that pediatric nurses readily equate adequate pain control with quality of life. Comfort was their greatest asset because when a child's pain was adequately controlled, that child could lead an active life. As one participant remarked, "Comfort makes all the difference in the world." Even though comfort was deemed a priority, pain management was sometimes difficult to achieve. Pediatric nurses were required to assert their advocacy role to ensure adequate treatment of a child's pain.

I guess when it comes to palliative care, I do what I want, and I'll phone, I'll go to the top if I have to, but I'll get the answer from the clerk, or the intern, or the

resident. I'll phone the attending doctor, and it doesn't really matter what time of the day or night it is. I don't have a problem with that. (E)

Other physical comfort measures included good basic nursing care, such as bathing, skin and mouth care, and when incontinence became a problem, inserting a urinary catheter. Routine nursing care measures such as turns and range of motion exercises were deemed less important and were often performed less often because of the pain they caused the child. Participants recommended identifying which comfort measures worked best for each child. The nurse could then devote extra time and effort toward those particular measures to provide comfort for that child.

The biggest thing for me is making sure that the patient doesn't have any pain, that they're comfortable. If it hurts to move, then put in a catheter. If they don't get turned, what's the big deal? (C)

Although the participants acknowledged the importance of adequate pain management, their descriptions suggested that pain control could be difficult to achieve. In some cases, inadequate pain management was perceived to be a nursing problem, due to inadequate pain assessment or an inadequate knowledge base resulting in an inability to recognize when a child was suffering. In other instances, despite their best efforts, pediatric nurses were unable to completely relieve a child's pain. Inflexibility in the plan of care was also felt to be problematic. Participants suggested that some nurses had their priorities wrong, worrying about getting their work done rather than caring about the child's comfort.

Some of the ward staff and medical staff don't always recognize when the child is having pain, and so that some things aren't done right away.... Some nurses will just do it accordingly, exactly to the letter, or else they think that this child's just lying there, so they're obviously not having pain, but in fact, they are.When it comes right down to it, nurses don't always remember what's important or how to recognize some of the more clinical signs. (A)

Many recalled a particular case, reflecting that it was perhaps the most difficult case they had ever experienced because despite the best efforts of the entire health care team, the child continued to experience pain and suffering.

With Jesse, we never really got control of his pain. Jesse just had so much pain. We had him on Morphine. We had him on Dilaudid. And we still never got control of his pain. Jesse was still screaming, many, many times. And that wore down his family. No matter how much good nursing care there was, Jesse was still uncomfortable. You could never tell if he was comfortable or at peace. How could he be? He was still in pain. (L)

Participants indicated that they faced significant role ambiguity when they talk about relieving pain since so many of their nursing measures caused pain and discomfort, and the children had difficulty understanding why people were hurting them.

A lot of times, you're the person that has to poke them or prod them when you have to do invasive things to them as a part of your treatment.... Why poke Chantelle? You know how distressing this is to her. Chantelle would cry and cry. And one time, I can clearly remember her having her physio done with her head tipped down, and she was about to have a finger poke, and Chantelle just yelled out the door, begging me, "Don't let them poke me, don't let them poke me."I felt like my aorta was being crushed. (H)

3.2. Behaviors that Satisfied the Child's Psychological and Emotional Needs

The participants suggested that the nurse must know the child in order to understand what is important to that child, and to get a sense of the psychological and emotional needs of the child. They recommended always listening to the child.

Ellen stirred a little bit and asked me to come and sit beside her. So, I was sitting beside Ellen on the bed, and she just said, "Will you lie down with me?" So, I just lay down beside her, and held her. (N)

When discussing physical comfort, the participants focused primarily upon the perceived needs of the child. However, when considering children's psychological and

emotional needs, it was notable that they not only identified the needs of the child, they also described the personal qualities, or personality traits, that they felt best satisfied the child's need for love and security.

I think that the best thing is to help them live until that last breath, and to love them, to give them lots and lots of love. Not only on the parents' part, but also on our part. To give them unconditional love and just be as warm and loving a person as you can be. That's really important.One nurse is a very gentle, soft person, and really has a very warm-hearted way about her.... I think the nurses that are caring that I've seen are like her. They have a very soft, gentle manner about them, and they're there.... I really like that nurse's approach. She's good, and she's just got a nice, down-to-earth approach. And she has a sense of humor, and sees that you can use a sense of humor, too, even when it's really bad. (A)

The participants described nurses who were comfortable being with dying children, who were not afraid of physical contact, who were willing to share of themselves. These nurses considered caring for a dying child to be a privilege. Their concerns extended beyond the physical care of the child. They worried about how well the children were taken care of for their little demands, and would willingly forgo other assignments to be with a dying child.

When somebody's hurting, when children are dying and stuff, all you want to do is just hold them, and love them, and make them comfortable, and make them know that somebody cares. (H)

Not all nurses are able to give of themselves in this way. Some nurses are able to provide excellent physical care, but avoid becoming involved in the emotional care of the dying child.

One of our nurses on our floor is an excellent caregiver. She knows what to do, when to do, how to do, but very rarely gets involved, like we do. That's just the way she works. (L)

4. Enhancing the Quality of Life During Dying

Pediatric nurses seemed especially attuned to quality of life issues that surrounded the dying child. Once again, participants dwelt upon knowing the children, being open and honest, understanding what was important to them, and helping them to do those important things. Participants' descriptions went beyond the child's information needs. They described helping the children "finish their business," and caring gestures that demonstrated nurses wanting to make the children feel good. Nursing actions that promoted the dying child's quality of life included the following themes:

1) behaviors that responded to the child's need for information, 2) behaviors that helped dying children do things that were important to them, and 3) behaviors that made dying children feel special.

4.1. Behaviors that Responded to the Child's Need for Information

The participants spoke about the dying child's information needs apart from the those of the family. They described that nurses must understand the child's perception of death. To accomplish this, nurses must know what the child is like, understand how the child copes, and listen to what the child tells them, because "children let you know what they want." Many of the participants spoke about the intuition and wisdom that dying children possess, and admitted that the children have been their best teachers. They respected the honesty of the children, and recognized that the children wanted truthfulness in return.

The first thing Kenny said to me was, "How is Garry?"And I had to say, "Kenny, he died." He never said anything to me, nothing after that, until two months later. He just said, "How did Garry die?" And then I had to explain to him why and how. And it's really funny. A lot of the kids know, but they don't talk about it. And you can't lie to them, I mean you can't. They know. They have an intuition, sometimes. He knew that Garry had died. He really did. And if I had lied to him, our trust would have been finished for good. So you can't lie to them. You have to tell them the truth. (H)

Participants explained that pediatric nurses are often the first to ask what a child knows, if a child is prepared for dying, and if the child has any questions. These nurses recognized that dying children have learned much of “what’s going on” during their hospitalization, and know that their nurses will answer their questions or seek out answers for them. Many told of dying children approaching a particular nurse because they knew that nurse had cared for a certain child at the time of death (most often a friend, or sibling who died of the same disease). Dying children approached these particular nurses to ask their most specific and detailed questions about death and dying.

One little guy, Jake, he’s six. His sister died of cystic fibrosis, and he’s really talking a lot about it now. But he actually talks a lot more about another boy, Karl, who just died before Christmas, who he knew very well.... And he’s asking all sorts of questions about dying. Jake will probably die in the next six months. He’s not doing very well. And he talks about it very openly, about dying. He said, just the other day, “Well, when I die I won’t have CF anymore.” That’s exactly what Jake said. But he’s curious, and just totally wants to know what it’s like, what it’s going to be like, and he wanted to know everything that happened to Karl when he died, and exactly what room he was in. (F)

Participants identified that although a child’s behavior may be deceiving, nurses should not be fooled by such apparent disinterest. Children are very interested in their illness and treatment, and want to know what will happen in the future.

Kelly eventually started asking about dying. So the nurse was truthful with her, saying things are getting harder to work at now, and asked how much she knew about her disease. Kelly was able to rattle off everything about it, saying “Do you know that most kids die when they’re five, and I’m nine?” She got her information from medical books at the library. Her mother gasped, “You mean you’ve been reading about your disease?” (J)

The participants reported that pediatric nurses talked to families about the information needs of their dying child. Parents were encouraged to provide any information the dying child wanted, and dying children were encouraged to talk about

their condition. Pediatric nurses often acted as role models, demonstrating how the family could approach their dying child with relevant information.

Ian was slipping in and out (of consciousness), but no one was talking to him. All the family could do was cry. So, I sat down on the side of the bed and held his hand, and said "I hear things aren't going too well." And Ian just opened his eyes, but he didn't say anything. He never did talk to me, but I could tell that he was hearing me and listening to me. I said, "I think you know it's time, so I wanted to be here to say good-bye to you. It's important for me to say good-bye, because you mean so much to me....." And Ian sort of closed his eyes, and then he opened them again, and looked at me in a certain way. He knew that he was dying. (J)

The participants identified the difficulties faced when working with families who had not been told, or who requested that information be withheld from the dying child. The nurses felt that withholding information in such circumstances placed their relationship with the dying child in jeopardy. One participant likened it to "walking on egg shells." Others agreed that they were especially careful to "tip-toe around" any delicate issues in such situations.

Sometimes it's really hard, because on the ward you have people saying, "And they don't know this yet, so don't tell them." Ugh! Like, major personal dilemma. What are you supposed to do? Somebody asks you a question, and you know the answer's there, and you're like "cough, cough." It's hard. (H)

All participants agreed that children had the right to know, and many stated that they felt comfortable expressing their convictions to the parents when the opportunity arose. Nevertheless, each participant was able to recall deaths in which a child had not been told, most often because the parents had not consented. The nurses expressed their regret that these children did not know and described such experiences in negative terms.

Lanny was eleven or twelve. And his parents, to the end, did not want him told that he was dying. He would ask us, "What's the matter with me? I know I am dying." And he would use that expression, but we had to honor these parents' request. We never really came out and said, "Yes, you're dying," but I hope, in

our non-verbal behavior, that Lanny came to realize that what we were doing for him was not the aggressive treatment we were doing for the child in the next room. I suppose we supported him in some way, but it was a terrible, terrible situation to be in.... The fact that Lanny got no answers, no direct answers, or the answers he was looking for, that probably speeded up his death. Lanny just gave up, and died. (M)

One participant described an especially challenging incident in which a nine year old child expressed her wish to discontinue aggressive treatment. Even though she knew she was dying, this child remained angry until the day she died. She was never willing to just "accept" it. This child coped through anger. The participant reflected that pediatric nurses must be able to accept and permit whatever method of coping the dying child has selected to be able to support that child's death and dying.

I know Carrie knew that she was dying. But she was angry about it. She was angry as anything. And one day, her mom called and said, "You'll have to come right away. Carrie's really sick." It was many, many hours before she started coming around a little. And Carrie looked at herself in a mirror, with this horrible tumor protruding from her mouth, and she said, "If I have to live like this, I would rather die." So I said to her, "Well, it isn't going to be very long," taking what she had said as my cue, right? Well, Carrie became hysterical! And she screamed, "You're lying, you're lying." ...After, her mother said, "You know, she just doesn't want to die." I think I had taken away her hope. For me to articulate it, even though Carrie could articulate it herself, she didn't want me to agree with her. She didn't want to die. (A)

4.2. Behaviors That Helped Dying Children Do Things That Were Important to Them

Dying children want to feel loved and cared for and want to be recognized as a unique human beings who know what is wrong and know that death is near. The participants described how pediatric nurses demonstrated respect and understanding as the children came to know and understand that they were dying. The nurses "were there" for them.

Oscar was the most adorable, beautiful little boy. He was three years old. And he just wasn't feeling good over the last week. He was feeling very bad. When we

talked to his mom and dad, Oscar was just sitting on his mother's lap, just laying back with his head against her chest. He had hardly moved from that lap for hours. He hardly moved at all. But when we told them the bad news, that he was dying, Oscar kind of got up from her lap.... He got up, and he went and stood by himself, right beside the scale, across the room. And he just kind of looked down, and then looked over at us, with these big eyelashes, and these beautiful, big eyes. It was like Oscar crossed a different line. He was in a different place. The three of us were here, and he went over there, and just stood there and looked at us for a few minutes. And that, to me, was a real metaphor, because when children get that news, they feel that they've crossed a line that none of us can hope to get to until it's our turn. (A)

The participants noted that not all families were comfortable with their child's knowing. Sometimes parents could not accept that their child was dying and were not able to talk about it with their child. In situations such as this, the child could adopt pretense behaviors in an effort to please the parents.

Tina was nine years old. And the family were jovial all the time, and you know, Tina was trying to keep the family perked up. And we couldn't figure out where she was getting all this energy from.... Her parents always came in happy. They knew that she's dying, but they didn't want her to know, so Tina tried to act as though she didn't know. They didn't know how to talk to a dying child. (J)

The participants believed that the dying children knew more than anyone else. A number expressed their continued amazement at the insight dying children possessed. Even though the children did not focus on death and normally did not talk about when, where or how, they did recognize when people were acting differently toward them.

Dying children wanted a sense of control in the midst of their dying. Numerous examples were provided of children as young as seven and eight years old requesting no more treatment. The following examples demonstrated the nurses' respect and acceptance of the child's right to participate in decision-making.

Janine just said "Enough." And her parents really had a hard time with it, but Janine just said, "It's me that's going through this. It's me that's getting sick, and

losing my hair, and feeling horrible. And I just don't want to do it again. I just don't want to do it again." And it took some convincing. (N)

Although many children were able to say "enough is enough," the participants reiterated that others were not ready to die, and fought until the end. The participants provided examples of children "hanging on to life."

Derek was fourteen when he died. He had leukemia, and then he relapsed shortly after treatment. And then he started treatment again, and went for a (bone marrow) transplant. But shortly after he came back from the transplant, within a few months, Derek relapsed again. And he wanted to continue treatment right until the end. Derek didn't want to give up. He wanted to fight to the end. That's what he told his parents. (A)

However the child died, the nurses tried to approach them with a positive attitude. They worked to make the child's life as normal as possible and brought the outside world to the child.

You tend to let them into your life, and they know all about your family and what you do outside. I mean, they want to know more than just what's going on in the four walls of the hospital room. They want to know what movie you saw, and where you went for dinner last night.... That makes it, I guess, more of a normal life and not just hospital and medicines. (E)

The participants described how many pediatric nurses "went that extra mile," to find out what was important to dying children in order to fulfill their last wishes. In a number of cases, the wish involved people who were particularly close to the child or celebrities that the child wished to meet. Pediatric nurses recognized the importance of significant others to the dying child and included them in the child's hospital experience. Nurses even arranged for a favorite celebrity visit the child in hospital.

We do have rules for your basic patients, but some of the kids have actually had their best friends sleep over with them when they were to the point that they

weren't going to go home again. And we sort of make up our own rules, I guess, on the ward, and make exceptions. I mean, our head nurse is really supportive that we can use our nursing judgment and let friends stay over and stuff, and let the children watch movies till midnight. Lots of things, last wishes, are arranged. And we can arrange that, like getting a hockey player to come and see them. And if they want their friends to see that hockey player sitting on their bed, we'll arrange that. Sometimes they can go out on passes. And if they can go out with their friend, even for a car ride, you know, for a sixteen year old, that's important. So we arrange it. Whether or not we carry them and lay them in the back seat. We've done that kind of thing, too. (E)

Many times, the nurses were the initiators, discovering what in the world the child would most like to do, and working to make it happen.

They can make choices. We even instigate the making in a choice. Like "Do you want to go to a movie, or do you want to go shopping?" Or, if the kids are pain-free, well, "Should we get a hold of the Rainbow Society? What would you want to do that you've never done before?" Like, Angela. She has cystic fibrosis. We encouraged her to try and pick something from the Rainbow Society, because we know that's probably her final wish. And she wants to go to visit a relative... And Angela's really sick. One of the things that worries me is that she doesn't have that much longer, but I really want to get her well enough so she can go. It's important that she go because if we put it off much longer, I don't think she'll ever be able to go. (E)

The toddler's quality of life was thought of differently. The participants explained that younger children often had more simple needs.

A child is laughter and a child is the whole spirit of life. You know, this world would be so glum without children. Play is part of the children's life, and how can you take that away from them? If they still want it, you have to offer it to them. (J)

Pediatric nurses recognized the importance of including pets, toys, and play in the lives of their young patients, and endeavored to do whatever the child wanted. One wonders if the nurses in the following vignettes ever imagined what their nursing role would entail!

Evan was really cute.... He had this Little Tikes car, and he would be in that car first thing in the morning till bedtime. And you'd be continually chasing him up and down the wards, running after Evan with his pump because he would often forget it was attached, just driving his car all around the ward. (E)

We've had to fight a couple of times to bring pets in. But we've won. Gina wanted her dog. That's all there was to it. She'd been in the hospital so long. We got her pup in, and he played in that room. And Gina laughed, and laughed. I mean, that's the first time we really heard her laugh.... (L)

The participants identified that a failure to listen to the child and family, or the continuation of aggressive treatment despite the wishes of the child, demonstrated a lack of respect for the child and family. They agreed that "quality time" was more important than "quantity time."

Dying children just want control, and to do what ever they wanted to do, but for the last two years they had no control over.... Why not let them be happy with their last little time? Just give them whatever they want for control of their own body. I mean, everybody's done what they could do. They knows they're dying.... Let them control the last moments of their life. (J)

4.3. Behaviors that Made Dying Children Feel Special

Pediatric nurses took great pleasure in being able to bring happiness to dying children and became particularly attuned to those things that brought pleasure to each child.

It's nice to do special things for special people. And it might just be that on your way to work on nights, you stop and pick up a Slurpie at 7-11 because one of the kids really likes a Slurpie, or something like that. It's a small thing. When you really look at it, it's a small thing, isn't it? It takes five minutes, and costs eighty-nine cents, or whatever it is, but the impact that it has is priceless. (N)

The participants also recommended giving hospitalized dying children "freedom and liberty."

There's nothing better than if, for instance, there's a movie on, and I'll say, "You can go and we'll make some popcorn." And when the teenagers get together, they'll talk, and talk, and talk.... And that's the difference between being by themselves and going to sleep alone, or to finally say, "Now, hush, kids. It's 12:00. Off to your rooms," and having them go to sleep with still a bit of a happy feeling, you know. Yea, I think that most of us go the extra mile, so the rules are being bent. (K)

These descriptions illustrate that pediatric nurses knew and thought of dying children as unique human beings. They worked to understand the child's world view, and appreciated the special, favorite things that were important to each child. Such gestures of caring provided the dying child with a sense of well-being and created an atmosphere of joy. In addition, these gestures demonstrated the commitment of pediatric nurses to the dying child's quality of life.

Conversely, detached, impersonal behaviors were discussed in negative terms. The participants provided examples of colleagues who seemed unable to reach out to a dying child, who did not allow themselves to become too involved. Instead, these nurses maintained their distance in an effort to protect themselves from the possibility of pain and suffering when the child died.

You have to give a lot of love. You have to just give of yourself, and if you can't do that, you're going to struggle in pediatric nursing. (K)

You can't just be there, in this isolated cocoon.... You can't do things in a vacuum. (N)

5. Responding to Anger

Provocative situations did arise when caring for terminally ill children and their families. Children and families could experience anger at the system and might openly criticize the nurses, their nursing care, the physicians, the child's treatment, or the institution. In addition, conflicting opinions about the child's care could result in feelings

of anger and frustration within the health care team. Two themes represented the responses of pediatric nurses: 1) behaviors that demonstrated respect and empathy, even when anger was directed at the health care team, and 2) behaviors that promoted resolution when anger occurred within the health care team.

5.1. Behaviors that Demonstrated Respect and Empathy, Even When Anger was Directed at the Health Care Team

The participants recognized that dying children needed to express anger at their diagnosis, treatment and prognosis. This anger was most often directed at their parents and their caregivers. The manner in which pediatric nurses responded to these outbursts varied. In certain instances, the child was comforted, but in other instances, the nurses actually gave the child permission to be angry and encouraged the child to “let it out.” Less frequently, they found it necessary to set limits regarding what behavior was acceptable, and reprimanded or disciplined a child who misbehaved.

Because of her deterioration, they took Yvonne off the transplant list. She was no longer an acceptable candidate. Yvonne reacted with anger. Like, “How could they do that? I’m still living. They’re telling me I’m dead.” And we just let her rant and we let her rave and said we would do the same thing. You know, we would either do that or we would give up completely. (J)

More frequently, pediatric nurses were exposed to the anger and frustration of the parents. The participants described a number of support services available to pediatric nurses within the hospital setting, including social workers, nurse clinicians, physicians, and child life therapists. However, when asked to describe a particular encounter, most participants recalled an incident in which a colleague had been required to respond without the aid of these alternative support services. The participants identified the responsiveness and sensitivity that had been demonstrated by their colleagues as they

dealt with the angry event, sought to understand the parents' point of view, and searched for an appropriate and acceptable solution.

First of all, if you say to the parent, "I can understand what you're saying," if you sort of take the parent's point of view and let them know that yes, you respect that they think that, but then, sort of follow up with another point of view, the way it really is. I think that helps sometimes, to not be directly confrontational with them.... Most times you can sort of, you know, go in a round-about way to get your point across as well. (I)

When discussing the methods used to address families' outbursts of anger, the participants were able to identify behaviors that were not felt to be helpful. If the caregivers failed to understand or minimized the child or family's point of view, the participants reported that the family were more likely to remain angry, and nurses were more likely to react in anger and limit their contact with child and family.

Glenda yelled at her doctors, which I was so proud of. She was very angry because she had no energy. She could hardly sit up to breathe. To walk to the bathroom and back was more than she could manage. And Glenda was very angry. She said, "You said that when I was going to die that you would tell me and that I would have more time. And I don't have any more time," because she was already so weak and tired. She had wanted them to say, "Okay, you've got a week." And then, in that week, she wanted to be able to go and see people and wrap up business. But that's not what happened. And even that day, they still talked about changing her antibiotics. Like, there Glenda is, sucking air, and blue, and angry, and they're still saying "Well, we're going to try and change your antibiotics, and you may still get out of here yet." Which, of course, she never did. (N)

The most difficult situations arose when agreement was never achieved and the anger persisted. Many described a particular "worst case" scenario in which the parents blamed the doctors and nurses for not curing their child, discontinued all treatment and pain management, and signed their child out of hospital. One participant reflected that she and her colleagues had never forgotten this case. They continued to regret that the conflict had not been resolved and grieved the child's agonizing death.

One other incident I know that was really negative, it was awful. It was hard for the staff to cope with because a set of parents got very frustrated with the hospital and they pulled their child out and stopped treatment. And for the staff nurses, it was very difficult when the parents took Brianne out because we thought we could control her pain better.... I felt really bad for Brianne when she died, because she died in a lot more pain than what she needed to be in. That's probably one negative incident that I remember a lot. (E)

5.2. Behaviors that Promoted Resolution When Anger Occurred Within the Health

Care Team

Interdisciplinary disputes also arose. In some instances, the participants identified that physicians did not appear interested in nurses' opinions or suggestions regarding patient care. In other instances, the physicians failed to recognize or accept that a child was dying and continued to prescribe active, aggressive care. Problems also arose if the physician did not fully inform the family that the child was dying, or conveyed a sense of "false hope" that the child would recover. The participants described "being caught in the middle." It was difficult to communicate openly and honestly with children and families if physicians were not doing the same.

What's very frustrating, as nurses, is that the medical staff keep doing things that give the parents hope. You know, we'll all of a sudden start some more heroic measures on this baby, and the parents go, "Maybe she'll be okay." That's when it gets down to calls and stuff. And that's a problem we all have to deal with.... Giving people mixed messages is wrong. (F)

Not surprisingly, nurses could respond angrily when placed in such awkward situations. They dealt with their anger in a number of ways. They sometimes talked among themselves and formulated strategies to address their concerns. The participants noted that pediatric nurses have become more assertive in recent years. They provided examples of nurses insisting upon team or family meetings and debriefings to ensure that their opinions were heard and to develop strategies for change.

Hal was a fourteen year old boy who was diagnosed with cancer gone rampant. And every single thing that could go wrong went wrong. Even a breakdown in communication. No one really wanted to believe the nurses. We told the doctors that things weren't right and were ignored.... Hal eventually went to Intensive Care and he died. He was not supposed to die, but he did, and there was a lot of anger on the ward because the nurses felt that Hal didn't get a fair shot. The nurses were ignored, and they felt that his case was mismanaged. There was lots of hard feelings. But the one positive thing was that our head nurse saw the anger and recognized how upset the nurses were, and had the head of the hospital speak to us, not about the care, but about the case and that things just went wrong. She made people a little bit more comfortable so that the guilt and the blaming didn't go on. (E)

Pediatric nurses also responded angrily when nursing associates behaved in an insensitive or superior manner. For example, when a child died in an Intensive Care Unit rather than on the ward, the Intensive Care nurses could be impatient or discourteous toward ward nurses who inquired about the well-being of the child and family. Few seemed to recognize or appreciate the role the ward nurses had played in the illness experience of the child and family. Similarly, the death of a "hospital orphan" could be problematic. The participants expressed their frustration and anger that nursing colleagues failed to recognize ward nurses' need for time to grieve the loss of the child.

The supervisor, two minutes later, was on the phone with another admission for this baby that had just succumbed. And we nurses just looked at each other. I mean, 3 or 4 of us just broke into tears. I mean, we physically had to stop and bundle this baby and hold him. And that's what we did! Like, it just stood out as just an awful, awful way for any soul to leave this earth. I mean, with no parent. We were the parents of this baby. We shed the tears. We held him. (M)

When problems arose with the physicians, pediatric nurses seemed to rally together to find a solution. When difficulties occurred between nurses, the participants reflected that pediatric nurses felt uncomfortable voicing their concerns. Nor were their superiors always willing to acknowledge that a problem existed. In many cases, the

nurses were unable to identify a workable solution. Instead, they vented their anger among themselves or took their anger home.

Sometimes we yell at each other. I mean, that happens a lot. Sometimes it's like a brick wall talking to your head nurses, or team leaders, or supervisors. They don't understand when you want extra staff because you have a child dying and you think it's important that you be with them. That's where the frustration comes in, and we're seeing a lot of it now. Because we don't have the same amount of staff as we used to. We use each other, a lot, to vent. (E)

6. Facilitating the Transition to Palliative Care

The participants distinguished that there were no set guidelines regarding palliative care. Many reflected that a significant difference existed between the terminal care provided by the oncology service and other pediatric services, and in particular, the respiratory service. They suggested that the difference might be that cancer is a disease that allows the oncology service to be more attuned to palliative care because it had a predictable illness/treatment trajectory.

We've learned that there is a difference between the oncology patients and those with cystic fibrosis. When an oncology child dies, it's usually because the steps have been done. You're given this sentence, and you're given the hope, and you either have chemo and everything is fine, or you're given radiation and chemo. And sometimes you relapse, and then you do it again and you're fine. Or it doesn't work, and you slowly see your child slip away. You become conscious of the pain, and the alternative must and has to be better than this. Everything has been done. We can't do anything more and the normal process keeps going. And parents make that adjustment. Our oncology team is geared to palliative care, and we do everything we can to arrange around palliative care.... (L)

On the other hand, chronic illnesses, such as cystic fibrosis, have no predictable illness trajectory. Symptoms, which are a consequence of progressively deteriorating organ function, can often be modified or eliminated with aggressive medical care.

A cystic always has hope. When does it become the point that you've done enough? It's just that their lungs are too full. So why can't we empty out their

lungs? It's not that they're still in pain. They're never really in pain. They're never really mutilated. They've never lost a leg. And you have to keep hoping, but there's only so much, and it's like an endless death. It's always facing you, because all it is is if you can empty their lungs, or give them some air, or give them oxygen. So why can't we make them live? With the cystics, you keep trying, and trying, and trying, until the very last.... They still have hope that there could be a lung transplant. So that death is going to be very, very different. True palliative care? I don't think it will ever come to the cystics, because until they know that they've exhausted the chance of a lung transplant there's still that hope.... The respiratory team, they don't know what palliative means at all, yet. They just have not learned that. (L)

Many pointed out that the children tended to become labelled as "no 99s" or "palliative care." Pediatric nurses believed that these terms should be synonymous, but often they were not.

When we label those kids, depending on what people think that means, you can have a complete breakdown of communication, and you might think that your child that's "no 99s" should have what I consider to be "palliative care," but in fact the physicians think completely opposite, and that makes things not go well. (H)

Rather than receiving supportive care, many children continued to undergo aggressive treatment that prolonged their lives, and in some cases such treatment left an impression that the child might or actually would recover. The participants related such problems to a lack of continuity of care in a teaching hospital (due to frequent changes in the rotations of interns and residents), and the preference of physicians themselves.

They still had calls on Taylor even though they had discussed that there was nothing more they could do. We said "Why? Why, if there's nothing more we can do, and there's no family involved?" He should be palliative care, right, so we could just do comfort measures and whatever. Anyway, the decision was to be made in the next few days, but by then it was too late. (M)

In some instances, aggressive treatment may be appropriate. Especially in the case of a chronic, debilitating illness, the participants agreed that it could be difficult to

determine when aggressive management should end. Nevertheless, a number of examples were provided of cases in which the participants felt that aggressive care had “gone on too long.” The participants voiced their regret that in too many cases supportive care measures had never been instituted.

Starting new treatment is very unfair to the child and to the parents. I think it just prolongs the inevitable and it doesn't let them get on with dealing with the grief that their child is probably going to die anyway. It just gives them hope, and hope is a wonderful thing but it's also a very hard thing if there's not any real hope to be relying on. That's what physicians do when they start medical treatments unless they're very specific and say, “What we're doing is just to make the baby more comfortable.” But they don't always do that. So the family never really get on to thinking, to start to grieve for their child, and this child is going to die. (F)

The participants described the role of pediatric nurses in facilitating the transition to palliative care. Pediatric nurses preferred to see the child and family have a good quality of life, rather than quantity, especially if the extra time was filled with illness and pain. The nurses listened to the dying child and parents and became forceful advocates for the right of the child to die with dignity. Pediatric nurses often were the persons initiating team meetings, physician-family conferences, and case-management conferences. The nurses worked to ensure that the child's voice was heard, that the parents were prepared, and that all members of the team were facing the child's dying.

When it's “palliative care,” I don't think that you should be doing aggressive kinds of things. The most important things are letting that person die in love, you know, knowing that there's somebody there just holding their hand, or even a voice, if they can't hold your hand, to know that there's somebody there listening, and, and talking to you, and touching you, and stuff like that. (H)

7. Responding During the Death Scene

Most participants believed that the nurse should be with the child and family at the time of death, but some felt that the nurse should only be there if the child or family

wanted the nurse to be there. Whether or not the nurse was present at the moment of death, the participants provided very similar descriptions of the nursing role around the death of the child. Three themes were identified in relation to the death scene:

1) behaviors that acknowledged the child's dying, 2) behaviors that supported the child and family as death approached, and 3) behaviors that maintained a sense of calm.

7.1. Behaviors that Acknowledged the Child's Dying

The participants spoke in detail about the need to give the child permission to die, and being honest with the child at the time of death.

I think what's important to the dying child is to die without pain, with family around, knowing that they're loved, and that they are special, and being told that it's okay to die, that they don't have to be scared. That would be important to me, to give that to the child. (C)

Participants provided examples of cases in which children had not been told, or in which the nurses themselves failed to realize or accept that a child was dying. These situations were described in negative terms. The participants continued to recall them with sorrow, even though most of these instances had occurred early in their careers, before they had refined their knowledge and skills in caring for a dying child.

The lesson that I learned was that I had lost to opportunity to talk with Susan about dying, and not only helping her along with it, but helping me accept the fact that she was dying. You know, in the back of my head, I know I knew that Susan was dying. But it was the denial for me. (J)

The participants felt that it was also important to acknowledge the child's dying to the family. Good clinical assessment and provision of accurate and timely information could facilitate the family's preparation for their child's imminent death. Even in emergency situations, the participants stressed the need to keep the parents informed.

You certainly have to keep the family out at the time of a crisis situation, like a 99. You're kind of shooing the parents out of the room and doing what you have to do to save that child. But one person always goes with that family and stays with them and says "This is what's happening." I don't think we've ever ignored them. It's much different dealing with a crisis incident, but you do to the best you can to keep them informed. (F)

7.2. Behaviors that Supported the Child and Family as Death Approached

Participants identified the need to "be there" for dying children and their families. A number reported that they felt comfortable allowing the family to choose whether or not the nurse should be present, and interpreted "being there" to mean being available for the family should they want a nurse with them.

Sometimes the family want it just to be that, just to be their family, and that's their right, I think. And sometimes, they want you there all the way with them, and I've been there before for that, too; and they want you more to hold them than to hold their child that's dying. And with some of our adolescents, they want you to be there for their parents because they know that their parents are going to have a rough time when they're gone. (E)

Others interpreted "being there" to mean being physically present in the room with the dying child and family throughout the death event. These nurses expressed their belief that the nurse ought to be there to do whatever is necessary to support the child and family. They maintained that the grieving family is particularly vulnerable, and considered it inappropriate to expect a family to ask for help or to know what assistance the nurse could provide during such a stressful time.

Families are particularly vulnerable and families never want to impose, to be a bother, and a family may have difficulty in saying to a nurse "Yes, I want you to be there."Nurses should be there. They should be there for the whole thing to make sure that the family has the things that they need. The nurse is there to comfort the family. Quite often what happens is that the parents can become totally hysterical, and totally prostrate over the child, you know, crying, and crying, and crying.... So, it's important that there is somebody there, just to help them through that. Not just a family member.... The nurse should be there to provide support and comfort. (A)

Despite this difference in interpretation, all participants identified the need to spend time with dying children and their families and to communicate clearly with them in order to know what the dying child wanted and what the family wanted. In this way, pediatric nurses could “give control back” to the child and family, allowing them to identify who they wanted to be there, and what was important to them. Nurses could then guide family members, help them to support each other, and encourage them to talk to their child and hold their child. Behaviors that were felt to support families included sitting with them, touching or holding them, talking with them, and providing relief during their bedside vigil.

We’re there to just be there to hold on to. Sometimes, it’s just to hold a hand, or just to bring in a cup of coffee, just to make sure that they’re eating, just to make sure that they’re getting some sleep. Maybe it’s just to sit there by that patient while the parents catch a ten-to-fifteen minute catnap, and it’s okay to close their eyes because you’re there for their child. But you need to be there. You need to pass on that love, to know that there is a circle of hope and love. (L)

The participants stressed the importance of sibling involvement during this final time and provided examples of pediatric nurses helping the parents communicate with their surviving children.

Heidi’s mom looked at me and said, “Is she gone?” And I said yes. So mom looked at the two younger sisters and told them that Heidi had died. And the oldest of the two, Sarah, was about five. Well, Sarah looked at Heidi and said, “But she still looks the same.” And her mom said yes, that Heidi wouldn’t look any different. So Sarah just continued to sort of study Heidi’s face for quite a long time. She stayed with Heidi and was holding her hand, and asked, “Can I touch her face?” And I stepped in and said, “Yes you can. You can touch her, and kiss her, and talk to her, and do what ever you want to do.” Which Sarah did. She stayed with Heidi, and, she was crying, but was glad that she was able to be there, and touch Heidi, and look at her and know that it wasn’t scary. (H)

The need to spend additional time with the grandparents was also addressed by two participants.

It's devastating for grandparents. I mean, they always think that they're the one who's going to die and suddenly, it's their grandchild who's dying. You know, they're sometimes the forgotten group. The sorrow that they feel is double-edged. It's for the loss of their grandchild, but also the sorrow they feel for their child who's experiencing that grief. So sometimes you need to maybe spend a little time with them and comfort them a little bit. (A)

Most participants recalled death scenes which they associated with less positive outcomes. They explained that negative behaviors could originate with family members or with colleagues. One described a death scene in which the family were not in touch with their dying son. They were unable to communicate with him and were not able to support him during his final moments.

I went to see Frank the night he died and there were all these people there. People, people, people. All over his room. Who were all these people? I had never seen any of them. Where were they all those hours and days and weeks that Frank had spent in the hospital? I had only ever met his mother briefly, and his grandmother once, and his best friend, Adam. And there were thirty, forty people there. It was like a circus. All of them standing around Frank's bed. His sister was the only one that was actually physically touching him. Everybody else was just looking at him.... I was really upset at all the family that were lurking about, nobody that I had ever seen before. I felt uncomfortable with that because I felt very much that even though Frank was surrounded by people he was very alone, and I was very unhappy about that. (N)

Pediatric nurses regretted that some children died in other areas of the hospital, such as Intensive Care, rather than on the ward. They worried when the child and family were among "strangers" rather than being with nurses that had known them and loved them throughout their child's illness. Another described the distress that nurses experienced when a child died suddenly or when a family had not been present at the time of death.

We never saw Estelle's family. They were from out of town. She was a native girl, a teenager, who had come in with bleeding. It was like a twenty-four hour period. Her family were not even there. And I think that was very hard for us. We didn't think it was going to happen. We tried to prolong Estelle's life, but

there was nothing we could do. And you almost feel like we didn't have time to support her. We didn't have time and we had no opportunity to support Estelle's family. You are just left dangling with lots of unanswered questions and feelings, because when you don't have a family present, you feel like something's incomplete, like you haven't finished your job. (M)

Some participants observed that not all pediatric nurses were able to support families during the death scene. In some examples, nurses remained in the room but busied themselves with trivial tasks and avoided relating to the family in a meaningful way. In other examples, the nurses avoided entering the room unless they had a specific duty to perform.

With John, I observed that there were some people that didn't come to see him in those last three days, and I don't really understand that because even if he hadn't been my patient, I would have been in there, you know, giving him a kiss and giving him a hard time and everything else. So I don't understand it from that perspective, but I appreciate that *that* particular person just couldn't do it. (N)

7.3. Behaviors that Maintained a Sense of Calm

Participants provided comparable descriptions of "the optimal death scene." Pediatric nurses preferred a tranquil environment that accommodated the family's need for privacy and encouraged sharing, closeness and love. They recommended nursing behaviors that presented a calm and gentle manner, demonstrated respect for both patient and family, and maintained dignity at the time of death.

It's those situations where communication is at a degree where everybody is in total agreement and understanding of exactly what the plan of care is for this child and family. Everybody has a basic understanding and you know exactly what you're going to do, where you can provide excellent care, like good emotional support and good physical support for the child, and where everybody's got the same goal in mind. And that goal being that you want that child to die in dignity, and without pain, and in a good environment, and that the parents have a good experience, if you could ever have a good experience, but where they can remember back years from now, knowing that their child died in a situation that pleases them, that is warming to the heart rather than something that is harsh and painful. (H)

All participants reflected that dying children should receive adequate analgesia so that they are peaceful and comfortable. In addition, they should feel safe and loved, and should never be left alone. Pediatric nurses preferred, wherever possible, for the child to be held and comforted at the time of death, knowing that they were loved.

Les didn't look beautiful that day because he was just terrible with all this swelling. He was puffy all over, edematous everywhere, and basically, he was unconscious, but Les's two sisters and his parents were there, and when they took him off the respirator, his family played church music, hymns, and they sang, and they talked, and smiled, and laughed that whole night until Les died. It took many, many hours, but Les's death really was one of the most beautiful experiences I've had. Despite the sorrow, the tremendous sorrow, there was still a lot of joy in that room.... (A)

Each participant was able to recall a death scene that had left them with feelings of horror and anguish. Once again, their stories were strikingly similar. The deaths of children who were not undergoing palliative care, or who were not expected to die, were described as "very traumatic." The nurses responded instinctively "doing what they're trained to do." They initiated the resuscitation effort and called the 99-team, but the resuscitation could be distressing for everyone. The parents were removed from the room while the bedside nurses focused on reviving the child. The nurses felt that these children died alone, in suffering.

One night, in the middle of the night, Bert crashed, and he went through a full 99, and was poked and prodded, until finally in the end, they called it off, and he died. It was totally distressing for everyone involved, because we felt that Bert deserved to die with dignity...., and he wasn't being treated that way. In the end, Bert died in pain and suffering, and we just didn't think it was fair.... Almost, in a way, we felt that Bert was killed... The nurses felt, during the 99, that they were torturing him, and causing pain and suffering. They were bound to call the 99 because he was on full active care, but emotionally and spiritually, they didn't feel that was the right thing to do.... In the end, Bert died a gross death, a really uncomfortable and unsatisfactory death. He died not in somebody's arms like he should have. Bert died flat on the bed, with tubes in his nose and mouth. I mean, that's ugly. (H)

Participants recalled situations in which families became completely hysterical, and expressed their concern that nurses could be especially overwhelmed when the family were not prepared for the child's death. Pediatric nurses felt ill prepared to deal with such families. In other situations, participants told of pediatric nurses who had become so emotionally involved that they were unable to support and comfort the family. Deaths that occurred in such emotionally-charged atmospheres were not easily forgotten. Nor were the nurses' feelings of anguish and distress that things had not gone well.

The mother and father had just left the room, and Becky died! And I had to get them to come back from the end of the hall and gently tell them that she died. It was like an explosion when they came in the room, I mean, there was wailing, and howling, and I was kind of shocked, in a way, because I had never met or dealt with this before. Everybody was crying, but I felt like I couldn't, you know, because I felt, God, these poor people. Like, this is just *so* devastating to them, I mean if they see me cry, they'll just, I mean, they'll think there's nobody they can turn to. And, it was really the most uncomfortable death I've ever dealt with. I guess, maybe in a way because I didn't feel like I could cry. (H)

Children whose deaths were prolonged, who died in pain and suffering, were also remembered. These children did not die in peace and their families were required to endure their child's endless suffering. The participants described their feelings of frustration and dismay that they were not able to make things better for the dying child. They also found it difficult to support the family because they felt as though they had "let the family down."

Richard's pain, we weren't quite on top of that. We weren't able to keep him as comfortable as I would have liked.... That is going to be a running theme, I think. The long, drawn-out, prolonged deaths are so much more difficult, especially for the family.... Richard died probably the most horrible, lingering death I've ever seen. (N)

8. Responding After Death Has Occurred

The participants reported that even when a family was prepared, the death of their child was traumatic. Immediately following the death, the nurses focused their attention upon the family, following which they attended to the body of the dead child. In many instances, their involvement with bereaved families did not end with the death of the child. Three themes have been identified within this category: 1) behaviors that demonstrated respect and supported families through the realization of death, 2) behaviors that demonstrated respect for the body during post-mortem care, and 3) behaviors that supported families beyond the death of their child.

8.1. Behaviors that Demonstrated Respect, and Supported Families Through the Realization of Death

In order to best support the family following the death of their child, the participants identified the need to appreciate what was important to that family. Who did they want or need to call? Did they want the nurse to call anyone? Who needed to be there with them? The participants recommended allowing the family time alone to say their farewell to their child. They recognized that this could be the first death experience for a family. Such families were likely to require more specific information about the post-mortem care of their child's body. A number of participants also described a bereavement package that was routinely given to newly bereaved families before they left the hospital.

Usually, what I do is I ask them if they'd like to hold their child, if they would like to be alone for awhile, which is usually what a lot of them want. And then I'll go back and ask them if there's anything that I can do for them, if there's anybody they'd like to call. We can bring phones into the room for them. (I)

I've had families that have wanted to take their child home and didn't realize that they couldn't do that. I've had families ask to do that. And they ask, sometimes,

“What do we do? What do you do?” They want to know what you do. And so you tell them, very briefly. But that’s sort of the big mystery, you know, they leave, and then, somehow, the child shows up at the funeral home. Well, how does that happen? (N)

The participants described how pediatric nurses shared the end of the child’s life with the family and with each other. Nurses felt especially close to these newly bereaved families. The nurses were respectful of the family and honored the life of the deceased child.

I like holding the child afterwards.... I just know that communicating some sort of respect to that child and that family is important, and that can be conveyed through touch. I guess, in a way, it’s like losing your own child if you’ve been that close to a patient. You feel like you’ve lost a piece of you. You feel a profound loss. (H)

Many related that it is especially difficult for the parents say their final good-bye and leave following the death of their child. Pediatric nurses often assisted the family to prepare for departure, suggesting that it was time to prepare for the final farewell. One participant stressed that it was important for the nurses to gather around and express their condolences and say good-bye, and recommended that the nurse accompany the family to the door.

I always walk them to the door. If I can, I walk them down to the front door. I just feel it’s really important to do that because many of them have said it’s so hard leaving their child there, in that bed, and knowing that the next time they’ll see their child is in a coffin. (A)

Although the participants reported that many families needed help to “gather their forces” to leave their child for the final time, the communication of a sense of urgency was not felt to be helpful. On the other hand, allowing a family to stay for an indefinite period of time or avoiding the family could also be associated with a negative outcome.

A number of participants explained that the longer a family stayed, the more difficult it became to leave. In certain situations, nurses had been required to take a child away from a parent in order to help that inconsolable parent to leave. Although they found this to be a disturbing task, the participants explained that they were not aware of any alternative that would help the parent at that time.

One mom was denying. She didn't even believe that her baby was gone. I think that was really hard on everybody, because in the end I just sort of had to go in and physically take her baby and say to the mom that she should go. And it might sound awful to say that you had to do that, but I don't think if this mom would have sat there for half the night, that it would have made a difference. It would have just made things harder. (I)

Displays of emotion were only felt to be negative if they impeded the nurse's ability to support a family.

I mean, of course you're crying, at least I am. Most people in the room are crying. You're just, sort of, the tears are just running down your face. You're just crying very quietly, and then, you're just going up to the family and saying, "Is there anybody that you want me to call," or those kinds of things. (N)

8.2. Behaviors that Demonstrated Respect for the Body During Post-Mortem Care

The participants reported that for some, the care of the body after death could be a particularly onerous task. Certain nurses had a difficult time with it, and would rather not care for the body after death. However, most nurses recognized that it was equally difficult for their colleagues and rarely deferred the task to others. Colleagues knew and understood that certain nurses preferred to not be alone with a dead child and provided companionship and support during post-mortem care.

The least favorite thing of a child dying is probably taking care of the body afterwards. It really hurts. It's really hard, especially if it's somebody you're really close to, to do the last few things that you have to do. Usually you get

support from the other staff. Sometimes, there'll be a whole room full of people in there to help you. (E)

Many participants stated that they appreciated an opportunity to spend time alone with the dead child to express their grief and say their private farewell. These nurses considered post-mortem care to be the ultimate component of care for the child, and even if a child died near the change of shift, would prefer to stay, to personally fulfill this final duty.

This is notable for me. What really stuck out in my mind was the care that this nurse did after Brett died. She took out a basin and very tenderly washed him, and got him ready to go.... I think it was the way she did it. She was very close to Brett, and very close to his family. It was just her tenderness and the care. (C)

It is not uncommon for parents to want to help bathe and groom their child after death. Some recalled parents who chose to accompany their child's body to the morgue. Although the nurses seemed less comfortable with this, the parents were always allowed to "do whatever they needed to do." One participant told of a father who not only accompanied his son's body to the morgue but also placed the body by himself. Most participants thought of the morgue as a cold, impersonal place and expressed misgivings about parents seeing it even though they have never had a negative experience with a parent in the morgue.

I only once ever had a father who could not leave. He had to do up the body and he had to come to the morgue, and he put the little boy into the cubicle. It was the most awful thing I ever had to go through, but for that dad, that's what he needed to do. He just could not accept it. That was a final kind of parting, or the way he had to end it. (M)

Negative behaviors that the participants have observed in the care of a body after death included neglect, approaching the body without compassion, and the handling of

the body in a casual, impersonal, or hurried manner. One participant's reaction to such behaviors was reminiscent of a parent's response. She was outraged and offended, and when the behavior occurred in the morgue she didn't want to leave the child's body behind.

I have a lot of difficulty with the morgue, taking treasured little individuals to this horribly cold and awful room. I understand that they don't have any emotional attachment to these people but I do expect that they'll be professional, and somewhat compassionate, and that they will handle the children carefully. And they don't.... Like, are you going to be rough with them because they're dead? Because they can't feel anymore?There's got to be some way to make that a little bit better because it's very difficult to leave the kids there. I don't want to leave them there. I want to put them back on the stretcher and take them back. (N)

Pediatric nurses continued to demonstrate their respect for the deceased child even after the child's body has been removed from the room.

This was sort of a special thing that we did with all the nurses that were there on that last day.... I think it's a great story. Wes liked Kahlua and his dad had brought him a bottle which we kept locked up in our narcotics cupboard.... When Wes died his father didn't want to take that Kahlua.... I don't remember how it came about, but at the end of the day we just decided to have a little ceremony. We decided we should toast Wes. And all of us from the day shift went into his room, because we still thought of it as Wes's room, and we shut the door, and we toasted, "To Wes."We all shared a loss that day.... We shared the loss of this incredible kid and it was like we were all members of the same club. "All for one and one for all." It was a real uniting of spirits. (N)

8.3. Behaviors that Supported Families Beyond the Death of Their Child

For many participants, their relationship with the family did not end when the child died. Although they acknowledged that certain pediatric nurses felt uncomfortable attending funerals, they reported that the vast majority considered the funeral to be "the final chapter." Many pediatric nurses chose to attend the funerals of the children they had known and in a number of examples they travelled quite a distance to do so.

When asked why they attended funerals, participants provided both personal and professional reasons. Pediatric nurses appreciated the opportunity to celebrate the child's life, and in many instances, welcomed the opportunity to say good-bye because they had not been with the child at the time of death.

Often, you go to the funeral and you know very well you were the last one to bathe this child. You were the last one to hug them, to one last time put your arm around this child, and hug them and kiss them. That's why we so often, as nurses, have a strong tie with those children. (K)

Pediatric nurses were also grateful for the opportunity to see the family another time, to express their condolences, to see how the family were coping, and to offer them support. A number of participants reported that it was important for the family to know that their child's nurses were there. In certain instances, families planned a memorial service at the hospital to make it easier for staff to attend. In one particular case, the nurse proved to be the best support person for a newly bereaved mother.

For a lot of the nurses it's kind of the final chapter. And sometimes, the family will reserve a whole pew for nursing staff. And, I find you try to put the other person in your place. I think parents would feel terrible if there is now, all of a sudden, no more nursing involvement, because for months, or years, you have been their extended family. You literally have been their extended family, and now, it's over and finished.... And I do know, from what parents have said, that they really, really appreciate the fact that the nurses come. (K)

Pediatric nurses recognized the important part they had come to play in the lives of these families. They continued to care about each family after the child had died and their attendance at the funeral was just one way of demonstrating that caring. The participants suggested that the funeral provided a mechanism for intermediate contact and facilitated future follow-up.

I always try to go to the funeral because I think the family sees you as being such an important part of their time when they were in hospital, and when they look across and see you there, well, I think it really means something to them. And it makes it maybe a little easier to sort of follow things up, and it maybe lays it to rest a little better. (F)

One participant also described the impact of nurses' attendance on the public. She expressed pride in her profession and welcomed the opportunity to shatter stereotypes and show the public what "nursing is really like."

People sometimes think that nurses just care for patients because it's what we're paid to do, that it's our job. And it is our job, but it's our chosen job.... I do it for a reason, because it's what I really like to do. And people, if they haven't had an experience with the hospital, they really are totally blown away by the fact that we really, actually care for these kids.... Like, they're surprised that we would come. But I want other people to see and know that we're nurses, that we're more than what they see on TV. (N)

If the funeral was the last chapter, then in the most cases there was also an "epilogue." The bereavement package contained a card that the nurses routinely sent to the family several weeks after the death, to let the family know that the nurses had not forgotten, and that they continued to care about the family. Certain nurses also sent their own personal card of remembrance to families.

I would wait a few months and I would write a letter to just capture a few of the memories that I had of these children, and I just thanked these parents for what they had done. I would just say to the parents, "I really admire what you did and your child could never tell you this, but it was really important for you to be there. It was really hard for you, but if your child could have told you, this is what they would have said." And a lot of them have told me that they have kept these cards, and they still take them out and read them. (M)

If the death experience had been positive, whether or not it occurred in the hospital setting, it was not uncommon for families to return to the hospital. It might not happen for weeks, or months, or in rare cases, years. Nevertheless, participants

recognized that many parents needed to come back to see the ward another time, to spend time in the room that had been their child's, and to reminisce with the nurses. Certain families became more involved and continued to support other patients on the ward in the memory of their deceased child.

Parents who have had children that have died on the ward, and even children that have died at home but have been very known to us through the whole experience, I would say that 90% of them come back to the ward. Some of them just come back and sit. They have to go and look at the room just for a few minutes, or even go and sit in the room.... Other people come back and they just need to talk to you a little bit about it. (H)

If the death experience was negative, families tended to never come back. The participants expressed regret that things had not gone well and voiced their ongoing concern for these families.

One mom couldn't cope. She never, I mean, six months later, her son's bedroom door was still shut in that house. And you often wonder, you know, now that it has been a year or so, or two, has she ever opened that door? You know, like, and you lose that. You know, you often wonder if there should be a follow up, a year later, or two years later, because some of them can never come back. (L)

When a nurse was particularly close to a family, it was not uncommon for that nurse to maintain a relationship with that family beyond the hospital setting. Pediatric nurses recognized that they had shared something very special with these families and their attachment did not end when the child died. Many participants described long-standing friendships, but not all nurses were comfortable establishing or maintaining a long-term relationship following the death of a child.

Mindy's mom actually came and stayed with me for a weekend after Mindy died.... But, I usually just call a few months down the road to see how they're doing. And then, this is the part where I never know how long. Some people really want to keep in touch, and it's like, I don't know if I want to anymore. I do it for a while, but I don't really want to become a long time friend. (F)

The participants learned that the manner in which a nurse cared for a dying child and family could have a life-long effect on that family. Families seldom forgot who was with them when their child died. Nor did they forget the sensitive, caring relationship that they shared with that nurse.

It doesn't really end, I guess, because I was hospitalized myself last fall. And somehow, people heard. And two mothers came, from children that had died years and years ago. They actually came to see me! And that was really a tear-jerker, you know, because I thought "You actually did this," because I knew that they had never been able to go back into the Children's Hospital. It was too painful for them. So yes, I think even though it's almost impossible to keep up, there is always this tie. (K)

The participants also described the outcomes of casual encounters with families of children who have died. If the death and dying experience has gone well, nurses and families were more likely to go out of their way to talk to each other. If a death experience was unpleasant, nurses and families were more likely to avoid each other and maintain their distance.

Chance meetings at the shopping mall, even, are weird. For some parents, you can just talk, and you can talk about the child now, and you can laugh about things that happened, but for some parents, they can't even say "Hi." They'll just go. (M)

One participant made reference to the additional challenge that nurses face when they are required to face the family again in the near future because the nurses also provide care for a sibling of the recently deceased child.

It was hard dealing with Nancy's family because they have another child, Billy, who has cystic fibrosis and who is probably going to die in the near future. And just knowing that you have to see them again, and all the feelings that surround that, to know that after Nancy had died and everybody had said their good-byes, that maybe in a month Billy would be admitted. It was really quite difficult. I mean, you just have to get over it.... You just deal with it at the time. You say your good-byes and how you feel and then you move on and say okay, now I have

to deal with this other situation. But this mom was extraordinary. She really let us off the hook.... Her attitude towards everything really made us feel a lot better. (H)

9. Enhancing Personal Growth

The participants reflected about how they had learned to care for dying children. They recognized that each death and dying experience had been unique and acknowledged that they learned from each experience. They also noted that each death had brought forward their own personal experiences with death and dying. Accordingly, they advised their nursing colleagues to take time to consider their personal feelings about death and dying before working with anyone in these situations.

It does bring forward your own experiences with death in your own family, your friends. And you have to take a really deep breath and remember what you're there for, who you're there for.... People sometimes forget or get lost in their own feelings when it comes to death and dying, and I think it's really important to know that it's not a time that you should be expressing your own feelings. You may be feeling them, and that may be unavoidable, but you certainly shouldn't be expressing them. I don't think that's right. (F)

"Being comfortable with it" was another priority. Being comfortable with death requires self-confidence, clinical proficiency, and an ability to place oneself in the position of that family.

You have to realize how important your actions and behavior are, what your facial expression is like, what your body expression is like. You have to be cognizant of it all. You just don't go in there without thinking. Parents are sitting in that room, and they look at your face and your expression. They're so aware of that, and I think we just so often forget how important we are to these people. You just have to keep it in mind, why you're there. (F)

Participants noted that for less experienced nurses, these skills required practice, but practice could be difficult to obtain in the acute care setting because of improved

medical therapies and outcomes for formerly fatal childhood illnesses and because a number of parents opted to take their children home to die.

The only way that you can become good is by really looking at your patients all the time so that you can learn when that time is drawing near. When are the subtle changes happening? Are there changes in color?So, nurses really need to monitor those signs and must be able to decide what they're doing with the family. They've got to have really good clinical assessment skills. They have to know how to manage the symptoms. That's the most important thing of all, is managing those symptoms. (A)

The participants also discussed the personal qualities that they felt enhanced the caring relationship with the dying child and family. These qualities included a willingness to become involved, being sensitive to the needs of the child and family, and an ability to share the family's pain when their child has died.

You have to be able to give of yourself. That's what you're doing. You have to be able to open yourself up to the possibility of pain. You can't just be there in this isolated cocoon.... You don't do things in a vacuum. In order to be able to deal effectively with a child's death and with the family, you basically have to make yourself vulnerable, knowing that by doing that, when it happens, it's going to hurt you too. Not just them, but you. But if you don't do that, then I don't think you can make the contact you're going to want to make with the family. So, you're taking a gamble, because to do it is basically to walk head-on into something that you know is going to hurt you. But you do it anyway. (N)

The participants agreed that they have learned from each child's death and reaffirmed that the children and their parents have been their best teachers. These nurses had taken time to reflect after each death event, to consider what could have been done differently, or to remember what behaviors had been especially helpful.

If they were to advise a colleague, the participants would recommend that one learn wherever possible by talking to people with experience. Then, they suggested taking time to analyze one's first death event to form a baseline. Subsequently, thoughtful analysis of each death event could provide valuable lessons.

I don't even call it wisdom because it's something that you learn from death to death. You compare one to the other, and it's not that you get used to the deaths. You never get used to them. But you learn from one to another. You can remember the knowledge that you have, their worries, and you get, not comfortable, but you hesitate less, or you can be more precise, saying, "What is it that you want?" We don't hesitate so much. Your first death, you go around wondering how do you ever approach it. (M)

The participants agreed that their most difficult experiences probably provided the most vivid memories and perhaps the best lessons.

I'll tell you, when Pauline told me, "You're lying, you're lying," I thought my heart fell right to the bottom of my toes. And I thought, "Oh, my God. What have I done?"And I always analyze these things, and go over in my mind how could I have done it better, and what we could have done better. (A)

The participants identified one major deficiency in their working environment that could hinder personal growth. The wards were extremely busy, and following the death of a child, nurses rarely were offered an opportunity to take a few moments to organize their thoughts and feelings before resuming their day's work. The participants felt that most nurses would appreciate being offered some time to "pull themselves together" before facing their other work. Only one participant made reference to the emotional needs of the other children and families on the ward. She stressed the need to be able to answer their questions and support them in their grief because they were well aware that a child they knew had died.

It would be nice if you could have a little, sort of, down time. And because the other people around, chances are, particularly in the next few rooms, I mean, they know. They can sense it. People are going in that room. They're coming out, crying quietly. There's sort of 'activity.' They know, and they'll often ask, you know, "What happened?" And if they knew the child.... Well, of course. Other patients know which child is in that room, and they know the child is not doing well. Well, they'll ask you. And it's very difficult to, sort of, just get yourself together and be able to sit there very calmly, and say, you know, whatever. (N)

Some participants discussed the need for more formal support for staff nurses following the death of a child but there was not agreement regarding what supports would be appropriate.

We've done a lot of things on the ward because, for a while, we had a lot of deaths and we were finding that there wasn't anything. There's nothing for nurses to deal with how they're feeling about death. I mean, it's just sort of an informal thing. Somebody pats you on the back and says "It's going to be okay," and then you go home and do whatever you do, you know, run, or take a bath, or listen to loud music, or whatever it is. So we did a few things. We had one of the nurse psychiatrist people come over and sort of do some de-briefing with us. Which was okay but I found that people grieve differently, and those group grieving things, unless you're that kind of a person, they don't work. And so what happens on our ward, anyway, is that we just sort of talk about it a lot, you know, informally. (H)

10. Responding to Colleagues

The participants worked to develop a close working relationship with their nursing colleagues. Rather than taking personal credit for their work, most insisted that they were just a part of a team and maintained that the team deserved the credit.

It's hard to really take credit for doing something myself because we work as a team a lot. (E)

Although they talked about the team effort, the participants recognized that each member of the team had a certain role to play. Co-workers offered assistance to a colleague who was caring for a dying child and provided emotional support and reassurance.

When a child is dying and it can't be one-on-one nursing, the other nurses are good. Mysteriously, you lose your other four patients, and you've got the time to be with just that child. On the whole the nurses that I work with are really good for trying to help each other out, and if one patient's really special to me, they're there for me, too, because they know it's hard on me to watch, I want to say. "my baby" die. (E)

More experienced nurses also provided encouragement and guidance, and facilitated the learning of their junior colleagues.

For the younger nurses, you would never leave them alone. You would make yourself available.... You would provide an opportunity where they wouldn't feel like it's something they should be doing. You would never make them feel bad if they couldn't do something. (M)

One participant suggested that pediatric nurses also relied on their colleagues for words of commendation and approval, because they were not likely to hear words of praise from other health professionals. However, a second suggested that nurses themselves rarely appreciated what they had given or what their work entailed.

We probably try to talk amongst ourselves about what happens. But we don't do it as often as we should, and we don't do it as a group, to say, "You did a really good job with this." Like, we don't give ourselves enough credit, sometimes, for what we do for a lot of these families. I don't think many of the nurses even realize what they give to these families. It's a natural thing to them. (M)

If a physician was seen to behave in a negative manner, pediatric nurses felt comfortable consulting their nursing colleagues and developing a strategy to address the matter.

I had to write an incident report because this person just wouldn't listen to me. Trevor needed an analgesic but the surgical service said it could wait till morning, but that meant four more hours of pain. The respiratory service did address that and speak to that person. But I had to go to that extreme to make people listen. (M)

If the wrongdoer was a nursing colleague, pediatric nurses behaved differently. The participants acknowledged that most pediatric nurses were reluctant to provide critical feedback to their colleagues. They felt that pediatric nurses would not consider a colleague's conduct to be their responsibility. Nor would they be likely to relay their

observations or concerns to a head nurse or supervisor. Pediatric nurses appear to have difficulty differentiating between the behavior of a colleague and their personality. Even the participants acknowledged that they would more likely excuse a colleague's negative behavior than challenge it.

I try not to focus on the negatives.... Like, maybe you tend to overlook the negative things because there's so many positives. Or, if they happen, you excuse them as happening on a bad day, or there's something else that caused it. (M)

Only one participant provided an example of a situation that could have been different had she received critical feedback from a nursing colleague. This particular nurse has continued to approach inexperienced nursing colleagues to share her story, to help them learn from it and avoid making a similar mistake.

You know, if somebody from the ward would have come and pulled me aside, like, even the head nurse. She must have seen what was going on, because, I mean, I would have seen it. If she would have pulled me aside and even had to slap me in the face and say, "Get a grip on yourself. Do you see what you're doing?" Like, come right out and say, "Valerie's dying. Accept the fact that she's dying." Like, that would have helped. It would have been rough and gruff, but that's the reality orientation that I would have needed.... So I just help the new grads along. I can see how they may fall into the same trap. So whenever we get new grads, I try to relay the story to them in some way or another. (J)

Conclusion

Eleven "expert" pediatric nurses shared the wealth of their knowledge and understanding regarding the nursing care of dying children and their families (see Appendix D). These nurses provided detailed descriptions of the dimensions of care that they considered to be central to pediatric palliative care. Ten key categories emerged from the interview data. The following chapter will include a discussion of the research findings and the author's recommendations for nursing education, practice and research.

CHAPTER VI

Discussion and Recommendations

This final chapter includes: 1) an analysis of the sample, 2) a discussion of the research findings, 3) the relation of the findings to the conceptual framework, 4) consideration of the results in relation to the proposed research questions, 5) recommendations for the integration of these findings with the previous work of Degner, Gow and Thompson (1991) and McClement (1993), 6) limitations of this study and 7) implications for nursing research, education, and practice.

The Sample

The participants in this investigation represented only three nursing units at the Children's Hospital. Therefore, the findings cannot be generalized to all nurses at the Children's Hospital or to pediatric nurses in other institutions. In addition, three potential respondents chose not to participate in this investigation. One offered an explanation that although she has cared for dying children in the past, her experience was not recent enough to make her feel comfortable participating at this time. It is not known why the others chose not to participate. One nurse who declined to participate was featured in the stories of her colleagues as they recalled her relationship with a particular child and family, noting that the child's death had been especially difficult for her. The author wonders whether this nurse declined because it would have been too difficult for her to talk about her relationship with this child and family. It is possible that the nurses who declined to participate would have offered a different perspective on nursing care of dying children and their families.

Pediatric nurses from the emergency ward and the intensive care units were excluded from this study. Consideration of patient demographics from the nursing

department (see Figure 6) revealed that the greatest number of children die in the Intensive Care areas of this particular Children's Hospital. It is probable that nurses from these areas would identify different or additional behaviors.

Many of the participants included the care of the dying child at home in their discussions with the interviewer. The study design specified the care of dying children in the hospital setting but it became apparent that many families chose to have their child die at home and Children's Hospital nurses willingly provided additional care and support for the child and family at home. Data was not available regarding the exact number of children who died at home, but one participant estimated that half of the children with cancer die at home. Since many of these children required additional nursing services in the home, the perspective of community health and home care nurses should also be considered.

Paradigm Cases

Benner (1984) defined paradigm cases as clinical episodes that alter one's way of understanding and perceiving future clinical situations. Paradigm cases stand out in the clinician's mind. While simple lessons are easily learned, complex knowledge requires many paradigm cases. Proficient and expert nurses develop clusters of paradigm cases around different patient care issues.

During the course of the interviews, nursing experts in the care of dying children demonstrated this ability to readily bring to mind clinical situations that altered their approach to pediatric terminal care. Certain children represented paradigm cases for all of the nurses that had cared for them in the pediatric setting. For example, when they were asked to recall an incident in which a student or colleague had a positive attitude toward the care of a dying child or family, all of the nurses from the adolescent ward made reference to the same nurse and her care of a particular child and family. This

incident was notable because it represented the first time that her colleagues had seen this particular nurse extend herself and become involved in an intimate way with a dying child and family. This incident was also notable because the nurse's caring relationship with the family extended to the home and continued well beyond the death of the child. The participants recognized how difficult it had been for their colleague to become involved in this way and they expressed their admiration that even though it had been difficult for her, their colleague had found the strength to "do it."

Participants from the adolescent unit also selected the same cases to exemplify an incident that had gone unusually well and an incident in which there was a breakdown. The first case involved an adolescent male who accepted that he was dying and approached death in a positive way. This boy was surrounded by a loving family and was loved by all the nurses who cared for him. Although his death was painful for everyone, they considered the case to be a paradigm because of the family's ability to communicate and share his death and dying and because the family were able to accept the support and care of the nurses and were able to support each family member in a positive way. The second case involved an adolescent male who suffered a slow, agonizing death. The drawn out suffering of the child and family marked this as a paradigm case for the adolescent nurses because things did not go as planned. The nurses were unable to relieve the child's pain and suffering and could not comfort the parents who endured their child's prolonged suffering. The parents' inability to leave the bedside and their exclusion of their only other child from this lengthy death and dying process were also viewed in negative terms.

It also became apparent that the caring relationship that is formed between pediatric nurses and their patients extends beyond childhood. Most participants from the adolescent unit made reference to a certain young man with cystic fibrosis even though his care had been transferred from the Children's Hospital some years ago. This young

man's case was memorable because it represented the extent of the caring relationship that can develop between pediatric nurses and their patients. Pediatric nurses who knew and loved him maintained a relationship with this young man throughout his many hospitalizations. These nurses proved to be his best supports during his decision to withdraw care and they also were the people who were best able to "be there for him" during his final illness in a General Hospital.

Two paradigm cases were also identified in the stories from the infant/toddler ward. The first involved a beloved couple whose only child was dying. The sudden death of the father in a motor vehicle accident one month before his infant son's death intensified the nurses' relationship with the mother and the extended family. This case exemplified the ability of pediatric nurses to face their personal pain and grief, to share the family's pain and to support the family through the deaths of their loved ones. The second paradigm case involved a young child's coming to terms with his cystic fibrosis and his impending death. The participants identified his desire to know, respected his right to know and recognized that the child felt most comfortable expressing his personal thoughts and feelings to his nurses.

Nursing Behaviors

Ten categories of nursing behaviors were identified in this investigation. Although each category consisted of specific properties or behaviors, particular nursing behaviors appeared in more than one category. In the subsequent discussion, references to each of the ten categories have been underscored. The defining properties, or *behaviors*, that were found within each category have been italicized.

1. Connecting

Connecting represented the caring relationship that developed between nurses, children and families. Davies and O'Berle's (1990) description of the clinical component of the nurse's role in supportive or palliative care included a dimension known as connecting, which referred to the nurse's getting in touch with the patient and family and entering their experience (p. 89). The caring relationship in this investigation was similar. Pediatric nurses shared of themselves in a personal and private way. A mutual intimacy could evolve that demonstrated the willingness of pediatric nurses to make themselves vulnerable to the experience of dying children and their families.

Descriptions of behaviors by pediatric nurses in this investigation did not support Friedman and Huls' (1991) recommendation that distinct boundaries be established among nurses, patients and families. Friedman and Huls (1991) cautioned caregivers not to cross the line between professional and personal intimacy because of the risk of harming patients and their families. In contrast, pediatric nurses in this study suggested that in many instances, things went well because the nurses had been willing to become intimately involved with the children and their families.

Martinson (1983) recognized the need to establish a relationship with the dying child and family in order to recognize and respond to subtle cues regarding treatment and care. The focus of care would then be the physical, emotional and comfort needs of the dying child and family, recognizing the child's emotional need to be cared for and surrounded by loved ones. Coody (1985) described the unique relationship that develops between the dying children, families and their nurses. By getting to know and understand each child and family, pediatric nurses developed a knowledgeable appreciation and sensitivity toward their unique sensitivities and needs. Papadatou (1989) described the need to understand the personal experience of dying adolescents in order to relate meaningfully with them and share the remainder of their life. Davies and Eng (1993)

noted the intensity of the nurse-patient relationship in pediatric chronic illness and terminal care, as evidenced by a long-term investment in time, energy and emotional involvement. Pediatric nurses develop personal and professional relationships with dying children and their families.

Connecting appeared to underlie all the subsequent categories. Nurses repeatedly made reference to the need to know and understand the child and family, to understand their pain and suffering, to fulfill their needs and wishes, and to provide them with the best possible quality of care. This broad interpretation is supported by O'Berle and Davies (1992), who proposed that some degree of Connecting precedes all other dimensions of care. Connecting was not identified in the previous work of Degner, Gow and Thompson (1991), or McClement (1993).

2. Responding to the Family

Most of the properties that comprised Responding to the Family corresponded to existing descriptions in the literature and the previous studies of Degner, Gow and Thompson (1991), and McClement (1993). Degner and her colleagues described behaviors that included or relieved the family of the responsibility for care according to what is best for the family. A similar property in this investigation constructed a broader scope of support--*Behaviors that Supported the Family, Including Them or Relieving Them of the Responsibility for Care According to What's Best for the Family*. The participants recognized that in many instances, other children at home also required their parents' care. Pediatric nurses expressed their interest in and concern about the well-being of those at home and supported parents in their decisions about care of all family members. Participants stressed the need to consider the needs of each family member when planning care. Comparable behaviors were catalogued as Family Care in the review of the literature (see Appendix C).

Bringing Families Together depicted a new element of family care that was not recognized to be a distinct property in previous work of Degner, Gow and Thompson (1991), or McClement (1993). References in the literature could be said to support this dimension in that authors have described the need to focus on the family as the unit of care and to help families dialogue and sort out their experiences (Neidig & Dalgas-Pelish, 1991; Reimer *et al.*, 1991). However, the narratives of pediatric nurses in this investigation introduced an additional perspective that has not been previously described. Pediatric nurses appeared to grasp both the dying child's need to have their family there and the family's need to be there with their child. Pediatric nurses worked to mend rifts between family members and supported fellowship and sharing among family members to enable them to "be there."

Behaviors that Fostered a Homelike Environment were classified as a separate dimension in this investigation. Similar descriptions in the literature were listed under the heading Manipulation of the Environment (see Appendix C). Only within the actual death scene did nurses mention this in palliative care (Degner, Gow & Thompson, 1991). Nor did McClement's (1993) research interpret these behaviors as a distinct entity. Pediatric nurses, on the other hand, clearly identified the surrounding environment to be of significant importance to both dying children and their families. The participants provided detailed descriptions of their efforts to create the best-possible environment for dying children and their families.

Pediatric nurses' descriptions of *Behaviors that Responded to the Family's Need for Information* were analogous to those of palliative care nurses (Degner, Gow and Thompson, 1991) and intensive care nurses (McClement, 1993). Participants identified two additional negative behaviors that could result if the caregiver expected the family to understand and accept what had been said or if the caregiver was threatened by a family's

advanced knowledge about their child's condition. Most references to the family's information needs in the literature provided general descriptions only.

Degner, Gow and Thompson (1991) and McClement (1993) considered cultural and religious interventions to be a component of *Behaviors that Reduced the Potential for Future Regret*. In this investigation, *Behaviors that Supported the Child and Family's Cultural and Religious Beliefs and Practices* appeared as a separate property. While culture and religion were recognized to be essential to the achievement of "total agreement" about the child's care, they were also essential to the child and family's sense of being and living through dying.

The participants recognized that most families relied on their inner beliefs and faith to help them deal with their child's death and dying and reported that the majority of pediatric nurses also turned to faith to understand and "survive" the pediatric deaths they faced. In the review of the literature, spiritual and religious needs were most often combined with psychosocial and emotional needs (Conrad, 1985; Flood, 1989; Gyulay, 1989). Relatively little has been written about the unique spiritual issues surrounding the death of a child (Rando, 1985). Dobratz (1990) included the management of physical, psychological, social and spiritual problems of the dying patient and family in her description of the special skills and knowledge that comprised intensive "caring."

Behaviors that Reduced the Potential for Future Regret matched those described by Degner, Gow and Thompson (1991) and McClement (1993). Descriptions included open and honest communication, understanding the child and family's adjustment, being there for the child and family and staying during difficult times in order to lessen the family's guilt after the death of their child. Similar behaviors in the literature were coded as Patient Feelings and Family Care (Adams, 1985; Adams & Deveau, 1986; Gray, 1989; O'Berle & Davies, 1992).

3. Providing Comfort

Behaviors that Provided Comfort have also been expanded in this investigation. Degner and her colleagues (1991) only made reference to the physical comfort needs of the patient, while McClement (1993) combined physical and psychological pain in her descriptions of providing comfort. The participants in this investigation reported that pediatric nurses not only attended to the physical comfort needs of the dying child (*Behaviors that Reduced Physical Pain and Discomfort*), but also worked to *Satisfy the Dying Child's Psychological and Emotional Needs*. In addition to making the child feel safe and secure in a nurturing environment, pediatric nurses provided acceptance, warmth, and love. Adams (1985) also described this psychosocial dimension of care and recommended that nurses provide dying children with love and care beyond the requisites of physical needs.

4. Enhancing Quality of Life During Dying

Many of the behaviors that depicted Behaviors that Enhanced the Quality of Life During Dying were classified as Patient Feelings and Patient Rights in the review of the literature (see Appendix C). Dying children's need to acknowledge their awareness of their illness and prognosis has been well documented (Adams, 1985; Bluebond-Langner, 1978; Waechter, 1985). Bluebond-Langner (1978) provided in-depth descriptions of the unique information needs and perspectives of dying children. *Behaviors that Responded to the Dying Child's Need for Information* corresponded with Bluebond-Langner (1989, 1978) and Reimer *et al.*'s (1991) recommendations that parents and nurses should respond to the cues of the children, answering only what the children want to know using everyday language.

Behaviors that Helped Dying Children Do Things that were Important to Them were similar to descriptions provided by palliative care nurses (Degner, Gow, &

Thompson, 1991) and intensive care nurses (McClement, 1993). Pediatric nurses recognized dying children's need to be recognized and respected and helped them to find meaning and purpose in living (Adams, 1985; Bluebond-Langner, 1978; Davies & O'Berle, 1990; Gray, 1989; O'Berle & Davies, 1992; Papadatou, 1989; Reimer, Davies & Martens, 1991). Similar behaviors were classified as Patient Rights in the review of the literature (see Appendix C).

Some similarity to *Behaviors that Made Dying Children Feel Special* was found in Davies and O'Berle's (1990) dimension of palliative care called Valuing. Valuing provided the contextual basis for all nursing activities. It was broken down into two components, *Global* and *Particular*. The *Global* component reflected respect for the inherent worth of others, whereas the *Particular* component represented the nurse's understanding of each individual's unique abilities and characteristics.

One reference to *Behaviors that Made Dying Children Feel Special* was found in the literature. Hockenberry-Eaton and Minick's (1994) phenomenological study of school-age children's experiences with cancer identified a number of themes that influenced children's thoughts and feelings and provided strength during treatment. These children were made to feel special by others, and reported that this specialness provided them with much support during treatment. *Making Dying Children Feel Special* reflected the ability of pediatric nurses to treat dying children as unique individuals. Through particular gestures of thoughtfulness and caring, pediatric nurses demonstrated their "knowing" what was important to a particular child.

5. Responding to Anger

The term "Anger" was neglected in the literature, but general behaviors that had been classified as Supporting Colleagues and Family Care (see Appendix C) included: allowing colleagues to vent their feelings (Benoliel, 1988), listening when the family

voices their concerns (Reimer, *et al.*, 1991) and helping families to work things out (Reimer, *et al.*, 1991). Responding to Anger included one dimension previously described by Degner, Gow and Thompson (1991), and McClement (1993), *Behaviors that Demonstrate Respect, and Empathy, even when Anger was Directed at the Nurse*. In this investigation, the term “Nurse” was replaced with “Health Care Team” because in many instances the child or parents had expressed anger at their physicians. Nursing responses to family’s expressions of anger were similar to those described by Degner, Gow and Thompson (1991), and McClement (1993).

The participants in this investigation reported a number of incidents in which specific behaviors were required to *Promote Resolution When Anger Occurred Within the Health Care Team*. This component of anger within the health care team that has not been previously described. Even though Adams (1985) recognized that conflicting expectations could occur when palliative care was provided in the acute care setting, specific strategies were not provided to address the sources of conflict at that particular institution. Instead, nurses were encouraged to find solace away from the strain of caring. The participants in this investigation reported that a failure to resolve disputes within the health care team could result in sustained anger and the resulting conflict could hinder the entire team’s ability to provide proper terminal care.

6. Facilitating the Transition to Palliative Care

Some overlap existed between *Promoting Resolution When Anger Occurred Within the Health Care Team*, and Facilitating the Transition to Palliative Care. While a family could be angry about their child’s disease, treatment, care, and caregivers, the health care team could be angry about case management and treatment decisions. In many instances, pediatric nurses’ anger was a result of the health care team’s inability to make what the nurses felt were appropriate palliative care decisions. Pediatric nurses felt

that decisions to shift from active care to supportive care are even more difficult when the patient is a child. The participants described pediatric nurses' ability to advocate for the children. In many instances, pediatric nurses were key in facilitating the transition to palliative care.

Degner, Gow and Thompson's (1991) investigation failed to disclose behaviors that facilitated the transition, however the authors noted that this transition had likely occurred prior to admission to the palliative care unit. McClement (1993) classified facilitating the transition as a dimension of Responding to the Family, but in this investigation it was observed to be a separate entity. The participants described the difficulties associated with a child's death and dying that could compromise a nurse's ability to acknowledge a child's dying, and hindered the provision of suitable care.

Pediatric nurses not only facilitated the transition of the child and family, they also facilitated the health care team's transition toward palliative care. The recommendations of Bluebond-Langner (1978), Freyer (1992), and Papadatou (1989) about the care of dying children corresponded to the recommendations of the pediatric nurses in this study. Pediatric nurses were encouraged to share a truthful, meaningful relationship with the dying child (Papadatou, 1989), and to acknowledge the dying child's thoughts and feelings about their life and death (Bluebond-Langner, 1978; Zelig, 1974).

The participants also reported that pediatric nurses facilitated expression of parental grief during the transition to palliative care. These findings were supported by Adams (1985), Neidig and Dalgas-Pelish (1991), and Reimer *et al.* (1991). Pediatric nurses responded to psychological, spiritual, and ethical issues that surrounded parental grief and loss, and help parents to find their place in the world of their dying child. Pediatric nurses prepared families for what lay ahead.

7. Responding During the Death Scene

Few authors have specifically addressed the importance of nursing behaviors at the time of death. Most authors' references that had been categorized as Family Care (see Appendix C) included more general recommendations, such as: calming fears (Ryan, 1992), being available (Reimer, *et al.*, 1991; Ryan, 1992), providing information (Adams, 1985; Kristjanson, 1985; Neidig & Dalgas-Pelish, 1991), and providing emotional support (Ashby *et al.*, 1991; Flood, 1989; Gyulay, 1989; Martinson *et al.*, 1979, 1978; Ross-Alaolmolki, 1985). Degner, Gow and Thompson (1991), and McClement (1993) provided more detailed descriptions of specific nursing behaviors that could be employed at the time of death, which they called Responding During the Death Scene. A similar category was identified in this investigation, with properties that may be unique to the pediatric setting.

Pediatric nurses *Acknowledged the Child's Dying* to both child and family. A number of authors have corroborated the need to acknowledge the child's awareness of serious illness and impending death (Bluebond-Langner, 1978; Faulkner, Peace & O'Keeffe, 1993; Green-Epner, 1976; Gyulay, 1989; Kübler-Ross, 1983; Kuykendall, 1989; Thoma *et al.*, 1993; Waechter, 1985, 1971). Support was found for Gray's (1989) recommendation that dying children be given permission to die.

The participants stressed the need to prepare the family for the child's imminent death. This interpretation was supported by Chekryn (1985), Reimer, *et al.* (1991), Ryan (1992), and Thoma *et al.* (1993). Pediatric nurses then *Supported the Child and Family as Death Approached*. This interpretation differed slightly from Degner, Gow and Thompson's (1991) *Behaviors that Maintained Family Involvement*, since participants recognized that by giving control back to the family, the nurse allowed the family to choose whomever they wanted to be with them, and how involved the family wanted to be. Pediatric nurses then responded to the wishes of the family, *Including or*

Relieving Them of Responsibility According to the Preference of the Family. Participants preferred that someone who loved the child be with the child at the time of death. Martinson (1983), and Zeligs (1974) also discussed the need for a loved one to be with the child through the last moments of life.

Descriptions of *Behaviors that Maintain a Sense of Calm* were similar to those of Degner, Gow and Thompson (1991). Pediatric nurses preferred a tranquil environment and recommended behaviors and mannerisms that maintained a calm, gentle bedside scene.

8. Responding After Death has Occurred

McClement (1993) described a category of nursing behaviors that occurred following a death entitled Responding After Death has Occurred. Her first property, *Behaviors that Created a Peaceful Bedside Scene Following a Death*, was not identified in this investigation but her descriptions of *Behaviors that Supported the Realization of Death* and *Behaviors that Demonstrated Respect for the Body during Post-Mortem Care* were strikingly similar to the descriptions of the pediatric nurses in this investigation.

Pediatric nurses recognized the family's need to spend time alone with their deceased child and were sensitive to the family's emotional turmoil as they departed from the hospital and left their deceased child behind. These behaviors have been previously described by Reimer *et al.* (1991), and Ufema (1991). Families need time to disengage and many also need help to say good-bye to their dead child.

One variation in the dimension of *Post-Mortem Care* was notable. The pediatric participants reported, as did McClement (1993), that families often wished to participate in the preparation of the body of their loved one. In the pediatric world, many parents also chose to accompany the nurses as they transported the child's body to the morgue. The involvement of families in this final task has not been described previously.

An additional new dimension, *Behaviors that Supported the Family Beyond the Death of their Child*, received some support in the literature. Neidig and Dalgas-Pelish (1991) identified the need for professionals to recognize the intensity of the parental grief response, reporting that it could be especially prolonged. The caring behaviors that they recommended following the death of a child included demonstrations of sensitivity, compassion, and understanding. *Supporting Beyond* evidenced an enduring, caring relationship between pediatric nurses and bereaved families that has not been previously described.

9. & 10. Enhancing Personal Growth and Supporting Colleagues

The categories Enhancing Personal Growth and Supporting Colleagues were comparable to those described by Degner, Gow and Thompson (1991), and McClement (1993). These behaviors were also supported by descriptions of Nurses' Feelings Supporting Colleagues in the review of the literature (see Appendix C).

Participants' descriptions of their personal growth resembled Coody's (1985) depiction. Pediatric nurses developed an awareness of how best to care for each particular child and family. This developing awareness reflected personal growth, maturation, and adaptation that occurred over a period of years. One participant identified that an ability to make oneself vulnerable to the hurt and pain of a child's death and dying could enable one to care in a more intimate way. This depiction of caregiver vulnerability and intimacy in terminal care was analogous to that of Friedman and Huls (1991).

Pediatric nurses were able to support their nursing colleagues in a positive way, but they expressed discomfort at the prospect of providing critical feedback. There did not appear to be a clearly defined role for experienced nurses to correct or advise their

colleagues or to share their expertise in care of the dying. Similar findings were reported by Degner, Gow and Thompson (1991), and McClement (1993).

The participants have provided clear examples of critical nursing behaviors and the consequences when these behaviors were lacking in the care of dying children and their families. Storytelling allowed them to recreate the powerful emotional reality of each death and dying situation. Participants described the sensitivity, compassion, and personalized care that comprised their expert clinical practice in the care of dying children and their families. Narrative accounts of their personal experiences illustrated the context-dependent nature of this expert nursing practice. Although many nursing behaviors in the care of the dying have been outlined in the literature, behaviors tend to be summarized in general terms. Explicit descriptions and explanations of nursing behaviors in the care of the dying and the care of dying children and their families were rare, as were references to negative nursing behaviors and the impact of such negative behaviors on care.

Relation of the Research Findings to the Conceptual Framework

Quint (1967) maintained that nurses exposed to the care of the dying without accompanying educational support would adopt the behavior of professionals around them and would limit their involvement in death-related situations. She suggested that if nurses were to receive systematic death education with planned assignments, they would be less likely to withdraw from care of the dying. Quint's research based model provided the theoretical orientation for Degner and Gow's (1988) longitudinal evaluation of death education in nursing. Degner and Gow's findings supported those suggested by Quint. They identified that one year after graduation, nurses who as students had received death education that included clinical practice reported more approach behaviors in care for the

dying than did a control group and reportedly felt more adequate in caring for the dying. This experimental group also judged their undergraduate program to have been more adequate in preparing them for care of the dying than did the nursing control group.

Degner and Gow (1988) proposed that direct involvement in care of the dying could influence student nurses' attitudes and their subsequent behaviors in the care of the dying. They recognized the need for research-based knowledge to guide practice in the care of the dying. They employed Benner's (1984) methodology to identify nursing experts in the care of the dying in their 1991 investigation. The knowledge embedded in the practice of palliative care nurses and educators deemed "expert" in the care of the dying was revealed through description and analysis of tape-recorded critical incidents. McClement (1993) employed a similar methodology in her study of nursing care for the dying in the intensive care setting.

Benner's methodology allowed the identification of fourteen pediatric nurses who were deemed expert in the care of dying children and their families in the hospital setting. Eleven of these nurses participated in this investigation. Most seemed surprised that they had been nominated by their colleagues, stating they did not believe they did anything special or different when caring for dying children and their families. This response supported Benner's (1984) interpretation that clinical knowledge is gained over time and that clinicians are often unaware of their clinical achievements.

The personal experiences of a number of participants with particular death and dying incidents have had a lasting impact upon their responses to subsequent death and dying situations. Many found it necessary to recall their first death and dying experience from both a personal and a professional perspective. In most cases, this first experience was unforgettable and had served as the guide for their subsequent nursing practice.

Some participants recognized the unique personal qualities that enhanced their ability to care for dying children, but most considered themselves to be members of a

caring team, attributing successes to the team rather than to themselves. Nevertheless, when the participants began to talk about particular cases, their narratives reflected their ability to recognize special qualities in their colleagues and themselves, and talking provoked many to reflect about their nursing practice. Their descriptions supported Benner's (1984) interpretation that the perceptual grasp of expert nurses was context-dependent. Attig (1992) has suggested that nurses often employ story-centered knowledge in their daily practice.

A number of participants experienced a discovery process during the interview. The opportunity to sit back and think about what they had been doing for so many years and to express their thoughts and feelings challenged them to recognize exactly what they do for dying children and their families. These pediatric nursing experts demonstrated an ability to evaluate their judgments and opinions in actual patient care situations, and were able to elaborate upon the distinct nursing behaviors and abilities that enhanced the care of dying children and their families.

Relationship of the Research Findings to the Proposed Research Questions

The first two research questions addressed behaviors that expert pediatric nurses would describe as 1) having a positive influence on the care of the dying child in the hospital setting, and 2) having a negative influence on the care of the dying child in the hospital setting. The third and final query was to compare the behaviors identified in this investigation with those identified by Degner, Gow and Thompson in their 1991 investigation.

Content analysis of the transcriptions from the semi-structured interviews with eleven pediatric nursing experts in the care of dying children and their families led to the identification of ten categories of critical nursing behaviors. The researcher was able to develop operational definitions for each category which characterized both positive and

negative aspects of nursing behaviors for each property. The participants were asked to review the findings, and they responded that the researcher's descriptions accurately reflected their perceptions. Suggested changes in language and detail were easily achieved.

Comparison of results with those of Degner, Gow and Thompson (1991), and McClement (1993) revealed that several similarities exist between the three sets of data. Nevertheless, this investigation has identified a number of nursing behaviors that may be unique to the pediatric setting.

Recommendations for the Integration of Nursing Research Findings

Degner, Gow and Thompson (1991) developed a beginning list of critical behaviors in the care of the dying that served as a preliminary guide for structured nursing education programs regarding care of the dying. McClement (1993) was able to identify additional behaviors in the critical care setting, and this investigation has revealed a number of unique behaviors that are critical in the pediatric setting. Integration of these beginning lists of critical behaviors that have been drawn from various clinical settings will assist in the development of a model of expert nursing practice in the care of the dying. Such a model would not only guide nursing practice but would also provide a research-based framework to guide future education and research.

Limitations of this Study

The demographic data collected from the participants in this investigation did not specifically address whether any of the participants had ever received formal education or training in the care of the dying in general, or the care of dying children in particular. It would have been helpful to have considered their perceptions of their education and training.

One criticism that suggested that the Degner, Gow and Thompson (1991) framework is solely interventional (Reimer & Davies, 1991) may be unfounded. This investigation with eleven nursing experts in the care of dying children and their families has demonstrated the levels of assessment and planning that precede patient and family care decisions. This study demonstrates the "responsive" nature of nursing that characterizes caring for the dying child and family.

Nursing Implications

Nursing education in the care of the dying has been known to be deficient. Although formal education programs have been adopted by many institutions, there is much to be learned about what constitutes effective care for the dying. It is important that nursing educators be aware of ongoing research in the area of terminal care. Greater attention should be given to students who are directing their studies toward care of the seriously ill in the pediatric setting.

Educational programs should include general information regarding death and dying, grief reactions, family assessment, communication skills, and the concept of intimacy in caregiving. This study has revealed that intimacy in the care of dying child and family should not be considered unprofessional.

Consideration should also be given to the format of education programs. The relevance and impact of critical nursing behaviors in such terminal care situations could be lost if these behaviors are not considered in a context-dependent manner. The stories of nursing experts should be considered appropriate educational material for nursing students.

The patient population in this particular institution is such that exposure of most student nurses to a dying child would be difficult, there being less than twelve such patients each year. Alternatives might well include video-taped, or tape-recorded

narratives of nurses such as those who contributed to this work. However, an even more meaningful learning experience might well be presentations of personal experiences and reflections by experienced nurses or parents. Educators are encouraged to provide support and encouragement to their students during educational encounters or any clinical interactions with dying children and their families.

Recommendations for nursing practice have also been identified. Nursing administrators are encouraged to demonstrate sensitivity toward staffing requests when they relate to the care of a dying child, and should also be aware of nurses' need for "time to grieve and recover" immediately following a death and dying event. Colleagues should not only be encouraged to provide emotional support to one other, but should also be made aware of the importance of critical feedback in terminal care situations. Staff nurses seem to have difficulty separating their colleagues' behaviors from their personalities. Inservice education may be required to facilitate the provision of critical feedback.

Pediatric nurses are encouraged to get to know dying children and their families well in order to understand the unique meaning of their death and dying experience. Such patient and family assessment would facilitate the identification of individual needs, including information needs. The provision of timely and accurate information is important, and should include information that prepares the child and family for the death event and the family's subsequent bereavement. The recognition of additional needs or concerns would allow the nurse to include other health professionals in the plan of care. Persons caring for terminally ill children are encouraged to provide responsive care rather than prescriptive care.

This investigation only considered the perceptions of eleven pediatric nurses from the general wards of one pediatric institution. Pediatric emergency and critical care nurses were excluded from this study. In addition, the participants revealed that many

children choose to die at home. Repetition of this investigation in the home-care setting would be appropriate. It would also be important to repeat this investigation with other pediatric nurses in a variety of institutional and community settings to identify whether they would report a different list of behaviors in the care of dying children. This initial list may be incomplete.

The patient population was restricted to infants, young children, and adolescents. The knowledge and experience of neonatal, pediatric and adult nurses from different settings should also be explored to consider a variety of perspectives in the care of the dying. Finally, consideration of caring behaviors from the perspective of dying children and their families could refute or further validate those behaviors that have been identified in this investigation.

Conclusion

This investigation has expanded upon the previous investigations of Degner, Gow and Thompson (1991), and McClement (1993) to provide detailed descriptions of caring behaviors when the dying patient is a child. The essence of the caring relationship that develops between pediatric nurses, dying children and their families underlies all other components of care. Responding to the family considers the stage of the family, the developmental needs of the dying child, siblings, parents, extended family, and dear friends. Religion was also recognized to be an important component of care for both child and caregiver.

When providing comfort, pediatric nurses not only attend to physical and psychological pain but also recognize the child's developmental and emotional need to be loved and nurtured. Comfort and the need to be informed are quality of life issues, as are the exceptional things that pediatric nurses commonly do to make dying children feel special.

Significant difficulties arise when making the transition to pediatric palliative care. These difficulties are often the root of anger and conflict between families and caregivers, and between health care team members. Pediatric nurses recognize that a child's terminal illness and death represent a difficult time for both family and caregivers. In many instances, a pediatric nurse will maintain contact with a family for an extended period of time following the death of their child.

The participants were able to describe the role that they have played in caring for dying children and their families. They contemplated personal experiences and those of their colleagues, and understood the personal attributes that enhanced the nursing care of the dying child and family. Participants clearly described the nursing behaviors that are critical to the care of the dying child and family, and the consequences when these behaviors are not present. A number of the behaviors that emerged in this investigation have not been previously described.

This initial list of critical nursing behaviors in the care of dying children and their families remains incomplete. More information is needed to better understand such unique attributes of pediatric nursing care as connecting, and the blurred boundaries surrounding a nurse's "work." It would also be interesting to consider the possibility or potential of developing this type of reciprocity and intimacy of relationship in the adult world. One can only imagine what might unfold if nurses were to abandon parentalism in the care of the dying adult. The differences might be most notable in the acute care setting.

Knowledge generated from the critical nursing behaviors identified in this study can serve as a guide to those designing nursing education programs regarding care of the dying, in general, and the care of dying children and their families, in particular. The inclusion of nursing behaviors in the care of dying children in educational curricula could

result in students feeling better prepared to care for chronically ill and dying children and could improve students' perceived adequacy in such care.

Degner and Gow (1988) noted that although more attention has been directed toward death education in recent years, few educational programs have been systematically evaluated. There is an ongoing need to evaluate death education programs. The inclusion of critical nursing behaviors in the care of dying children in a death education program should be followed by some measure of its impact on student nurses. Measures could include assessment of death anxiety levels and appraisal of student nurses' perceived comfort in approaching dying children and their families.

Nursing behaviors that have been identified as a result of this study could also serve as a beginning guide to nurses in pediatric practice. The identification of empirically based interventions, and development of an awareness that there are specific behaviors that can be employed when caring for a dying child and family could help to diminish pediatric nurses' feelings of helplessness and inadequacy.

This study represents one of a series of comparative studies conducted by Dr. L. Degner and her associates. Nurses from a variety of clinical settings have participated in these investigations. It is hoped that the results of these various studies will contribute toward the development of a model of expert nursing practice in the care of the dying.

REFERENCES

- Adams, D. W. (1985). Helping the dying child. Practical approaches for non physicians. Issues in Comprehensive Pediatric Nursing, 8(1/6), 95-113.
- Adams, D. W. & Deveau, E. J. (1986). Helping dying adolescents: Needs and responses. In C. A. Corr & J. N. McNeil (Eds.). Adolescence and death. (pp. 79-96). New York: Springer Publishing.
- Adams, D. W. & Deveau, E. J. (1987). When a brother or sister is dying of cancer: The vulnerability of the adolescent sibling. Death Studies 11(4), 279-295.
- American Academy of Pediatrics Committee on Bioethics (1994). Guidelines on forgoing life-sustaining medical treatment. Pediatric Nursing, 20(5), 517-522.
- Anthony, S. (1940). The child's discovery of death. New York: Harcourt Brace.
- Ashby, M. A., Kosky, R. J., Laver, H. T. & Sims, E. B. (1991). An enquiry into death and dying at the Adelaide Children's Hospital: A useful model? Medical Journal of Australia, 154, 165-170.
- Attig, T. (1992). Person-centered death education. Death Studies 16: 357-370.
- Back, K. J. (1991). Sudden, unexpected pediatric death: caring for the parents. Pediatric Nursing, 17(6), 571-575.
- Bearison, D. J. (1991). Talking with children who have cancer. "They'll never want to tell you" -- Children talk about cancer. (pp. 3-26). Cambridge: Harvard University Press.
- Bendor, S. J. (1989). Preventing psychosocial impairment in siblings of terminally ill children. Hospice Journal, 5(3/4), 153-163.
- Benner, P. (1984). From novice to expert. Excellence and power in clinical nursing practice. Melno Park: Addison-Wesley Publishing Company.
- Benoliel, J. Q. (1972). Nursing care for the terminal patient: a psychosocial approach. In B. Schoenberg, A. C. Carr, D. Peretz & A. H. Kutscher (Eds.). Psychosocial aspects of terminal care. (pp. 145-161). New York: Columbia University.
- Benoliel, J. Q. (1985). Loss and terminal illness. Nursing Clinics of North America 20(2), 439-448.
- Birenbaum, L. K. & Robinson, M. A. (1991). Family relationships in two types of terminal care. Social Science and Medicine, 32(1), 95-102.
- Bluebond-Langner, M. (1978). The private worlds of dying children. Princeton: Princeton University Press.

- Bluebond-Langner, M. (1989). Worlds of dying children and their well siblings. Death Studies, 13: 1-16.
- Brink, P. J. & Wood, M. J. (1989). Advanced design in nursing research. London: Sage Publications.
- Brockopp, D. (1987). Palliative care: Essential concepts in the education of health professionals. Journal of Palliative Care, 2(2), 18-23.
- Bull, M. (1985). Global exchange commentary: Helping children cope with death. Journal of Palliative Care, 1(1), 43-45.
- Cahill, C., Panzarella, C. & Spross, J. A. (1990). Pediatric cancer pain. Oncology Nursing Forum, 17(6), 948-951.
- Campbell, T., Abernethy, V. & Waterhouse, G. J. (1983). Do death attitudes of nurses and physicians differ? Omega, 14(1), 43-49.
- Carlson, P., Simacek, M., Henry, W. F. & Martinson, I. M. (1985). Helping parents cope: A model home-care program for the dying child. Issues in Comprehensive Pediatric Nursing, 8(1/6), 113-127.
- Carpenter, P. J. (1992). Behavioral approaches in pediatric patients. American Journal of Hospice and Palliative Care, 9(6), 35.
- Caty, S. & Tamlyn, D. (1984). Positive effects on nursing students' attitudes toward death and dying. Nursing Papers--Perspectives En Nursing, 16(4), 41-53.
- Chekryn, J. (1985). Support for the family of the dying patient. Home HealthCare Nurse, 3(3), 18-24.
- Childers, P. & Wimmer, M. (1971). The concept of death in early childhood. Child Development, 42(4), 1299-1301.
- Coleman, F. W. & Coleman, W. S. (1985). Helping siblings and other peers cope with dying. Issues in Comprehensive Pediatric Nursing, 8(1/6), 129-150.
- Connolly, M. (1994). Partners in care. Nursing Times, 90(44), 58-61.
- Conrad, N. L. (1985). Spiritual support for the dying. Nursing Clinics of North America, 20(2), 415-425.
- Coody, D. (1985). High expectations: Nurses who work with children who might die. Nursing Clinics of North America, 20(1), 131-142.
- Corless, I. B. (1994). Dying well: Symptom control within hospice care. Annual Review of Nursing Research, 12: 125-146.
- Corner, J. (1991). Cancer nursing research. Nursing Times, 87(37), 42-44.
- Corr, C. A. & Corr, D. M. (1985). Pediatric hospice care. Pediatrics, 76(5), 774-780.

- Cotton, C. R. & Range, L. M. (1990). Children's death concept: Relationship to cognitive functioning, age, experience with death, fear of death, and hopelessness. Journal of Clinical Child Psychology, 19(2), 123-127.
- Crane, D. (1970). Dying and its dilemmas as a field of research. In O. G. Brim, E. H. Freeman, S. Levine & N. A. Scotch (Eds.). The dying patient. (pp. 303-325). New York: Russell Sage.
- Davies, B. & Eng, B. (1993). Factors influencing nursing care of children who are terminally ill. A selective review. Pediatric Nursing, 19(1), 9-14.
- Davies, B. & O'Berle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. Oncology Nursing Forum, 17(1), 87-94.
- Davies, B., Chekryn Reimer, J. & Martens, N. (1994). Family functioning and its implications for palliative care. Journal of Palliative Care, 10(1), 29-36.
- Dawson, N. J. (1991). Need satisfaction in terminal care settings. Social Science and Medicine, 32(1), 83-87.
- Degner, L. F. & Beaton, J. I. (1987). Life-death decisions in health care. New York: Hemisphere Publishing Company.
- Degner, L. F. & Gow, C. M. (1988). Evaluations of death education in nursing: a critical review. Cancer Nursing, 11(3), 151-159.
- Degner, L. F. & Gow, C. M. (1988). Preparing nurses for care of the dying. A longitudinal study. Cancer Nursing, 11(3), 160-169.
- Degner, L. F., Gow, C. M. & Thompson, L. A. (1991). Critical nursing behaviors in care for the dying. Cancer Nursing, 14(5), 246-253.
- deHennezel, M. (1989). Denial and imminent death. Journal of Palliative Care, 5(3), 27-31.
- Dobratz, M. C. (1990). Hospice nursing: Present perspectives and future directives. Cancer Nursing, 13(2), 116-122.
- Dominica, F. (1987). The role of the hospice for the dying child. British Journal of Hospital Medicine, 38(4), 334-336, 340-343.
- Duffy, C. M., Pollock, P., Levy, M., Budd, E., Caulfield, L. & Koren, G. (1990). Home-based palliative care for children--Part 2: The benefits of an established program. Journal of Palliative Care, 6(2), 8-14.
- Dufour, D. F. (1989). Home or hospital care for the child with end-stage cancer: Effects on the family. Issues in Comprehensive Pediatric Nursing, 12(5), 371-383.
- Faulkner, A., Peace, G. & O'Keeffe, C. (1993). Future imperfect. Nursing Times, 89(51), 40-42.

- Faulkner, A., Webb, P. & Maguire, P. (1991). Communication and counseling skills: Educating health professionals working in cancer and palliative care. Patient Education and Counseling, 18(1), 3-7.
- Flood, D. M. (1989). Handle with care. Canadian Nurse, 85(4), 24-26.
- Florian, V. (1985). Children's concept of death: an empirical study of a cognitive and environmental approach. Death Studies, 9: 133-141.
- Florian, V. & Har-Ever, D. (1983). Fear of personal death: The effects of sex and religious belief. Omega, 14(1), 83-91.
- Franke, K. J. & Durlak, J. A. (1990). Impact of life factors upon attitudes toward death. Omega, 21(1), 41-49.
- Franklin, P. (1994). Straight talking. Nursing Times, 90(8), 33-34.
- Freyer, D. R. (1992). Children with cancer: Special considerations in the discontinuation of life-sustaining treatment. Medical and Pediatric Oncology, 20(2), 136-142.
- Friedman, N. & Huls, J. (1991). Intimacy: The cornerstone of caring. American Journal of Hospice & Palliative Care, 8(2), 31-35, 44.
- Friedman, S. B., Chodoff, P., Mason, J. W. & Hamburg, D. A. (1963). Behavioral observations on parents anticipating the death of a child. Pediatrics, 32, 610-625.
- Futterman, H., Hoffman, I. & Sabshin, M. (1972). Parental anticipatory mourning. In B. Schoenberg, A. C. Carr, D. Peretz & A. H. Hutscher (Eds.). Psychosocial aspects of terminal care. (pp. 243-271). New York: Columbia University.
- Gartner, C. R. (1976). Growing up to dying: The child, the parents, and the nurse. In R. E. Caughill (Ed.). The dying patient. A supportive approach. (pp. 159-190). Boston: Little, Brown & Company.
- Gibbons, M. B. (1992). A child dies, a child survives: the impact of sibling loss. Journal of Pediatric Health Care, 6(2), 65-72.
- Graham-Pole, J., Wass, H., Eyberg, S., Chu, L. & Olejnik, S. (1989). Communicating with dying children and their siblings. Death Studies, 13(5), 465-483.
- Gray, E. (1989). The emotional and play needs of the dying child. Issues in Comprehensive Pediatric Nursing, 12(2/3), 207-224.
- Green-Epner, C. S. (1976). The dying child. In R. E. Caughill (Ed.). The dying patient. A supportive approach. (pp. 125-157). Boston: Little, Brown & Company.
- Gronseth, E. C., Martinson, I. M., Kersey, J. H. & Nesbit, M. E. (1981). Support system of health professionals as observed in the project of home care for the child with cancer. Death Education, 5, 37-50.

- Gullal, J. P. (1992). Family assessment and its relation to hospice care. American Journal of Hospice & Palliative Care, 9(4), 30-34.
- Gyulay, J. - E. (1989). Home care for the dying child. Issues in Comprehensive Pediatric Nursing, 12(1), 33-69.
- Hall, M. D. (1990). The way it is. American Journal of Nursing, July, 86.
- Hare, J. & Pratt, C. C. (1989). Nurses' fear of death and comfort level with dying patients. Death Studies, 13, 349-360.
- Heslin, K. & Bramwell, L. (1989). The supportive role of the staff nurse in the hospital palliative care situation. Journal of Palliative Care, 5(3), 20-26.
- Hickey, S. S. (1986). Enabling hope. Cancer Nursing, 9(3), 133-137.
- High, D. M. (1989). Truth telling, confidentiality and the dying patient: New dilemmas for the nurse. Nursing Forum, 24(1), 5-10.
- Hockenberry, M., Coody, D. K. & Bennett, B. S. (1990). Childhood cancers: Incidence, etiology, diagnosis and treatment. Pediatric Nursing, 16(3), 239-246.
- Hockenberry-Eaton, M. & Benner, A (1990). Patterns of nausea and vomiting in children: Nursing assessment and intervention. Oncology Nursing Forum, 17(4), 575-584.
- Hockenberry-Eaton, M. & Minick, P. (1994). Living with cancer: Children with extraordinary courage. Oncology Nursing Forum, 21(6), 1025-1031.
- Hoffman, S. I. & Strauss, S. (1985). The development of children's concepts of death. Death Studies, 9, 469-482.
- Hunt, M. & Meerabeau, L. (1993). Purging the emotions: the lack of emotional expression in subfertility and in the care of the dying. International Journal of Nursing Studies, 30(2), 115-123.
- Katsenbaum, R. (1991). Death, society, and human experience. (4th Edition). Toronto: Collier Macmillan Canada, Inc.
- Katsenbaum, R. (1967). The child's understanding of death: how does it develop? In E. A. Grossman (Ed.). Explaining death to children. (pp. 89-108). Boston: Beacon Press.
- Kincade, J. E. & Powers, R. (1984). An assessment of palliative care needs in a tertiary care hospital. Q. R. B.: Quality Review Bulletin, 10(8), 230-237.
- Koocher, G. (1974). Talking with children about death. American Journal of Orthopsychiatry, 14(3), 404-411.
- Kristjanson, L. J. (1989). Quality of terminal care: Salient indicators identified by families. Journal of Palliative Care, 5(1), 21-28.

- Kübler-Ross, E. (1969). On death and dying. New York: Macmillan Publishing Company.
- Kübler-Ross, E. (1983). The natural way to prepare children for life. On children and death. (pp. 60-76). New York: Macmillan Publishing.
- Kuykendall, J. (1989). Death of a child -- the worst kept secret around. In L. Sherr (Ed.). Death, dying and bereavement. An insight for caregivers. (pp. 112-122). Boston: Blackwell Scientific.
- Lauer, M. E., Mulhern, R. K., Hoffmann, R. G. & Camitta, B. M. (1986). Utilization of hospice/home care in pediatric oncology. A national survey. Cancer Nursing, 9(3), 102-107.
- LeBaron, S. & Zeltzer, L. K. (1985). The role of imagery in the treatment of dying children and adolescents. Developmental and Behavioral Pediatrics, 6(5), 252-258.
- Levy, M., Duffy, C. M., Pollock, P., Budd, E., Caulfield, L. & Koren, G. (1990). Home-based palliative care for children -- Part 1: The institution of a program. Journal of Palliative Care, 6(1), 11-15.
- Lockard, B. E. (1989). Immediate, residual and long-term effects of a death education instructional unit on the death anxiety level of nursing students. Death Studies, 13, 137-159.
- Lubin, S. (1992). Palliative care--Could your patient have been managed at home? Journal of Palliative Care, 8(2), 18-22.
- Maguire, P. (1985). Barriers to psychological care of the dying. British Medical Journal, 291, 1711-1713.
- Maguire, P. & Faulkner, A. (1988). How to do it -- Improve the counselling skills of doctors and nurses in cancer care. British Medical Journal, 297: 847-849.
- Maguire, P. & Faulkner, A. (1988). Communicate with cancer patients: 1. Handling bad news and difficult questions. British Medical Journal, 297: 907-909.
- Maguire, P. & Faulkner, A. (1988). Communicate with cancer patients: 2. Handling uncertainty, collusion and denial. British Medical Journal, 297: 972-974.
- Martinson, I. M. (1993). Hospice care for children: Past, present and future. Journal of Pediatric Oncology Nursing, 10(3), 93-98.
- Martinson, I. M. (1979). Caring for the dying child. Nursing Clinics of North America, 14(3), 467-474.
- Martinson, I. M. (1983). Care of the dying child--part 1. Nursing Times, 79(11), 56-57.
- Martinson, I. M. (1983). Care of the dying child--part 2. Nursing Times, 79(12), 63-64.

- Martinson, I. M., Armstrong, G. D., Geis, D. P., Anglim, M. A., Gronseth, E. C., MacInnis, H., Kersey, J. H. & Nesbit, M. E. (1978). Home care for children dying with cancer. Pediatrics, 62(1), 106-113.
- Martinson, I. M., Coughlin Colaizzo, D., Freeman, M. & Bossert, E. (1990). Impact of childhood cancer on healthy school-age siblings. Cancer Nursing, 13(3), 183-190.
- Martinson, I. M., McClowry, S. G., Davies, B. & Kuhlenkam, E. J. (1994). Changes over time: A study of family bereavement following childhood cancer. Journal of Palliative Care, 10(1), 19-25.
- Martinson, I. M., Moldow, D. G., Armstrong, G. D., Henry, W. F., Nesbit, M. E. & Kersey, J. H. (1986). Home care for children dying of cancer. Research in Nursing & Health, 9(1), 11-16.
- Martinson, I. M., Palta, M. & Rude, N. V. (1978). Death and dying: Selected attitudes of Minnesota's Registered Nurses. Nursing Research, 27(4), 226-229.
- Mauksch, H. O. (1975). The organizational context of dying. In E. Kübler-Ross (Ed.), Death. The final stage of growth. (pp. 7-24). Englewood Cliffs: Prentice-Hall.
- McClement, S. (1993). Critical nursing behaviors in care of the dying adult in the intensive care setting. Master of Nursing Thesis. Winnipeg: University of Manitoba.
- Miles, A. (1994). 'Am I going to die?' Dealing with death. American Journal of Nursing, July, 20.
- Milton, I. C. (1984). Concerns of final year baccalaureate students about nursing and dying patients. Journal of Nursing Education, 23(7), 298-301.
- Munhall, P. L. & Oiler, C. J. (1986). Nursing research. A qualitative perspective. Norwalk: Appleton-Century-Crofts.
- Morse, J. (1989). Qualitative nursing research: A contemporary dialogue. Rockville: Aspen Publishers, Inc.
- Nagy, M. H. (1948). The child's theories concerning death. Journal of Genetic Psychology, 73, 3-27.
- Natterson, J. M. & Knudson, A. G. (1960). Observations concerning fear of death in fatally ill children and their mothers. Psychosomatic Medicine, 22(6), 456-465.
- Neidig, J. R. & Dalgas-Pelish, P. (1991). Parental grieving and perceptions regarding health care professionals' interventions. Issues in Comprehensive Pediatric Nursing, 14: 179-191.
- O'Berle, K. & Davies, B. (1992). Support and caring: Exploring the concepts. Oncology Nursing Forum, 19(5), 763-767.

- Orbach, I., Talmon, O., Kedem, P., & Har-Even, D. (1987). Sequential patterns of five sub concepts of human and animal death. Journal of the American Academy of Child and Adolescent Psychology, 26(4), 578-582.
- Papadatou, D. (1989). Caring for dying adolescents. Nursing Times, 85(18), 28-31.
- Peace, G. (1994). Sensitive choices. Nursing Times, 90(8), 35-36.
- Peace, G. & O'Keeffe, (1993). Future imperfect. Nursing Times, 89(51), 40-42.
- Pearlman J., Stotsky, B. A. & Dominick, J. R. (1974). Attitudes of nursing students and nursing faculty toward death. Nursing Research, 23, 50-53.
- Petix, M. (1987). Explaining death to school-age children. Pediatric Nursing, 13(6), 394-396.
- Piaget, J. (1973). The child and reality -- problems of genetic psychology. New York. Grossman.
- Piaget, J. (1965). The child's conceptions of the world. C. K. Ogden, (ed.). Totawa, New Jersey. Littlefield: Adams.
- Piaget, J. (1930). The child's conception of physical causality. New York. Harcourt, Brace.
- Piaget, J. (1926). The language and thought of the child. New York. Harcourt, Brace.
- Pickeran, J. & Leverett, P. (1990). Evelyn had plans--And they didn't include dying. Nursing '90, 20(11), 45-49.
- Polit, D. F., & Hungler, B. P. (1991). Nursing research. Principles and methods. (4th edition). Philadelphia: J. B. Lippincott Company.
- Quint, J. Q. (1967). The nurse and the dying patient. New York: Macmillan Publishing Company.
- Quint, J. Q. (1966). Awareness of death and the nurses composure. Nursing Research, 15, 49-55.
- Quint, J. Q. (1966). Obstacles to helping the dying. American Journal of Nursing, 66(7), 1568-1571.
- Rando, T. A. (1985). Bereaved parents: particular difficulties, unique factors, and treatment issues. Social Work, 30(1), 19-23.
- Reimer, J. C. & Davies, B. (1991). Palliative care: The nurse's role in helping families through the transition of "fading away." Cancer Nursing, 14(6), 321-327.
- Reisetter, K. H. & Thomas, B. (1986). Nursing care of the dying: Its relationship to selected nurse characteristics. International Journal of Nursing Studies, 23(1), 39-50.

- Richmond, J. B. & Waisman, H. A. (1955). Psychological aspects of management of children with malignant diseases. American Journal of Diseases of Children, 89, 42-47.
- Rochlin, G. (1967). How young children view death and themselves. In E. A. Grollman (Ed.) Explaining death to children. (pp. 51-85). Boston: Beacon Press.
- Ross-Alaolmolki, K. (1985). Supportive care for families of dying children. Nursing Clinics of North America, 20(2), 457-466.
- Ryan, P. Y. (1992). Perceptions of the most helpful nursing behaviors in a home-care hospice setting: Caregivers and nurses. American Journal of Hospice & Palliative Care, 9(5), 22-31.
- Sahler, O. J. Z., & Greenlaw, J. (1992). Pediatrics and the patient self-determination act. Pediatrics, 90(6), 999-1001.
- Schilder, P. & Wechsler, D. (1934). The attitudes of children toward death. The Pedagogical Seminary and Journal of Genetic Psychology, 45, 406-451.
- Shusterman, L. R. & Sechrest, L. (1973). Attitudes of registered nurses toward death in a general hospital. Psychiatry in Medicine, 4, 411-427.
- Siever, B. A. (1994). Pain management and potentially life-shortening analgesia in the terminally ill child: The ethical implications for pediatric nurses. Journal of Pediatric Nursing, 9(5), 307-312.
- Speece, M. W. & Brent, S. B. (1984). Children's understanding of death: A review of three components of a death concept. Child Development, 55, 1671-1686.
- Spencer, M. (1985). Foundations of modern sociology. (4th Edition). Scarborough: Prentice-Hall Canada, Inc.
- Spinetta, J. J. (1974). The dying child's awareness of death: A review. Psychological Bulletin, 81, 256-260.
- Strauss, A. L. & Glaser, B. G. (1970). Patterns of dying. In O. G. Brim, H. E. Freeman, S. Levine & N. A. Scotch (Eds.) The dying patient. (pp. 129-155). New York: Russell Sage.
- Swain, H. L. (1979). Childhood views of death. Death Education, 2, 341-358.
- Taber, C. W. (1970). Taber's Cyclopedic Medical Dictionary. (11th Edition). Toronto: Ryerson Press.
- Thoma, M. E., Hockenberry-Eaton, M. & Kemp, V. (1993). Life change events and coping behaviors in families of children with cancer. Journal of Pediatric Oncology Nursing Journal of Pediatric Oncology Nursing, 10(3), 105-111.
- Tong, K. L. (1994). The Chinese palliative patient and family in North America: A cultural perspective. Journal of Palliative Care, 10(1), 26-28.

- Ufema, J. (1991). Helping loved ones say good-bye. Nursing '91, 21(10), 42-43.
- Vachon, M. L. S. (1987). Occupational stress in the care of the critically ill, the dying, and the bereaved. New York: Hemisphere Publishing.
- Vachon, M. L. S., & Pakes, E. (1985). Staff stress in the care of the critically ill and dying child. Issues in Comprehensive Pediatric Nursing, 8(1/6), 151-182.
- Waechter, E. H. (1971). Children's awareness of fatal illness. American Journal of Nursing, 71(6), 1168-1172.
- Waechter, E. H. (1985). Dying children: Patterns of coping. Issues in Comprehensive Pediatric Nursing, 8(1/6), 51-68.
- Wass, H. (1985). Concepts of death: a developmental perspective. Issues in Comprehensive Pediatric Nursing, 8(1/6), 3-24.
- Wass, H. & Cason, L. (1985). Fears and anxieties about death. Issues in Comprehensive Pediatric Nursing, 8(1/6), 25-49.
- Wass, H., Dinklage, R., Gordon, S., Russo, G., Sparks, C. & Tatum, J. (1983). Young children's death concepts revisited. Death Education, 7, 385-394.
- Weininger, O. (1979). Young children's concepts of dying and death. Psychological Reports, 44: 395-407.
- Wenestam, C. - G. & Wass, H. (1987). Swedish and US. children's thinking about death: A qualitative study and cross-cultural comparison. Death Studies, 11(2), 99-121.
- White, E., Elsom, B. & Pravat, R. (1978). Children's conceptions of death. Child Development, 49, 307-310.
- White, P. D., Gilner, F. H., Handal, P. J. & Napoli, J. G. (1983). A behavioral intervention for death anxiety in nurses. Omega, 14(1), 33-42.
- Whyte, D. A. (1992). A family nursing approach to the care of a child with a chronic illness. Journal of Advanced Nursing, 17(3), 317-327.
- Wilkinson, S. (1991). Factors which influence how nurses communicate with cancer patients. Journal of Advanced Nursing, 16(6), 677-688.
- Wilson, D. C. (1982). The viability of pediatric hospices: A case study. Death Education, 6, 205-212.
- Wilson, H. S. (1987). Introducing Research in nursing. Don Mills: Addison-Wesley Publishing Company.
- Winston. (1974) The Winston Canadian Dictionary. Toronto: Holt, Rinehart and Winston of Canada, Limited.

- Wright, L. M. & Leahey, M. (1984). Nurses and families: A guide to family assessment and intervention. Philadelphia: F. A. Davis Company.
- Yoder, L. (1994). Comfort and consolation: A nursing perspective on parental bereavement. Pediatric Nursing, 20(5), 473-477.
- Zeligs, R. (1974). Children's experience with death. Springfield: Charles C. Thomas, Publisher.

APPENDICES

APPENDIX A

Definition of Terms

The following terms have been defined as they were used in this study.

<u>Active care</u>	aggressive, therapeutic case management, including full cardio-pulmonary resuscitation (author)
<u>Bereavement</u>	an objective fact; the loss of a loved one (Katsenbaum, 1991)
<u>Expert</u>	one who is skilled or thoroughly informed in a particular subject (Winston, 1974)
<u>Expertise</u>	the state of becoming an expert (Winston, 1974); develops through the testing and refinement of theoretical and practical knowledge in actual situations; the development of a deep background understanding of clinical situations based upon many past paradigm cases. (Benner, 1984)
<u>Family</u>	a social system comprised of individuals related to each other by reason of their strong reciprocal affections and loyalties, and demonstrating durability of membership (Wright & Leahey, 1984)
<u>Grief</u>	one's psychological, social and somatic response to bereavement (Katsenbaum, 1991)
<u>Mourning</u>	culturally patterned expression of the bereaved person's thoughts and feelings (Katsenbaum, 1991)
<u>No "99"</u>	medical case management, up to, but not including full cardio-pulmonary resuscitation (author)
<u>Palliative care</u>	supportive, non-curative case management that ease pain and suffering, and excludes cardio-pulmonary resuscitation (author)
<u>Paradigm case</u>	a clinical experience that transforms one's way of understanding; a reference point for current and future clinical decision-making (Benner, 1984)
<u>Terminal care</u>	physical and psychosocial assistance during the final stages of life (Quint, 1967)

APPENDIX C

Nursing Behaviors Described in the Literature**LEGEND:**

non-italics: general Death and Dying Literature

*italics: pediatric Death and Dying Literature***1. Comfort Care** -- *Making the patient comfortable.*

provides excellent physical care	<i>Adams, 1985; Benoliel, 1972; Connolly, 1994; Dawson, 1991; Gyulay, 1989; Hockenberry-Eaton & Minick, 1994; Kristjanson, 1989; Ryan, 1992; Siever, 1994</i>
symptom management to ease pain and discomfort, relieves suffering, facilitates freedom from pain	<i>Adams, 1985; Bramwell, 1989; Brockopp, 1987; Cahill et al., 1990; Corless, 1994; Connolly, 1994; Corless, 1994; Davies & O'Berle, 1990; Dobratz, 1990; Freyer, 1992; Heslin & Kristjanson, 1989; Hockenberry, Coody & Bennett, 1990; Hockenberry-Eaton & Minick, 1994; Siever, 1994</i>
attends to food and fluid needs	<i>Chekryn, 1985; Gyulay, 1989; Martinson, 1983</i>
provides personalized care; practices primary nursing to ensure continuity of care	<i>Ashby et al., 1991; Davies & O'Berle, 1990; Petix, 1987</i>
develops individualized strategies to control nausea and vomiting	<i>Corless, 1994; Hockenberry-Eaton & Benner, 1990</i>
maintains personal appearance	<i>Adams & Deveau, 1986; Gyulay, 1989</i>
uses humor and touch	<i>Flood, 1989, Gray, 1989</i>
provides opportunities for touching; transmits security and support through human touch	<i>Adams & Deveau, 1986; Hockenberry-Eaton & Minick, 1994; O'Berle & Davies, 1992</i>
recognizes need for participation of parents to provide love, comfort and reassurance	<i>Adams & Deveau, 1986; Bluebond-Langner, 1978; Martinson, 1983</i>
recognizes parents' ability to respond and provide comfort	<i>Adams & Deveau, 1986; Flood, 1989; Martinson, 1983</i>
demonstrates love and care beyond physical needs	<i>Adams, 1985</i>
provides comfort, compassion and care	<i>Dobratz, 1990; Flood, 1983; Martinson, 1983</i>
coordinates care	<i>Dobratz, 1990; O'Berle & Davies, 1992</i>
performs specific physical comfort measures	<i>O'Berle & Davies, 1992</i>
provides physical support and technologic interventions	<i>Davies & O'Berle, 1990; O'Berle & Davies, 1992</i>

APPENDIX C

1. Comfort Care -- *continued.*

manages physical problems, including pain and symptom management	Dobratz, 1990
coaches children through difficult situations by implementing distraction methods	<i>Hockenberry-Eaton & Minick, 1994</i>
attention to developmental stages enables age-appropriate nursing interventions	<i>Cahill et al., 1990; Hockenberry-Eaton & Benner, 1990</i>
demonstrates clinical competence	Corless, 1994; <i>Siever, 1994</i>
recognizes the essential role of parents in identifying pain problems in children and in providing comfort and consolation	<i>Cahill et al., 1990; Hockenberry-Eaton & Benner, 1990</i>

2. Patients Feelings -- *Talking with the patient with respect to feelings about dying.*

assesses locus of control and adopts a developmental approach with child	<i>Carpenter, 1992</i>
assists patients; provides direct support	Dobratz, 1990; O'Berle & Davies, 1992
elicits perceived needs	Ryan, 1992
promotes open, honest communication	<i>Coody, 1985; Flood, 1989; Kuykendall, 1989; Reimer et al., 1991; Reisetter & Thomas, 1986; Waechter, 1985</i>
provides age-appropriate communication	<i>Green-Epner, 1976; Martinson, 1983, 1979; Zeligs, 1974</i>
recognizes the need for information and instruction; provides clear explanations; answers questions honestly	<i>Adams & Deveau, 1986; Dobratz, 1990; Flood, 1989; Hockenberry-Eaton & Minick, 1994; Kristjanson, 1989; O'Berle & Davies, 1992; Petix, 1987; Ryan, 1992</i>
recognizes the importance of, and the need to integrate stressful experiences through play	<i>Cahill et al., 1990; Gray, 1989; Green-Epner, 1976; Kuykendall, 1989</i>
provides time for listening; listens to what the patient wants; recognizes when they need to talk about death	<i>Adams & Deveau, 1986; Dobratz, 1990; High, 1989; O'Berle & Davies, 1992; Ryan, 1992</i>
serves as a confidante, "being there for" and "being available to;" stays during the difficult times	<i>Adams, 1985; Coody, 1985; Gray, 1989; O'Berle & Davies, 1992; Ryan, 1992</i>
becomes acquainted with and understands family behaviors that may influence adjustment	<i>Adams, 1985</i>
promotes self-expression and understanding; gains knowledge about thoughts and feelings	<i>Adams, 1985; Adams & Deveau, 1986; Bearison, 1991</i>

APPENDIX C

2. Patients Feelings -- continued

acknowledges child's awareness of seriousness of disease and impending death	<i>Bluebond-Langner, 1978; Green-Epner, 1976; Kübler-Ross, 1983; Kuykendall, 1989; Spinetta, 1974; Waechter, 1985, 1971</i>
sustains contact; provides emotional support	<i>Benoliel, 1972; Bluebond-Langner, 1978; Brockopp, 1987; Connolly, 1994; Coody, 1985; Flood, 1989; Green-Epner, 1976; Gyulay, 1989; Heslin & Bramwell, 1989; Kincade & Powers, 1984; Kristjanson, 1989; Kuykendall, 1989</i>
integrates the psychological and spiritual aspects of care	<i>Connolly, 1994</i>
recognizes and respects needs, desires and concerns	<i>Adams, 1985; deHennezel, 1989</i>
enables hope	<i>Hickey, 1986</i>
helps them live as actively as possible until death	<i>Connolly, 1994</i>
recognizes the need to mourn	<i>Adams, 1985</i>
acknowledges the accumulated impact of disease and treatment processes; fosters coping	<i>Adams, 1985; Bluebond-Langner, 1978; Carlson et al., 1985; deHennezel, 1989; Gyulay, 1989</i>
understands, accepts patient's way of coping and helps them cope with feelings	<i>O'Berle & Davies, 1992; Pickeran & Leverett, 1990</i>
recognizes the need for spiritual support	<i>Conrad, 1985; Flood, 1989; Gyulay, 1989</i>
talks with/to patients; provides support and diminishes fears	<i>O'Berle & Davies, 1992; Ryan, 1992</i>
forms a bond with the patient; is available; is interested in them; makes them feel special and normal	<i>Corless, 1994; Davies & O'Berle, 1990; Hockenberry-Eaton & Minick, 1994; O'Berle & Davies, 1992</i>
establishes mutual trust; provides a helping-trusting relationship	<i>Friedman & Huls, 1991; Reimer et al., 1991, Ryan, 1992</i>
offers an honest and meaningful relationship, demonstrating a willingness to share the remainder of their life and death	<i>Papadatou, 1989</i>
manages psychological, social and spiritual problems; provides psycho-social care	<i>Connolly, 1994; Dobratz, 1990; Ryan, 1992</i>

APPENDIX C

3. Nurses Feelings-- *Nurses coming to terms with their own feelings about dying.*

promotes self-exploration: "knowing thyself;" comes to terms with own feelings about death and dying; acknowledges own death-fear and anxiety	Benoliel, 1985; Conrad, 1985; <i>Davies & Eng, 1993</i> ; Hare & Pratt, 1989; <i>Papadatou, 1989</i> , <i>Petix, 1987</i>
comes to terms with own concept of death, including childhood death	<i>Coody, 1985</i> ; <i>Siever, 1994</i>
critically examines the ethical issues and underlying principles of nursing care for dying children	<i>Siever, 1994</i>
balance own self-care needs with the complexities and intensities of repeated death encounters	Dobratz, 1990
acknowledges stress and difficulties related to exposure to dying	Benoliel, 1985; 1988
acknowledges own emotions, limitations and their impact on one's ability to provide comfort and care	<i>Adams, 1985</i> ; <i>Coody, 1985</i> ; <i>Flood, 1985</i> ; <i>Petix, 1987</i>
recognizes the need to "escape" at times of crisis	<i>Adams, 1985</i>
recognizes ongoing impact of terminal care on own emotional resources	<i>Adams, 1985</i>
recognizes the need to provide social and emotional care	<i>Adams, 1985</i> ; <i>Davies & Eng, 1993</i>
comfortable talking about death and dying	Reimer et al., 1991
shares feelings regarding life and death issues	<i>Papadatou, 1989</i>
preserves own integrity	Davies & O'Berle, 1990; O'Berle & Davies, 1992
recognize personal and professional interaction	Reimer et al., 1991
provides intimacy, sharing on a more personal and private level	Friedman & Huls, 1991
make oneself vulnerable to another in a disciplined, intimate relationship	Friedman & Huls, 1991
develops expert clinical skills and theoretical knowledge in palliative care	Dobratz, 1990
recognizes the need for knowledge and skills, including: managing, instructing, and communicating	<i>Davies & Eng, 1993</i> ; Dobratz, 1990
recognize role as "helper"	Reimer et al., 1991
develops emotion-regulating and problem-solving strategies for coping with terminal care	Vachon, 1987

APPENDIX C

4. Supporting colleagues- *Providing emotional support to colleagues.*

acknowledges that exposure to death and dying is stressful	Benoliel, 1985
provides systematic and regular support for caregivers	Benoliel, 1985; <i>Flood, 1989</i>
recognizes conflicting expectations between acute and palliative care	<i>Adams, 1985</i>
recognizes the difficulties and stress of caring for the dying	Benoliel, 1988
recognizes the need for colleagues to "escape," to find relief and solace away from the strain of caring	<i>Adams, 1985</i>
allows colleagues to vent their feelings	Benoliel, 1988; Hall, 1990

5. Patient Rights- *Respecting patients as individuals as they are dying.*

helps them make sense of what is happening to them; gives meaning and purpose to their life and death	Davies & O'Berle, 1990; <i>Hockenberry-Eaton & Minick, 1994</i> ; O'Berle & Davies, 1992; <i>Papadatou, 1989</i>
believes in their strengths and capabilities; helps them to develop strength in the face of adversity	Davies & O'Berle, 1990; <i>Hockenberry-Eaton, 1994</i> ; O'Berle & Davies, 1992
respects their right to self-determination	<i>American Academy of Pediatrics, 1994</i> ; Davies & O'Berle, 1990; <i>Franklin, 1994</i> ; <i>Sahler & Greenlaw, 1992</i>
respects their sense of identity, dignity and worth	<i>Martinson, 1983</i>
believes in and supports their sense of dignity and inherent self worth in the face of dying	<i>Adams, 1985</i> ; Davies & O'Berle, 1990; O'Berle & Davies, 1992
helps them to find and build strength	Davies & O'Berle, 1990; O'Berle & Davies, 1992
facilitates a sense of belonging; acknowledges their contribution to the family; and their need for ongoing social contacts	<i>Adams, 1985</i> ; <i>Papadatou, 1989</i> ; Reimer, Davies & Martens, 1991
neither hastens nor postpones death	Connolly, 1994
respects the child as a willful and purposeful individual	<i>Bluebond-Langner, 1978</i> ; <i>Hockenberry-Eaton & Minick, 1994</i>
gives the child permission to die	<i>Gray, 1989</i>
understands and accepts their desire to live	deHennezel, 1989

APPENDIX C

5. Patient Rights -- *continued*

acknowledges awareness of impending death	<i>Green-Epner, 1976; Kübler-Ross, 1983; Spinetta, 1974; Waechter, 1985, 1971</i>
recognizes the emotionally-taxing experience of terminal illness; and responds to the child's expression of feelings and needs	<i>Adams, 1985; Hockenberry-Eaton & Minick, 1994</i>
understands child's personal experience and the practical meaning of their illness	<i>Freyer, 1992</i>
acts as a patient and family advocate	<i>Dobratz, 1990; Kincade & Powers, 1984</i>
respects the right to be informed; recognizes that knowing provides a sense of control	<i>Adams & Deveau, 1986; Bearison, 1991; High, 1989; Kuykendall, 1989; Hockenberry-Eaton & Minick, 1994</i>
supports and promotes open, honest and factual communication	<i>Adams, 1985; Adams & Deveau, 1986; Hockenberry-Eaton & Minick, 1994</i>
recognizes the need to share in decisions about care	<i>Adams & Deveau, 1986; Gray, 1989</i>
provides information to facilitate participation in decision-making	<i>Ryan, 1992</i>
assesses child's decision-making capabilities	<i>Freyer, 1992; Hockenberry-Eaton & Minick, 1994</i>
involves them in, and recognizes their identification of needs, and what is most helpful	<i>Ryan, 1992</i>
helps them to conquer fear, develop strength and resilience in the face of adversity, and find bravery and courage to affirm life	<i>Hockenberry-Eaton & Minick, 1994</i>
recognizes the need for good communication skills to overcome difficulties arising from conflicting views	<i>Peace, 1994.</i>
promotes continued involvement in informed decision-making	<i>Ryan, 1992</i>
promotes and enhances quality of life; optimizes quality of life through control of symptoms	<i>Lubin, 1992; Papadatou, 1989; Ryan, 1992</i>
provides moral support	<i>O'Berle & Davies, 1992</i>
responds to psychological, spiritual, and ethical issues, grief and loss	<i>Dobratz, 1990</i>

APPENDIX C

6. Family Care-- *Providing support to the family during the dying process.*

recognizes the threat of childhood chronic illness to personal equilibrium and family well-being	<i>Thoma et al., 1993</i>
demonstrates a non-judgmental attitude	Corless, 1994
adjusts care according to the family's level of functioning	Davies, Chekryn Reimer & Martens, 1994
understands cultural traditions in order to deliver more culturally-sensitive care	Tong, 1994
includes the family as recipients of care; supports the family unit; focuses on the family as the patient	Dobratz, 1990; Gullal, 1992; Reimer et al., 1991
ensures patient comfort and adequate pain relief	Chekryn, 1985; Corless, 1994
establishes trust; provides a helping-trusting relationship sensitive to the perceptions of the family	Reimer et al., 1991; Ryan, 1992
involves family in the identification of their needs and how they can best be met; elicits perceived needs	Reimer, <i>et. al</i> , 1991
assesses and evaluates family system	Ryan, 1992
establishes effective communication	Gullal, 1992; <i>Thoma, 1993</i>
identifies coping patterns; assesses how much a family can endure; know what is most helpful	Corless, 1994; <i>Yoder, 1994</i>
recognizes that each family member must cope personally	<i>Adams, 1985</i> ; Ryan, 1992
helps the family to cope with uncertainty	Benoliel, 1985
	Connolly, 1994; <i>Hockenberry, Coody & Bennett, 1990</i> ; Reimer <i>et al.</i> , 1991; <i>Whyte, 1992</i>
helps them to find meaning	<i>Whyte, 1992</i>
provides information and answers questions	Corless, 1994; <i>Whyte, 1992</i>
provides a link between clinic, hospital and home	<i>Whyte, 1992</i>
provides individualizes and compassionate family care	<i>Neidig & Dalgas-Pelish, 1991</i>
supports families at times of vulnerability	<i>Faulkner, Peace & O'Keeffe, 1993</i> ; <i>Whyte, 1992</i>
promotes holistic, interpersonal care	Ryan, 1992; <i>Whyte, 1992</i>
tailors interventions to meet members varying abilities to assimilate change	Reimer et al., 1991
develops and nurtures a relationship that will help to sustain the family	<i>Whyte, 1992</i>
demonstrates caring, support, and encouragement	<i>Neidig & Dalgas-Pelish, 1991</i> ; Reimer et al., 1991

APPENDIX C

6. Family Care -- *continued*

supports adjustment as parents come to understand and adapt to their child's terminal illness	<i>Adams, 1985</i>
recognizes and anticipates mourning behaviors, responding with compassion and sensitivity	<i>Yoder, 1994</i>
facilitates parental grief experience; responds to psychological, spiritual and ethical issues surrounding grief and loss	<i>Dobratz, 1990; Neidig & Dalgas-Pelish, 1991; Whyte, 1992; Yoder, 1994</i>
manages physical, psychological, social, and spiritual problems	<i>Dobratz, 1990</i>
seeks to normalize the experience; helps them to put their situation in context	<i>Reimer et al., 1991</i>
allows parents to participate in decision-making; encourages them to make decisions; promotes continued involvement in informed decision-making	<i>Neidig & Dalgas-Pelish, 1991; Reimer et al., 1991; Ryan, 1992</i>
mutual goal setting and decision making regarding initial and ongoing assessment of pain and responses to intervention	<i>Cahill et al., 1990; Hockenberry-Eaton & Benner, 1990</i>
provides opportunities for, and encourages active participation in care	<i>Adams, 1985; Adams & Deveau, 1985; Benoliel, 1983; Martinson, 1983; Neidig & Dalgas-Pelish, 1991</i>
enables them to take on tasks that are appropriate to their comfort level and skills; teach them how to provide physical comfort	<i>Reimer et al., 1991; Ryan, 1992</i>
facilitates access; supports parents "being there;" offers reassurance, advice and guidance; helps them to explore options and plan; suggests alternatives	<i>Adams, 1985; Adams & Deveau, 1985; Reimer et al., 1991; Whyte, 1992</i>
answers questions honestly, openly, and willingly	<i>Corless, 1994; Ryan, 1992</i>
helps them sort out their experiences; encourages dialogue to work things out; promotes as open communication as the family can handle	<i>Reimer et al., 1991</i>
reinforces family relationships	<i>Reimer et al., 1991</i>
is available to family; listens carefully and repeatedly; provides opportunities to talk and discuss things as often as necessary	<i>Corless, 1994; Reimer et al., 1991; Ryan, 1992</i>
provides and shares accurate information; teaches and reinforces; counsels and supports; helps them to understand and prepare	<i>Adams, 1985; Benoliel, 1972; Chekryn, 1985; Dobratz, 1990; Kristjanson, 1985; Neidig & Dalgas-Pelish, 1991; Reimer et al., 1991; Whyte, 1992</i>
responds to cues; demonstrates ease when exploring and discussing family concerns; listens to their concerns	<i>Reimer et al., 1991</i>

APPENDIX C

6. Family Care -- *continued*

provides support to diminish fears	Ryan, 1992
provides family counselling and support	<i>Whyte, 1992</i>
helps family members to understand and support the patient's need to stay involved	Reimer et al., 1991
trains parents to be coaches for their children during procedures; coaches parents to improve their effectiveness in aiding children through difficult situations	<i>Carpenter, 1992; Hockenberry-Eaton & Minick, 1994</i>
encourages parents to be honest with their child	<i>Miles, 1994</i>
encourages open communication between family members	<i>Faulkner, Peace & O'Keeffe, 1993</i>
encourages parents to support their child in dealing with stress, pain, and fear	<i>Carpenter, 1992</i>
provides emotional support; meets psychosocial needs of family	<i>Ashby et al., 1991; Carlson et al., 1985; Dawson, 1991; Dobratz, 1990; Flood, 1989; Gyulay, 1989; Heslin & Bramwell, 1989; Martinson et al., 1978; Reisetter & Thomas, 1986; Ross-Alaolmolki, 1985; Whyte, 1992</i>
encourages demonstrations of pain and sorrow	<i>Miles, 1994</i>
provides a sense of security	Reimer et al., 1991
provides advocacy	Dobratz, 1990
recognizes need for spiritual support	<i>Conrad, 1985; Flood, 1989; Gyulay, 1989</i>
anticipates and prepares family for what is ahead	Reimer et al., 1991
supports crying as a healthy way to express feelings	<i>Miles, 1994</i>
understands that families need time to disengage, and embrace new orientations	Reimer et al., 1991
prepares family for the death event; provides information about what to expect around the time of death	Chekryn, 1985; Ryan, 1992; <i>Yoder, 1994</i>
helps them to say good-bye	Reimer et al., 1991; Ufema, 1991; <i>Yoder, 1994</i>
provides counseling; helps them to deal with the burden of their feelings	Dobratz, 1990; Reimer et al., 1991
avoids taking sides in family conflicts	<i>Whyte, 1992</i>
alleviates suffering	Reimer et al., 1991
acknowledges and accepts siblings' awareness of seriousness of disease and impending death	<i>Bluebond-Langner, 1989</i>

APPENDIX C

6. Family Care -- *continued*

recognizes siblings' need for age-appropriate, factual information and emotional support	<i>Adams & Deveau, 1986; Kuykendall, 1989; Martinson et al., 1990</i>
recognizes siblings' need to be fully informed and to feel involved	<i>Bendor, 1989; Coleman & Coleman, 1985; Graham-Pole et al., 1989; Martinson et al., 1990</i>
encourage siblings to visit	<i>Neidig & Dalgas-Pelish, 1991</i>
helps siblings to feel important and loved	<i>Martinson et al., 1990</i>
takes time to be with siblings and talks with them about everyday activities and concerns; maintains interaction	<i>Martinson et al., 1990</i>
encourages siblings to be involved in the life of the ill child	<i>Martinson et al., 1990</i>
keeps siblings interacting in as normal a manner as possible	<i>Martinson et al., 1990</i>
develops clinical interventions for siblings	<i>Martinson et al., 1990</i>
encourage sibling involvement in funeral planning, including the opportunity to attend	<i>Martinson et al., 1990</i>
reaches out to families beyond their child's death	<i>Yoder, 1994</i>

7. Manipulation of Environment -- *Arranging equipment to promote interaction.*

supports and promotes the creation of safe, familiar surroundings	<i>Bluebond-Langner, 1978; Martinson, 1983</i>
respects the right to privacy; provides "alone" time	<i>Adams & Deveau, 1986</i>
recognizes the need for play	<i>Adam, 1985; Green-Epner, 1976</i>
provides a secure environment that is filled with warmth and love	<i>Adams, 1985; Hockenberry-Eaton & Minick, 1994</i>
creates climate for talking	<i>Bearison, 1991; Hockenberry-Eaton & Minick, 1994</i>
provide a supportive environment	<i>Ryan, 1992</i>
provide an environment that allows the exploration of personal feelings and concerns	<i>Reimer et al., 1991</i>
create an environment of caring	<i>Reimer et al., 1991</i>
provides a nurturing environment that allows them to feel special	<i>Hockenberry-Eaton & Minick, 1994</i>

APPENDIX D

Critical Nursing Behaviors in the Care of Dying Children
in the Hospital Setting

<u>NURSING</u> <u>BEHAVIORS:</u>	<u>OPERATIONAL DEFINITIONS:</u>	
	<i>Positive</i>	<i>Negative</i>
<u>Connecting</u>	<ul style="list-style-type: none"> • behaviors that promote a mutual closeness 	<ul style="list-style-type: none"> • reserved behaviors • maintaining one's distance
	<ul style="list-style-type: none"> • behaviors that embrace the child and family 	<ul style="list-style-type: none"> • behaviors that demonstrate over involvement, and loss of one's professional identity
<u>Responding to the Family</u>	<ul style="list-style-type: none"> • behaviors that support the whole family, including or relieving them of the responsibility for care according to what's best for the family 	<ul style="list-style-type: none"> • passing judgment on family decisions and behaviors toward the dying child • controlling, or avoidance behaviors
	<ul style="list-style-type: none"> • behaviors that bring families together 	<ul style="list-style-type: none"> • judgmental, controlling behaviors that exclude family members, or force them to spend time together
	<ul style="list-style-type: none"> • behaviors that foster a home-like environment 	<ul style="list-style-type: none"> • providing a stark room, with harsh lighting and a rigid 'hospital' atmosphere
	<ul style="list-style-type: none"> • behaviors that respond to the family's need for information 	<ul style="list-style-type: none"> • deferring to the physician • avoiding the family's need for information • providing ambiguous or conflicting messages • defensive behaviors, in response to a family's superior knowledge
	<ul style="list-style-type: none"> • behaviors that reduce the potential for future regret 	<ul style="list-style-type: none"> • refusing to discuss death and dying issues, even when the family wants to discuss them
	<ul style="list-style-type: none"> • behaviors that support the child/family's cultural and religious beliefs and practices 	<ul style="list-style-type: none"> • cultural/religious practices that interfere with the care of the dying child

APPENDIX D

<u>Providing Comfort</u>	<ul style="list-style-type: none"> • behaviors that reduce physical pain and discomfort 	<ul style="list-style-type: none"> • methodical behaviors, that demonstrate a lack of awareness of the child's suffering • poor symptom management due to inadequate knowledge base
	<ul style="list-style-type: none"> • behaviors that satisfy the child's psychological and emotional needs 	<ul style="list-style-type: none"> • distancing behaviors that result in psychological and emotional neglect
<u>Enhancing Quality of Life during Dying</u>	<ul style="list-style-type: none"> • behaviors that respond to the dying child's need for information 	<ul style="list-style-type: none"> • withholding of information, or lying to the dying child
	<ul style="list-style-type: none"> • behaviors that help dying children do things that are important to them 	<ul style="list-style-type: none"> • behaviors that demonstrate a lack of respect for the dying child and family
	<ul style="list-style-type: none"> • behaviors that make dying children feel special 	<ul style="list-style-type: none"> • detached, impersonal behaviors
<u>Responding to Anger</u>	<ul style="list-style-type: none"> • behaviors that demonstrate respect and empathy, even when anger is directed at the health care team 	<ul style="list-style-type: none"> • denigrating, or angry responses • avoidance behaviors
	<ul style="list-style-type: none"> • behaviors that promote resolution when anger occurs within the health care team 	<ul style="list-style-type: none"> • passing judgment on the decisions and behaviors of colleagues • venting anger at colleagues • avoidance behaviors
<u>Facilitating the Transition to Palliative Care</u>	<ul style="list-style-type: none"> • behaviors that respect and support the child's right to die with dignity 	<ul style="list-style-type: none"> • aggressive behaviors that defy death, inflict pain and suffering, and prolong dying

APPENDIX D

<u>Responding During the Death Scene</u>	<ul style="list-style-type: none"> • behaviors that acknowledge the child's dying 	<ul style="list-style-type: none"> • failure to recognize the child's dying due to poor knowledge base • avoidance behaviors
	<ul style="list-style-type: none"> • behaviors that support the child and family, as death approaches 	<ul style="list-style-type: none"> • avoidance behaviors that result from the nurse's discomfort with care of the dying
	<ul style="list-style-type: none"> • behaviors that maintain a sense of calm 	<ul style="list-style-type: none"> • behaviors that demonstrate the nurse's horror and anguish over the death scene
<u>Responding After Death has Occurred</u>	<ul style="list-style-type: none"> • behaviors that demonstrate respect, and support the family's realization of death 	<ul style="list-style-type: none"> • avoidance, or controlling behaviors that restrict the family's expression of grief
	<ul style="list-style-type: none"> • behaviors that demonstrate respect for the body during post-mortem care 	<ul style="list-style-type: none"> • rough, impersonal handling of the body
	<ul style="list-style-type: none"> • behaviors that support the family beyond the death of their child 	<ul style="list-style-type: none"> • avoidance behaviors
<u>Enhancing Personal Growth</u>	<ul style="list-style-type: none"> • behaviors that demonstrate that the nurse has defined a personal role in the care of dying children and their families 	<ul style="list-style-type: none"> • behaviors that demonstrate anxiety and a lack of confidence in the care of dying children and their families
<u>Responding to Colleagues</u>	<ul style="list-style-type: none"> • behaviors that provide emotional support, and critical feedback to nursing colleagues 	<ul style="list-style-type: none"> • behaviors that demonstrate a nurse's difficulty in providing or receiving support or criticism from colleagues

APPENDIX E

Introduction to the Study:Background Information About
Critical Nursing Behaviors in the Care of Dying Children in the Hospital Setting

Investigator: Lois Hawkins, RN. BN.
January, 1993
pH.

Pediatric nurses can play an important role in meeting the needs of both the dying child and their grieving family, however, little is known about what constitutes effective nursing care for the dying child in the hospital setting.

The purposes of this study are:

1. to describe nursing behaviors that "expert" pediatric nurses identify as essential for optimal care of the dying child;
2. to compare those behaviors with the beginning list of seven critical nursing behaviors identified in Degner, Gow and Thompson (1991) in their initial study of critical nursing behaviors in care for the dying. (Informants, in this preliminary investigation, were palliative care nurses and nursing educators.)

To begin, all pediatric nurses wishing to participate in the first phase of this study will be asked by the investigator to read three paragraphs describing attributes of nurse experts in the care of dying children. The nurses will be invited to write down the names of three colleagues that meet the description of these criteria. The individuals mentioned most often as best fitting the description in each of the paragraphs will be considered "expert". Expert nurses from the pediatric units of the Children's Hospital, who agree to participate in the study, will constitute the purposive sample of ten nurse experts in the care of dying children.

Identifying Nurse Experts:

The tool that will be used to identify nurse experts in care of the dying child in the hospital setting (the Educational Influential Instrument) has been developed using Benner's (1984) descriptions of attributes of expert nurses and descriptions of optimal nursing behaviors in terminal care in pediatric health care literature.

The attributes of nurse experts that have been identified by Benner (1984) include:

- **the ability to make clinical judgments or manage complex situations in a truly remarkable way
- **possessing a vision of what is possible in patient care situations
- **having an intuitive grasp of each patient care situation and being able to zero in on the accurate region of the problem without wasteful considerations of unfruitful, alternative diagnoses and solutions
- **having at least five years of clinical experience
- **currently involved in clinical/patient care at the Children's Hospital

APPENDIX F

Background Information to the Educational Influential Tool
For the Identification of Nurse Experts

The tool used to identify nurse experts in care of the dying child in the hospital setting has been developed using Benner's (1984) descriptions of attributes of expert nurses and from descriptions of optimal nursing behaviors in terminal care in pediatric health care literature. The attributes of nurse experts that have been identified by Benner (1984) include:

- ** the ability to make clinical judgments or manage complex situations in a truly remarkable way
- ** possessing a vision of what is possible in patient care situations
- ** having an intuitive grasp of each patient care situation and being able to zero in on the accurate region of the problem without wasteful considerations of unfruitful, alternative diagnoses and solutions

Adapted from: Benner, P. (1984). From Novice to expert. Excellence and power in clinical nursing practice. Melno Park: Addison-Wesley.

APPENDIX G

Educational Influential InstrumentINSTRUCTIONS

Please read each paragraph carefully, and indicate the name(s) of the pediatric nurse(s) you work with that best fit each description.

The nurse must have had at least five years of experience in pediatric nursing, and must presently be involved in patient care.

You may write the names of up to three nurses for each paragraph. The same nurse may be named for more than one paragraph. You may name yourself if you feel it is appropriate.

DISCLAIMER

You are being asked to voluntarily give your opinion about the statements on this form. By identifying the name(s) of your nursing colleagues that best fit the description outlined in each of these paragraphs, you will be giving consent to participate in this aspect of the study. You are asked to not write your name on this form to identify it as your own.

You may choose not to respond to one or all of the paragraphs, if you so desire. Whatever you decide, your employment in this institution will not be affected in any way. Any questions you have will be answered, and you may withdraw from the study at anytime. There are no known risks to you, should you decide to complete this form.

Paragraph A

They are nurses who can facilitate the transition from curative-oriented to palliative care for dying children and their families. Although they realize that there is little they or others can do to prolong the life of the child, they are able to maintain a vision of what is possible when it comes time to provide comfort care. They are able to provide compassionate nursing care and are able to give meaning to the child's life. They help the child to maintain dignity and self-esteem, and are able to sustain hope. They are able to be there for the child and family, and facilitate the child's understanding of dying.

Name _____ ward _____

Name _____ ward _____

Name _____ ward _____

APPENDIX G

Educational Influential Instrument (continued)Paragraph B

These nurses are especially sensitive to the needs of the families of dying children. They are particularly attentive to siblings of the dying child. They recognize that many families feel the need to be helpful. They promote an environment that invites the family to participate in care should they so desire. Because they appear to have an intuitive grasp of the needs of dying children and their families, they are able to provide terminal care in a truly remarkable way.

Name _____ ward _____

Name _____ ward _____

Name _____ ward _____

Paragraph C

These nurses are excellent communicators. They promote clear, rational communication between dying children, their families and other health care team members. They are sensitive to the needs of both the patient and family to talk about their impending loss and what it means to them. They understand children's cognitive development and are able to talk to dying children and their families in a very special way. They can respond effectively to the fear and anger that dying children and their families may express. They seem to be able to accurately zero in to the correct region of a problem.

Name _____ ward _____

Name _____ ward _____

Name _____ ward _____

APPENDIX H

Invitation to Participate in the Nursing Research Study:Critical Nursing Behaviors in the Care of Dying Children in the Hospital Setting

You have been nominated, by your colleagues, as a nursing "expert" in the care of dying children. As a nursing expert, you are invited to participate in a study that has been designed to discover the behaviors that expert pediatric nurses deem "critical" in the care of the dying child. The knowledge gained from this study will contribute toward the development of an expert model of nursing practice in the care of the dying child.

If you agree to participate, you will be asked to take part in a tape recorded interview, that will take approximately one to two hours, and at a later date you will be invited to critique the preliminary findings of this investigation. This critique will take approximately thirty minutes.

Please make the selection of your choice:

[] If you wish to know more about the study before making a decision, please contact *Lois Hawkins, PhD*:

[] Yes, I would agree to participate in this study. You can contact me with further information.

Name: _____

Phone: _____

[] No, I choose not to participate in this study.

Once you have marked your selection (above), PLEASE:

- 1) place the completed invitation in the accompanying envelope (marked "Confidential", and addressed to the researcher, care of the Nursing Office at Children's Hospital),
- 2) seal the envelope, and
- 3) send it (through internal mail), or drop it off at the Children's Hospital Nursing Office.

Arrangements have been made to ensure the researcher's prompt notification that the Nursing Office had confidential mail to be picked up.

Thank you for considering this invitation. A prompt reply would be appreciated.

APPENDIX I

Semi-Structured Interview Guide1. How would you describe the ward on which you work?

- * patient population
- * number of deaths
- * types of deaths: sudden, unexpected
sudden, expected
prolonged
- * types of terminal nursing: active treatment, including "99"
active treatment, but no "99"
palliative care
- * how many dying children have you cared for?
- * how many deaths have you been present for?

2. What constitutes a critical incident?

- * An incident in which a student or a colleague had a positive attitude toward care of a dying child or their family. Was it something they said or did?
- * An incident in which a student or colleague had a negative attitude toward care of the dying child or their family.
- * An incident in which you feel your intervention with a dying patient and/or his family really made a difference in patient outcome, either directly or indirectly.
- * An incident that went unusually well.
- * An incident in which there was a breakdown. Things did not go as planned.
- * An incident that you think captures what care of the dying child in the hospital setting is all about.

3. Details to think about, when describing particular incidents:

- * The context of the incident, for example shift, time of day, staff resources.
- * A detailed description of what happened.
- * What were the nurses' concerns at the time?
- * What was the respondent thinking about as nurses cared for that dying child and/or family?
- * What did the respondent feel during and after the incident?
- * What, if anything, did the nurse find most demanding about the incident?

***Adapted from: Benner, P. (1984). From novice to expert. Excellence and power in clinical nursing practice. (pp. 300-301). Menlo Park: Addison-Wesley.

Degner, L. F., Gow, C. M. & Thompson, L. F. (1991). Critical nursing behaviors in caring for the dying. Cancer Nursing, 14(5), 246-253.

APPENDIX J

Structured Data Collection Tool:

Study I. D. # _____

DATE ___/___/___

1. Age

Age (years) _____

2. Years of Pediatric Nursing Experience

Years _____

3. Years of Nursing Experience

Years _____

4. Most recent level of Nursing Education completed (please check *one*)

a) Registered Nursing Diploma _____

b) Post-Diploma Degree in Nursing _____

c) Baccalaureate Degree in Nursing _____

d) Master Degree in Nursing _____

5. Have you completed a post-basic course related to pediatric nursing?

Yes _____

No _____

APPENDIX K

Consent to Participate in a Nursing Research Study:Critical Nursing Behaviors in the Care of Dying Children in the Hospital Setting

I have been invited to participate in the above-titled research project. I understand that I would be one of approximately ten pediatric nurses taking part in this research study that will investigate critical nursing behaviors in caring for dying children in the hospital setting. The results of this study will contribute toward the development of a model of expert nursing practice in care of the dying.

I have been invited to participate because I was nominated by my colleagues as an "expert" in the care of dying children, I have at least five years of clinical experience, and I am currently involved in direct patient care.

If I agree, I will participate in a taped interview during which I will be asked questions about my observations and perceptions of essential qualities in caring for the dying child. The tape recorded interview will take approximately one to two hours to complete. I may decline to answer any questions and I may withdraw from the study at any time. At a later date, I will receive a preliminary draft of study results and will be invited to critique the findings. This critique will take approximately thirty minutes.

I have received a verbal explanation of the study and I have had an opportunity to have my questions answered. I understand that my decision to participate is voluntary, and that I have the option to withdraw my participation at any time.

I understand that there are no known risks to participating in this study. My decision regarding participation in this investigation will not affect my employment in any way.

There are no costs associated with my participation in this investigation. Although I may derive no direct benefits from my participation, I have been informed that knowledge gained through this investigation will contribute toward the development of an expert model of nursing practice in the care of the dying child.

APPENDIX K

Consent to Participate (continued)

I understand that my participation in the study will be considered confidential. I will be assigned a code number, and my name will not appear on any document. In no way will others ever know how I answered a particular question. In addition, all information gathered will be considered strictly confidential.

Interview tapes and transcripts will be accessible to the researcher and the thesis committee. They will be stored in a locked filing cabinet accessible only to the investigator and her advisors. Consent forms will be separately stored, in the same manner. At the completion of the study, tapes and transcripts will be retained for a period of seven years, following which they will be destroyed.

The results of this investigation will be published as a master's thesis and may be published in the form of a journal article. The members of the Thesis Committee are: Dr. Lesley Degner, RN, Ph.D., Faculty of Nursing, Dr. Elizabeth Hanson, RN, Ph.D., Faculty of Nursing, and Ms. Isobel Boyle, RN., MN., Director of Nursing, Children's Hospital.

My signature below indicates that I am informed and that I agree to participate as a volunteer respondent.

DATE _____

(respondent)_____
Lois Hawkins, RN BN
pH:
Graduate Nursing Student
Faculty of Nursing
University of Manitoba