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THE LIVED EXPERIENCES OF NURSES CARING FOR DYING PEDIATRIC PATIENTS

by

DANNA L. CURCIO, RNC, MS, FNP, PhD

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THE CITY UNIVERSITY OF NEW YORK
Abstract

THE LIVED EXPERIENCES OF NURSING CARING FOR DYING PEDIATRIC PATIENTS

by

DANNA L. CURCIO, RNC, MS, FNP

Advisor: Professor Martha Whetsell

The purpose of this research study was to explore the lived experiences of nurses caring for dying pediatric patients. Nurses and health care professionals may at times have difficulty adjusting and processing when life ends and this may have the potential to interfere with patient care. Reflection on past events and actions enable critical discovery of strategies to benefit both nurses and patients. The method for conducting this research study was from a qualitative phenomenological perspective exploring the lived experiences of nurses caring for dying pediatric patients. The philosophical underpinning of Merleau-Ponty (2008), in combination with the research method of van Manen (1990), was used for this research study. Nine female nurse participants, with between 1 and 4 years experience were interviewed. The meaning of the context of the lived experiences of nurses caring for dying pediatric patients uncovered seven essential themes of empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow bringing to a close that through the lived experiences of nurses caring for dying pediatric patients an overall theme of censoring becomes apparent. The Roy Adaptation Model (RAM) (Roy & Andrews, 1991; Roy, 2009) was found to be a nursing model that helped to understand that the nurse is an adaptive system functioning for a purposeful cause.
Keywords: pediatric nurses, dying pediatric patients, phenomenology, qualitative, Roy Adaptation Model
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Dedication

I dedicate this dissertation to the memory of my father and grandmother, both who left this earth too soon to see, experience, and be proud of my accomplishment.

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CHAPTER I: AIM OF THE STUDY

Introduction

The Innocents

“Then Herod, seeing that he had been tricked by the Magi, was exceedingly angry; and he sent and slew all the boys in Bethlehem and all its neighborhood who were two years old and under, according to the time that he had carefully ascertained from the Magi. Then was fulfilled what was spoken through Jeremias the prophet, “A voice was heard in Rama, weeping and loud lamentation; Rachel weeping for her children, and she would not be comforted, because they are no more.” (Matthew 2:16-18, Holy Bible, 1961).

This biblical passage represents the reflection of Rachel’s feelings towards children and dying. The interpretation of the death of children in this passage shows that Rachel could not be comforted; her experience of the death of children was her own pain and sorrow. Researchers may use a phenomenological approach to uncover and understand the meaning and essences of such lived experiences.

This study examined the lived experiences of nurses caring for dying pediatric patients. As this topic has not been explored, this study illuminated the meaning and essence of the nurses’ lived experiences in the caring for dying pediatric patients (Tubbs-Cooley, Santucci, Kang, Feinstein, Hexem & Feudtner, 2011; Davis et al, 1996). This study was conducted to shed light on a phenomenon that has not been rigorously examined, but deserves investigation.

Aim of the Study

The aim of this study was to explore, describe, and understand the lived experiences of nurses caring for dying pediatric patients and to gather information that may help future nurses when guiding the dying child. Participants were asked questions
related to the lived experiences of caring for dying pediatric patients. The questions were concerned with: the ways in which nurses know that their pediatric patients are approaching the final stages of life, nurses’ interactions with the pediatric patients and their families, thoughts processed by the nurses as their young patients approached death, ways in which the nurses cope with these thoughts, and ways that nurses integrate these issues into patients’ care. Additional questions that emerged and were addressed concerned the pediatric patients’ actions, feelings, and emotions during the final stages of life and how nurses were able to identify these cues. Themes and essences that emerged from the questions provided insight into understanding the ways in which nurses “nurse”, as well as information on nurses’ essential tasks in caring for dying pediatric patients.

**Research Question**

The research question that guided this study was, “What are the lived experiences of nurses caring for dying pediatric patients?” In achieving the clarification for this study, van Manen’s (1990) interpretive phenomenological design was employed to explore this phenomenon. The desired outcome of this study of nurses’ experiences of caring for dying pediatric patients was a clearer understanding of the importance of the phenomenon.

**The Phenomenon of Interest**

There are many different areas of nursing practice that span the life process. Some practice involves nurses who care for the sick and the dying. It is important to understand why nurses practice within this population because caring for the dying is unique. It is a worthwhile endeavor to understand the trajectory of professionals who practice nursing in this field and give care under such circumstances.
Therefore, the phenomenon of interest of this study was the lived experiences of nurses caring for dying pediatric patients. Throughout the course of their careers, nurses care for patients that are sick, patients who are in the throws of suffering, and they may also care for patients who are in the process of dying (Maeve, 1998). The death of a child is perceived as contrary to the natural process of life (Papadatou, Martinson & Chung, 2001). However, this phenomenon, taking care of dying children, becomes vital when helping nurses transition through the child’s dying process because health care professionals may have difficulty adjusting and processing when illness ends life (Papadatou, Martinson, Chung, 2001).

This difficulty of adjusting and processing may interfere with care. Nurses taking care of terminally ill patients of all ages fear burnout and may create psychological barriers between the patient and themselves that include the inability to become aware of death (Davies, et al, 1996). Barriers created by nurses who care for dying pediatric patients may be due to severe grief, and may even result in withdrawal from patients and families (Davies, et al, 1996). For this researcher and educator, exploring and understanding the lived experiences of nurses caring for dying children was important because of the impact the research findings will have on nursing education, nursing research, nursing reasoning, and substantiation of nursing practices.

**Justification for the Study**

This study sought to explore, describe, and understand the lived experiences of nurses caring for dying pediatric patients. Care includes facilitating the process of dying and support during the last moments of life. The last moments of life are extremely critical because the moment of death is a finite point in time in which each action
becomes a permanent fixture in the caregiver’s memories. In discovering the nurses’ lived experiences of caring for dying pediatric patients, we are able to understand the importance of knowing how to interact with these patients. This discovery of knowing how to interact may be due, in part, to personal knowing which concerns the inner experience of becoming aware of one’s own self and the self of others (Chinn & Kramer, 2008).

There is a paucity in the literature on the lived experiences of nurses who care for dying pediatric patients (Tubbs-Cooley, et al, 2011; Davies et al, 1996). Although the issue of palliative care, including policies, procedures and family interactions has been researched, the subject of nurses who work with dying pediatric patients had not been explored (Tubbs-Cooley, et al, 2011; Foster et al, 2009; Benini, Spizzichino, Trapanotto & Ferrante, 2008; Wiener, Ballard, Brennen, Battles, Martinez & Pao, 2008; Sahler, Frager, Levetown, Cohn & Lipson, 2000). The lack of investigation and exploration in this subject matter may be due to the emotional sensitivity of both the nurses and bereaved families.

**Phenomenon in Context**

The context of this study was the dying pediatric patient and the processes of the nurses who care for them. Death and dying at the end of a long life is understood as part of a natural life process (Mukherjee, Beresford, Glaser & Sloper, 2009). Death is observed as a natural occurrence when the patient is at the end of a long and fulfilled life. Conversely, the death of a child is considered to be unnatural and brings on a much different perspective when it happens (Dawson, 1995).
It has been said that when death comes to a pediatric patient, lifelong dreams and aspirations of parents also die (Papadatou, Martinson & Chung, 2001). Parents, families, and nurses all must grieve this loss in their own space and time (Morgan, 2009). This grief has lead to a new research in palliative care and a need to understand how to best provide care for dying pediatric patients.

Many dying children will be cared for by nurses. Therefore, the context of this study included the processes of the nurse in caring for dying pediatric patients, which can be thought of as one of the most stressful situations in a health care professional’s career (Papadatou, Martinson, Chung, 2001). However, contrary to the stress of pediatric death, the nurses’ experiences of caring for dying children can be considered meaningful and professionally satisfying (McGrath & Kearsley, 2011).

If this is true, then these meaningful and satisfying experiences hold insights for how we approach the care of dying pediatric patients. It has been stated that nurses possess the ability to read the actions of dying children and plan their patient care accordingly. Foster et al (2009) says a dying child has been known to express final thoughts and intentions in non-verbal actions.

The ability to read actions and cues helps nurses to reflect on previous events that involved their own mortality, ethical morality, and their ability to adequately care for dying pediatric patients. This ability combines empirical, personal, aesthetic, and ethical ways of knowing (Chinn & Kramer, 2008). As nurses read actions and cues when providing care for terminally ill patients they enhance their ability to become aware of death. Always the focus of awareness of death is attentive to the causal affects placed on the nurse herself, specifically ways of knowing (Zomorodi & Bowen, 2010).
Knowing how to handle the experience of last moments and dying, and being aware of the need for her own self-preservation may account for actions taken by nurses (Davies et al, 1996). In caring for dying pediatric patients, nurses become experts by calling on their own theoretical knowledge or conceptual knowledge they learned through their nursing education (Papadatou, Martinson & Chung, 2001). Nurses may also draw on their practical knowledge, which is a synthesis of both theoretical knowledge and learned actions from clinical experience.

Nursing care of dying pediatric patients becomes vital as nurses participate in the transition through the child’s dying process. This research will be valuable in presenting evidence for educators to use as they guide nursing students and new nurses on how to transition the dying child. This study will illuminate ways in which nurse scientists may conduct additional research on how to gain a deeper understanding of an inevitable life process.

**Assumptions and Biases**

My assumptions and biases were based on my experience as a Maternal-Child nurse. I believed that I would find that nurses who experience traumatic situations lack opportunities to verbally express their conscious or subconscious reactions to death, especially the trauma of a pediatric death. I also expected to learn that when people experience a traumatic situation, such as death of a child, they are better able to cope when they verbalize their feelings to concerned others.

I additionally identified five other basic assumptions. First, each individual reacts to trauma or pain differently. Each nurse interprets her own experience in a different way, adding to human meaning and convergence of the universe. Second, each
perception causes a stress reaction. A person’s consciousness and search for meaning is related to his or her integration into the environment. Third, perception may help with adaptation. An individual’s decisions are accountable through thinking and feeling which mediates human action. Fourth, nurses who were included in this study were new in the care of dying children, possessing between one and four years experienced. Participants that cared for terminally ill children within this timeframe would be able to clearly expand and recall long-standing experiences of bedside nurses. Fifth, nurses who have their own children might have been emotionally withdrawn or have trouble expressing their feelings due to the emotional connection.

**Methodology**

In conducting this study I used the methodology of van Manen (1990) to explore the phenomenon of nurses’ experiences in caring for dying pediatric patients. According to van Manen (1990), the purpose of phenomenological research is to establish a reconnection of recollection with the original experience, and give persons an opportunity to look at the world and re-examine the meaning of the event. In exploring the experiences of nurses caring for dying pediatric patients I sought a deeper and clearer understanding of the importance of the phenomenon.

**Relevance to Nursing**

The phenomenon under study was the lived experiences of nurses caring for dying pediatric patients. This study helped uncover important information with regard to the care of dying pediatric patients. This information will enhance knowledge in nursing education, adding to the development of personal knowledge of new nurses by describing and uncovering specific awareness in the moment of the context of the interaction. This
research thereby made possible meaningful, shared human experiences to allow for identification of patterns of actions of the nurses (Chinn & Kramer, 2008). Also, this research identified authentic patterns of behaviors, feelings, and actions that nurses use in the last moments of a child’s life that are new to the care of dying pediatric patients, and thus provide a rationale for nursing practices (Dobratz, 2002).

Several studies have been conducted on nursing care and nurses’ experiences with adult populations (Papadatou, Martinson & Chung, 2001); however, there is a gap in the literature on the lived experiences of nurses who care for dying pediatric patients (Tubbs-Cooley, Santucci, Kang, Feinstein, Hexem & Feudtner, 2011; Davies et al, 1996). This gap is significant for pediatric nursing. If nurses are to provide efficient care for dying pediatric patients, it is imperative that we discover how they dealt with their experiences, feelings, and actions.

Experiences, feelings, and actions create behaviors which guide individuals to interact with situations within a specific environment (Dobratz, 2002). These experiences, feelings, and actions, once identified, provide the basis for important nursing education and nursing theory to enhance patient care interactions. Nurses, through these interactions, make a difference, for the better, in patients’ lives (Dobratz, 2002).

The reflection of study participants on their past experiences, feelings, and actions allowed myself to discover critical concepts that affect the way in which nurses perform when a pediatric patient is dying, for the benefit of both nurse and patient. This discovery also provided insight into the nurses’ thought processes. These processes included emotional responses, nursing actions, nursing interpretation of the dying pediatric patient’s actions, and family concerns.
Summary

Chapter I described the phenomenon of interest for this phenomenological study which was to examine the lived experiences of nurses caring for dying pediatric patients. This discovery uncovered the nurses’ lived experiences as they cared for dying pediatric patients and in turn provided further insight in how we nurse. Gaps in the literature on the lived experiences of nurses caring for dying pediatric patients were described. Chapter II describes the evolution of the study and identifies the historical, experiential, and theoretical context.
CHAPTER II: EVOLUTION OF THE STUDY

Research has focused on the process of dying, but has not explored the lived experiences of nurses caring for dying pediatric patients. Focusing on this phenomenon, helped describe how nurses reacted and responded within this setting and experience. Caring for a dying child can be interpreted as uncomfortable and beyond our capacity to comprehend (Dawson, 1995). This chapter will explain the historical, experiential, and theoretical content related to this study.

**Historical Context**

Historically, caretakers have attempted to nurse sick and dying children within their communities by relieving suffering (Wilson, 2005). However, there is little in literature that documents how nurses cared for dying pediatric patients. Reasons for this gap may be due to the inability of healthcare providers to accept death in the pediatric population (Morgan, 2009). Other problems related to the death of pediatric patients may have been the diverse developmental levels of the patients. Pediatrics encompasses a span of approximately 18 years and the healthcare provider’s approach to each patient can depend on the patient’s cognitive and emotional maturity. Furthermore, dose-intensive therapies can prolong life and postpone pediatric death mostly due to the experimental nature of how pediatric illness is treated (Mukherjee, Beresford, Glaser & Sloper, 2009).

As described in the passage of “The Innocents”, we can understand that death of children is not a normal event. In this passage Rachel wept for the lost lives of her children and the children of Israel. Death of children is a tragic occurrence. It is an
incomprehensible event that is contrary to the way in which we expect life to unfold (Dawson, 1995).

**History of pediatric healthcare.** In biblical times pediatric death was seen as the work of evil spirits and revengeful gods. However, through what is now known as evidence based practice, Hippocrates found that disease patterns genetically, nutritionally, globally, or environmentally had an impact on health. In the United States, up until the middle of the nineteenth century, care of the sick child was done in the home partly because it was thought that children should not be separated from their mothers and partly because infectious diseases posed a threat to hospitalized patients (Bradley, 2003).

If care of the sick child in the home was not an option, children were sent to “poorhouses” and infant asylums where the mortality rate was close to 100% (Connolly, 2005). This rate prompted the need for construction of hospitals that specialize in children’s care. The first children’s hospitals housed indigent and abandoned children who may or may not have been ill. Admission to children’s hospitals was also a means of promoting healthy behaviors and health practices. Florence Nightingale, the founder of modern nursing, was the motherly and affectionate role model of a nurse in these early children’s hospitals (Jolley & Shields, 2009).

After the second half of the nineteenth century, medical organizations formed in the United States, specializing medicine into distinct disciplines. This specialization allowed pediatrics to develop a body of knowledge related to the care of a specific age population. Because medicine was evolving from an adult perspective, so did nursing practice. The specialization of pediatrics was formalized when the first pediatric textbook was published in 1923 (Connelly, 2005).
The evolution of pediatric medicine in the second half of the nineteenth century led to the discovery of germ theory (repair or replacement of a defective gene) and treatment modalities (method used to treat a patient for a particular condition). These discoveries changed pediatric medicine and nursing because care of the child was now directed at both indigent and ill populations. For this reason, as the end of the nineteenth century approached, children were hospitalized more often for medical and surgical conditions than for social welfare; infectious diseases and cross-infection within the hospital were seen as the primary causes of pediatric death (Connelly, 2005; Jolley & Shields, 2009).

During the 1870s and 1880s, the treatment of childhood illnesses became more scientific (Jolley & Shields, 2009). The identification of infections and contagious diseases led to the discoveries of new treatments and medicines to eradicate illnesses and decrease the mortality rate of children who were exposed to infectious germs. As healthcare changed, and science evolved, the primary cause of pediatric illness and death was then viewed as resulting from neurodevelopmental disorders, diabetes, allergic-related diseases, congenital difficulties, respiratory afflictions, oncology based illness, and childhood chronic diseases (Genuis, 2010).

Currently, approximately two-thirds of infant/pediatric deaths that occur during the first month of life are primarily attributed to congenital abnormalities, perinatal complications, infections, and other similar issues (Sahler, Frager, Levetown, Cohn & Lipson, 2000). During the first year of life pediatric deaths occur due to trauma, abuse, accidents, or acute unexpected events such as sudden infant death syndrome. In the toddler and school-aged group 45% of deaths are caused by trauma among adolescents,
80% of deaths are caused by accidents, homicide, or suicide (Sahler, Frager, Levetown, Cohn & Lipson, 2000). The remaining percentage rate of deaths in these populations can be attributed to chronic conditions and illness. In the United States alone, 55,000 children and adolescents under the age of 20 years old die from a lengthy illness, cancer being the leading cause of disease-related death (Morgan, 2009). Chronic disease treatments run the course of diagnosing and management of the disease to supervision of symptoms and treatment of the disease process.

Even though health conditions might be chronic and incurable, they might not be immediately life-threatening. Dying pediatric patients who have inevitably poor prognoses are cared for in a palliative manner. Nurses tending to dying pediatric patients provide care to a living child that is at the end of life, a condition that cannot be forgotten. To help ease the transition of death, nurses provide interventions that focus on the dying patients’ relief in suffering through palliative care and terminal care.

**Impact on nursing.** Exploring the lived experiences of nurses caring for dying pediatric patients helps us learn how the nurses feel, respond, and process the events. Nurses’ responses, or lack thereof, adds to research focused on positive actions such as caring, empathy, and therapeutic interventions within nursing. Limitations in research may further impact the way nurses care for their patients (Morgan, 2009). Pediatric death can be interpreted as a failure of the healthcare system to provide adequate, lifesaving measures, and may emphasize both the profession’s inability to protect children from harm, with the result of betraying parents who entrusted their children for care (Papadatou, 1997). This failure has the potential to increase the emotional distress experienced by nurses caring for dying pediatric patients.
Experiential Context

Throughout my career as a Maternal-Newborn nurse I experienced the joy of life with new parents. When times were happy they were very happy. However, there were instances when the outcome of birth was tragic and heart wrenching, far from a happy experience. It was at these times that I watched my fellow nurses care for and console their delicate patients and families. At times, life for these infants ended quickly, and at times their lives lingered. I was always respectful of how my colleagues provided care and interacted with the parents. What intrigued me most was how the nurses perceived the event.

One event in particular happened when I was 23 weeks pregnant with my second child. I must add that my pregnancy was wrought with problems that threatened my ability to carry to term (term is the length of 40 weeks gestation). One night while I was working the night shift, a mother had given birth to a preterm newborn that coincidentally was 23 weeks gestation as well. I was encouraged to go see the newborn, who was now a patient in the Neonatal Intensive Care Unit (NICU). As I walked into the NICU I could not help but notice how beautiful the newborn was. However, I was most intrigued by the reaction of the nurses to the newborn.

The nurses had placed the newborn in an isolete (an enclosed crib) and placed the crib in a quiet, dim-lit corner of the nursery. I did not understand why the nurses did this, but assumed that at 23 weeks gestation the newborn did not have a chance of survival, and the nurses knew what was inevitable. I was intrigued by what the nurses were feeling and experiencing at that moment, but concluded that they were experts in this realm of nursing and through many years of practice believed placing the newborn in a quiet,
secluded part of the nursery was the best thing to do. I wondered how these nurses knew what to do.

After many years working as a staff nurse, I decided to begin a career in nursing administration. This change brought on great challenges, far from ones encountered at the bedside. However, I am always drawn to the bedside nurses and how they perceive care, interpret their work, and whether they feel they may have helped their patients and families. These inquiries became evident when I conducted hospital rounds in the Intensive Care Unit and Cardiac Care Unit (ICU/CCU) patient care areas. There, critically ill adults were treated, managed, and comfortably eased into transitioning through the death process. I watched the nurses, sometimes in silence, create atmospheres congruent to the transition process. I wondered how these nurses knew what to do.

It wasn’t until the death of my father that I realized death is a process that cannot be stopped. It is inevitable, although it can be a slow process or can happen suddenly. My father’s illness was a progressive, and initially seemed to proceed slowly, but ultimately took his life in an instant. I believe my nursing education and training lead me to understand what was happening to his health. As an adult in deteriorating health, his death, in a sense, was not a surprise. This perspective of death is opposed to how one feels when a child is dying.

Though at times I felt uncomfortable discussing the events that took place with my father’s death, I also felt relieved at being able to communicate the events that occurred. In discussion of the events, I was able to understand what was occurring and how death was imminent. I drew upon my education, experiences, and my assessment of
the patient to understand what was happening. This knowledge needed to be bracketed when interviewing and questioning the nurses and interpreting the data.

I am respectful of how nurses work on a daily basis, especially as pediatric death is contrary to the normal life cycle. As a family nurse practitioner and mother of two children, I am humbled by nurses that care for dying pediatric patients. I believe that in exploring the nurses’ perspective on caring for this population I was able to discover the phenomenon of their experiences and provide further knowledge in this realm.

**Theoretical Context**

The Roy Adaptation Model (RAM) (Roy & Andrews, 1991; Roy, 2009) states that the person is viewed as a bio-psychosocial holistic being who is capable of adapting effectively to changes in the environment (Roy & Andrews, 1991). Therefore, the capability of the individual to adapt is his or her own conscious choice. According to Roy (1997), the nurse promotes positive patient outcomes. The nurse influences individual choices, promotes effective adaptation, and enhances individual well-being. In addition, the nurse creates conscious choices that influence his or her own personal level of adaptation. In order to consciously guide positive patient outcomes, the nurse has to continually update knowledge and remain competent practice.

The selected phenomenon of the lived experiences of nurses caring for dying pediatric patients can be viewed as an input, or adaptive stimuli, for the pediatric nurse. Therefore, the research question will focus on the nurse as the adaptive system in relation to stimuli and stressors. The experience of stimuli and stressors will help develop the research question and aims, using the adaptive modes pediatric nurses utilize, and then employ, to allow perceptions of adaptation to be explained.
The assumptions underlying the RAM (2009) is that adaptation is a function of the stimuli. The person is an adaptive system and the input process has an effect on four adaptive modes: physiological, self-concept, role function, and interdependence. Roy (2009) identifies input as stimulus and categorizes the stimuli as focal, contextual, and/or residual, and adaptation occurs when accounting for these. These stimuli act together and influence the adaptive level which is the person’s ability to respond positively in a situation.

Within this study the focal stimuli was the dying child that continuously confronts the nurse. Since the goal of nursing is to promote adaptation, the regulator and cognator subsystems control the processes of adaption that operate on the stimuli. The regulator subsystem is characterized by the physiological responses, coping and adaptation, which occur automatically in response to the stressor. An individual demonstrates effective or ineffective adaptive responses that require nursing interventions in the cognator subsystem and manages stimuli experienced. For this study, control processes, through subsystems, refer to how pediatric nurses coped with the conditions of their patients.

The four adaptive modes previously discussed should help in providing balance in the physiological, interdependence, role and self-concept of individuals within their environmental stimuli. After stimuli have been experienced, and the coping process has begun, the adaptive output can be achieved. Outcome depends on how a person adapts to a given situation, resulting in feedback. Feedback plays an important part in how an individual learns the process of coping within similar as well as different situations. This feedback then facilitates learning, so that the individual uses feedback to either repeat or correct the adaptive course of action.
Adaptation can be understood as a process in which individuals use awareness and choice to integrate human and environmental factors to aid in adaptation. Adaptation is a positive response while maladaptation is a negative response. By examining their feelings about dying children, nurses were able to evaluate the effectiveness of their self-adaptation, as demonstrated by the outcomes of their actions.

**Summary**

Chapter II described the evolution of the study in the historical, experiential, and theoretical context. The history of pediatric healthcare and the impact on nursing addressed the historical evolution of the study. The personal and experiential events that lead me to choose this as my research topic, were discussed. The Roy Adaptation Model (RAM) (Roy, 2009) and theoretical aspects were addressed. Chapter III describes the phenomenological method of research that was chosen for this study.
CHAPTER III: PHENOMENOLOGICAL METHODOLOGY

The purpose of this study was to explore the lived experiences of nurses caring for dying pediatric patients. The method for conducting this research study was a qualitative phenomenological framework in which the researcher investigated the lived experiences of nurses who care for dying pediatric patients. Phenomenology has been defined as a systematic process of uncovering and describing the internal meaning and structure of an event as it is lived in one’s everyday existence, in their lifeworld (van Manen, 1990). A phenomenological framework was chosen because it is a way in which to study the human experience and issues that present themselves to humans within the context of specific experiences (van Manen, 1990). The ideas of phenomenology were developed by Husserl, Merleau-Ponty, and van Manen. This study utilized the phenomenological research method of van Manen and the philosophical perspective from Merleau-Ponty.

Rationale for Selection

The rationale for selecting the methodology of van Manen (1990) was to uncover the lived experiences of nurses caring for dying pediatric patients. According to van Manen (1990) the researcher uses inquiry and allows the participants to tell their experiences. Through interviews, I gathered information to describe the deep and rich meaning of the phenomenon. As the researcher, I became the instrument through which the participants were able to tell their story and recollect, reflect, and share on their experiences. This method was helpful in understanding and describing the phenomenon as told by the participants. Through a phenomenological inquiry I illuminated and revealed the phenomenon of the experiences of nurses caring for dying children.
**Phenomenology**

Phenomenology is the science in which we come to know the mind as it is in itself through the study of the ways in which it appears to us (Merleau-Ponty, 2008). Phenomenology is the study of our experiences and how we experience them; our perceptions of the events we experience. Phenomenology attempts to identify the invariant features of how objects are perceived and pushes our consciousness into reality to attribute how we perceive events. The essence of our consciousness is experienced in the first person and is defined by the first person.

These essences of our consciousness are then a description of the phenomenon. The objective of the research is in the investigation, interpretation, or description of what is, as consciously experienced. The objectives of phenomenological research are our conscious learning of things through our lived experience and the ways of learning we derive from such experience. Therefore, phenomenological research is the study of both our experiences and how we experience them, while learning about the experience within a cultural and historical context (Polifroni & Welch, 1999). We then create meaning of our learning through what has influenced us in the past and through how we have learned to learn. In nursing we use phenomenological research to understand individual’s lived experience, which gives us a better understanding of the philosophy within our discipline.

**Edmund Husserl.** Edmund Husserl (1859-1938), the “father” of the philosophical movement known as phenomenology, used phenomenology to give meaning to interpretation, directing our consciousness, or our conscious interpretation, towards assumptions of previous experiences. According to Husserl, we create a pattern from pieces that are understood by ourselves therefore, consciousness is scientific knowledge.
Scientific knowledge lends to directness of consciousness of an object or event where assumptions create patterns of knowing or patterns of being (Husserl, 1983). We use the knowledge and learning we derive from past experiences to define a lived experience. When experiencing events first hand, we gain the knowledge to be able to overcome the conflict when we experience it once again. Phenomenology is a first-person knowledge, which can also be thought of as intuition when recalling this knowledge at a later time. This recall of knowledge is the lived experience.

Husserl states phenomenology is a description of phenomena made possible by “bracketing” all assumptions about the existence of an external world (Husserl, 1983). “Bracketing” is the blocking out of the researchers personal experiences and focusing on the unique perspective of the phenomenon being studied. This is concentration on pure consciousness. Husserl believed the mind is the only source of meaning and interpretation, hence the mind-body split. Here “bracketing” becomes central to the knowledge and learning of the lived experience. Separation of the mind from the body becomes vital to interpretation. What is “seen” is the essence of perception.

Maurice Merleau-Ponty. Merleau-Ponty (1908-1961), expanded on Husserl’s ideas by focusing on understanding experiences and how they exist in context (Merleau-Ponty, 2008). His work expanded on the rediscovery of the original experience, adding clarity to it. Merleau-Ponty stated the importance of the perception of experiences in the context of the individual’s situation (Merleau-Ponty, 2008).

Merleau-Ponty’s framework focused on the existence of the human “form” in terms of the lived experience, embodiment, or the meshing of the individual and the world in which he exists, and perception. Merleau-Ponty defined lived experience as the
individual’s perception and how perception is influenced by embodiment within the lifeworld: through spatiality, corporeality, temporality, and relationality (Merleau-Ponty, 2008). Spatiality, corporeality, temporality, and relationality all influence experiences allowing for understanding of the lived experience within the lived world.

Spatiality occurs when the parts of the experience, interrelated in some way, become enveloped in each other and give rise to the totality of the experience itself (Merleau-Ponty, 2008). Spatiality within the context of this study defines the connectedness between the nurse and the dying pediatric patient. Spatiality between the nurse and the child becomes essential when describing the experience of the nurse because it is within this relationship that the experience develops.

Corporeality is an essential, distinguishable, and tangible part of the experience that individuals relate to when reflecting on past experiences. This reflection through such areas as the consciousness, the world, and the human body, create and define the meaning of current experiences thereby defining our experiences through past, present and future events. Corporeality within the context of this study may be recognized as the feelings the nurses had through past events when caring for dying pediatric patients, and which are reflected upon in present and future experiences.

Temporality is a conscious, absolute point of orientation, in which past events define our orientation to the present. Temporality within the context of this study may be defined by the descriptions of the experiences the nurses felt currently as they were influenced by past experiences. A recollection of past experiences, tempered by one’s physical place within the experience, is an integral part of the memory.
Relationality refers to the kinship of meanings between experiences, which allows for connection of perceptions. Connection of perceptions gives meaning to the phenomenon in the totality of the experience. Relationality within the context of this study may be defined as the ways in which nurses related to several experiences and applied meaning to the way in which those experiences occurred.

For this research study, I used Merleau-Ponty’s philosophical framework, which includes the concepts of awareness and consciousness. Awareness allows the individual to sense what he or she is experiencing at any moment. Consciousness refers to the individual’s relation to the world and interpretation of that relation within his or her experience. These concepts, when used in researching the lived experiences of nurses caring for dying pediatric patients, helped illuminate the possibilities of awareness and consciousness experienced by nurses.

**Max van Manen.** Max van Manen (1942-present), a phenomenologist, expanded on the contributions of Merleau-Ponty by explaining that the lived experience includes intersubjectivity (validation between individuals), bracketing, and reflectivity. He further expanded upon the Merleau-Ponty’s (2008) concepts of person, time, space, and relationships, which define the lived experience of the individual through unique perceptions. In researching the lived experience, phenomenological questions are raised to describe meaning and give significance to certain phenomena (van Manen, 1990).

Van Manen (1990) supported the notion that the researcher and the participant, through communication and interpretation, come to describe and understand the meaning of a phenomenon. This scientific research cannot be understood unless it is actively performed. Participating in the interaction of the lived experience allows for illumination
of the existential meanings, descriptions, and interpretations, providing the methodology of the research process created by van Manen to allow for understanding of the phenomenon.

**Background of the Method**

Van Manen’s method (1990) is an interpretive phenomenological research approach, in which the researcher’s involvement has a primary place in questioning the way individuals experience the world. This research method explains phenomena as it is presented to the consciousness, beginning in the life-world or the world as we experience it. Van Manen’s method of inquiry involves six steps or methodological themes in the research process as a way to create meaning. The six steps are:

1. Identify a phenomenon that interests us.
2. Conduct an investigation of the phenomenon as the lived experience, not as it is conceptualized.
3. Reflect on illuminated essential themes that characterize the phenomenon.
4. Write and rewrite in order to describe the phenomenon.
5. Maintaining a strong relation to the phenomenon in terms of pedagogy.
6. Balance the context by considering the parts as well as the whole.

First, the researcher must identify a phenomenon of interest by identifying a lived experience that is of strong interest to the researcher. The need to understand the discovery of the phenomenon becomes the beginning and end point for the research (van Manen, 1990). Second, the researcher should then be open and aware of the world of the individual participants to allow for better understanding of the individual’s perspective of the experience. Third, by using reflectivity, thoughtful insight and understanding the
researcher can report of the significance of the phenomenon. Essential themes are identified which define the meanings of the experience. Forth, through writing and rewriting thoughtfulness and illumination brings meaning to the description of the experience. Fifth, through a relationship to the phenomenon, rigor and strength in the research process becomes clear and will hold meaning and guidance. By adhering to the phenomenological research beliefs, the researcher will achieve a genuine description and understanding to the lived experience. This will be done through interpreting the perception of the individual’s experience, writing and interpreting the essences and meanings, relating these essences to relevant literature, and the ability to learn and understand the phenomenon. Finally, the researcher must carefully analysis of each part of the research process and relating them to the whole phenomenon (van Manen, 1990).

Summary

Chapter III described the methodology of the study. Phenomenology was explained and described through the works of Husserl, Merleau-Ponty, and van Manen. Van Manen’s six-step method of phenomenological research was presented. Chapter IV describes the methodology applied to this research project.
CHAPTER IV: METHODOLOGY APPLIED

From a qualitative perspective, exploration was used to study the phenomenon of the lived experiences of nurses caring for dying pediatric patients. The philosophical underpinnings of Merleau-Ponty (2008) were used for this research, in combination with the research method of van Manen (1990). Qualitative research proposes to discover the perceptions of individuals within a particular phenomenon. This process guided the researcher in collecting and analyzing data that explored and described the meanings that comprised the lived experiences of the nurse caring for the dying pediatric patient.

Research Activities

According to van Manen (1990), the purpose of phenomenological research is to establish a reconnection of recollection of the original experience. This lived experience of a phenomenon gives an opportunity to look at the world and re-examine the meaning of the event. According to the research process of van Manen (1990), there are 6 activities or steps that the researcher needs to follow.

The first step in van Manen (1990) was to identify a phenomenon of interest, turning to the nature of the lived experience. The lived experience of the nurse caring for dying pediatric patients had always been a phenomenon of my interest due to personal factors within the context of work related experiences. Watching nurses care for the sick and dying of all ages, as well as caring for my ailing father, probed my inquistion as to how nurses interpret, respond to, and adapt to the experience. I interviewed nurses who had the experience of caring for dying pediatric patients. This expressed reflection by the participants made sense of the meaningful experience (van Manen, 1990).
The second step pertained to the investigation of the phenomenon. In light of this, using van Manen’s methodology, face-to-face interviews provided the opportunity for participants to describe their experiences from their own perceptions. It also provided me the opportunity to gain first hand knowledge of the lived experience from individuals emersed within the phenomenon itself (van Manen, 1990). As a Maternal-Child nurse, I was able to relate to aspects of nursing care within this realm and was able to explore the lived experiences of nurses caring for dying pediatric patients due to my background and experience in this area. Investigating the experience as it is lived, I listened to each participant as they described their experience. Verbal interviewing provided an easier account of personal experiences (van Manen, 1990). While listening, I audio taped the interviews for future reflection and documentation of raw data, to which the phenomenon was then studied. The audiotapes were then transcribed into text, providing the richness of the human experience in relation to the research (van Manen, 1990).

The third step: reflecting upon themes that characterize the phenomenon, the fourth step: writing and rewriting activity, the fifth step: maintaining a strong relation of the phenomenon in relation to pedagogy, and the sixth and final step: balancing the context of the study by considering the parts as well as the whole, will be discussed in the data analysis section of this chapter.

**Protection of Human Rights**

After the City University of New York (CUNY) Institutional Review Board (IRB) approval was obtained, voluntary participation of individuals were selected through networking and purposeful sampling. Flyers were posted at colleges of nursing bulletin boards. Participants were asked to give information to other potential participants
through word of mouth, creating a snowballing effect of participant recruitment. Individuals interested in participation in this study were instructed to contact Danna L. Curcio through the e-mail address or cell phone number provided. Both participant and researcher then arranged interviews in a private location chosen by the nurse participant.

After the CUNY-IRB application was submitted and approved, formal consent was obtained from each participant prior to interviews and data collection (Appendix A). Invitation to participate, disclosure of pertinent information for the purpose of the research, procedures of the interview process, and the participants’ voluntary agreement to participate were all included in the informed consent. All aspects of the study were explained including my role as the researcher.

To protect confidentiality, participants were not referred to by name. Each participant’s identity was masked, and he or she was provided with a pseudonym to use for reference. The interviews were then tape-recorded, and all audio recordings and transcriptions were stored in a locked file cabinet of which only I had access to. Any computerized memos of the encounters were secured in the researcher’s computer under password access.

In addition to face-to-face interviews, demographic data was also collected. This demographic data was collected using pen and paper and these documents were stored in a locked file cabinet of which I, solely, had access to. There were no identifying sections of information on the demographic questionnaires, only coded numbers to refer to the taped interviews if needed. For example, each tape recorded interview was placed into a numbered digital file that correlated to the demographic data documents.
In reliving the experience of caring for dying pediatric patients, I provided appropriate resources and referral to the nearest hospital emergency room if participants or I felt they may have needed mental health counseling (Appendix C). This recounting of experiences could have been traumatic to participants, especially when memories involved dying patients. Therefore, participants were allowed to withdraw from the study at any time they wished and ceased interviews when they felt necessary.

Sample Selection

A purposeful sample of registered nurses that worked on pediatric units and cared for dying pediatric patients were chosen on the basis of availability and likelihood of participation in this study. Purposeful sampling allowed selection of individuals who had similar experiences within the phenomenon, and then permitted the researcher to understand the phenomenon in question (Polit & Beck, 2004). Participants were selected by word of mouth and snowballing recruitment.

Nurses chosen for this study were professionals who had a minimum of one to four years of pediatric nursing experience, allowing for a timely recall of pediatric death experience. Professional nurses are the individuals that are in direct contact when caring for dying pediatric patients and their families. The reason for selection of this population was that registered professional nurses are at the forefront of primary care, spending a majority of time with terminally ill children at the end of their lives. Registered nurses are the individuals who would be more apt to interpret physiological changes with the status of their patients, are the individuals in tune with psychological changes of their patients, and are the individuals who interact most with patients and family members.
Exclusion criteria were nurses who have had their own child die, or have experienced a child within their immediate family die from terminal illness.

Registered professional nurses were selected by voluntary participation through networking, purposeful sampling, word of mouth, and snowball sampling. Subjects interested in participation in this study contacted the principle investigator through e-mail address or telephone (Appendix D). After initial contact between participant and researcher, a brief screening for eligibility for participation in the study was conducted (Appendix B). Once participants met the criteria for the study and anonymity was assured, a demographic form was given, and an informed consent to conduct and audio tape the interview was signed by each participant (Appendix A). Each participant was also given information for emotional/psychological help in case they needed psychological support after the interview (Appendix C). Interviews were conducted in a private location convenient for both participant and interviewer. Interviews lasted between 35 to 45 minutes. The content of which were then transcribed, and the transcriptions were sent to the specific participant for clarification. To maintain confidentiality, names were withheld from the transcriptions, and a number identified each participant.

**Data Collection**

Potential participants contacted me through email or cellular telephone number that were provided with the invitation paperwork. Demographic data was also collected to define the population that was included in the study. Demographic data included age, educational level, and number of years in this specific nursing specialty. Family status was also asked, including the number of children the nurse might have had (Appendix B).
Data collection included interviews of nurses who cared for dying pediatric patients. The estimated number of participants was to have been between 4 and 10 individuals mainly because qualitative research consists of small sampling populations (Polit & Beck, 2004). This study concluded with 9 nurse participants, determined data saturation, new information was no longer forthcoming, and the participants adequately described the phenomenon of the lived experience of caring for dying pediatric patients. After the initial interview, when the transcriptions were completed, participants were then asked to conduct a second interview as suggested by van Manen (1990), to clarify the transcription and data analysis of the dialogue. This was done in order for the participant to review the initial transcripts, provide accuracy of the analysis, and to determine if they reflected their experience as they told it.

Face-to-face in-depth interviews took place; each lasting for approximately 35 to 45 minutes. An in-depth interview is defined as a process whereby a researcher asks questions to participants and they respond with their thoughts, perspectives, and narratives based on their lived experiences (de Marrais & Tisdale, 2002). Each interview was audio-taped by two digital recorders. One digital recorder was used as a back-up in the event of equipment failure.

Interviews are used for exploration and gathering of narrative data that may be a source of rich, deep understanding of a specific human phenomenon and can be used as a conversational way of gathering data (van Manen, 1990). Interviews, which were used for data collection in this study, allowed for flexibility of the conversation, yet also allowed for specific information to be elicited defining the phenomenon. Each nurse was asked to share their experience of caring for the dying pediatric patient and what it meant
to them. Open-ended, non-judgmental, and non-leading questions were asked so that each participant was encouraged to share their stories.

Questions were asked related to the lived experiences of nurses caring for dying pediatric patients. Interview questions were open-ended and relevant to the research question to provide full discovery of the phenomenon. Questions were interjected concerning how nurses knew when their pediatric patients were approaching the final stages of life, what were the nurses’ interactions with the pediatric patients and their families, what thoughts were being processed by the nurses at these times, how the nurses coped with these thoughts, and how the nurses integrated these issues into their patient care. Other questions that emerged addressed the pediatric patients’ actions, feelings, and emotions during the final stages of life, and how the nurses were able to identify these cues.

An open-ended question was asked uniformly at the start of each interview, and from that free flowing conversation then generated nuances of feedback within each interview. Questions were asked such as: “Tell me what it is like to care for dying pediatric patients.” Subsequent interview questions were guided by the responses of the nurses, using the same approach of, “Tell me what it is like…” I then sought exploration and clarification during the interview process and asked clarifying questions such as: “What does that mean?” or “Can you give me an example?” I was mindful to allow the participants time to speak without interruption.

Each interview ended with my asking the participant if there was anything else they would like to share. Exploration of the experience was unique to each participant, and absent of uniformity. However, properties and dimensions of the interviews then
developed into categories of data. When no new categories or relevant themes in the data emerged, saturation was then said to have been achieved (Corbin & Strauss, 2008). Participants were recruited until data saturation or clarity of understanding about the phenomenon were reached. The sample size was determined based on the level of saturation, when themes were seen in repetition within the analysis of the interviews.

These interviews, carried out at a convenient place and time for the participants and me, were conducted to allow for responses to specific questions aimed at clarifying the phenomenon of nurses caring for dying pediatric patients. The nature of any phenomenological research questions should adhere to the methodology used within the research study, reaching into what kind of knowledge will be retrieved from the research analysis (Levy, 2006). Furthermore, gathering and collecting information through conversation, interview, and close observation is the basis of phenomenological data collection (van Manen, 1990).

**Analysis of Data**

Analysis of the data starts with the third step of the research process, reflecting upon themes that characterize the phenomenon. Analysis of a phenomenon is a reflection of the essential meanings of the experience (van Manen, 1990). Analysis of the data therefore begins with the experience as related by the participant as a whole.

When each interview was concluded and each participant had exhausted the phenomena, verbatim transcribing began. By transcribing the interviews of each nurse verbatim, I allowed myself to be immersed in the data of the verbal account of events, and found themes and essences of the nurses’ responses within the lived experiences of caring for dying pediatric patients. Insight into the essences through reflection,
clarification, organization, and illumination made the meaning of the lived experience explicit (van Manen, 1990). Through listening, transcribing, and reflecting on the emerging themes, the phenomena arose.

Once the interviews were transcribed, the participants were asked to review and provide modifications, revisions, or clarifications of their experience. Minimal clarification was provided by one of the participants, focusing on her construction of the English language in several sentences. Overall, the participants did not add clarification feedback of the interviews, and felt the transcripts reflected an accurate documentation of the interviews. Reflection provided insight on the essential meanings of the phenomenon of the lived experiences of nurses caring for dying pediatric patients (van Manen, 1990). Once information was revealed, I then attempted to understand what the participants were telling me. I engrossed myself in the audio tapes as well as the written transcripts to truly understand and be able to describe the nurse participants’ experiences.

By immersing myself in the verbal and written accounts of the nurses’ experiences of caring for dying children, I was able to dwell with, and become familiar with the phenomenon under investigation. This was a demanding and time consuming process. Reading and re-reading the transcripts, as well as listening to the audio tapes several times, allowed this researcher the ability to reflect, gain understanding, and provided insight into what the participants said. I approached the transcripts remembering that themes are not objects, and that not one statement can represent the experiences of nurses caring for dying pediatric patients. As van Manen (1990) states, “Any lived experience is an appropriate source for uncovering thematic aspects of the phenomenon it describes” (p. 92).
The fourth step began with the writing and rewriting activity, which was the combination of language and thoughtfulness that allowed the experience to “show itself precisely as it shows itself” (van Manen, 1990, p. 33). Constant attention to the overall interpretation of the study was incorporated into the separate themes that emerged to give totality to the data. Here, with each interview, I was then able to study the lived experiences of nurses caring for dying pediatric patients through re-writing, re-thinking, reflecting, and revealing the experience.

Coding, writing memos, and diagramming all utilized the analysis process building on each other. The essential themes that emerged comprised the essences of the nurses’ lived experiences of caring for dying pediatric patients. Direct analysis of the data by the researcher allowed for robust interpretation, so this process was utilized.

First and foremost, bracketing occurred to allow for a clear interpretation of the data. Bracketing is the ability of the researcher to suspend their own beliefs of their interpretations of the world, so they are able to study the essential structures of the world under the study context (Merleau-Ponty, 2008; van Manen, 1990). Van Manen (1990) refers to bracketing as reduction, which starts with a questioning of the meaning of the phenomenon. Then, there is a need by the researcher to overcome subjective or private feelings, preferences, inclinations, or expectations which may all create a barrier to live through the phenomenon or experience (van Manen, 1990). Theories, conceptions, and thematizations need to be stripped away so that the phenomenon can be seen in a clearer fashion. Finally, the essence should reveal itself once the phenomena is studied in the totality of the lived experience. Reduction is then noted to be “the ambition to make reflection emulate the unreflective life of consciousness” (van Manen, 1990, p. 185).
Bracketing and reduction both rely on the ability of the researcher to use the strategy of reflexivity, allowing the researcher to gather lived experiences and give memory to them (van Manen, 1990). Absolute and total bracketing cannot completely occur. However, when a researcher utilizes reflexivity, there is active involvement in self-examination, self-appraisal, and self-critique of potential biases and predispositions. The researcher then becomes aware and attempts to control biases. Even when bracketing is attempted, the researcher may still hold experiences to memory, giving depth and meaning to the analysis of the data.

Bracketing took place throughout the research process to have a clear interpretation of the interviews of the lived experiences of nurses caring for dying pediatric patients. Attempts to bracket out personal beliefs were achieved in order to perceive the experiences as original and unbiased. Once this was attempted, critical thinking and a thorough analysis was accomplished.

Analysis of a phenomenon is a reflection of the essential meanings of the experience (van Manen, 1990). Analysis of the data therefore begins with the experience as related by the participant as a whole. The themes identified in the data were highlighted, and the raw data was reduced to more concise concepts as a way to organize themed data. These themes were then coded as a representative of some thesis, doctrine, or message of the unfolding analysis within the study (van Manen, 1990). The focus of this study was to understand and explain the lived experiences of nurses caring for dying pediatric patients.

According to van Manen (1990), there are three phenomenological approaches in doing this. First, the researcher looks at the wholistic or sententious approach. Second,
analysis through selective highlighting occurs. Third, analysis is done through a detailed line-by-line approach. I utilized all three ways of analysis to adhere to van Manen (1990) and illuminate the phenomenon of the lived experiences of nurses caring for dying pediatric patients. Once interviews were transcribed, I coded the interviews in reference to the conversations. In reading and reflecting on the interviews, I highlighted and underlined each section of the interview, writing codes in the margins, grasping the essences or the phrases that captured the meanings of the section.

I made an effort to summarize the overall meaning of the interview by coding sentence by sentence, or as van Manen (1990) states, line by line. These codes were then grouped in relation to each interview revealing 9 lists, correlating to each of the 9 interviews. After this process of analysis was done, the codes were then listed and grouped together according to their underlying meanings. These codes then created meanings of the themes to surface, which captured ideas and recurrent themes throughout the interviews (van Manen, 1990).

Analysis and coding for themes were done after each interview was completed, and before the next interview was conducted to identify recurrent themes. Once recurrent themes surfaced, saturation was then accomplished, and the study was terminated for data interpretation and description. Analysis began when the interviews were being conducted. Analysis continued throughout the study, during transcribing, listening to the taped interviews, reflecting on previous transcripts, coding, and synthesizing. Analysis then continued once essences were identified and reduced from the context of the interviews, giving insight and meaning to the research question and the world it encompassed (van Manen, 1990). Conducting ongoing analysis allowed for elaboration
and clarification of concepts within future interviews and permitted more observant and sensitive ways to approach the participants. Categorizing codes, reducing the codes within the themes, and thematic analysis will be discussed in the next chapter. Furthermore, chapter V will also discuss the fifth step of maintaining a strong relation of the phenomenon in relation to pedagogy and the sixth and final step balancing the context of the study by considering the parts as well as the whole.

**Summary**

Chapter IV described the applied method of phenomenology using van Manen’s analysis of qualitative research. The research activities, protection of human rights, sample selection, data collection, and analysis of data were also addressed. Chapter V discusses the findings of the study.
CHAPTER V: FINDINGS OF THE STUDY

This study sought to explore the phenomenon of the lived experience of nurses caring for dying pediatric patients. The participants were nurses who were, and are still, involved in the care of children, some of which in the process of dying. I adopted a descriptive phenomenological approach to analyze the data following methods outlined by van Manen (1990). This chapter will help the reader to understand the study recruitment, study participants, description of the participant’s experiences, methodology applied to the research process, narrative phrases that captured the meanings, the themes, and concluding finding.

Research Setting

The setting for this study took place in locations convenient for each of the participants and at locations of the participants’ choice. In choosing a setting comfortable and convenient for the participants, any potential emotional issues were avoided. The setting for the interviews were discussed prior to meeting with the nurses.

Study Sample

The study sample consisted of 9 participants. All participants were female registered nurses actively employed on pediatric units with between 1 and 4 years experience. The interviews were conducted face to face and were digitally voice recorded for transcription purposes. The participants’ ages ranged from 24 to 37 years of age. Three of the participants were married, 6 of the participants were single, 4 of the participants were mothers, and 5 of the participants did not have children of their own.
Of the 9 participants, 8 lived in a suburban area, 1 lived in a metropolitan area in a large city in the northeast states. All 9 were actively employed at large metropolitan hospitals. The following section will give a further description of each participant.

**Study Findings**

This study explored, described, and illuminated the phenomenon of the lived experiences of nurses caring for dying pediatric patients. Interviews were conducted and used to explore and gather experiential material, as stated by the participants themselves, to illuminate a descriptive understanding of the phenomenon being studied. Interviews were also used to develop a relationship with the participants, giving a first hand account of the phenomenon being studied. The following sections will provide a descriptive picture of each nurse participant and the setting in which each interview took place. It is important to understand the characteristics of each nurse participant to be able to understand the entirety of the descriptions that formulate the phenomenon.

**Participants’ Experiences**

According to van Manen (1990), it is easier to talk about experiences rather than write about them because talking leads to a more genuine and true to the lived experience dialogue. Aside from the actual dialogue, descriptions of the participants are helpful to understand the meaning to which the experience is derived from. Descriptions of the participants can provide an imagery of the person and an understanding of the personality each participant possesses.

**Abby.** After asking several of my colleagues if they knew of any nurses that might be interested in participating in my study, they agreed to help me locate participants. A week later Abby contacted me by telephone. After a brief conversation about her
experience with pediatric patients, I formally asked her if she would be willing to be interviewed by me. We decided she was a candidate, and scheduled an appointment to meet. We met in my office at the college where I teach. It was a quiet time of the day, and I have my own office, which helped with the privacy of our meeting. After I placed a sign on the door to not be disturbed, we sat across from one another at my office desk. A short, petite woman with long dark hair, Abby told me she started working on the pediatric unit after graduation. She had an Associates Degree and 4 years experience as a pediatric nurse. At first Abby was quiet, reserved, and seemed apprehensive about the conversation, but quickly began to tell her story and spoke about her experiences when caring for dying children. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“It’s hard to be the person who cares for the pediatric dying patients. It’s hard to watch the family more than anything go through the struggle of watching their child dying, knowing that there’s pretty much nothing that you’re going to be able to do to comfort them or make their child better or, um, you have no words that can make the parents feel anything better than knowing that they’re just going to lose their child.”

The interview lasted approximately 30 minutes, and Abby spoke about her experiences, expressing emotion while crying, throughout parts of the interview. Several times she needed to stop to wipe her eyes. Her passion to tell her story was evident as she continued with the interview even though she was visibly sad in that moment.

After we finished with the interview, I thanked her for sharing her experiences. I asked her how I could share the transcription of our conversation, and she told me to send the information through an email and she would give feedback if needed. I reassured her that her identity would remain anonymous, and that her story would help other nurses
who care for dying pediatric patients. We hugged and she reassured me she was okay. After she reviewed the transcript, she felt there was no further need for clarification.

**Betty.** Betty contacted me by telephone after hearing from one of my colleagues about the study. After introducing each other, I formally asked her if she would participate in the study. She described her experiences with pediatric patients, and we both agreed she met the criterion for the study. Betty, as opposed to Abby, wanted to meet at her home stating she would be more comfortable in her own surroundings. After agreeing, we set the date and time I would go to meet her. She chose to see me late in the morning because it was a time when her daughter was at school, and her husband was at work, and we had the house to ourselves. As I walked into her house, she directed me to her dining room, showing me where she wanted me to sit. I placed my recorder on the table, sat across the table facing her, and we began the interview. Betty, a tall, thin woman with straight blonde hair, was the oldest of the participants, and had an air of experience and maturity about her, even though she was a pediatric nurse for only 4 years and had an Associates Degree. In the beginning of the interview, she appeared guarded and succinct in her answers. However, after a short while, when a synergy was established between the two of us, she began to open up and even became visibly emotional and began to cry as she started to tell her story. As she felt more comfortable, she gained composure and related her experiences in a story using reflection. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“I went into nursing as a second career specifically to work in pediatrics. And, more specifically, Pediatric Hem/Onc. But um, for me, I had Hodgkin’s Lymphoma. I was diagnosed when I was a Senior in high school. And so I never had the pediatric experience because I was at that cusp where it’s like, ‘Oh, she could go to a regular doctor. She could go to the chil—‘ either way. And I
probably should’ve gone the pediatric way. That’s my feeling. I had a great doctor – I loved him, but he was very brash, and I don’t think everybody would’ve done well in that environment. To the point where nurses were like, ‘You know you don’t have to keep him, right? Like he’s just the doctor here today.’ Um, so that propelled me into wanting to do it.”

The interview lasted approximately 45 minutes, and Betty allowed for time to disclose her own experiences with her health as well as her experiences with the pediatric patients. I asked her how I could share the transcription of our conversation, and she told me to send the information through an email and she would give feedback if needed. Once she finished her story, we stood up, I thanked her, we hugged, and said goodbye. After she reviewed the transcript, she felt there was no further need for clarification.

Conny. Conny called me after she heard about my study through a friend. After a telephone conversation between the two of us, some basic information was exchanged, and I formally asked her if she would participate in my study. Different than Abby and Betty, she asked if she could come and meet with me at the college I attend. We agreed to meet early in the morning. Conny was a tall, thin, dark haired woman, who came to the meeting in her scrubs because she had just left her shift at the hospital where she worked. We sat at a conference table perpendicular to one another. Conny disclosed she was a Baccalaureate Degree nurse with 2 years experience in pediatrics, and a single mother of a 10-year old child. In the beginning of telling her story, Conny was quiet, reserved, and guarded until we established a trusting relationship. She then became talkative when she started discussing her experiences with dying children without becoming sad or crying.

The interview lasted approximately 38 minutes, and she talked extensively about her experiences. She did not discuss anything else that related to her personally. I asked
her how I could share the transcription of our conversation and she told me to send the information through an email and she would give feedback if needed. Conny never became emotionally upset, however her inflections in her speech led me to understand her compassion for the children. Her conversation focused on her experiences, and she did not offer any interpretation of the events, just factual recounts of her nursing care. After she reviewed the transcript, she felt there was no further need for clarification.

**Dotty.** Dotty, as with the others, contacted me after hearing about the study through another participant. After a brief telephone conversation between the two of us, I formally asked her if she was willing to participate in the study. Basic information was exchanged, and it was decided that she was a candidate for participation. She, like Conny, also wanted to meet at the college I attend. We agreed to meet late in the afternoon. For that purpose, I had secured a comfortable classroom and we sat across from one another. She had just come from work, but was dressed in street clothes because she attended a conference and was not at the bedside that day. Dotty, one of the youngest nurses that I interviewed was of average built with long dark hair and dark eyes. She was a single female, enrolled in a Masters Degree program in nursing, and had 2½ years experience as a pediatric nurse. Dotty seemed apprehensive yet, unlike the other participants, started the interview asking me questions about my nursing experience, what my nursing background was, and how I came about studying nurses who care for dying pediatric patients. Once I answered her questions, she became more comfortable and started to share her experiences. The following is a brief excerpt from the descriptions related to her experience working with dying children:
“I do still care for oncology patients and some other kids with other chronic diseases that we do see, either when they’re preparing to die, when they do die, or even at the beginning stages when you know that it’s something that will eventually lead to them dying. I guess as a pediatric nurse, too, especially, your role sometimes changes from just taking care of the child to really you’re taking more care of the parents when the child’s passing, and they look to you to kind of tell them – to guide them through the process when you’re trying to figure out yourself how to go through the process.”

The interview lasted approximately 32 minutes, during which she vividly shared her experiences in caring for dying pediatric patients. Similar to Conny, she never became emotionally upset, however, her stories were genuine and caring. She intensely discussed the many patients and families she cared for throughout the dying process. I asked her how I could share the transcription of our conversation, and she told me to send the information through an email and she would give feedback if needed. After she reviewed the transcript, she clarified some of the use of her language and wording, but felt there was no further need for any other clarification.

Eddy. Eddy, as with the others, contacted me after hearing about the study through another participant. After a telephone conversation, I formally asked her if she would participate in my study. It was determined Eddy was a candidate for the study and we agreed to meet at her college. We met in the late afternoon once she secured a private conference room. Through a large window in the room, as I witnessed the sun beginning to set, we sat across from each other at the conference table. She seemed comfortable to meet me. Eddy had 4 years experience as a pediatric nurse. She was an average sized woman with highlighted shoulder length hair and a warm smile. She revealed that she had a 3 year-old child. As it happened with some of the other participants, she appeared reserved and guarded at first. She asked about my nursing experience and what I did in
nursing presently. Once I disclosed my personal history and a trusting relationship was established, she began to narrate her experiences with dying children. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“It’s definitely harder having your own children and going back (to pediatrics), ‘cause when I started, um, I had no children. And it was hard. And then when I came back from my maternity leave, [sniffles] it was awful. Because you’re, you’re imagining your own child in these situations, and you can’t even fathom, you know, what you would do or how you would feel.”

She cried as she narrated her experiences.

“And I think that just goes back to that maternal instinct and, [sniffles] um, I just, you know, I always say – I feel it, and I always say, like, ‘I just hope that, God forbid I was ever in that position, I’d be strong enough, and not selfish enough, to say when enough is enough.’ If, if it came to that point.”

The interview lasted approximately 36 minutes. After she finished telling her experiences she was calm and composed. I asked her how I could share the transcription of our conversation and she told me to send the information through an email and she would give feedback if needed. We hugged and said goodbye. After she reviewed the transcript, she felt there was no further need for clarification.

Fanny. Fanny called me after she heard about my study through a mutual friend. She contacted me by telephone, and after formally asking her to participate, we talked about her experiences in pediatrics and determined she was a candidate. She wanted to meet at the college where I teach. It was early afternoon and a quiet time of the day. Once again, like with Abby, I placed a “do not disturb” sign on my office door and we started the interview. We sat at my office desk, across from each other. Fanny, a slightly overweight, bubbly woman with blonde hair pulled back in a ponytail, was a single, divorced female. She was the least practiced nurse I interviewed with only 14 months of
pediatric experience. Even though this was a limited history with dying children, Fanny had an emotional story to tell and quickly became engrossed in her memories. She was the most emotional of all the participants interviewed and started to cry from the start of the conversation. Several times she apologized for her emotional state, and I assured her we could stop at any time. She declined and continued. Different than the other nurses I interviewed, she seemed immediately comfortable and began the conversation; eager to talk about her experiences. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“I was an adult nurse for eight years prior, so I got put into that setting (pediatrics) without the choice. And it was a very tough transition, and at first, it was very nerve-racking, because they’re so fragile. I went home crying for like three months [chuckles] initially. Because the children haven’t had a chance to live. You know, their life is so short. And you want that beautiful miracle to live, and have a great life, and when you see that that’s taken away from them, it’s devastating. For me, at least.”

The interview lasted approximately 42 minutes. She cried throughout the interview and yet had the strength to continue. Her story was rich with experiences and emotions and gave a descriptive picture of what it was like caring for dying pediatric patients. I asked her how I could share the transcription of our conversation and she told me to send the information through an email and she would give feedback if needed. Once the interview ended, we stood up, hugged, and said our goodbyes. After she reviewed the transcript, she felt there was no further need for clarification.

**Gabby.** Gabby, as with the others, contacted me after hearing about the study through a mutual acquaintance. She allowed me to contact her by telephone. After discussing her background and experience, I formally asked her to participate in my study. We decided she met the criteria and agreed to meet. I interviewed Gabby in her home and she took
me into her living room. We sat down, across from one another, face to face. She was an average built woman with dark brown, wavy hair. Gabby was a Baccalaureate prepared nurse with 4 years of pediatric experience. She never cried or became overly upset, and spoke clearly and frankly, without hesitation about her experiences with dying pediatric patients. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“Um, I work in the (pediatric) ICU setting, and I would say that I unfortunately have a lot of experience with it, so it would be kind of hard to pinpoint exact things. But I guess as a starting point, I would say that, um, usually I find that I wish they had a more easy death. Like, that sounds wrong, but that they didn’t get, you know, tortured, so to speak. Like, people have a lot of trouble accepting pediatric deaths, and I think because of that, they almost flog them, and try everything above and beyond – you know, experimental treatments… really everything. You know, nobody – it’s always wrong, it goes against your nature for a child to die, but there are good ways and bad ways that it can be done. And I think that that’s something that people struggle with a lot. Um, so I would say that’s probably one of the hardest things about it is not the actual death, but what leads up to it.”

The interview lasted approximately 45 minutes. Her story was rich with experiences, and she discussed the children of different ages that she cared for. Her extensive experience with dying pediatric patients allowed her to tell about the many experiences she lived. I asked her how I could share the transcription of our conversation, and she told me to send the information through an email, and she would give feedback if needed. Once the interview ended, we stood up, said our goodbyes, and hugged each other. After she reviewed the transcript, she felt there was no further need for clarification.

Heidy. Heidy contacted me after hearing about the study through Gabby. After contacting me by telephone and meeting the criteria of the study, I formally asked her to
be a participant. She wanted to be interviewed early in the morning at her parent’s house where she lives, and asked to meet there. She walked me to her living room and we sat face to face, across from one another on her couch. Heidy, a young, thin woman with long blonde, curly hair, was a single female with 3 years experience in pediatrics. She held a Baccalaureate Degree in nursing and talked about enrolling in a Master’s program soon. She spoke frankly about her experiences without hesitation. As with previous participants, a trusting relationship was established, and it was easy to start the interview. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“My experience – it’s conflicting, I’ve had situations that I’ve dealt with where it is conflicting. You know, a child may be in a situation where if they do pull through, you’re not sure what their quality of life may be. So it’s mixed emotions I think, being the care provider, doing everything that you’re supposed to be doing based on, you know, what the parents want for the child. You kind of have to do what it is you’re told based on someone else’s views and feelings, which as nurses we have to respect. So I think that we have to find ways to deal with what we’re supposed to be doing. But when you’re there at the hospital, you have to kind of put all that aside and just do what it is you’re there to do. So I find that it’s a lot to manage. And sure enough, they may die, and what I find the most difficult feelings to deal with are those where you think to yourself, “What could I have done? What else could I have done? Should I have done? If I did this differently, would it have changed the outcome?”

The interview lasted approximately 40 minutes. Her story was rich with experiences, and she continually referred to her role as the nurse and the importance of what nursing brings to the pediatric patient. I asked her how I could share the transcription of our conversation, and she told me to send the information through an email and she would give feedback if needed. Once the interview ended, we stood up, said our goodbyes, and hugged each other. After she reviewed the transcript, she felt there was no further need for clarification.
Ivy. Similar to Heidy, Ivy contacted me after hearing about the study through Gabby. After contacting me by telephone and meeting the criteria of the study, I formally asked her to participate, and she agreed to be interviewed. Ivy requested to meet at her house late in the afternoon. She lived alone and her house was quiet and peaceful, which allowed for privacy. We walked into her kitchen and sat at the table across from one another. Ivy, an average built woman with shoulder length dark hair, was a single female with 4 years experience as a pediatric nurse. She held a Baccalaureate Degree in the arts as well as a Baccalaureate Degree in nursing. She was currently enrolled in a Master’s program specializing in Family Nurse Practitioner. Like Fanny, Gabby, and Heidy, she offered her experience without much hesitation, and was succinct in her delivery of her experiences in caring for dying pediatric patients. The following is a brief excerpt from the descriptions related to her experience working with dying children:

“When you think about it, they’ve (experiences) probably gone from really good experiences to really bad experiences. I started as a new grad. I definitely feel like I’ve seen a wide range of scenarios. But overall, it’s been – I mean, I love my job. It’s been a very good experience. You know, each scenario is just so different that it’s hard to – I think it’s hard to like sum it all up into one thing. But you know, I am happy where I am, in terms of what I do, and things like that.”

The interview lasted approximately 45 minutes. Like some of the other participants, she did not cry nor become upset. Her conversation focused on her experiences working in pediatrics. I asked her how I could share the transcription of our conversation, and she told me to send the information through an email and she would give feedback if needed. Once the interview ended, we stood up, said our goodbyes, and hugged each other. After she reviewed the transcript, she felt there was no further need for clarification.
Thematic Analysis

The fourth step refers to writing and rewriting to describe the phenomenon. I wrote notes, or codes, within the margins, representing each narrative phrase within the dialogue in relation to the experience. Narrative phrases were underlined in colored pencil and assigned a different colored pencil according to the represented and interpreted meanings the participants described. Writing and rewriting allowed for a textual reflection of situations of the lifeworld, concretizing the understanding of what was the experience and creating meaningful relations to physical and mental being (van Manen, 1990).

Every sentence, and groups of similar idea sentences, were analyzed within each of the interviews. This line-by-line analysis uncovered narrative phrases. The notes, or codes, in the margins were also color-coded with the same color of the narrative phrase it was related to. For example, empathy (the first theme) was coded with the color light green. I assigned each color to represent a different meaning and repeated this with all six other themes that emerged. Similarly color-coded notes, or codes, from the margins were grouped together to represent similar ideas or concepts. These similar ideas or concepts captured the meanings, which allowed for combining and uniting themes, expressing the essences within the meaning of what was said.

The process of writing and rewriting provided me with the tools to understand the emerging narrative phrases and corresponding codes that captured the meanings of themes the nurses were discussing. By reflecting on these narrative phrases and corresponding codes, I was able to group the similarities and define the differences. Initially there were 7 categories of codes.
The following number of codes were identified according to the themes that emerged: theme 1 had 14 corresponding codes, theme 2 had 12 corresponding codes, theme 3 had 20 corresponding codes, theme 4 had 15 corresponding codes, theme 5 had 13 corresponding codes, theme 6 had 14 corresponding codes, and theme 7 had 16 corresponding codes. A more thematic analysis was then done in an effort to reduce the codes within the themes according to their relevance to the theme. The 7 themes were retained, however, some of the codes had similar meanings and were able to be collapsed into a more concise number of codes. This then reduced the codes to the following: theme 1 now had 8 corresponding codes, theme 2 now had 6 corresponding codes, theme 3 had 9 corresponding codes, theme 4 had 7 corresponding codes, theme 5 had 9 corresponding codes, theme 6 had 7 corresponding codes, and theme 7 had 15 corresponding codes. Ultimately, 7 essential themes were identified integrating the codes, or meaning units, to which the themes were given names for identification. Each theme contained several descriptors from the participants’ interviews considered essential in identifying and understanding the phenomenon of the lived experiences of nurses caring for dying pediatric patients. The 7 themes were identified as empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow.

**Essential Themes**

Writing the themes allowed the researcher to identify internal and external knowledge making it specific to the phenomenon researched (van Manen, 1990). Thematic identification gives order to the research, disclosing the evolving meanings and imagery of the lived experience. By inquiring about the lived experiences of nurses caring for dying pediatric patients the following seven themes were found: empathy,
feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow.

Each of the nurse participants was sent the following themes for clarification and review. Participants felt the themes were reflective of the interviews and words they chose. The seven themes were also confirmed with an expert researcher and revised to reflect the following in the table provided:

**Table 1: Themes and Corresponding Codes**

<table>
<thead>
<tr>
<th>THEMES</th>
<th>CODES OR MEANING UNITS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>You are working with parents almost more than you are working with children</td>
</tr>
<tr>
<td></td>
<td>Nursing is more rewarding and there is more pride in helping a patient die peacefully</td>
</tr>
<tr>
<td></td>
<td>It’s just too hard to wrap your head around a child dying…it’s not the natural order of things</td>
</tr>
<tr>
<td>Feelings of Ambivalence</td>
<td>You’re not making life better (for the child), you are making life better for you</td>
</tr>
<tr>
<td></td>
<td>It’s hard to feel good about, sometimes, what you are doing</td>
</tr>
<tr>
<td></td>
<td>Sometimes you should let them go and not do all these extra heroic things</td>
</tr>
<tr>
<td>Inevitability</td>
<td>You just can’t prepare yourself for it, it’s just something that happens (death)</td>
</tr>
<tr>
<td></td>
<td>You try to do the best because it doesn’t matter if you do or not, it’s still going to happen (death)</td>
</tr>
<tr>
<td></td>
<td>Because I’ve seen this so much (death), I can predict how this is going to go</td>
</tr>
<tr>
<td>Inspiration</td>
<td>Even if I just came here to be that moment,</td>
</tr>
<tr>
<td><strong>Relationship</strong></td>
<td><strong>Self-Preservation</strong></td>
</tr>
<tr>
<td>------------------</td>
<td>----------------------</td>
</tr>
</tbody>
</table>
| in that moment for that person, then everything else is worth it  
Every day I will have a smile on my face for her, because I know she would | You fall in love with them  
You become very attached to these kids  
There is always somebody who picks that kid to love, and becomes attached to that child  
I can still remember the name and face of every child I’ve seen die  
I’ll never forget him | It’s almost easy to compartmentalize and forget  
Trying to manage, today I’m just managing today, I’m just taking care of today  
…distance yourself from them (dying children) because otherwise you couldn’t go back the next day  
They just don’t understand how close we all have to become in order to be as professional as we are |
| | | You have to get in your car some days and cry the whole way home  
It moves you….you have to pull for these kids; you pull for their families  
If you weren’t crying, I would be very concerned about you right now, you really would be in the wrong spot (nursing)  
You cry later when you get home….I got out of the building and I sat in my car and I cried |
The nurse participants’ interviews revealed the seven themes identified through descriptions of the experiences of caring for dying pediatric patients. After further emersion in the interviews, and the thematic analysis, it was found that within each theme the nurses described the context of their experiences in relation to three factors. They described each theme 1) in relation to the dying pediatric patient, 2) in relation to the families, and 3) in relation to nursing. It was evident that these three entities, within the context of the seven themes, were common threads in each of the nurse participants’ discussions, and each theme had a component that addressed the dying pediatric patient, the families, and nursing.

**Establishing Rigor**

The fifth step of the research process, maintaining a strong relevance of the phenomenon in relation to pedagogy, gave orientation to the method used. This avoided deviation, guessing, and bias opinion that may have tainted the study (van Manen, 1990). Referring and constant re-orientation to the question of what was the lived experiences of nurses caring for dying pediatric patients allowed for the true phenomenon to emerge, without being side tracked, speculated on, settled on preconceived opinions, self-reflections, self-indulgence, or abstract theories (van Manen, 1990). This activity was done through maintaining a strong interpretation of what was discussed within the dialogue, reflecting and relating back to the phenomenon. In doing so, the phenomenon
permitted me to “meet with it, go through it, encounter it, suffer it, consume it, and be consumed by it” (van Manen, 1990, p. 153). The nurse participants were asked to provide feedback throughout the written process, further enhancing the rigor of the research method, and allowing for clarification and agreement of what was discovered.

Rigor involves strict enforcement of the rules to maintain strong, systemized, ordered, and visible steps which are applied to the research process, allowing for a sound analysis and conclusion, mindful towards partiality and limits (Davies & Dodd, 2002). Rigor in a qualitative research study also means maintaining an ethical guidance in the research process. Ethics enhances rigor by remaining steadfast in the approach to the research, and in asking, responding to, and reflection on the research questions and answers (Davies & Dodd, 2002). Examples from the participants’ interviews further established rigor of the research process. In the following sections are actual interview statements from which the essences of the lived experiences of nurses caring for dying pediatric patients were identified through 7 themes. The phenomenon would not exist without these themes.

**Theme 1: Empathy**

The following phrases captured the meanings that were contained in the theme of Empathy: *you are working with parents almost more than you are working with children; nursing is more rewarding and there is more pride in helping a patient die peacefully; it’s just too hard to wrap your head around a child dying…it’s not the natural order of things*. Empathy was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These
phrases, as stated by each of the nurse participants, within the context of their dialogues, became the theme of Empathy.

**Empathy in relation to the dying pediatric patient.** Empathy was further illustrated with each of the nurses’ descriptions associated with the innocence in children and the notion that death is not supposed to happen in childhood. Abby described the feelings she experienced concerning pediatric patients when she said, “It’s someone’s baby. It’s a child. You know, you – they’re not supposed to die. They’re supposed to be healthy, you know. It’s sad.” This was further enhanced by Betty, “You have those kids and you have those times with them where you think that they’re not going to – you know, that you think that they’re not going to make it. But they’re small, they’re young, you know…” Conny conferred with the empathy felt towards children when she stated, “Because it’s a child. Because it’s an innocent human that hasn’t had a chance to live, basically. They’re just so innocent.” This was also described by Heidy, “I’m not saying that a child losing a father isn’t just as sad, because I do think it is that. But I think what differentiates is just that this person (child), who knows what their life could have been”

Further illumination of empathy was suggested with the description Conny gave in her interaction with one particular dying child:

“He would look at me like, ‘I’m tired.’ Like, ‘Can you just stop? Like, I just – I don’t want to do this anymore.’ You know, he’d give you that look, like a pleading look. And it’s just like – you’re like, ‘Aww.’ Just like, you know, I want you to feel better. I want to do what I can to make you feel better.”

This statement described the way Conny felt when she empathized with the care she gave. She described the child pleading, even when he could not speak, and the way in
which she internalized his pain with the care. Fanny also expressed empathy when she described her feelings towards the dying child:

“…at this time he was six months, you know. And he could follow you with his eyes, and he would respond to you and you know, he was himself. He was a person, and he just was suffering the entire time. And it was very, very hard for me to deal with…”

Ivy suggested empathy when describing the quality of life of dying pediatric patients. She empathized with the lack of ability to behave the way other children that age would behave when she stated, “…you look at their quality of life, and this is – they’re 10 years-old, six years-old, whatever it may be, and they can’t sit up, they can’t really play. Maybe they watch TV.” She described what the quality of life was for this particular 10 year-old as compared to healthy 10 year-olds.

Gabby expressed empathy when she talked about dignity in dying, and how creating a dignified setting for pediatric death is important for peace and comfort during the process:

“But there can be a lot of dignity in death, and it can be really, really peaceful, and quite, and comfortable for them. And I think a lot of people can’t really see it that way. Because, you know, it’s just too hard to wrap your head around a child dying. It’s not the natural order of things, and I get that... I don’t think that death is the worst thing, and I think that can be a lot of dignity found in death, even for the smallest children.”

**Empathy in relation to the families.** Abby described empathy when she stated:

“You just, I guess you try to be strong for the family and make sure that they have everything that they need so they can grieve and, um, say good-bye to their child and make sure that their child is – like we clean up the baby, make sure they’re presentable looking, that they look healthy. You know what I mean, even though they’re not.”

She further emphasized this point when she described the physical appearance of the children and what it must be like for the parents to see their child as normal as possible.
She stated, “Like, they’re all clean; their diapers are clean; their mouths are suctioned and the lines, everything’s in place. You just don’t want to leave a mess or um, you want them to look more like their kid than you know than this poor puffy baby full of fluid…”

Conny also described a similar experience of empathy felt towards parents when she placed herself in the parents’ situation:

“I think to be able to see them without all the tubes, without all the — everything coming out of them, without seeing them three times their size because they have all this fluid on them — I don’t want to remember that. You know, I don’t want that — I don’t want to remember seeing my child like that. You know, even if he or she lives for like five minutes, I don’t want to see them like that, see them suffering.”

Abby further elaborated on her empathy towards parents and the amount of time they spend with their dying child, not wanting to leave because they cherish every last moment. She stated:

“A lot of them don’t even leave their children’s side. At that point, they’re there 24/7. We try and accommodate them so that they always have like a place to be with that child—’cause they don’t want to leave. They are there constantly. They live there. They shower, eat, all their meals are there…..”

Betty spoke about the parents and empathized with their needs and care. She describe how the parents are in need of care, just as much as the children are, when she stated, “I think – when you work with children, you are working with parents almost more than you are working with children. Because they are the hardest ones to deal with. They are needier, they want this, they need that…”

Empathy felt towards parents was described by Eddy, “I have a child of my own, and I can only – well, first I would hope that I would never be in this situation, but God forbid I was, I’d hope that I would have the strength to recognize when enough is
enough…” She discussed empathizing towards the parents by personifying their situation when she stated:

“When I came back from my maternity leave, it was awful. Because you’re, you’re imagining your own child in these situations, and you can’t even fathom, you know, what you would do or how you would feel or, um – and you know, then perfectly healthy children coming in and you kind of hear the parents go, ‘You know, they’ve been really tired and fatigued like the last couple weeks. Like I don’t know, I just brought him in,’ and they have leukemia or something. It’s, it’s – that to me scares me to death.”

Reinforcing this point, Heidy spoke about the parents and her empathy, “And to have to see a parent lost a child in a way that, like, nature just shouldn’t allow almost – like I’m not a parent, and I’m sure one day when I do become a parent, I’ll know it when I say it that a parent shouldn’t have to see their child die before themselves.”

Ivy described how she felt empathy for the parents, and rationalized the parents’ tenacity and need to exhaust all efforts:

“I always say, when I have children, I don’t know if I can work there, because I think I would just drive myself insane. So but from the outside perspective, we do look at these children and we see the parents try every last effort, and sometimes they just can’t seem to, you know, it seems like accept the fact or understand what is going on.”

**Empathy in relation to nursing.** Another aspect of empathy was when the nurses spoke about their co-workers. Empathy was discussed in relation to how the nurses accounted for their co-workers feelings when caring for dying pediatric patients. This was illustrated by Dotty:

“I guess that thing interesting for me is I don’t have children, and I do feel like nurses that do have children, when there’s a dying child, it’s a much much deeper toll. My mom always tells me that as soon as I have kids I’ll be out of this job, out of this profession. I don’t know if she’s right, but… [laughs] I’m not gonna find out yet, but… I guess I just definitely see that in my co-workers, that the ones that have children, when there’s one passing away, it’s – it’s like you can feel the pain in their – in them, too.”
Even Eddy described her empathy with co-workers when a child with a long history on the pediatric unit passed by stating, “Just so, so many people, physicians and nurses were so invested in this child emotionally…..But um, everyone took it really hard.”

**Theme 2: Feelings of Ambivalence**

The following phrases captured the meanings that were contained in the theme of Feelings of Ambivalence: you’re not making life better (for the child), you are making life better for you; it’s hard to feel good about, sometimes, what you are doing; sometimes you should let them go and not do all these extra heroic things. Feelings of Ambivalence was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These phrases, as stated by each of the nurse participants within the context of their dialogues, became the theme of Feelings of Ambivalence.

**Feelings of ambivalence in relation to the dying pediatric patient.** Betty spoke about feelings of ambivalence as it related to dying children. She described her feelings of ambivalence by questioning why the children were subjected to the treatments and drawn-out life prolonging procedures.

“I’m sure a nurse said like, ‘What are we doing here? Like what are we doing here,’ but they did it (anyway)….And so that part’s difficult because you, you’re talking with them, you’re looking at them, and you’re just like, ‘I’m not making it better by touching you, I’m not making it better by not touching—‘ you know, you can’t….But you bring him back, and five minutes later, as soon as the adrenaline is gone, you’re like, ‘We just snatched him back from the light.’ Like you don’t even feel good about it. Like you can’t even feel good that you literally saved someone’s life because [pauses, voice waivers] it was for no reason…’”
Dotty spoke about her experience when caring for a dying child of Chinese culture, explaining that in this culture they do not speak about death and dying with the patient. It is taboo to do so. Her feelings of ambivalence was illuminated when she said:

“I find in the Chinese culture, they don’t want to let the patient know they’re dying or they have a risk of dying. We had a patient come over from China with a bone cancer, and, until he got to America, he didn’t know that’s what he had. In America, forget it! If we had a 14 year-old that you didn’t tell they were potentially dying, it’d be awful, but in Chinese culture that’s OK and that’s how they do it. So there’s also that aspect of the nurse, of separating your beliefs, because if you had told me six months ago that you could let a 14 year-old not know that he had something so serious, I probably would have, like, called child protective services, but then you learn that this is really what is acceptable and what’s wanted in that culture. Um, so that’s – that’s a struggle”

She described the struggle with her beliefs in what should have been told to the child, as opposed to what actually took place, and the secrecy behind revealing the disease presence, illuminating her ambivalence with the dying child.

Feelings of ambivalence in relation to the families. Abby spoke about her feelings of ambivalence when interacting with parents. She spoke about encouraging parents, and giving into their hope even when there isn’t hope. She describe this as:

“It’s almost like you’re lying to them, but you don’t want them to feel that way. You want them to think that you’re thinking positive. And you’re trying not to instill too much hope because you already know that there is, there is no hope at that point. And for you to have to sit there and like discuss, like every time they come to you and they’re excited, like, ‘Oh, he just moved his leg,’ and you’re like, they’re smiling, and you’re like trying to like gently tell them, ‘No, I’m sorry. I understand that you think that he moved his leg, but it’s just, he twitched,’ or something, or it’s posturing. It’s sickening almost.”

Nurses are not the only ones who felt ambivalence, as Dotty described the ambivalence felt by the parents. She described one encounter with a heart transplant patient:
“We were waiting and waiting for him to get a heart, for his second heart. And he was very, very sick. And now it really was, just, you know, counting the days to, hopefully he would get a heart because we knew any day, you know, he would not survive if he didn’t get one. And he did, he got a second heart. And I don’t think he did (make it home) after the second heart, because he had a myriad of other problems. The poor family went through so much, and they would ask us, ‘You know, what do you think? Am I doing too much for him? Should I, should I just let him go?’ This is too much. And it was hard to respond to that because it’s every parent’s own personal opinion and feeling about what is or is not too much for their own child. Whether it’s, are they suffering too much or eventually will they get better? But we really saw the suffering of this child and, as a nursing team, knew that he would never leave the hospital.”

She described her experience and interpretation of the parents’ feelings, knowing how sick their child was, and if it was really worth all the pain and suffering they were inflicting on the child.

This was further illustrated by the description Ivy gave when talking about parental choices in withdrawing care versus continuation of treatments, and the reactions by the dying pediatric patients:

“I’ll even have conversations with the family members, or something, and I see what the children go through, and maybe because, I guess, ‘cause I know what we’re doing to them, and how much we’re putting them through, and how it could – you know, I feel like they suffer sometimes, and so withdrawing care – I wouldn’t say that I’m not for it. People think, like, ‘how could a parent ever want to withdraw care on their child? How could they ever give up?’ But in some circumstances, I can now I think, understand.”

In her description of feelings of ambivalence she described her understanding of the parent’s approach to the situation, how at first there were feelings of ambivalence but then there was clarity to what the parent’s wishes were.

**Feelings of ambivalence in relation to nursing.** Betty described her feelings of ambivalence within the nurse and within herself. Ambivalence was a feeling she described concerning attitudes that were aroused by the care given when she stated:
“You’re not making life better (for the child), you are making life better for you for another 15 minutes. You know, you’re fighting the good fight. Like you’re really trying here. But in some of these children, you’re trying for the wrong person.”

She further illustrated this, “…it’s hard to feel good about sometimes, you know, what you’re doing, which is why I don’t work in the NICU because I don’t want to, you know, participate in that type environment…” She is describing the feelings she encountered when she had to perform nursing functions with children, knowing she might be inflicting undue pain and suffering. “You know, like let them go already. Like it’s, this is enough. This is too much.”

This was also expressed by Conny when she described her feelings surrounding the dying children’s care, “…babies are resilient, but it was too much. It was really too much for him, and, you know, I feel like, um – kind of sounds a little harsh, but, like, sometimes you should just let them go and not do all these extra heroic things.” Feelings of ambivalence were pervasive throughout the nurses’ interviews. Dotty talked about feelings of ambivalence in the thoughts surrounding treatments:

“I guess the staff and the doctors know that they probably won’t make it and it’s portrayed to them they probably won’t make it, but I think probably if you ask them if they’ll live after a bone marrow transplant, most of them will all say ye—all of them will say yes. So I don’t know if internally they accept it and they just don’t want to ever speak to it, but I think that they keep the hope, and so they don’t accept it.”

Hope was the driving force of ambivalence when she described the rationalization behind the tenacity of providing patient care.

Fanny described a similar experience when she talked about other health care providers choices and her conflict and ambivalence with their choices:
“And I’m like, ‘How can I do this? How can – how can we do this to him? Let him go.’ I used to beg the neo-natologist and the PA’s to speak to her (parent) about a DNR. And they wouldn’t do it, ‘Just give him a chance. Just give him a chance.’ I’m like, ‘we’ve given this a hundred chances.’ And that to me was, like – how selfish could you be? You know? Then, it would be to the point where I would say, “You’re playing God at this point.”

Some of the nurse participants spoke about feelings of ambivalence in terms of the wholeness of the experience. Heidy described the conflict between doing good for the parents versus doing good for the dying child. Respect of the choices patients and families make may sometimes add to feelings of ambivalence. This was illuminated when she stated:

“And I’ve had situations that I’ve dealt with where it is conflicting. You know, a child may be in a situation where if they do pull through, you’re not sure what their quality of life may be. So it’s mixed emotions I think, being the care provider, doing everything that you’re supposed to be doing based on, you know, what the parents want for the child. If they want everything done, or if it’s at a point that they want, you know, to withdraw care, you kind of have to do what it is you’re told based on someone else’s views and feelings, which as nurses we have to respect.”

**Theme 3: Inevitability**

The following phrases captured the meanings that were contained in the theme of Inevitability: *you just can’t prepare yourself for it, it’s just something that happens; you try to do the best because it doesn’t matter if you do or not, it’s still going to happen (death); because I’ve seen this so much, I can predict how this is going to go.*

Inevitability was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These phrases, as stated by each of the nurse participants within the context of their dialogues, became the theme of Inevitability.
**Inevitability in relation to the dying pediatric patient.** Abby discussed the inevitability of death as expressed by the child. She described how the children know they are dying; how they understand their inevitable future. She stated:

> “Like um, one child, he had three friends die in about a two-month period, and he’s like, ‘Well if they’re dying,’ he’s like, ‘I’m next, and there’s no way that I’m not next. I can feel it.’ And within um, I would say about three months, that he passed away. And but he also, he gave up, and it was hard watching him just giving up. It’s just – but most of the time they, they’ll tell you that they have the feeling that they’re gonna go….”

She described the dying pediatric patients’ reaction to the process of dying. She explained how this one child knew what was in the future, and what was waiting for him.

Betty described inevitability when monitoring the dying pediatric patient’s status:

> “Um, and so every day you’re watching. Well, like the DSat’s are lasting longer. Because it’s usually, you know, a respiratory issue. The DSat’s are lasting longer. And longer. And longer. You just see things start taking longer. Like he’s not coming back up as quickly as he usually does. And initially you’re standing there like, “Alright, this is his thing. This is what he does.” And then you see it. And then you see that it starts dropping….”

Conny illuminated inevitability when she described the experience through the eyes of the dying child, “I know it sounds a little – it sounds a little bad to say or a little – but sometimes you just need to let them go, I feel like. In a way, it’s like you’re just prolonging their suffering.” She described prolonging the suffering of the dying pediatric patient, knowing what would happen despite all efforts.

Gabby spoke about inevitability in the dying pediatric patient. She described one child and how, despite knowing what was waiting for him, he chose to fight one last time. Eventually the inevitable occurred and he passed:

> “And essentially, he thanked us for giving him two years. Um, but he knew in the end. He actually said to me – I said I… I said, ‘You’re pretty sick this time.’ He goes, he’s like, “Do you think I have one more in me?” Meaning one more round
of, like, intubation, flogging him, everything. And I said, ‘You know what, I think you have one more.’ He’s like, ‘I think my mom needs one more.’ And I said, ‘I think you’re right. One more.’ And then we did that one more time, and he got better, and he actually went home Mother’s Day…And he came back in the next day, and a couple weeks later, he goes, ‘That was it.’ And he was declining again, and I was like – he was like, “I don’t have any more in me.”…You know, he died in his bed, you know, with his dinosaur posters, surrounded by his cousins, his brother, his mom, his dad, his everybody.”

Some of the nurse participants described the dying pediatric patient’s response to the inevitable and knowing that they were going to die, even after all efforts were employed. As described by Heidy:

“She was admitted to our unit for an infusion of ketamine….and with all the pain that she was experiencing, as much as we could give her, you could just tell her wish just was, ‘Just give me everything you can, I just want it to be over. I want it to be over. I want to be over.’ And you know, you don’t want to have to tell someone, especially a child, ‘You know, what, I understand that you want it to be over. I understand that.’ But I think I found myself, once I took care of her after a few nights, I felt I knew what she wanted. She just wanted to not feel pain…. she did, maybe a week later, pass away. I hope she didn’t have to suffer, but she did verbalize, ‘This is what I want. I just, I just want it to be over,’ is what she said a lot.”

Ivy reinforced this point when she described one dying child, “She had fought her fight, and knew what was happening to her, and was OK with what was going to happen.”

**Inevitability in relation to the families.** Dotty talked about the families’ experiences and the parents’ “knowing” of the inevitable. She said:

“I’ll never forget the first child that I watched pass away, who was a retinoblastoma, who the parents knew the baby was diagnosed at like 9 months and she was now 4. They had fought the fight; they knew this was coming.”
Gabby supported this when she described her experience, “I think because everybody was ready and waiting for it (death).” This statement illuminated the thought that the family knew the inevitable would happen.

**Inevitability in relation to nursing.** Abby described inevitability in terms of nursing and knowing:

> “...you just can’t prepare yourself for it. It’s just something that happens, and it’s always a shock. It’s never like, ‘Oh well, you saw this happening.’ Even if you saw it happening, it’s still a shock and it hurts.”

This description illustrates the idea that inevitability is not something that can be prepared for and it is a process that cannot be avoided. This was also expressed by Betty, “You realize you know, the limits of what you can do…. And you know, you try to do the best because it doesn’t matter if you do or not, it’s still going to happen.” Betty described how sometimes nurses and healthcare providers, in knowing the inevitable, may not respond as they would if they were saving a life, “You see from the very beginning that you are just dragging things out.”

Knowing the inevitable was predominant in the interview of Dotty. She illuminated this when she said, “Because I’ve seen it so much, I can, you know, predict how this is going to go.” This expression of inevitability supports the “knowing” in nursing. Witnessing the same scenario time and time again, brings the nurse to a level of understanding and predicting what is to come.

Ivy spoke about the “knowing what was to come” even if the monitors and machines were painting an optimistic picture. It is nursing knowledge that brings on the knowing of the inevitable as she stated:
“So a lot of times, it’s not without seeing – not that it’s by looking at the vital signs and things like that. But a lot of our kids will already have been sedated, and on respirators – ventilators or oscillators, things like that. So I think half the time, maybe it’s because I’ve looked at numbers, and I know kind of what’s going on, and I know what the past history has been, and the circles that we’ve going in.”

**Theme 4: Inspiration**

The following phrases captured the meanings that were contained in the theme of Inspiration: *even if I just came here to be that moment, in that moment for that person, then everything else is worth it; every day I will have a smile on my face for her, because I know she would.* Inspiration was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These phrases, as stated by each of the nurse participants within the context of their dialogues, became the theme of Inspiration.

**Inspiration in relation to the dying pediatric patient.** Betty spoke about inspiration when she refered to the dying pediatric patients. One child in particular was a source of inspiration for her when she described how she felt about him and his condition:

> “Sometimes you do look at them and you’re like, This kid’s never going to ma— you know, you can look at them and sort of – and then you see them three weeks later and they’re bouncing up and down, and you’re like, ‘I can’t even – what’s happening,’ you know, so kids are resilient, and I guess that resilience kind of passes onto you…..”

She describe resilience and how in seeing resilience in her patient, it inspired her own resilience. She described that by observing this trait in someone else it provided a sense of “role modeling”. Resilience and inspiration was further illuminated when Conny spoke about one of her dying pediatric patients, “She was at death’s door a couple times,
and I was actually shocked to believe that – I come back to work, and she’s like – she’s getting better. So she’s – she’s a strong little one.”

Inspirational lessons can be learned from the experiences of caring for dying pediatric patients as Dotty describes, “Every patient I’ve taken care of that’s passed away has taught me something. At the very least, I can think, like, “OK, I’m a better nurse because of this child for this reason.” Dotty drew upon her interactions with the patient, and suggested that the inspirational lesson she learned had inspired her to be a better person. She further elaborated on this when she stated:

“I’m gonna laugh for her, no matter, like, what in a day. Like, if there’s a patient that’s driving me wild, I think, like, ‘Just laugh, just smile. It’s just… it’s easier that way.’ So in her passing I’ve learned, like, ‘this is for her.’ Like, every day I will have a smile on my face for her because I know she would.”

Inspiration can also be felt by the nurse when the experience of caring for dying pediatric patients defies the odds. Eddy described caring for her dying pediatric patients as “miraculous”:

“And just when you think – you can swear that a child’s not going to make it, you know, you really do see those miracles when you, you would bet anything that this child was not walking out of here. And they do….You’re, you’re doing your best to get that miracle. When you know that everything scientific is telling you that it’s impossible. But sometimes it can happen. And we’ve seen it.”

**Inspiration in relation to the families.** Sometimes the nurse participants found inspiration in the families. The way they cared for the dying child, and the way they interacted with the nurses, gave the participants a sense of inspiration. Betty stated, “There is one mother, she treats him (her son) the same as if he’s going to get up and walk out tomorrow. She does all his care herself. Like it’s the ones like that that you’re just like, are like a saint.” This statement described the way in which Betty viewed the
mother of a dying child as “never abandoning her role as mother”. Even when the child is in the process of dying, parents will continue to keep hope and strength throughout the experience.

This was also described by Dotty when she talked about parents continuing to be parents despite the inevitable death:

“They’ve never gotten to watch their kid score the winning goal in soccer or get an A on their test, so you may be the only person who gets to tell them, like, ‘You are such an amazing mother’ or ‘You are such an amazing father. You’re the best parent in the world.’ And you may be the only one who gets to tell them that if they’ve spent, like, their short – the short years or months or days of their child’s life in the hospital. So I guess being a part of that is just really powerful and really rewarding as much as it is draining.”

Her description of the experience as being rewarding and inspiring can be credited to the parents and their love for their children.

Inspiration was also spoken about with Heidy’s experiences. She described an experience in which one of the pediatric patients was in the process of actively dying.

The child’s mother was holding her in her last moments of life:

“Like she was already talking about her in the way that she was speaking of a memory, but still holding her child, which was just kind of an incredible thing to see a parent like have the strength to be able to talk about their child in that way. So that was hard being a care provider, seeing a parent be able to do that – not hard, but different and strangely inspiring.”

Heidy describe the strength this mother possessed, and the inspiring feelings the experience elicited in her.

**Inspiration in relation to nursing.** Betty described the inspiration she derived from her nursing care and her ability to be there for dying pediatric patients:

“And I feel like with nursing, in general, and I guess you know, with Peds, too, you have those moments where you’re like, ‘even if I just came here to be that moment, in that moment for that person, then everything else is worth it’ because
no one else was doing it. Maybe other people would’ve done it if they were there, but you’re the one who is there."

This description is significant for nursing because it is nurses who are at the bedside 24/7, caring for the dying child. This was also described by Fanny when she spoke about being inspired by her clinical instructor, who identified a quality in her that is “nursing”, when she stated, “She was my instructor and she told me in nursing school, ‘You are going to be a pediatric nurse. Somewhere, some way.’ And I tried to remember that, while I was doing it, like, someone saw this in me so I should be able to do this.”

**Theme 5: Relationship**

The following phrases captured the meanings that were contained in the theme of Relationship:

- you fall in love with them;
- you become very attached to these kids;
- there is always somebody who picks that kid to love, and becomes attached to that child;
- I can still remember the name and face of every child I’ve seen die; I’ll never forget him.

Relationship was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These phrases, as stated by each of the nurse participants within the context of their dialogues, became the theme of Relationship.

**Relationship in relation to the dying pediatric patient.** Throughout each of the interviews the nurse participants discussed their relationship with the dying pediatric patient. Abby stated, “And you don’t forget the names.” She also discussed the relationship that developed through attachment to the child:

“It’s hard because that you go to the wakes and stuff ‘cause you’ve been taking care of them forever. And um, that was hard, also. And it was hard for everybody that worked there because you get attached, you fall in love with them and their families and this is a baby, like they’re – you feed them when their
parents aren’t there. You hold them when they’re scared. You, you know, you get attached. A week, a day. You know, they’re… you fall in love with them.”

She concluded this thought by saying, “They melt, like they melt your heart”, demonstrating the connection and relationship that developed when caring for dying pediatric patients. This was further described by Dotty when she stated, “I can still remember the name and face of every child I’ve seen die.”

Relationship was also described by Betty when she discussed the love and attachment felt, “There is always somebody who picks that kid to love. And becomes attached to that child… And so there’s always people who are like, ‘Oh yeah, this is my favorite kid here right now.’… you know, so there’s always somebody who is looking out for them.” She continued on to say:

“You know, like we get kids who… they see you – and you know, they have their nicknames for you and they’re drawing your pictures. And maybe it’s the neediness. I don’t know. Maybe I need to be loved. But you get that love there.”

This statement described how sometimes the relationship is reciprocal between the nurse and the child, and love and attachment is a continuum.

Fanny summed it up well when she described her interactions and relationships with dying pediatric patients:

“I’ll never forget him. And uh, I used to take him out of the warmer and hold him, hooked up to the respirator when Mom wasn’t there. And you know, as much as they tell you in nursing school not to get attached, you can’t help it. Sometimes, you just can’t help it… And that was the beauty of working with children in the neo-natal ICU, because you bonded on such a level that you don’t have in the adult world, at all.”

Conny discussed how even when the children are actively dying their relationship with the nurses were strong. She described it as, “I don’t know if she knew she was dying or I don’t know if she knew she was so close to dying, but she would still
recognize the nurses who loved her and who are always coming to see her and to play with her.” The dying child developed such a strong relationship with her nurses that she recognized them even at the very end. This is not something that can be avoided, as Eddy reinforced this by stated, “You can’t stop the connections that you make of all of them…Um, you know, as hard as it is at times, I really do love taking care of kids.”

Gabby spoke about her relationships with dying children, and talked about one experience in particular which described not only her attachment to the dying pediatric patient, but also her relationship with the staff she worked with:

“The called the time of death. And I walked out of the room with one of my colleagues, and she looked at me, and she goes, ‘I’m so sorry for your loss.’ I had primaried him, and he was my baby. But she – and then I actually lost it. And she was more saying, ‘It’s OK now. He’s done.’ And that was more moving to me than him actually dying, was other people saying, “Hey now, he’s comfortable. You did everything already.”

It is important to realize that the colleague was consoling her when she said “I am sorry for your loss”, signifying the attachment felt towards the child.

Relationships with the dying pediatric patient can be beneficial for the child. Having a relationship creates a loving, caring environment. Relationships are sometimes established because of the amount of time spent with the dying child, as Ivy stated, ”You definitely (are) with the same patient over and over again, you can feel very involved in their care, and you can be (a) real good advocate for them and the family.” Investing emotions, becoming attached, and establishing a relationship was described as a positive aspect in patient care because you then become invested in the dying child and family, and can advocate for them when needed.
**Relationship in relation to the families.** Relationships with families develop because the families are usually there throughout the hospitalization. Dotty said:

> “You grow attached to them, you become part of the family. So I guess as a pediatric nurse, too, especially, your role sometimes changes from just taking care of the child to really you’re taking more care of the parents when the child’s passing, and they look to you to kind of tell them – to guide them through the process.”

This description shows how relationships form with parents because of their need to be cared for. Pediatric nursing is unique in that dying children and families both need a relationship with the bedside nurse to be able to adapt to the dying process. Fanny also recalls, “Not only am I taking care of this baby, I have to take care of the mom and the dad. So you have three patients.” This further emphasized the relationship that is developed with the families.

Even after the child has passed, families need to continue the relationships they established with the nurses. Fanny described this as:

> “They contacted me, the family, and they said please come to the services, and I’m like, ‘I can’t do that.’ There’s no way, like how am I going to get through that? Because I was with that child 37.5 hours a week, you know, and – I did, I went and they mentioned me in the obituary. Oh, I mean, it was heartbreaking, and I’m still kind of in touch with them. You know, they’ll e-mail me, or whatever.”

Heidy also spoke about mourning the loss of the child, similar to how the family mourns the loss, when she stated, “But for me, what I’ve experienced, is taking care of a patient, getting to know the family, and you know, mourning the loss – I mourn the loss, too.” She continued with this idea during the interview, illustrating her relationship with the family by attending children’s wakes by stating, “I’ve gone to a few services where I can feel myself get emotional just because I can’t imagine for the family what it’s like.”
Heidy “took on” the family and created a relationship. She added, “So the loss sometimes does feel a little bit more personal”, describing her relationship on a higher level.

Sometimes relationships with the families may not be positive. Ivy recalled an experience like that:

“They had switched my assignment, and they were like, ‘It’s nothing against you, but like the family had asked for a different nurse. And we have that a lot, where you can – you know, we all have different personalities, and sometimes it’s the personality of the nurse and the family. Like, I can – you know, I’ll just not ‘yes’ someone to death, but just go along with whatever. If they want to ask me a million questions, I’ll answer a million questions. Like, I don’t have a problem, and other people need a less hands on family. But so we definitely have families where the nurse and the parent interaction just isn’t working, and we try to accommodate that, and you can’t fault the nurse.”

Relationships aren’t always positive as illustrated by Ivy. However, she added, “We do have these like very rewarding experiences, and fulfilling, and like parents that couldn’t be more grateful, and will never forget their experience, and will always remember you”, giving dimension to a positive connection.

**Relationship in relation to nursing.** Relating nursing to the relationships that develop with the dying pediatric patient, Betty described how she felt:

“I love it. I wouldn’t not do it. Um… I don’t know. It’s – I think you have to have – we have people that come to Peds, and I say, ‘You have to, it has to be your passion or you can’t do it.’ I have such an affection for them (the children). I don’t know if this happens in other units because this is all I’ve ever done.”

She specifically described her thoughts about why she continues to practice in pediatric nursing, knowing that sometimes the outcomes can end badly. She further elaborated on this when she said, “So I think it does take a certain kind of nurse. And I think that you are like made for that position. You know, it would be very difficult to go do something
else. You would really feel like you’re abandoning the ship”, illuminating her contribution to pediatric nursing as beneficial to children and families. She continued to describe her attachment, generosity, and love for the dying pediatric patient, “For me, I get very attached to children. That’s just who I am. I like to buy them clothes and bring it (in).”

Conny further illuminates this thought when she described her attachment, generosity, and love:

“You’re going out and you’re buying things for them. Kind of like, um – it’s like you kind of feel like you’re bonding a little bit with the other staff members because of this one child, and it’s like something that we all have in common, like we take care of this kid, you know, and this is our baby, you know….It kind of helps to bring the staff together, bring them a little bit closer.”

Here, Conny described the relationship staff have with each other, because of dying pediatric patients. It is because of the circumstances and commonality of the experiences of death in children that staff become bonded to each other.

Fanny discussed how the staff, as a whole, cared for the dying pediatric patients on the pediatric unit. Even though nurses get individual assignments, the nature of the unit allowed for all the nurses to become a team. This was evident when she described the following:

“He wasn’t my patient, but you know, all the babies are everyone’s patients at that point. You know, if one nurse has three babies, the other nurse has two, all of those babies are each of the nurse – you just, ‘it doesn’t matter, it’s not my patient.’ No, that doesn’t happen.”

This was also illuminated by Ivy:

“And it definitely, for me – the people that I work with are like a huge factor in what I do, I think. Because if I didn’t enjoy that, and didn’t know that I had them there, I think it would definitely change how I felt about being on the unit and doing what I do.”
Having relationships with colleagues allows for support and longevity working on the pediatric unit. Gabby said it best when she described her relationship with the physicians and staff on her pediatric unit, illuminating the trusting and respectful relationship staff have, “We call everybody by their first name, and we try not to in front of the families, but like if I turn, and I’m like ‘[name], NOW.’ It’s just – I don’t even need to say the word “now.” He’s already walking towards me when he heard my voice”.

**Theme 6: Self-Preservation**

The following phrases captured the meanings that were contained in the theme of Self Preservation: *it’s almost easy to compartmentalize and forget; trying to manage, today I’m just managing today, I’m just taking care of today; ...distance yourself from them because otherwise you couldn’t go back the next day; They just don’t understand how close we all have to become in order to be as professional as we are.* Self-Preservation was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These phrases, as stated by each of the nurse participants, within the context of their dialogues, became the theme of Self-Preservation.

**Self-Preservation in relation to the dying pediatric patient.** Abby discussed her feelings about caring for dying pediatric patients, and being able to continue with practicing in this specialty, “So I just show up for work the next day and just try and do the best you can to make them comfortable while they’re going through this hard time. You just try and do your best and try and be strong and go home, cry about it later.” This statement illuminated the struggle nurses face when patients die. The ability nurses have to be able to put aside their feelings until it is a better time to deal with them shows self-
preservation of the nurse. She further illustrated this point when she added, “Do whatever you can and then worry about stuff later”, referring to patient care in the moment.

Betty also described this sentiment when she said, “I have found that it’s almost easy to compartmentalize and forget.” She described how she contends with the stimuli of death in children by putting her feelings aside. Sometimes this is needed to be able to function. She further discussed her self-preservation when she said, “I think that there is, um, like I said, some, some compartmentalizing it yourself. Again, just, “OK, I’m going to do this.” And almost sometimes like thinking of it like, “as the syndrome” or “as the disorder,” versus the person”, depersonifying the dying child to a disease process, enhancing coping and self-preservation with pediatric death. Heidy also described compartmentalizing of her emotions, “When you’re there at the hospital, you have to kind of put all that aside (emotions) and just do what it is you’re there to do.”

Sometimes nurses change their assignments when patients on the pediatric unit are complicated, and have the potential to cause work fatigue in the nurse. By changing the assignments, nurses are given a “lighter” patient population to help with the stress and emotional drain in caring for sick and dying children. Betty confered with this when she stated, “They’re heavy, so their care, so you frequently rotate it out because just like trying to manage, you know, it becomes exhausting.” She also spoke about detaching to conserve self-preservation:

“You have to be able to be their biggest advocate and like attach yourself to them to like fiercely fight for them, and be able to flip the coin over and be like in the hallway joking around and completely distancing yourself from them. Because otherwise you couldn’t go back the next day and do it.”
The ability to attach and detach was described as self-preservation, giving the nurse the ability to continue with their work.

Eddy also spoke about detachment as a form of self-preservation for herself, creating boundaries:

“For the most part in the PICU, they’re kind of in and they’re out, and if something tragic happens, it’s tragic and it’s sad, but you didn’t know them, and you didn’t have that relationship. So you can kind of just cut the tie and move on because you, you have to do your job… And I think, I think I do a better job than, detaching myself than others. I see other nurses like really attach themselves. Even now the kids are discharged and they’re still keeping in touch. And it’s just, I’m like, just, ‘I can’t be involved in any of that.’ [chuckles] I just personally, I just, um… that’s just for me. That’s how I cope and I feel best. But I mean, they come in and visit, and it’s great to see them. It really is. But it’s important to me personally to, to draw a line…I feel in order to do your job, like you just have to make boundaries. Otherwise you can’t function properly, and do what you need to do.”

Gabby explained that some of her pediatric patients are accident victims in which these patients are admitted due to an acute event. In these circumstances she described, it became an easier job to be able to cope with pediatric death because attachment with the child was not established, therefore providing a self-preserving atmosphere:

“I think of drowning victims as my example right now, so say, you get a kid in and they’re down, and you do everything in your power to continue to work on them, but you don’t ‘meet’ them. You receive them down. So that’s a lot easier to process, because you never hear them talk to you.”

Sometimes self-preservation is comprised of finding peace with oneself; knowing you did all you could, as Heidy discussed:

“The first patient I lost, I was really upset. And I think I’ve gotten better, too, at just being at peace with, you know, what, I think I did the best I could do, and I don’t think it was me that could have done any more. I think that the outcome was greater than us, if that’s what it was meant to be. So you just kind of have to be, you have to learn to be at peace, that’s what I’ve had to learn, really. It’s just letting go… I mean it makes me, if anything, appreciate life a bit more.”
By coming to terms with pediatric death, Heidy described her actions and feelings of self-preservation and coping.

**Self-Preservation in relation to the families.** Betty discussed self-preservation when she modeled her own behavior to the behavior of the parents, “So like you almost have to just keep, almost like I guess the parents do in some way saying, Oh well, today I’m just managing today. I’m just taking care of today”, describing her reflection on how parents contend with impending pediatric death.

Dotty spoke about her ability to keep dying pediatric patients at an emotional distance, so their passing does not affect her. When she does this, her ability to be there for the family is enhanced. She described this when she stated, “Then when they relapse (the children) and they don’t do very well, how you can kind of tie in to saying goodbye to them while not letting it affect you and still be able to support the parents as well as the child.”. She struggled with this during the interview, and further illuminated the experience:

“(The families) they have a real hard time saying goodbye when you treated their child for six or seven years and you became part of their family, but you can’t let every single child you take care of become part of your family... I guess it’s (that?) balance between being too detached and too attached, and there’s kids that I would take home I love them so much....On the other side, I don’t want to be too detached, because if I can’t be, like, support for the parents and if I can’t be there for the child, then it’s not the right job for me anymore. So I guess I’m still really working on trying to find that balance.”

At times nurses may need to exercise self-preservation by creating boundaries with families as described by Fanny:

“It feels nice, but then, it also feels –you feel like you can’t be rude, and say like, ‘OK, like, this is a little too much. Like, I’m the nurse, you’re the family.’ But sometimes you feel like they’re crossing a line, you’re crossing a line, like you shouldn’t have that relationship with them.”
Heidy further enhanced this point when she described boundaries she created, “I definitely get attached. I’ve gotten better over the years. I’ve kind of learned how to be close to the family, but with keeping a distance to protect myself some more.”

**Self-Preservation in relation to nursing.** Dotty described self-preservation through the support of the staff:

“Our PICU will have debriefings—there’s a lot of impromptu stuff, I guess, and co-workers really—peer-to-peer support. Um, but—and sometimes not in the healthiest of ways. We’ll go out and get drinks after—probably too many drinks, to cope with it, but…it’s part of the reality for better or worse. You turn to each other, and…that’s really all you can do.”

Whether it is formal debriefing, or informal social events, Dotty described how the staff support one another during the difficult process of coping with dying pediatric patients.

She further discussed staff support when she described invasive procedures:

“I work with one other nurse, and we almost, like, divide up the patients that we, like, really, really care for, and I can tell when one of her kids that comes in that’s, like, her favorite in there. So it’s like I’ll do their blood work that day, I’ll give their chemo ‘cause—so they can, like, almost detach a little bit, which…I don’t know. ‘Cause I don’t think there’s a right way or a wrong way to deal with it, but I do know that if you’re in—’cause I’ve only been here for three years, and I feel like if I plan on staying, I can’t get as emotional as I do with a lot of the kids.”

By utilizing teamwork, Dotty discussed how day to day coping and self-preservation happens. This support between staff members was also stated by Gabby when she described informal behaviors staff members have towards one another, “And I think that—that—even though, you know, people thinks it lacks professionalism, I think that means that they just don’t understand how close we all have to become in order to be as professional as we are.” Closeness between staff members aids in the self-preservation and coping that is needed to continue working with dying children.
Gabby elaborated further on this thought when she described how the nursing staff never leave each other to fend for themselves, helping with coping and self-preservation:

“Nurses to nurses, I think, are very, very, very supportive. You know. No one is ever alone in a room with a dying patient – unless they want to be, or they chose to be, or they don’t need the help. But there’s always, I can say, six or seven nurses standing outside that patient’s door, waiting for that nurse to come out, and say, ‘What do you need? What do you need? Did you go get lunch? Why don’t you have a soda? What can we do? I took the mom over to the waiting room.’ All of that sort of stuff.”

Self-preservation was described by Ivy in her comparison between the way she “nursed” in the beginning of her pediatric career, and how she “nurses” presently:

“I would love to remember how I really was when I first started, because I feel like I don’t remember what I thought when I first started there, and now I think I just have a totally different perspective. You know, like things need to get done, and in the end, we have a reason for doing everything we do. I feel like I tell that to my orientees sometimes, like, ‘You know, you may think I’m cold’… The way we talk about things is just so much different than someone on the outside. Like things, you know, the sense of like, things that we’re doing to prolong a child’s life. It just seems awful, and then others will see that as, ‘well, why wouldn’t you do something to protect – if this is an option for a child, why not do it?’ And we see it so differently….I think you have to, in a sense (detach). Not that you have to – there’s definitely been patients that have passed, and I feel like – you know, you start to get a little choked up, but when you’re doing – when I’m in there doing what I have to do, I am focused on things that I have to do. And I don’t want to say it is just task-oriented. But at the same time, I have to go into the room, I have to assess you, I have to turn you, even – how ever painful it may be for you, I still have to do this, because it’s part of my job. I can’t let you lay in a wet diaper all day. I can’t let you lay on the same side all day. But yeah, you kind of have to just remove the emotions sometimes, I guess. Or put them aside for a little.”

For Ivy self-preservation became a process of adaptation, where she described the changes that took place in her to enable self-preservation, coping, and continuation of her nursing career.
**Theme 7: Sorrow**

The following phrases captured the meanings that were contained in the theme of Sorrow: *you have to get in your car some days and cry the whole way home; it moves you....you have to pull for these kids, you pull for their families; if you weren’t crying, I would be very concerned about you right now, you really would be in the wrong spot (nursing); you cry later when you get home....I got out of the building and I sat in my car and I cried; I’m no good to them (children and families) if I am crying.* Sorrow was expressed by the nurse participants when they described their experiences in relation to dying pediatric patients, the families, and nursing. These phrases, as stated by each of the nurse participants within the context of their dialogues, became the theme of Sorrow.

**Sorrow in relation to the dying pediatric patient.** Abby discussed her thoughts and experiences in dealing with the sorrow of the dying pediatric patient. This sorrow was so vivid in her memory that she was able to describe the first pediatric death she was involved in:

“I – my first time a patient of mine, my first death, I remember my husband picking me up and just not knowing what to say because I was inconsolable. I don’t know how it is with an adult, but you have a child that dies and there’s 40 people outside the room screaming, crying. You know, and you’re trying not to look at them because the moment that you do, you’re going to burst out into tears.”

Betty described her sorrow felt towards experiences with caring for dying pediatric patients:

“Like I don’t know if I could do hospice care per se where all day long that’s all I saw....So I think that when we have kids where they might come to our floor and go over there, that come in healthy and quote/unquote “normal,” and then they deteriorate and pass very quickly, that’s tougher for everyone to deal with...But it definitely, you know, it moves you. You, you have to, you pull for these kids; you pull for their families.”
Her discussion addressed the nurses who work in pediatric hospice care. She rationalized her sorrow as minimal compared to their sorrow, in which they are subjected to pediatric death on a more frequent basis.

Gabby described her interpretation of sorrow as becoming a deterrent to providing quality care for the dying pediatric patients when she stated, “Some people lose it more, and I think that that’s actually detrimental, because we’re the ones that have to keep it together, and keep things moving, and say, you know, ‘OK, it’s time. Come hold his hand.’ You know, that sort of stuff.”. Sorrow can interfere with help in enhancing parental interactions with the dying pediatric patient and, as described by Gabby, can hinder the last moments between the dying child and family.

**Sorrow in relation to the families.** Abby described her feelings of sorrow in observing families deal with pediatric death. Watching families go through the struggle, as she described it, was a heartbreaking experience. She stated:

“It’s hard to watch the family more than anything go through the struggle of watching their child dying, knowing that there’s pretty much nothing that you’re going to be able to do to comfort them or make their child better or, um, you have no words that can make the parents feel anything better than knowing that they’re just going to lose their child. And it’s kind of heart-breaking.”

Dotty described sorrow in suffering of the family dynamics, causing strain within the surviving family members:

“Sometimes a dying child can cause fights between parents. I’ve seen it end up in divorce later on, lots of times separation. I think who I’ve seen suffer most in a lot of this is the siblings. It’s that one child’s dying, but there could be multiple others living, and kind of nobody’s really addressing them throughout all of it.”

Her description illuminated the way in which families are confronted with sorrow after the loss of a child. She rationalized:
“I don’t know if it’s they don’t know how to share the pain, they can’t support the other when they’re experiencing so much pain, they don’t know how to support the other... but, yeah, they turn against each other, and that type of – whether they emotionally shut down or physically don’t want to be near the other one because being with them, their love for each other, it’s too painful to watch the child they brought together.”

Fanny described her experience with a grieving family. Her reaction with the family was one of sadness and loss:

“The mom came and said, ‘What’s going on? What’s going on?’ I said, ‘He’s so sick. He’s suffering. There’s not much more we can do.’ And we cried together, with Grandma, Mom, and me. And um, they had to put up – I’ll never forget it, they had to put up the breast feeding shields, like the privacy window things. They put that up, so no other parents could see us crying, so it wouldn’t affect them, you know, when their child is thriving and they see this other child suffering. When I came back into work, the staff treated me like I was a family member of the kid. They were like, ‘Oh, you know, [sniffles] he passed away last night,’ and I was like – and I cried. I mean, I felt so sad.”

Sometimes families appreciate the caring, and express the identification of sorrow nurses exhibit when children die. As Gabby stated, “Family members do notice it, and they do appreciate that you put that much into it”, providing insight into the appreciation families express, knowing and acknowledging that nurses are experiencing sorrow and providing validation of their child’s life.

Sorrow in relation to nursing. Betty discussed her thoughts about caring for dying pediatric patients. Sorrow was a pervasive context of her discussion. She summarized her past experiences by stating, “Um, I think that, like personally for me, it’s difficult in that you have to get in your car some days and cry the whole way home. But, I wouldn’t want to do anything else.”

She continued:

“You know, like some of the young girls, like the newer girls, like one of them particularly comes to mind... you know, crying, and she’s like, ‘I’m sorry. I’m
Eddy discussed sorrow, especially one experience when she first started working on the pediatric unit:

“I was new on the unit, and we were taking the sickest kids, and three of them died. And my, my preceptor clearly saw that I was about to break down, and she said, ‘You don’t cry now. Do your work, and you cry later when you get home.’ And it made sense. And I remember biting the inside of my cheek to feel a little bit of pain to hold back tears so I can get through my, my notes and my work. And one of the social workers came up to me and said, ‘Are you OK?’ and I was just like, ‘Don’t talk to me.’ I’m like, ‘Thank you, but please,’ I’m like ‘cause if you try to like hug me right now, I’m going to break down and I have to finish this.’ And then I got out of the building and I sat in my car and I, I cried.”

Sorrow and saddness was an emotion she could not contain. Her sorrow for the loss of life was expressed in her crying.

Heidy discussed the repercussions that sorrow inflicted on the pediatric staff:

“We went through a few months of a lot of deaths. I think more than three in a month. And it was, took a toll on the staff. And our acuity was really high. So you knew people were really being affected by what was going on... just to deal with the death of another person and see like the face of the family that loved them, is hard. And it’s hard to not bring that home with you. So we were all talking about going home, and, you know, how we deal with going home, and trying our best in the hospital, but no way you can erase that from your memory. So that’s hard to go home and think about what happened when you were in the hospital, and ruminate on, What else could I have done? What else could I have done for the family?”

Ivy also discussed sorrow:

“The attending came over, and things like that, and we took away her BIPAP, and that was the first time I think I had ever cried at work. Because I felt like I was just suffocating her. There was nothing more I could do, she was on a morphine drip. We were giving her – we were doubling the morphine, like every minute, giving her boluses, and you know, I think that was – that stands out to me as one of the times, you know, besides seeing where her oxygen was going, just looking at her, and seeing her like, the gasping.”
Both Heidy and Ivy described sorrow in a self-doubting interpretation. Heidy stated, “What else could I have done?”, similar to what Ivy described when she stated, “I felt like I was just suffocating her. There was nothing more I could do.”

**Interpretive Statement**

The interpretive statement and concluding finding that arose from this research study brought to a close that through the lived experiences of nurses caring for dying pediatric patients an overall descriptive meaning of adaptation becomes apparent when stimuli affect behavior. This is the sixth and final step, balancing the context of the study by considering the parts as well as the whole. I included reflection, and stepped back from the data (parts), to grasp the entirety of the research phenomenon itself. It is suggested by van Manen (1990) that throughout the research process one must step back and evaluate the wholeness in context to its parts, to see how the parts contribute to the whole. Narrative phrases and codes and meaning units provided essences and themes that captured the lifeworld the nurses illuminated. Narrative phrases from each interview illustrated these themes, relating the parts of the study to the wholeness of the phenomenon.

In keeping an open mind, I incorporated each theme from the nurse’s experiences to culminate into an interpretive statement about the experience of nurses caring for dying pediatric patients. Interviewing, reflecting on themes, writing, rewriting, and interpreting then became the application of van Manen’s method and through this process, I sought to uncover and illuminate the lived experiences of the nurse caring for dying pediatric patients.
An interpretive statement was formulated from the combination of the themes, capturing the totality of the lived experiences of nurses caring for dying pediatric patients. The final thematic interpretive statement was a formation of the seven themes that emerged from this study of the lived experiences of nurses caring for dying pediatric patients. The process of adaptation pediatric nurses use is “Censoring, as an adaptive process by the pediatric nurse, is a result of confrontation by the stimuli of the dying child, creating behaviors of empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow.” This statement reflects the connection of all seven themes and the overall meaning derived from them. The phenomenon of censoring is a combination of these themes as they related to the dying pediatric patient, the families, and nursing.

Summary

Chapter V described the findings of the study including the research setting, study sample, participants’ experiences, thematic analysis, essential themes, rigor of the study, and the themes defined by the participants’ responses. An interpretive statement was discussed. Chapter VI presents a reflection of the findings.
CHAPTER VI: REFLECTION ON THE FINDINGS

Seven themes were found and identified through reflection of the findings and analysis of the interviews: empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow. These seven themes are the constructs that form censoring as a mediator in the descriptive meaning of the adaptive process. This chapter will provide supporting statements to synthesize the data and literature. The themes will then be understood through explanations defined by the nursing model chosen to guide this study. Limitations, implications, and recommendations will then be addressed.

Essential Themes

By inquiring about the lived experiences of nurses caring for dying pediatric patients the following 7 themes were found: empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow. The nurse participants identified the 7 themes as constructs of the censoring process, which gives rise to the notion that the nurses use censoring as a mediator in the adaptive process to be able to contend with the stimuli of the dying pediatric patient.

Synthesis of Data and Literature

Theme 1: Empathy

Empathy can be thought of as an individual’s identification with, and response to, an event (Wilson & Kirshbaum, 2011). Empathetic reactions may be a result of understanding and compassion felt towards the patient and family. The nurse participants discussed feelings of empathy and compassion for dying children and their families. As with other research studies (Morgan, 2009; Dawson, 1995) the nurses, in their
discussions felt it was not a natural process to see a child in the throws of dying and death, and not congruent with the way the life process should unfold. Nurses perceived children as individuals who should be living productive, healthy, happy lives, which concurs with Morgan (2009), that when children die the potential for the future of the child’s life is lost, leaving parents and nurses to grieve.

Empathy can further be viewed as an emotion felt by the nurse when they place themselves in the patient’s situation, personifying the experience and treating the patient as they would want to be treated. When empathy involves alleviation of pain, avoidance of suffering, and promotion of a new level of health (Mattsson, Forsner, Castren & Arman, 2013), nurses will try to deliver their patient care in which these concepts can be achieved. This was evident when the nurse participants discussed their feelings of empathy, describing their reactions to the pain inflicted on the children, making the children more presentable to the family, making the children feel better, bringing on a peaceful death, and even placing themselves “in the parents’ shoes”. Stayt (2009) found that empathy towards patients and families contributes to the emotions of caring provided by nurses.

The nurse participants stated that sometimes the empathy felt by nurses is resultant of perceptions surrounding how the families react and cope. The nurses stated how parents wanted and needed help in processing the impending pediatric death and sometimes needed help in comprehending what was happening. In parent-oriented nursing care, nurses are sensitive to parents’ needs, feelings, and well-being, all culminating into empathy (Mattsson, Forsner, Castren & Arman, 2013). Yam, Rossiter & Cheung (2001) state by helping parents experience the impending death, nurses
provide emotional support and opportunities for intimacy between the dying pediatric patients and their family.

The nurses stated that by empathizing and identifying with the family they had the ability to create loving and intimate last moments, allowing parents to fulfill their parental role and find closure with their child’s death (Yam, Rossiter & Cheung, 2001). The nurses stated that empathizing and guiding parents through the final moments is the part of nursing care that provides help in the grieving process. It might be that the amount of time spent with the families, and the amount of empathy expressed towards the families, is due to the proximity and hours of care provided (Stayt, 2009). It might also be that empathy is carried out through the role of caregiver when there is a need to make a difference in another’s life by easing pain, suffering, and sadness (International Work Group on Death, Dying, and Bereavement (IWGDBDB), 2006). Censoring, through empathy, filters the stimuli of death, allowing nurses to perform to the best of their ability.

**Theme 2: Feelings of Ambivalence**

Ambivalence is defined as the state of having mixed feelings, mixed beliefs, or contradictions of thoughts and feelings (Petty & Krosnick, 2014). When discussing ambivalence in patient care, the nurses described a sense of doubt as to whether or not the care rendered was appropriate for the situation. Each nurse participant discussed similar issues related to ambivalence, whether the issues were concerned with the health care prescribed for the dying children, or struggles with their own emotions. The nurses spoke about the care they gave, and questioned whether their care caused pain and suffering. In relation to this, Morgan (2009) found ambivalence may be emotionally distressing when
nurses are asked to behave in a manner contradictory to their beliefs. Research concludes perhaps it is feelings of “disquiet”, or listening to the “conscience” concerning nursing actions, that create ambivalent feelings about what is experienced (Lee & Dupree, 2008).

The nurse participants reported ambivalence in the type of care rendered, specifically comfort measures and curative treatment. The nurse participants spoke about their understanding of the experience and their interpretation of what transpires as opposed to what families interpret. Sahler, Frage, Levetown, Cohn, and Lipson (2000) stated that it might be that families ultimately dictate the course of treatment, even if it is not the course recommended by health care providers, illustrating the difficulties and ambivalence in separating treatment routines.

Nurses may experience ambivalent feelings when required to carry out physician’s orders and parental decisions, holding themselves to a legal responsibility versus ethical and moral obligations to the comfort of their pediatric patients. These are very different approaches to the care of dying pediatric patients when conflicts involving invasive, aggressive procedures override less intrusive, more comfort providing treatments (Yam, Rossiter & Cheung, 2001). This conflict can arise feelings of ambivalence because nurses are educated to provide dignified, peaceful, and comfortable death (Epstein, 2008), minimizing pain and suffering to promote peace at the time of death (Yam, Rossiter & Cheung, 2001). Censoring, with respect to ambivalence, allows the nurse the ability to let go of their own judgements and adhere to the ethical role of nursing; focusing on the needs of the dying pediatric patient and not their own personal needs.
**Theme 3: Inevitability**

Inevitability is defined as a situation that is unavoidable and an event that is certain, but yet to come (Peach, 2014). Death is sometimes an inevitable outcome for patients despite technology, increasing survival rates, and cures for illnesses (Lehto & Stein, 2009). Pediatric nurses may from time to time face the burdensome task of helping patients and families manage the inevitability of death.

The nurse participants disclosed their thoughts when discussing inevitability. Most spoke of “knowing”, through experience, when death was near. It was evident during the interviews that each nurse struggled with the concept of children dying. However, each nurse spoke about humanity and compassion concerning their perceptions of what the dying child and the family were going through at the time of death and dying.

At times, the nurse participants expressed thoughts in that the procedures and treatments they performed on the pediatric patients would not be their personal choice. However, as Lee and Dupree (2008) found, they continued caring for the dying child because it is what is right for the family. The inability of the family’s acceptance of what is inevitable stems from the efforts to fight until the very end for dying children. This stimulus fuels the internal conflict within the nurse, knowing what is the inevitable.

The nurses made several references to the effect of questioning why treatments and procedures were being done. Even though the nurse participants were aware of child suffering, due to extensive and invasive procedures, they reflected on how parents overlooked this. This suffering is increased when ignored by family and healthcare providers, who deny the inevitable (Mattsson, Forsner, Castren & Arman, 2013).
Censoring becomes the mediator to compensatory adaptation when nurses experience inevitability. Nurse participants used censoring as they reasoned why dying pediatric patients were subjected to sufferable procedures, knowing what the outcome would ultimately be. They described situations where they went along with treatments because it was expected of them by the parents and the healthcare team, and because dying pediatric patients seem to be most vulnerable due to the inability for society to give up hope (Mattsson, Forsner, Castren & Arman, 2013).

The nurse participants instinctively knew what the outcomes were going to be because they had seen it play out so many times before. Pearson (2010) found that families might not understand the inevitable because they visually see their child’s heartbeat on the monitors or see the rise and fall of the chest, remaining optimistic that their child’s life is not ending. The nurses unanimously reported the inevitability of what was to be, recognizing through past experience, “what is”.

**Theme 4: Inspiration**

Inspiration is a process of being mentally stimulated to do or feel something, creating a eudemonic reaction typically experienced when facing challenges in the process of goal attainment (Straume & Vitterso, 2012). Inspiration includes spiritual feelings and coping that compel an individual to make meaning of incomprehendable events. Pendleton, Cavalli, Pargament & Nasr (2002) found that inspiration and spiritual coping, influenced by external and/or internal demands, goes beyond the resources within the person themselves, and creates a search for significance and meaning in a stressful time.
Inspiration and inspiring reflections were mentioned by the nurse participants during their interviews, providing descriptions of the religious and spiritual coping they seemed to have interpreted from their nursing care of dying pediatric patients. Inspirational reflections by the nurses were described as the actions of, and thoughts spoken by, the dying pediatric patients and their families. Even something as symbolic as smiling created an inspirational representation of a dying pediatric patient.

Each nurse discussed the inspirational aspect of caring for dying pediatric patients whether it was through the eyes of the child, family, or the nurse themselves. This was concurred by the research literature which adds that being part of such an emotionally volatile and profound time in a dying pediatric patient’s life, and having the chance to care for these families, has been described as a rewarding experience where nurses feel privileged (Epstein, 2008; Lee & Dupree, 2008; Ungureau & Sandberg, 2008). Nurses report a sense of satisfaction, meaning, and reward when contributing to the care of dying children and this has been recognized and appreciated by the dying children’s families (Papadatou, Martinson & Chung, 2001). The nurse participants reflected on this point when they spoke about how the families thanked them for caring for their children, soon after they had died.

The nurse participants described the gratitude and strength families expressed and displayed towards them, which added to the inspirational affects felt. The participants included in their statements and discussions that strength within the children and families relates to inspirational aspects of caring for dying pediatric patients. According to Taubman-BenAri and Weintroub (2008), healthcare providers, including nurses, have
reported growth in their appreciation of the human resilience and spirituality, providing inspirational insights of inner strength shown by their patients.

Being inspired by individuals at their most vulnerable moments helps define what is important in life, and arouses redefinition of priorities and life significance. Inspiration takes on meaning making, in which positivity is perceived from the care-giving experience (IWGDDB, 2006). This was reinforced when one of the nurses stated how she “every day I will have a smile on my face for her, because I know she would”, relating the inspiration of her dying pediatric patient with how she presently views life. When nurses use censoring in their practice, they create a level of tenacity as a result of inspiration. Censoring, in the presence of inspiration, provides nurses with the thoughtfulness and courage to endure the dilemmas they face themselves (Maeve, 1998).

**Theme 5: Relationship**

Relationship is defined as the state of being connected in a physical, emotional, and/or spiritual sense (Goldberg, 1998), and may be used to define the association a nurse experiences with others. Relationships are defined by the associations that surround the connecting circumstances and shared events. Relationships develop among nurses, dying pediatric patients, and families due to extenuating issues and events such as death and dying (IWGDDB, 2006).

Relationship was evident in each of the nurses’ interviews, and was illuminated as connections between nurses and dying pediatric patients, nurses and families, and nurses and collegues. Hagerty and Patusky (2003) found that relationships between the nurse and others are the basis and foundation of nursing practice. Relationships that form between the nurse and the dying pediatric patient is a profound event because of the
natural tendency to become attached to children, especially when they are in a vulnerable state such as illness and impending death. Miller (2007) also found that when a patient is dying and close to death a sense of connection is cultivated through presence, caring actions, compassion, and empathy. Dying pediatric patients, their families, the health care team, and nurses connect on a level beyond the scope of everyday nursing. Studies define the concept of relationship through love, affection, and attention shown towards dying pediatric patients (Epstein, 2008).

Relationships are also evident when nurses report thinking of dying pediatric patients during their off hours, producing a loving and affectionate connection elicited when they take on their patients, as if their own children. Several of the nurses reported buying clothes or other gifts for the children. Congruent to this, Epstein (2008) reported that nurses purchase toiletries, or other items, for their dying pediatric patients because they feel these gestures are forms of kindness, love, connectedness, and define the relationship.

Relationships form when there are caring moments with patients, and when nurses understand how important relationships are to dying children and their families. Nurses feel a sense of satisfaction and contribution when a close relationship develops and is recognized by the family (Papadatou, Bellali, Papazoglou & Petraki, 2002). This relationship is profound in the notion that nurses create physical, emotional, and spiritual connections with dying children and their families.

The nurse participants discussed receiving workplace support when colleagues took over new admissions, provided time for debriefing and discussion, and offered breaktimes to allow for the nurse to regroup and refocus. Research suggests this support
and connection becomes a beneficial experience to improving patient care when colleagues discuss and deal with shared experiences (Pearson, 2010; Hawkins, Howard & Oyebode, 2007). Lee and Dupree (2008) found relationships, through mutual connection among staff, allows for perseverence in moments of devastation and also provides support so that nurses can continue to do their job. These relationships, when positive, enhance teamwork, reinforce patient outcomes, and sustain caregivers during the difficult process of patient care (IWGDB, 2006).

Relationships allow the nurses to cope with the event of pediatric death through censoring. Relationships the nurse participants had with their colleagues were mediated through censoring, when there was continuous supportive help during difficult times. The stimuli of pediatric death created the need for colleagues to help the nurse censor the moment, take a break from the situation, and return when they felt they were ready.

**Theme 6: Self-Preservation**

Self-preservation can be defined as self protection from harm, regarded as a basic human instinct of survival (Khantzian & Mack, 1983), and a coping strategy that allows for an understanding and processing of what takes place in our world. The construct of self-preservation helps nurses deal with the emotional demands of patients, their families and patient outcomes, either good or bad (Hawkins, Howard & Oyebode, 2007). Self-preservation in the interaction nurses have with their dying pediatric patients, helps maintain a therapeutic relationship while maintaining mental well being.

The nurse participants spoke about issues surrounding self-preservation in a sense that they contradicted many key aspects of the relationships, the love, and the connectedness they also reported. Self-preservation overcomes stressful, emotional, and
sensitive situations. Sahler, et al (2000) found it is common for healthcare providers to become emotionally distant from the dying child and family. Self-preservation is part of the process which nurses need to shield themselves from what can deeply hurt them. Research studies found distancing and disconnecting from patients facing a troubling situation is common with nurse self-preservation and self protection (Lipp, 2011; IWGDBB, 2006).

The nurse participants described self-preservation by the statements of managing for today, taking care of the issues at present, and addressing the delivery of optimal nursing care. Self-preservation may aid in coping strategies such as priority setting and use of humor (Yam, Rossiter & Cheung, 2001). As most of the nurses disclosed, part of how they retained self-preservation was to socialize with co-workers, use team nursing in their patient care by not allowing one nurse to face the dying pediatric patient and family alone, and possessing the ability to allow each member of the health care team to laugh and joke. Censoring, mediated through the actions of self-preservation, provides strength and endurance, so that the nurse can give optimal patient care.

**Theme 7: Sorrow**

Sorrow is distinctly conceptualized as a normal response to a situation involving a loss (Eakes, Burke & Hainsworth, 1998). This normal response is labeled as sadness or some other grief response, associated with a gap between what the nurse expects and what actually is. Nurses experience sorrow when patients die, and this is especially significant when nurses care for dying pediatric patients (Lee & Dupree, 2008).

The nurse participants collectively talked about the emotional aspects when caring for dying children. During the interviews, several of the nurses became outwardly
emotional and cried, illustrating their lived experiences. Those that did cry were appologetic for their emotional outbursts. Research suggests crying for someone else is a display of sorrow, and when nurses witness children dying they internalize the pain and suffering, they themselves feeling the emotion (Morgan, 2009; Ungureau & Sandberg, 2008).

Sorrowful reactions are a predominant theme nurses disclose in qualitative studies about nurses’ experiences of caring for dying pediatric patients (Morgan, 2009; Lee & Dupree, 2008). Emotions are felt, not only for the children, but also for families, where nurses’ bear witness to their grief and loss (Lee & Dupree, 2008). Even though emotions were present, and reinforced the humanity in nursing, the nurse participants spoke about how they needed to hide this until they felt comfortable and isolated from others. Some participants stated they censored the display of their emotions until they were away from the work environment, in order to focus on the nursing care that was needed.

The use of censoring to mediate emotions until it is appropriate, gives the nurse the opportunity to carry on with patient care without distraction. While the nurse uses censoring to mediate the stimuli of sorrow that accompanies a dying pediatric patient, she also adapts to the moment and gives herself the ability to experience the sorrow at a more appropriate time. Repressing emotion can be healthy for the moment; helping to effectively function in the role of the nurse (Papadatou, Martinson & Chung, 2001). The nurse participants spoke about carrying on with the technical components of patient care while desperately trying to hold their emotions in check. Nurses may sometimes concentrate on the technical and physical components of patient care and try to minimize interactions as much as possible to avoid such emotionally distressing events (Yam,
Rossiter & Cheung, 2001; Morgan, 2009), once again utilizing censoring to mediate their emotions to a more appropriate time.

**Thematic Statement Reflection Using A Nursing Model**

The concluding finding that arose from this research study brought to a close that through the lived experiences of nurses caring for dying pediatric patients an overall descriptive meaning of adaptation becomes apparent when stimuli affects behavior. This descriptive phenomenological study of the lived experiences of nurses caring for dying pediatric patients was conducted to illuminate the experiences of nurses. Often time’s pediatric nurses may encounter dying children and may even participate in caring for children during the death process. It is important to understand what are the nurses’ experiences, to be able to comprehend and learn from them. Interviews with the participants unfolded after asking the question, “What was your experience when caring for dying children?” In-depth interviews then illuminated the nurses’ experiences and their perceptions related to their experiences.

The experiences of nurses caring for dying pediatric patients were explored using a descriptive phenomenological approach following methods outlined by van Manen (1997). The Roy Adaptation Model (RAM) (Roy & Andrews, 1991; Roy, 2009) served as a nursing model that guided the process to understand the nurse as an adaptive system functioning for a purposeful cause. The nurse creates conscious choices that influence his or her personal level of adaptation and this study concluded that it is the mediator of censoring of stimuli that create the adaptive process.

The assumptions underlying the RAM (2009) are that adaptation, in the form of censoring, is a mediator response to stimuli. Censoring then becomes a compensatory
adaptation process in pediatric nurses. Within this study, the focal stimuli, the dying child, continuously confront the nurse. Adaptation, through the mediator censoring, can then be seen as a process where nurses use awareness and choice as integrating human and environmental factors to be able to adapt to their experiences with the dying child. The nurse’s feelings and knowledge about dying children provide the nurse with the mechanism for evaluating effective or ineffective self-adaptation behaviors as measured by the level of actions and responses created by the nurse. This is illustrated by the essential themes that emerged through data analysis. Essential themes of empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow became the behaviors that mediated the nurses’ compensatory adaptation of censoring. This process of censoring concurs with the RAM (2009), that states that adaptation (censoring) creates an optimal integration of human and environmental stimuli, resulting in optimal well-being.

The mediator censoring, possessed by the nurse, supercedes empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow over the pediatric death. Nurses utilize their sorrow, relationships, and empathy when giving care to dying children to provide a humanistic approach to the experience while holding at bay their own mental health and well being. Inevitability, inspiration, and self-preservation maintain the drive to care while balancing self health. Ambivalence provides an equilibrium of ethics and beliefs within the process of caring for dying pediatric patients by creating uncertainty and questioning of the ethical dilemas nurses face. It is through these themes that nurses are able to process the aspects of the
profession and censor what needs to be processed, versus what needs to be repressed, to make meaning of the experience.

The mediator censoring, as a compensatory adaptive process, is utilized when nurses must contend with the stimuli of the dying pediatric patient. Through the experience of the nurse caring for dying pediatric patients, we have the ability to learn about the adaptation process so that this information can be studied and communicated to nurses and nursing students, applying this knowledge in their practice. According to Roy (2009), adaptation, including role socialization, allows nurses to function as nurses.

As nurses continue to provide care to dying pediatric patients they more clearly come to know and understand the focal stimuli, which is the dying child. Once they come to recognize the stimuli, they can become more adept to censoring. It is important for the nurse to understand and recognize the stimuli of the dying child to allow censoring to become the internal mediator in which the nurse can then utilize empathy, feelings of ambivalence, inevitability, inspiration, relationship, self-preservation, and sorrow in her behavior.
Thematic Model

Figure 1: Thematic Model of Censoring

CENSORING BY THE NURSE

Empathy

Feelings of Ambivalence

Inevitability

Inspiration

Relationship

Self-Preservation

Sorrow

The Dying Child
Limitations of the Study

Limitations of this study must be considered. The information gathered through this research study was specific to the context of the lived experiences of nurses caring for dying pediatric patients. The data that emerged may or may not be applicable to other populations, specifically to nurses caring for dying adult patients. Furthermore, this study, as any qualitative study, is not generalizable as findings are limited to the experiences of the participants within the context of this study.

The participants in this study were all female lending to a more “mothering” perspective of the experience of caring for dying pediatric patients. Three of the participants were married giving these nurses the advantage of spousal support when needed. Four of the participants were mothers, allowing maternal focused self-reflection when caring for dying children. The remaining participants may have had a disadvantage in the areas of support and relating to being a mother. These factors may potentially alter the processing and perspective of the single and childless nurse when caring for dying pediatric patients.

Another limitation of this study is the setting in which the participants work. The geographic locations of their workplaces may account for a different perspective in patient care. All 9 participants are nurses in large metropolitan hospitals, which may allow the opportunity for exposure to sicker children with higher acuity levels in a higher nurse-patient ratio than in a rural hospital setting.

Implications

Implications of this study will then be discussed. This is one of the few studies that explored the lived experiences of nurses caring for dying pediatric patients.
Exploring the lived experiences of nurses caring for dying pediatric patients allowed this researcher the opportunity to hear stories about nurses and their patients and families. Personal and emotional stories of lived experiences provides the identity to which nursing is (Graham, Andrewes & Clark, 2005). These events, as told by the nurses, provided a better understanding of what it is like to be a pediatric nurse caring for dying children. In listening to and exploring the description to which the nurses told their story, it is believed that lessons can be learned and translated to nursing students and novice nurses. This personal knowledge of what was narrated by the nurse participants can be woven into nursing curriculum. By using the findings of this study we learned about the behavior, self-discipline, and knowledge of the nurses through an integration of reflection on the lived experiences (Chinn & Kramer, 2008), bringing to light the knowledge that needs to be transferred to nursing students and novice nurses.

Nursing has always been in the forefront of bedside patient care, and caring for dying patients is a job done by bedside nurses. Nursing curriculum focuses on health promotion and maintenance and rarely speaks to end of life issues in children. The aim of phenomenological research is to create meaning and expression of the lived experience through a reflective re-living, breathing life into a specific event (van Manen, 1990). This research study attempted to help uncover knowledge significant to nurses caring for dying pediatric patients.

Understanding this knowledge and the experiences of the nurses is important because it adds to the development of personal knowledge in nursing education by describing and uncovering specific awareness, the moment of the context of interaction, which makes meaningful, shared human experience eventually allowing for identification
of patterns of actions of the nurses (Chinn & Kramer, 2008). This research study also allowed identification of authentic patterns of behaviors, feelings, and actions that nurses use in the last moments of a child’s life, new to the nursing care literature of dying pediatric patients. These authentic patterns resulted in an identification of censoring as a means of adaptation, utilized by pediatric nurses.

Knowledge gained from this study will provide reasoning and substantiate practices in nursing, increasing knowledge and experience sharing within the domain of pediatric death and dying. It was revealed that in learning about the nurses lived experiences many similar themes emerged deepening the understanding of the events surrounding pediatric death. These themes incorporated actions, feelings, relationships, and spirituality as well as “meaning making” of life. Caring for dying pediatric patients involves not only the dying child, but the family and other health care providers. Preservation of the nurses’ mental well being lead to the conclusion that when the nurses are put in demanding experiences during the dying process, they use censoring to carry on.

Information gained in this research study may aid in the preparation of nurses and nursing students who come in contact with death and dying by teaching about censoring and how to create a censoring mindset to be able to adapt. Even though current nursing school curricula teaches students about death and dying issues concerning patient care, additional content may discuss how to adapt, cope, and ultimately censor, in order to effectively provide optimal nursing care to dying pediatric patients. Curricula should focus on the generalized concepts of what was told by the nurse particiants, who provide care in this domain. This concept knowledge may allow for a deeper understanding of
the process and insight into other’s experiences, providing information in which nurses and nursing students can identify with. Experiences can be unique in each other, however, sometimes there can be an identification of similarities, aiding in the understanding of what it is like to care for dying pediatric patients. These similarities may be helpful for nurses to recognize that others have been through this process and it is okay to encounter these experiences, and censor what is processed and what needs to be repressed, to be able to function in a productive, professional manner.

**Reflections of Researcher’s Experience**

This researcher’s experience of asking nurses to describe and tell about their lived experiences of caring for dying pediatric patients allowed me to learn about this phenomenon and was pivotal in constructing a theory for nurses. Findings from this study helped to understand how nurses practice nursing in this capacity. This study has further enhanced the respect I have towards pediatric nurses and how they do what they do on a daily basis, especially when confronted with pediatric death.

The nurses and their stories of experiences in caring for dying pediatric patients profoundly humbled me. Some of the participants became visibly emotional during the interviews, which was unexpected to me. I did not realize the traumatic emotions many pediatric nurses encounter when pediatric patients die in their care. These reactions increased my respect for nurses in this field and broadened my insight as to why nurses practice in pediatrics. After extensive data analysis, I now understand the nurse participants’ experiences, and depth of their feelings of inevitability, sorrow, relationships, self-preservation, ambivalence, empathy, and inspiration. These feelings were created because of the circumstances involving the lived experiences of caring for
dying pediatric patients, resulting in an adaptation behavior of censoring which mediated their responses to the stimuli of the dying pediatric patient.

**Recommendations for Further Study**

Recommendations for further research studies will now be discussed. This study provided information within the realm of nurses’ experiences with dying pediatric patients. Hopefully, the information generated may be used for studies within other patient populations. Studies may be done to look at themes formulated from the experiences of nurses caring for dying adults. Moreover, further studies may want to focus on dying pediatric patients of similar cultural backgrounds, or similar religious beliefs. Even still, further research studies may want to focus on gender differences in participant populations. This particular study included only female participants, however male nurse participants may be studied, and results can be compared to the findings presented here.

Additional research studies are needed to add to further knowledge development in the realm of censoring as a central construct in the theory of the human life process of adaptation (Roy, 2009). Theoretical clarification on the construct of censoring will enable the questioning and understanding of how nurses utilize adaptation through censoring. Interventions to enhance censoring may also be studied within the context of dying patients.

Also, it may be possible to use the information provided by this study in other health care domains aside from nursing. It seems as if a humanistic experience of caring for dying patients may evoke similar research findings using different participant
population groups within health care. When research has the ability to cross several domains, it may be helpful for education and curricula within other disciplines.

**Summary**

Chapter VI compared the research findings with established literature. Themes where compared to other research studies to collaborate findings and secure meaning in what the participants revealed. A thematic statement reflection using a nursing model was discussed as well as presentation of the thematic model, the limitations of the study, and reflection of the researcher’s experience. Recommendations for further study were examined to encourage further knowledge on the lived experiences of nurses caring for dying pediatric patients.
Appendix A

CITY UNIVERSITY OF NEW YORK

Graduate Center

Department of Nursing

CONSENT TO PARTICPATE IN A RESEARCH PROJECT

Project Title: The Lived Experiences of Nurses Caring for Dying Pediatric Patients

Principal Investigator: Danna L. Curcio RNc, MS, FNP, DNS(c)
Faculty-Lecturer
Department of Nursing
College of Staten Island-CUNY
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Staten Island, New York 10314
718-982-3822

Faculty Advisor: Dr. Martha Whetsell, Associate Professor
Department of Nursing
Lehman College-CUNY
50 Bedford Park Boulevard West
Office: T3 Room 203
Bronx, NY 10468
718-960-8199

Site where study is to be conducted: CSI Building 5S Room 208; private locations convenient for participants

Introduction/Purpose: You are invited to participate in a research study. The study is conducted under the direction of Danna L. Curcio, a doctoral student in the Department of Nursing at the Graduate Center, City University of New York. The purpose of this research study is to explore, describe, and understand the lived experiences of nurses caring for dying pediatric patients. The results of this phenomenological study may help uncover knowledge significant to nurses caring for dying pediatric patients and aid in increasing the development of personal knowledge in nursing education. The participant’s interviews will be audio-recorded and all recordings and transcriptions will be stored in a locked file cabinet of which only I, myself, have access to. Any computerized memos of the encounters will be secured in my, the researcher’s, computer
under password access. Audio-recorded interviews will be helpful when referring to the conversations and clarifying the transcriptions.

**Procedures:** Approximately 4 - 10 individuals are expected to participate in this study. Each subject will participate in one initial interview and then another interview for clarification of transcription of the dialogue. The time commitment of each participant is expected to be approximately 60 minutes in length. Each session will take place at either at the College of Staten Island, 2800 Victory Blvd, Staten Island, New York 10314 or at private locations convenient for the participants.

**Possible Discomforts and Risks:** Your participation in this study may involve minimal risk due to stress, no more than encountered in everyday life. There should be no physical discomfort experienced. If so, to minimize these risks you will be allowed to withdraw from the study at any time and cease interviews when feeling necessary. If you are upset as a result of this study you should seek mental health counseling at the following locations:

1. Crisis Intervention, New York City Department of Health and Mental Hygiene at 1-800-LIFENET
2. Mobile Crisis Unit, Staten Island University Hospital, NSLIJ at 1-718-818-6900

**Benefits:** There are no direct benefits to participating in this study. However, participating in this study may increase the general knowledge of what it is like to care for dying pediatric patients.

**Alternatives:** There are no alternatives to participating in this study other than refusing participation.

**Voluntary Participation:** Your participation in this study is voluntary, and you may decide not to participate without prejudice, penalty, or loss of benefits to which you are otherwise entitled. If you decide to leave the study, please contact the principal investigator Danna L. Curcio to inform them of your decision.

**Financial Considerations:** Participation in this study will involve no cost to the participant.

**Confidentiality:** The data obtained from you will be collected via audio recordings and transcribed into written documents. The collected data will be accessible to myself the researcher (PI), and my dissertation sponsor. The researcher will protect your confidentiality by coding the data for future clarification by the participants and securely storing the data. The collected data will be stored in secured areas, whereas audio recordings will be kept in a password secured computer file and transcriptions in paper format will be kept in a locked file cabinet of which only myself the researcher (PI) and my dissertation sponsor have access to. Consents and demographic data will also be kept...
in a locked file cabinet of which only myself the researcher (PI), and my dissertation sponsor have access to. To protect confidentiality, participants will not be referred to by name. Participants will choose pseudo-names to use for reference.

**Contact Questions/Persons:** If you have any questions about the research now or in the future, you should contact the principal investigator, Danna L. Curcio (646) 670-1560, at nursedlc@aol.com or dissertation sponsor Dr. Martha Whetsel (704) 778-1157, at marwhet@hotmail.com. If you have any questions concerning your rights as a participant in this study, you may contact Tara Prairie, Lehman College (718) 960-8960 at tara.prairie@lehman.cuny.edu.

**Statement of Consent:**

“I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntary agree to participate in this study.

By signing this form I have not waived any of my legal rights to which I would otherwise be entitled.

I will be given a copy of this statement.”

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Appendix B
Participant Survey Questionnaire

How old are you now?_____________________

What is your educational level?_____________________

What are the number of years you have been a nurse in this specific nursing specialty?______________

Are you male or female?____

What is your marital status?
                             Single___ Married___ Separated___ Divorced___ Domestic Partnership___

Do you have any children?____________

If yes how many and their ages ________________________________

                                      ________________________________
                                      ________________________________
Appendix C

Resources available if there is any emotional/psychological discomfort related to our discussion

Individual Provider: Crisis Intervention
Hospital for Emergency: New York City Department of Health and Mental Hygiene
Online or Phone: 1-800-LIFENET

Individual Provider: Mobile Crisis Unit
Hospital for Emergency: Staten Island University Hospital, NSLIJ
Online or Phone: 1-718-818-6900

Individual Provider: St. Luke’s Outpatient Behavioral Health Clinic
Hospital for Emergency: 411 West 114th Street
New York, New York 10025
Online or Phone: 1-212-523-7668
Appendix D
Invitation to Participate

You are invited to participate in a research study looking at your experiences in caring for dying pediatric patients.

My name is Danna L. Curcio and I am a registered nurse and doctoral student in Nursing. I am studying what it is like to care for dying pediatric patients. I would like to hear about your experiences in this area.

Participants must be:

• Nurses currently working at the bedside on a pediatric unit
• Nurses who care for dying pediatric patients
• Nurses who have never experienced pediatric death within their immediate family or they themselves have not experienced pediatric death with their own children
• Nurses must have a minimum of one year to a maximum of four years experience

The study consists of an interview, which may last for approximately for one hour. I would like to interview people within the next few months and would arrange to meet you wherever it is most convenient for you. Your participation is completely voluntary. All participants completing the study will be given a token of appreciation.

Interested parties should contact:

Danna L. Curcio
nursedlc@aol.com
(646) 670-1560
References


