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The Experience of Intensive Caring Nurses
Caring for Patients for Whom Life Sustaining Treatment is Being Withdrawn

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The Experience of Intensive Caring Nurses

Caring for Patients for Whom Life Sustaining Treatment is Being Withdrawn

By Brandi Vanderspank

Thesis submitted to the Faculty of Graduate and Postdoctoral Studies in partial fulfillment of the requirements for the degree of Master of Science in Nursing

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Abstract

The Experience of Intensive Care Nurses Caring for Patients for Whom Life Sustaining Treatment is Being Withdrawn

The aim of this study was to describe, and to further understand the lived experience of intensive care nurses, who care for patients for whom life sustaining treatment is being withdrawn.

It is known that a large percentage of patient deaths that occur in the Intensive Care Unit (ICU) follow the withdrawal of life sustaining treatment. Nurses are the primary care givers of patients in the ICU and are directly involved in end-of-life care and the initiation of withdrawal of life sustaining treatment.

Interpretive phenomenology served as the methodology by which the researcher explored and interpreted the lived experience of these ICU nurses. Unstructured face-to-face interviews were conducted with six intensive care nurses employed in the ICU of a large tertiary care hospital. The interviews were transcribed verbatim and analyzed using approaches outlined by Colaizzi (1978) and van Manen (1990).

The essence of this experience was described by intensive care nurses as "trying to do the right thing". Three major themes emerged from the data: A Journey – Creating Comfort Along the Way; Working in Professional Angst and Providing Memories. The findings have given a voice to intensive care nurses in their role of providing care to patients and families during this experience.

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Mom, Rob and Dad...thank you for encouraging me to do what I love: school and nursing!

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Chapter 1 – Introduction

Erinn, an intensive care nurse, is receiving a verbal report on Mr. P from the night shift nurse. Despite multiple interventions over the past three weeks, Mr. P's health has continued to deteriorate especially over the past 24 hours. A family meeting is scheduled for that afternoon to discuss the plan of care for Mr. P and the discussion will revolve around redirecting care from curative to comfort measures. When the family arrives in early afternoon, Erinn finds herself in a family conference with the staff physician and 27 family members whom she has never met. The family is informed of Mr. P's continually deteriorating health status and a decision is made to withdraw life sustaining treatment. Erinn returns to the bedside and begins the process of withdrawing the ventilator support and appropriate intravenous medications. Immediately upon decreasing the ventilator support Mr. P begins to show signs of respiratory distress. Erinn increases Mr. P's intravenous sedation and pain control. Within 20 minutes of the family conference and the initiation of the withdrawal of life-sustaining treatment, Mr. P dies.

As an intensive care nurse in a Medical/Surgical Intensive Care Unit, the opening story is reflective of patient situations I have encountered. Having been the primary care nurse in multiple cases involving withdrawal of life sustaining treatment, my personal experiences have led me to want to explore this phenomena in greater detail. Intensive care nurses witness death following withdrawal of treatment on a regular basis. Little is known about the experience of nurses involved in the withdrawal of life sustaining treatment.

1.1 Background

In Canadian teaching hospitals, 27% of all deaths occur in special care units such as the Intensive Care Unit (ICU) (Heyland, Lavery, Tranmer & Taylor, 2000). The majority of deaths that occur in this environment follow a decision to discontinue the use of life sustaining technology (Keenan, Mawdsley, Plotkin, Webster & Priestap, 2000; Kjerulf, Regehr, Popova &

Baker, 2005; van Rooyen, Elfick & Strumpher, 2005). The literature has identified nurses as the primary care givers of patients who are terminally ill and dying in many settings (Bradley et al. 2001; Dawe, Verhoef & Page, 2002) and, in intensive care, it is the nurses who are directly involved in end-of-life care and the initiation of withdrawal of life sustaining treatment. (Ingham, 2001; Nelson & Danis, 2001).

1.2 Description of Terms

In order to fully understand the context and outcomes of this study the following description of terms have been included:

1.2.1 Intensive Care Nurse:

Intensive care nurses are part of a group of nurses referred to as critical care nurses. Throughout this report, the terms critical care nurse and intensive care nurse are used interchangeably, however in this instance both refer to nurses working in an intensive care environment. Through their continual presence 24 hours per day, intensive care nurses play a pivotal role in the assessment, planning, implementation and evaluation of the care and treatment provided to critically ill patients and their families. They are patient advocates and integral members of the health care team who facilitate communication between the team, patients and their families. Their role encompasses the provision of life sustaining interventions as well as ensuring patients are receiving comfort care such as skin care, repositioning and pain management. They work in an environment that is fast paced, unpredictable and is fraught with high emotion and uncertainty.

1.2.2 Withdrawal of Life Sustaining Treatment

The decision to withdraw life sustaining treatment is directly related to the context and complexity of the patient for whom care is provided. It is initiated following a decision made with the families of patients and the health care team including the physician, nurse, and allied health members (registered respiratory therapists, pastoral care) and is commenced following a written order from the physician. Treatments are withdrawn with the expectation that patients will die from their underlying disease process(es). Treatments withdrawn may include ventilatory support (which encompasses the use of mechanical ventilation), medications to support blood pressure and heart function (inotropes and vasopressors), antibiotic therapy, nutritional support in the form of either enteral or parenteral feeding, hemodialysis and potentially all prescribed medications with the exception of medications used for the provision of patient comfort such as opiates and sedatives.

1.2.3 Comfort Care/Measures

Comfort care and comfort measures refer to interventions that focus on pain and symptom control. Medications such as sedatives and narcotics are often used to control pain and dyspnea (difficulty breathing). Other non-pharmacologic measures used in providing patient comfort include frequent repositioning, mouth care and skin care.

1.3 Purpose of the Research Study

The purpose of this study was to describe and seek to further understand the lived experience of intensive care nurses caring for patients for whom life sustaining treatment is being withdrawn.

1.4 Objectives of the Research Study

1. To describe and seek to further understand the experience of intensive care nurses who have cared for patients throughout the process of withdrawal of life sustaining treatment.

2. To identify factors that facilitate the nurse caring for a patient for whom life sustaining treatment is being withdrawn.

3. To identify factors that hinder the nurse caring for a patient for whom life sustaining treatment is being withdrawn.

Chapter 2 – Review of the Literature

The literature review encompasses research related to the context of the Intensive Care Unit environment (including a brief description of early intensive care units), the role of intensive care nurses, death in the ICU, and the withdrawal of life sustaining treatment. The literature was retrieved through a selective review that searched medical and nursing literature from 1990-2007. Databases including CINAHL, Medline and PubMed were searched. Search terms included: intensive care, critical care, withdrawal of life sustaining treatment, nurses' experience, and end-of-life care in critical care. A brief historical overview encompasses the use of literature reflective of the development of Intensive Care Units from the 1950s to present day.

2.1 What is Intensive Care?

The years 1950 to 1970 marked a time of radical change taking shape in health care delivery. Health care was affected by an increased birth rate post World War II, expanding medical knowledge, growth in technological equipment and changes in society's expectations of what medical care should consist of in hospital (Fairman & Lynaugh, 1998). The public's perception of health care now encompassed a view that hospital care emphasized successful treatment and cure. The public "expected the hospital and its professional staff to do something for previously untreatable chronic illness" (Fairman & Lynaugh, 1998, p.22).

The development of ICUs arose in part from inadequate staffing on medical-surgical floors (Wilson, 1990) and well as the need to closely observe acutely ill patients. Although the gathering of patients together was not an entirely new concept as evidenced by the polio-units of the 1940s and early 1950s as well as post-anesthesia recovery rooms of the 1930s,

the 1950s saw the development of a permanent area for critically ill patients as an imperative (Fairman, 1992). On large wards in the 1950s , for example, 3 nurses provided care for over 40 patients. Because of the vast numbers of patients on wards as well as their physical set up, patients in crisis had to be stumbled upon by a nurse doing routine rounds in order to receive appropriate interventions (Fairman & Lynaugh, 1998). This ratio of nurses to patients proved insufficient for patients who required more intense observation or had more complex treatment regimes such as the administration of oxygen (Fairman & Kagan, 1999).

Therefore, the purpose of the first intensive care units in the 1950's was to alleviate the problem of patients requiring more intensive observation. Critically ill patients were grouped together in a confined space (usually four to six beds per unit) and concentrated nursing staffing patterns were implemented (Fairman & Lynaugh, 1998). The physical space available for care was relatively small and was taken up by familiar tools such as oxygen tanks, drainage bottles and suction devices (Fairman & Lynaugh). The difference however, was that the equipment these patients needed, instead of being spread around and stored in different areas, was now readily available. The first intensive care nurses have stated that they did not have more technology; they just used what they always had (Fairman & Lynaugh). Monitoring parameters of the patients in these first units encompassed vital signs, assessing level of consciousness, intake and output as well as patient weights (Fairman & Lynaugh).

2.2 What is intensive care and intensive care nursing in 2008?

In 2008, critical care nursing encompasses the provision of complex nursing care in several environments: the emergency room, post anesthesia care units or recovery

rooms, operating rooms and intensive care units. The critical care environment particularly in intensive care, is fast paced, technologically complex, fraught with uncertainty and ultimately cares for a patient population requiring complex medical management and intensive observation and monitoring.

The atmosphere of the 21st century ICU has maintained one similarity of the early intensive care unit: intensive observation. However this observation has expanded to not only include closely observing the patient and their vital signs but also incorporates the patients response to use of mechanical ventilation, cardiac monitors, hemodynamic monitoring and manipulation related to the vast array of medications used to influence cardiac function, hemodialysis and intra-aortic balloon pumps, to name but a few. The physical environment (the close proximity of nurses to their patients) facilitates continuous monitoring and observation of the patient and technologically complex machinery is plentiful. Care provision takes place in and amongst the technology.

Patients are typically admitted to ICU with life threatening and complex health problems such as pulmonary and cardiovascular disease, sepsis, trauma, cardiac arrest as well as gastrointestinal and central nervous system disease (Cook et al., 2003). Often patients manifest signs and symptoms of multiple organ dysfunction/failure and subsequently require mechanical ventilation, inotropic (mediation to support cardiac function) support or both (Cook et al).

In order to properly care for these patients being admitted with life threatening and complex health problems, ICUs are made functional by using large inter-professional teams consisting of nurses, social workers, physicians, allied health, pharmacists, spiritual care and support staff. Nursing care in the majority of ICUs is kept as close as possible to a one nurse to one patient ratio due to the need for continuous monitoring and the constant potential that rapid intervention be required. Intensive care nurses facilitate communication amongst the

health care team, the patients and their families as well as provide the care necessary to stabilize critically ill patients. In situations where critical intervention is to no avail and a patients' health status continues to deteriorate, critical care nurses provide comfort care measures and support both patients and families through the experience of dying in the intensive care unit.

2.3 Death in Intensive Care Units

As in other areas of health care, death and dying has been a reality of intensive care since its inception. Historically, patients have died in ICU as a result of their injuries or failure of the body systems to respond to treatment. Despite the advances that have been made in critical care medicine, there continues to be a high number of deaths occurring in ICUs. Heyland et al. (2000) noted that 27% of all hospital deaths occurred in special treatment units in Canadian teaching hospitals and in the United States approximately 20% of all deaths occur in the ICU (Curtis, 2005). Despite the evidence of a large percentage of deaths occurring in ICUs, the literature frequently focuses on the goal of critical care (intensive care) as saving lives and restoring health (Hylton Rushton, Williams & Hartman Sabatier, 2002) while death of patients in this environment can be seen by intensive care physicians as medical failure (Cicarrello, 2003).

Advances in medical technology have made it increasingly possible to sustain critically ill patients for prolonged periods of time (Jones & FitzGerald, 1998; Stroud, 2002), however, recent literature has begun to explore the consequences of critical intervention and examine issues related to death and dying in the intensive care environment. It is often only upon the exhaustion of technological interventions that the redirection of care from curative to palliative measures is instituted (Miller, Forbes & Boyle, 2001). As such, the majority of deaths occurring in ICUs follow a conscious decision made by the health care team and the family of the patient to

discontinue the use of life supporting technology (Keenan et al. 2000, Kjerulf et al., 2005; van Rooyen et al., 2005).

Intensive care nurses provide a continual presence at the bedside for patients and their families. Nurses in these units deliver highly sophisticated and technological interventions as well as provide measures to promote patient and family comfort and well-being. However, prior to the late 1990s and early 2000s, there was a limited amount of literature which focused specifically on the role that intensive care nurses play in regards to the care of patients dying in intensive care units. Julie Fairman of the University of Pennsylvania was one of the first historians who through the lens of social history to began to explore the nursing role in intensive care. Of particular interest was that in her doctoral work, Fairman and Lynaugh (1998) indicated that a reevaluation of the impact of critical care medicine and technological advancement needed to begin to take place. In fact, recent literature pertaining to death in ICU has focused on withdrawing and withholding treatment, the needs of families of ICU patients and also the experience of nurses and other members of the health care team including respiratory therapists in regards to end-of-life care in the ICU.

2.4 Withdrawal of Life Sustaining Treatment

Upon the decision to admit a patient to the ICU, life sustaining interventions begin to take place. For example, if a patient is experiencing severe respiratory distress, interventions could possibly include the use of high fractions of inspired oxygen and subsequently a need to intubate the patient in order to either prevent or treat the impending respiratory failure. The consequence of the need to implement life sustaining treatment in order to stabilize and treat a patient can result in the patient experiencing continued dependence on the technology without showing signs of improvement. Because of the technological intervention patients can be sustained for prolonged periods of time. Death then comes as a result of a conscious decision to withdraw the

life sustaining interventions and to provide the patient with comfort and support in the dying process. Death via withdrawal of life sustaining treatment is a reality of the ICU environment.

Despite the majority of deaths in the ICU occurring subsequent to withdrawal of life sustaining treatment, the literature had identified that policies and procedures related to treatment withdrawal may not be clear (Burns, Mitchell, Griffith & Truog, 2001; McLean, Tarshis, Mazer & Szalai 2000). The nature of the ICU environment itself also can lead to inconsistency and lack of continuity of care. Bowman (2000) identifies that ICUs typically have large inter-professional health care teams composed of members that can come with different backgrounds and therefore varying educational and philosophical perspectives may influence the course of treatments provided. Inconsistencies regarding end-of-life care may also be related to the continual turn over of medical teams in the ICU. For example, physician teams in the ICU often rotate on a weekly basis thus the plan of care for patients may also change. Hylton Rushton, Williams and Hartman Sabatier (2002) have indicated that urgent time frames for decision making in the ICU and conflicting values among team members can also contribute to inconsistency and lack of continuity of care. In addition, once the decision is made to withdraw treatment, the families are faced with a situation where the patient may die in minutes or it may take several hours.

For example, a retrospective study conducted by Rocker et al. (2005) helps to illustrate the variable time frame for patient death following withdrawal of life sustaining treatment. Ninety-eight patient records were reviewed after death and revealed a mean time of death of 1.5 hours (range 0.5 – 5.3 hours) following the withdrawal of the first treatment modality. The results of this study demonstrate that a narrow time frame exists from the actual decision to withdraw treatment until death occurs (Rocker et al.). For example, patients may die within minutes of the nurse commencing withdrawal of treatment leaving the nurse to care for an emotionally distraught and shocked family.

2.5 The Role of the Intensive Care Nurse in Withdrawal of Life Sustaining Treatment

The literature has identified nurses as the primary care givers to patients who are terminally ill and dying (Bradley et al., 2001; Dawe et al., 2002). Intensive care nurses are directly involved in the withdrawal of life sustaining treatment (Badger, 2005; Ingham, 2001; Nelson & Danis, 2001) and are providers of end-of-life care in the ICU environment. Interestingly, Rushton et al. (2002) recognize that death is not the expected outcome of critical care interventions from the perspective of health care professionals, as well as patients and their families. Critical care nurses face dilemmas that stem from the initial attempt to save lives to a redirection to end-of-life care when medical interventions are no longer maintaining the life of the patient (Pattison, 2004).

2.6 Phenomenological Studies Addressing the "Experience" of Critical Care Nurses

A search of the nursing literature revealed three phenomenological studies addressing the experience of critical care nurses in withdrawal of life support (Halcomb, Daly, Jackson & Davidson, 2004; Jones & FitzGerald, 1998; van Rooyen et al., 2005).

A study by van Rooyen et al. (2005) conducted in South Africa used exploratory-descriptive interviews of six registered nurses (all female) employed in ICU as a means to explore the lived experience of the nurse in regards to withdrawal of treatment from critically ill patients. There was limited demographic data regarding the sample therefore the experience level of the participants was unknown. Thematic analysis identified two key themes within the data. The first theme evolved around the various intra- and inter-personal relationships that nurses developed with individuals throughout the process of withdrawal of treatment. The description of the intrapersonal relationships described the nurse's relationship with him/herself. Nurses described their feelings of guilt, sadness, helplessness and frustration. Feelings of

helplessness derived from the inability to save a person's life, despite every attempt having been made to do so. Frustration with the process stemmed from the participants' feelings regarding prolonged and unnecessary treatment. In regards to intrapersonal relationships, a subcategory also identified the participants' use of coping mechanisms. Interpersonal relationships were described as the relationship the nurses developed with the patients and also the patients' family. The participants described their experience with the families as emotionally draining. They often attempted to keep the "flame of hope alive" (van Rooyen, et al., p.47) for the patients and the families, however the reality of the situation often interfered with this particular goal. The second major theme identified was moral conflicts that the nurse experienced related to the ethical implications of withdrawal of treatment. The overall experience of withdrawal of treatment was described as emotionally draining for nurses. The limitations of the study identified by the authors included difficulty in securing interviews with participants and a lack of a multi-cultural approach (van Rooyen, et al.). Although the authors identified their approach as contextual, limited description of the context was available to the reader. The role of the ICU nurse was described in limited detail as was the environment of this particular ICU thus making the transferability of this data questionable.

Jones and FitzGerald (1998) conducted a study using interpretive phenomenology to explore the experience of critical care nurses. Seven nurses (two male and five female) with work experience ranging from three to nine years in ICU were interviewed. Thematic analysis of the transcribed interviews revealed several key themes including "being there"; "being comfortable and uncomfortable"; "being in control and out of control"; "being in time" and "being able to talk" (p.120). Their study provided evidence of nurses being a physical presence with the patient ("being there" (p.120) until they passed away however a dichotomy also existed

where some nurses felt the need to distance themselves from the situation. "Being there" (p.120) also encompassed how the nursing staff was able to be there for each other. Nurses were identified as being both 'comfortable' and 'uncomfortable' at the same time. Nurses could be comfortable with the decision to withdraw treatment but uncomfortable with the ethical issues regarding the actual process of withdrawal. Nurses felt both 'in' and 'out of control', unclear about the direction of care, uncertain of the protocols being used and expressed overall feelings of frustration, hopelessness and helplessness. "Being in time" (p.120) referred to both the objective time (hours) as well as the subjective time of the process of withdrawing life support seeming to "take 'ages and ages'" (p.120). The last theme identified by the authors "Being able to talk" (p.120) describes how nurses in the study learned to deal with the experience of withdrawal of life-support and the coping strategies they had developed.

A criticism of this study is that the authors do not specifically discuss the limitations of their study. Due to the nature of the study, the authors suggest that it may be difficult to make recommendations from this study due to the inherent nature of the study to not attempt to generalize the understandings generated. The authors do suggest however, that this study may serve as a catalyst for further research employing different methodologies in order to make more specific recommendations for policy change.

In an Australian study conducted by Halcomb et al. (2004), a convenience sample of ten female ICU nurses were interviewed. The participants were employed in three different ICUs, with their locations ranging from a major teaching hospital to smaller urban centres. Halcomb et al. used van Manen's (1990) phenomenological framework to form the basis of their study. Key themes identified within this study included comfort and care, tension and conflict, do no harm, nurse-family relationship and invisibility of grief and suffering (Halcomb et al.). 'Comfort and

comfort care' encompassed the provision of physical comfort to the patient as well as physical and psychological comfort to the family and significant others. The theme 'tension and conflict' described conflict for the participants with regards to their role in the decision making process related to withdrawing and/or withholding treatment. 'Do no harm' described the ethical concerns expressed by the participants in relation to their perceptions of harm caused by prolongation and unnecessary treatment and suffering of the patient. In the theme "Nurse-family relationship" the participants expressed both the profound effect that presence of the family had on them during the process of withdrawing treatment and also the stress that family presence also produced. Lastly, the theme 'Invisibility of grief and suffering' described the tremendous personal cost that the experience of withdrawing treatment had on them both physically and emotionally. Overall the experience of withdrawal/withholding of treatment in the ICU represented both a personal and professional struggle for the nurses involved. Communication, education and debriefing were elements identified that would be beneficial to both the staff and families who were involved in or affected by withdrawal of treatment in the ICU. These three elements were also identified as having the potential to improve patient care and reduce the burden placed on nurses (Halcomb et al.). A limitation of this study identified by the authors included the potential for those with more positive or negative experiences to be over represented in the study as a result of the use of purposive sampling. No other discourse related to the limitations of the study was included by the authors.

2.7 Summary of Literature Review

The brief historical overview provides context as to how caring for patients in intensive care evolved into a technologically complex environment where intense

monitoring and observation are critical to patient care. Secondly, the literature has specified that although the intensive care environment is technologically complex and has made marked strides in promoting patients' survival of critical illness, there remains a death rate of approximately 27% in Canada. It was also identified that most often death in intensive care follows a decision to withdraw life sustaining treatment when all medical interventions have been exhausted. Thirdly a review of literature pertaining to the nursing role in intensive care identified nurses as the primary care givers to patients and families. Intensive care nurses maintain a continual presence at the bedside that is unwavering twenty-four hours per day. Finally, a review of previous studies of the experience of intensive care nurses who care for patients during withdrawal of life sustaining treatment reveals a situation involving relationships, emotions and reflection on treatment provided.

Further investigation of the experience of intensive care nurses caring for patients during the process of withdrawal of treatment is merited in that previous explorations of the ICU nurses' role as it pertains to the withdrawal of life sustaining treatment have not described the process of what these nurses do, (what is the process of withdrawal of life sustaining treatment as it relates specifically to the nursing role) and also the process of caring for families who are an integral part of this experience.

Chapter 3 – Methods

The purpose of this chapter is to describe the methods used in this study. A brief overview of phenomenology as both a philosophical stance and as a research method will be followed by a description of the sample, setting, research process and criteria for rigour in a qualitative study which provide transparency in the research process.

3.1 Methodological Assumptions: The Nature of Reality and Knowledge

Understanding the nature of reality and subsequently knowledge as it relates to a research study helps the reader to better understand the lens through which the researcher developed the study. The nature of reality or ontology as it relates to research can be described by explaining the two dominant perceptions of reality. Ontological realism describes a reality that is fixed, objective and directly observable (Guba, 1990). Ontological realists view the researcher as outside of the experience and impartial. Ontological relativism however, encompasses a view of reality in which multiple realities can exist. Relativists describe reality as constantly changing, subjective, socially constructed and a co-creation of both the researcher and the participant (Denzin & Lincoln, 1994). Therefore from the point of view of the ontological relativist, the presence of the researcher is not removed (or bracketed) from the research process but is readily acknowledged and accepted as an integral component of the research. The researcher is therefore an active participant in the research process. The purpose of this study (through the lens of ontological relativism) is not to capture a single, objectified experience of intensive care nurses caring for patients during withdrawal of life sustaining treatment but rather to accept the subjective nature of the experience with the

understanding that the socially constructed nature of the experience of the individual participants may vary from nurse to nurse, it may vary across health care facilities and it may vary both nationally and internationally.

Epistemology, the nature of knowledge, as it pertains to this study, is not a constant. Knowledge is not fixed and as such, the knowledge gained as a result of this study is also not a constant, meaning that the possibility exists that it will vary over time and from one experience to the next.

3.2 Research Design

This study used an interpretive phenomenological approach in order to better understand the experiences of intensive care nurses caring for patients for whom life sustaining treatment is being withdrawn. Phenomenology is philosophically concerned with being.

Husserl, often referred to as the founder of phenomenology, viewed phenomenology as a purely descriptive process (Fjelland & Gjengedal, 1994). As such, a phenomenological study conducted through the lens of Husserlian phenomenology would simply describe the experience of the participant. Martin Heidegger, a student of Husserl, felt that description alone was not sufficient and that inherent in the process of description is interpretation. Thus, Heideggerian hermeneutics (the study of interpretation) emerged (Fjelland & Gjengedal). Ironically however, due to the complexity of Heidegger's writing and also due to the process of translation (Heidegger's work is originally written in German), interpreting meaning in Heidegger's work is also a challenge for phenomenological scholars. In recent years researchers have begun to rely

on other interpretations of Heidegger's "interpretive" phenomenology. One such scholar is Max Van Manen.

Van Manen (1990) describes phenomenological research as the study of the lived experience: the deeper understanding and meaning of the everyday experience. The experience of each individual is dependent on the context of his/her own life. Thus the goal of a hermeneutic phenomenological inquiry is to seek to understand, at a greater depth, the everyday skills, practices and experiences of people (Leonard, 1994). Through the exploration of lived experience, meaning can be extracted through reflection and interpretation.

In other words, this current phenomenological study explored what it is like to walk in the shoes of an ICU nurse caring for a patient and his/her family during the process of withdrawal of life sustaining treatment. What is this experience like for an ICU nurse? What are the skills involved? How do nurses feel in this situation? What makes it easier or more challenging for them? What emotions are evoked? This phenomenological study takes the experience of ICU nurses caring for patients during withdrawal of treatment and makes their experience known. It is an experience that is in constant flux as the experience of each nurse is dependent on the context of the patient's health care status, and interactions with the health care team, with families and amongst ICU nurses themselves. Meaning and experience is created in light of the context of the situation.

It is also however, imperative to discuss, in light of phenomenological inquiry, some of the key concepts such as context, personal interpretation and time. In a phenomenological study, context is everything. Context, as it relates to a phenomenological study is what van Manen (1990) would refer to as 'the world in which we as human beings live'. The aim of a phenomenological inquiry is to know the world in which humans live. The 'world' as it

relates to this study is the environment in which intensive care nurses work: the intensive care unit. In order to best understand the experiences of these nurses, one must have a thorough understanding of the context of this world. Therefore, a thorough description of this 'world', (the intensive care unit environment) and its structure have been provided.

Viewing the person as a self-interpreting being is also an essential concept related to phenomenology. Each individual sees the world in a unique way. Thus while gathering data for a phenomenological study, the researcher readily accepts that each individual interviewed will describe their experience (or story) in an individualistic fashion. The way in which they describe their story is also linked to the third key concept of phenomenology: time. An individuals' understanding (or interpretation) of their experience is shaped both by the context in which that experience develops and it is also shaped by the time. As these intensive care nurses continue to experience various situations and as they grow and change over time, their present interpretation of their experience is thus influenced and shaped by their past experience.

3.3 Sample

Typically phenomenological studies rely on very small sample sizes which can vary from twelve or fewer participants (Polit & Beck, 2004; Ray, 1994). A purposive sample of six intensive care nurses was selected for this study. Throughout the process of data collection the sample size was continually re-evaluated. The process of data collection continued until commonalities within the data were revealed through thick rich descriptions with numerous comments and examples (Munhall, 1994).

3.3.1 Eligibility Criteria for Participants

In order to meet the purpose and objectives of this research study, the participants (registered nurses) were required to meet the following inclusion criteria:

1. Be currently employed in the designated ICU full-time or part-time,
2. Have cared for a patient, for whom life sustaining treatment has been withdrawn within the last 6 months dated from the initiation of the study,
3. Have been employed in the designated ICU for 6 months prior to consenting to the interview,
4. Be English speaking.

The inclusion criteria for this study were chosen in order to maintain a homogenous sample. The criteria ensured that the sample included only intensive care nurses and that these nurses had adequate exposure to the phenomenon under study in order to be able to share their experiences of caring for patients during the process of withdrawal of life sustaining treatment.

3.4 Setting

Participants in this study were recruited from an Intensive Care Unit at one of three sites of a 944 bed academic health sciences centre in Ontario. The intensive care unit has a total of 24 beds. As of March 2007, 110 registered nurses were employed as full-time and 25 part-time (F. Lemaire, personal communication, March 8, 2007). Of the 110 registered nurses employed in this unit, 8 are male (F. Lemaire, personal communication, March 8, 2007).

3.4.1 Physical Setting of the Designated Intensive Care Unit

As the physical setting largely impacts the interpretation of the statements made by the participants, a thorough description of the physical setting of the designated intensive care unit is provided.

The intensive care unit is often a restricted area for non-hospital employees. In order for families to gain access a telephone is located outside of the main doors to the intensive care unit. Family members are instructed to call into the unit to identify themselves as visitors and are then welcomed into the unit. There is a central communication station from which 24 beds are divided into two sections. All of the rooms are enclosed by glass walls and doors with greater privacy being gained through an ability to pull curtains across the glass windows. The glass partitions allow patients to be constantly observed. Portable tables and chairs serve as observation posts for the assigned nurses, each of which is located just outside the glass doors. The nurses themselves are continually situated at or within several feet of the patients' bedside.

Inside patients' rooms one can observe the monitoring equipment particular to this and most other intensive care units. Patients are attached to monitors that facilitate observation of heart rate and rhythm, and respiratory status including rate of breathing and oxygen saturation. Blood pressure is monitored by both traditional cuffs as well as more invasive arterial catheters that provide continuous uninterrupted monitoring. Mechanical ventilators connected to tracheostomies and endotracheal tubes and are common methods of delivering respiratory support. Patients may be observed to have other monitoring equipment such as intra-ventricular catheters, which serve to monitor the level of intra-cranial pressure. Other patients require support for their renal (kidney)

function in the form of both hemodialysis and continuous renal replacement therapy. Nursing and medical care as well as care from other allied-health professionals is given in and amongst the massive amounts of technological support required by these critically ill patients.

3.4.2 Patient Population

The patient population cared for in the designated ICU includes a high percentage of surgical patients. Amongst the surgical population are patients admitted from general surgery as well as Vascular, Trauma and Neurosurgical patients. Medical patients admitted to the unit include those with exacerbations of chronic disease including chronic obstructive pulmonary disease and acute renal failure, as well as patients who are admitted for complex management related to septic shock and acute respiratory distress syndrome. Patients are admitted to the unit through several avenues which include: direct admission from the Emergency Department, consultations from Medical and Surgical units within the hospital as well as patients transferred from other centres who require more complex interventions and monitoring. The current average length of stay in the designated ICU is 7.5 days, with a 24% death rate based on hospital statistics from 2004-2005 (A. Hain, personal communication, June 20, 2007; F. Lemaire, personal communication, March 8, 2007).

3.4.3 Nursing and Medical Team Composition

The structure of nursing care in the unit includes a care facilitator whose primary responsibility is to create the nursing assignment (which nurse is assigned to which

patient) and to monitor the flow of patients in and out of the unit. The care facilitator also acts as a source of support for nurses and may help to facilitate communication between the nurses and medical team as necessary.

The assignment of nurses to patients is generally based on a one to one ratio (one nurse for one patient). Occasionally due to various factors arising within the unit, it is possible that a nurse will be assigned to two patients. In this instance, both patients tend to be more stable or transferable (ready to leave the unit when a bed on the appropriate service becomes available). In general, if a nurse is working more than one shift consecutively (either days or nights) the care facilitator will try and maintain continuity of care by assigning the nurse to the same patient for his/her next couple of shifts.

The medical team composition in the unit of study is one that is in constant flux. There are 6 staff intensivists (plus 3 corporate physicians who also work at this hospital's sister ICU) who become the leaders of the medical teams. Each week there are 2 staff physicians in the unit who then form two different teams. Each team will consist of an intensive care fellow, medical residents and potentially medical students. The staff physicians general rotate in and out of the unit on a weekly basis. The fellows most often stay for one month at a time and the medical residents typically rotate in and out of the unit on a four week basis (A. Hain, personal communication, June 20, 2007; F. Lemaire, personal communication, March 8, 2007). It is therefore possible that the intensive care nurses as well as the patients and families will interact with various staff physicians, fellows and residents over the course of a patient's ICU admission.

3.5 Process of Data Collection

3.5.1 Main Study

During the preliminary stages of protocol development, the researcher initiated contact with the nursing unit manager as well as the program director for critical care of the designated Intensive Care Unit. The purpose of these interactions was to describe the goals of this particular study, to determine if staff of the designated ICU met the criteria for participating in the study and third, to determine if there was sufficient interest to partake in the study. Verbal support was obtained from both the unit manager as well as the director of critical care nursing and a copy of the research proposal was sent to the unit manager. Written consent was also received from the unit manager as this was a necessary step in obtaining ethical approval from the University of Ottawa Faculty of Health Sciences Human Research Ethics Committee. Permission was also sought from the appropriate research ethics committee at the target hospital.

Prior to data collection, a second meeting was held with the unit manager in order to discuss how the recruitment process would proceed. The researcher received support from the unit manager to distribute posters throughout the unit as well as to attend a staff meeting in order to discuss the study directly with the nursing staff of the designated ICU. The poster (Appendix A & B) distributed within the unit explained the purpose of the study, inclusion criteria as well as the involvement that would be required of the nurses. The contact information of the researcher as well as the researcher's supervisor was indicated on the poster. The nurses were then able to contact the researcher directly to express their interest in participating in the study. The face-to-face meeting with the nurses via a staff meeting also proved to be beneficial to the recruitment process. Many

nurses at the meeting expressed their interest in participating in the study. Contact information was provided so those interested in participating could access the researcher.

3.5.2 The Interview Process

For the purpose of this study, the researcher conducted one-on-one unstructured interviews with six intensive care nurses. There was no predetermined interview guide and the unstructured nature of the interview allowed the interaction between the researcher and participant to be conversational in nature (Polit & Beck, 2004) as is common in phenomenological studies. Prior to the commencement of the interview, the purpose of the study was reiterated and informed consent from the participants was obtained. The participants were aware that the interviews would be audio-taped and that if they felt the need to pause or take a break from the interview, they were free to do so at any time.

The interview began with a broad question related to the aim of the study: "Can you tell me what it is like to care for patients during withdrawal of life sustaining treatment." Prompts were available to facilitate meeting the objectives of the study. These prompts included: "What makes the process harder or easier for you as the nurse?" "Is there a specific situation that you can recall that would help to describe what makes it harder or easier?"

The interviews lasted approximately one hour with each participant. The researcher also kept field notes and a reflexive journal in order to record the researcher's personal thoughts and reflections throughout the study. The reflexive journal served to

record all methodological decisions made in regards to the study so as to provide an audit trail.

In consenting to participate in the study, the participants also agreed to a second audio-taped interview which lasted approximately 30 minutes. The purpose of the second interview was to provide the participants with a written summary of the researcher's interpretation of the data. This process serves as a form of member checking which is described in greater detail in 3.7.1 Methods to Ensure Rigor: Credibility.

3.5.3 Characteristics of Participants

In total, six intensive care nurses participated in this study. Five participants were female and one male. The age range of the participants was between 21 and 60 years. The range of experience in intensive care nursing ranged from one to 26 years. The length of employment in the designated Intensive Care Unit ranged from less than 1 to 19 years. All participants had received additional training or certification in the area of critical care.

Table 1 provides a complete description of the participants which was obtained through the completion of a demographic data questionnaire (Appendix C). All participants have been assigned a pseudonym.

Table 1: Description of Participants

Name	Robert	Anne	Susan	Isabelle	Trish	Margo
Age	≥41-50	≥21-30	≥41-50	≥51-60	≥41-50	≥21-30
Gender	Male	Female	Female	Female	Female	Female
Years of Experience As a Nurse	19	9	14	30	20	1.5
Years of Experience As an Intensive Care Nurse	17	6	14	26	19	0.5
Years of Experience in Current Intensive Care Unit	17	6	1	9	19	0.5
Basic Education	Diploma	BScN	Diploma	Diploma	Diploma BScN for RNs	BScN
Education in Critical Care	In-house Course	In-house & College Courses	CCNC(C)* & College Certificate	Critical Care Courses	CCNC(C)* Critical Care Diploma	Critical Care Course

* CNCC(C) refers to the Adult Critical Care Certification from the Canadian Nurses Association.

3.6 Data Analysis

The purpose of this phenomenological study was to describe and seek to further understand the experience of intensive care nurses who care for patients during the process of withdrawing life sustaining treatment.

The process of data analysis was based on the procedures outlined by Colaizzi (1978) and van Manen (1990). The procedures were based in part on Heideggerian existential phenomenology which focuses on interpretation rather than solely describing

data. As such, the process of data analysis was compatible with the methodological assumptions inherent in the study as well as the ultimate aim of the study. The methodological assumptions included those which reflected the relativist perspective in which the study was conducted, and also the researcher's assumptions that were recognized a priori to the commencement of the study. The researcher's assumptions were as follows:

- Intensive care nurses are exposed on a regular basis, to patients who die following the withdrawal of life sustaining treatment.
- Decisions to withdraw life sustaining treatment are made by a group of people who usually include the family of the patient, the physician and the intensive care nurse assigned to the care of the patient.
- Often the decision to withdraw life sustaining treatment is made in a short period of time that ranges from a few hours up to 72 hours.
- The health status of patients for whom life sustaining treatment is withdrawn usually encompasses multi-system failure with maximal medical management.
- The context surrounding the decision to withdraw life sustaining treatment causes stress for families and health care professionals alike.

The primary phase of data analysis required the researcher to be immersed in the data. Immersion in data refers to the researcher becoming intimately familiar with the data, reading and re-reading the interviews. The researcher completed transcription of the audio-taped interviews. This process was begun within 24 hours of completing each interview. The researcher verified each transcript by replaying the audio recordings and

verifying the transcripts for accuracy as well as adding notations regarding changes in voice, pauses and inflections (Morse & Field, 1995).

The second phase of data analysis, as per Colaizzi (1978), comprised of reading all of the participants' descriptions (transcripts) regarding their experience of caring for patients during the process of withdrawal of life sustaining treatment. The initial reading of the descriptions served to identify key words and phrases that were particular to the phenomenon. Subsequently, the key words and phrases were highlighted and colour coded and used to sort the data. The codes were placed into broad categories as patterns were being identified. The left and right margins of all of the transcripts provided a place for the researcher to make pertinent comments.

Furthermore, as the analysis of the data continued, significance statements were identified within the transcribed data. As per Colaizzi (1978) and van Manen (1990) the researcher was then faced with the task of attempting to interpret the meaning of each significance statement. The latter process was repeated for each transcribed interview. The interpreted meanings of the significance statements were then organized into clusters of themes. The researcher continually referred back to the transcribed data to ensure that no data had been ignored or inadvertently added. Throughout the process of interpreting the data, the themes were compared as the researcher attempted to find meaningful connections between the themes and underlying categories.

Finally, a detailed description of the analysis of the transcripts was written. The researcher returned to the participants (member checking) to determine if they verified that the researcher's interpretation of their experience accurately reflected what they perceived their experience to be.

It should be noted that the process of analysis did not proceed in a linear fashion. The process consisted of multiple readings of the transcribed data, multiple interpretations and refinement of themes and categories and continually returning to the text for validation and clarification of the researcher's interpretations.

3.7 Methods to Ensure Rigor

The seminal work by Lincoln and Guba (1985) identified four criteria for establishing trustworthiness (confidence in the data) of qualitative data: credibility, confirmability, dependability and transferability. As such these four criteria have been further explained, and the efforts made by the researcher to satisfy these criteria in the establishment of trustworthiness of the data have been identified.

3.7.1 Credibility (Truth Value)

Credibility is the believability of the findings that the researcher has produced (Leininger, 1994). The findings should reflect what the truth is, as seen through the perspective of the participant. In order to establish credibility in this study, the researcher, upon completion of data analysis, returned to the participants for 'member checks'. Member checks refer to the researcher returning to the participants with an interpretation of the data thus seeking to obtain their reaction (Polit & Beck, 2004).

In this instance, the researcher provided the participants with a five page, double spaced summary of the analysis with the identified themes, categories and brief citations from the various interviews. Prior to commencing the audio-taped portion of the 2nd interview, the researcher provided the participants with a copy of the summary for them

to read. When the participant had finished reading the summary, the recorded portion of the interview began with the researcher asking the broad question: does this summary reflect your experience of caring for patients during withdrawal of life sustaining treatment?

The audio-taped member checks were subsequently transcribed verbatim by the researcher. Comments from the participants related to the summary of the data included: *"Very much so, very much so...I like the categories you put in there"* (Isabelle); *"With each part of it I can basically see...it's the essence of who we are"* (Trisha); *"I certainly didn't disagree with you with...anything that you said"* (Robert). None of the participants refuted any of the themes identified and interpreted by the researcher and the thesis committee.

3.7.2 Confirmability

Confirmability reflects the objectivity and neutrality of the data (Polit & Beck, 2004). In order to assure confirmability, the researcher's assumptions related to the phenomenon of the study were made explicit prior to the commencement of data collection. Confirmability was also assured through consistent communication and feedback from the researcher's thesis committee. In addition, the researcher recorded personal reflections and feelings through the use of reflexive journaling. Since the researcher is also an intensive care nurse who has experienced caring for patients and families during the process of withdrawing life sustaining treatment, the reflexive journal allowed the researcher to reflect on her experience of listening to the stories of the participants. The researcher took note of her feelings in addition to points of interest to

discuss with her supervisor and thesis committee. Reflexive journaling also allowed the researcher to keep personal interpretations of the data in check and not to allow her own feelings and experiences to supersede the experience of the participants. (Lincoln & Guba, 1985)

3.7.3 Dependability

Dependability is assessing the data to ensure that it would remain consistent over time and over similar conditions (Polit & Beck, 2004). An audit trail of all decisions related to data analysis as well as methodological decisions was kept by the researcher. Sandelowski (1986) contends that a study and its finding are consistent when another researcher can clearly follow the 'decision trail' used by the researcher. In addition, the researcher has included excerpts of the rich descriptions provided by the participants for the reader.

3.7.4 Transferability

Lincoln and Guba (1985) refer to transferability as the extent to which the research findings can be transferred to other settings or groups. As such, the researcher provided rich details related to the context of the study, the intensive care unit environment and the process of withdrawal of life sustaining treatment. It is then the responsibility of the research consumer to determine the applicability of these research findings to other contexts (Lincoln & Guba).

3.8 Protection of Human Rights

Prior to commencement of the study, ethical approval was received from the University of Ottawa Health Sciences and Sciences Research Ethics Board as well as the Ottawa Hospital Research Ethics Board. In order to ensure the participant's right to informed consent, all were provided with an information sheet (Appendix D) which included an explanation of the study. Upon meeting with the participants, the researcher provided information regarding the purpose of the study, the potential risks and benefits of participating, information regarding confidentiality and the use of direct quotation as well as their right to refuse participation and their right to withdraw at any time from the study. After a thorough explanation of the study and the rights of the participants, written informed consent was given by the participants prior to the commencement of the first interview. Copies of the consent form were given to the participants.

The audio-taped interviews were numbered and participants were assigned pseudonyms in order to ensure participant anonymity and confidentiality. All participant information (demographic data and consent forms), transcripts and audio-taped interviews were kept in a locked secure cabinet in the thesis supervisor's office.

Chapter 4: Findings

4.1 Introduction

The following chapter describes the experiences of 6 intensive care nurses caring for patients during withdrawal of life-sustaining treatment. The six participants were all employed in a medical/surgical intensive care unit of a university affiliated tertiary care hospital. Factors that the nurses found challenging or that facilitated caring for patients during withdrawal of life-sustaining treatment are presented.

4.2 Overview of the Findings

The interpretation of the experience of caring for patients during the process of withdrawal of life sustaining treatment could be described by elaborating on three major themes identified by the researcher: *A Journey: Creating Comfort Along the Way*, *Working in Professional Angst*, and *Providing Memories*.

A Journey: Creating Comfort Along the Way was a major theme that was divided into three categories: *Stepping In, In the Middle of It – Withdrawing Life Sustaining Treatment* and *At the End of the Journey*. *Stepping In,* described how nurses established rapport with families, how nurses worked to get families to a place where they could accept the death of the patient and how the nurses themselves strived to gain comfort in their own role during the process of withdrawing life sustaining treatment. *In the Middle of It – Withdrawing Life Sustaining Treatment*, described the various aspects of patient comfort, comfort for the families, and the moral and ethical thought process related to the use of sedation and analgesia that intensive care nurses experience when caring for these

patients and their families. *At the End of the Journey*,elaborated on the work entailed in caring for patients and families during the process of withdrawal of life sustaining treatment and also how nurses required both support and recognition in their role. *At the End of the Journey*, also explored how nurses reflected upon their experiences and their role.

Working in Professional Angst, comprised two categories: *Not Being on the Same Page* and the *Runaway Train of Technology*. *Not Being on the Same Page*, described in detail the experience that intensive care nurses had in trying to navigate the conflict that stemmed from lack of communication with regards to treatment and goals of care that were either unclear or constantly changing. The nurse became the 'middle man' dealing with the health care team as well as patients and their families. The *Runaway Train of Technology* explored the appropriateness of technology and the multitude of treatment options often discussed or offered to critically ill patients.

Lastly, *Providing Memories* was a theme that described the lengths that intensive care nurses would go, to ensure that despite the unfortunate circumstances related to critical illness, that patients and in particular the families had the most positive experience possible. *Providing Memories* depicted what one participant referred to as *"the little pearls"* of her career.

4.2.1 The Essence of the Experience "Trying to do the right thing"

The experience of caring for patients during the process of withdrawal of life-sustaining treatment has been described as a journey that intensive care nurses embark upon with a multitude of individuals: patients, families, nurses, physicians and any other

individual who may be involved in the care of their assigned patient. The overall essence of this experience of caring for patients during the process of withdrawal could be captured by intensive care nurses *"trying to do the right thing"*. The journey of caring for patients during this process was one that varied from patient to patient as each experience was dependent on the context and complexity of the patients' illness. The journey might unfold as an experience that flowed easily from one event to the next with little disruption or conflict. On the other hand, depending again on the context of the particular patient situation, the journey might unfold amidst conflict and in angst. However, no matter the context or phase of the journey, throughout the entire process of caring for patients during withdrawal of life-sustaining treatment, the intensive care nurse was *"trying to do the right thing"*. Anne shared, *"You're always trying to do the right thing, the right thing by the patient, the right thing by the family and the right thing by even the nurses, even by the staff."*

4.3 A Journey – Creating Comfort Along the Way

Describing the process of caring for a patient during withdrawal of life sustaining treatment as a journey came directly from a statement made by the participant Anne, who stated: *"I am contributing to their comfort, to the journey that they have to go through and the death of this patient, their family member or themselves, whichever it happens to be"*. The notion of a process infers that there was both a beginning and an end, as was such with a journey. Comfort and creating comfort were key concepts emphasized by all of the participants. Comfort, however, could not be isolated as an individual theme because it was interwoven throughout the entire process of caring for these patients.

Comfort and comfortable encompassed how nurses described their relationships with families, patients, other nurses and themselves. The level of comfort of the patient was also paramount to the experience. As such, the theme: *A Journey – Creating Comfort Along the Way* encompassed both the process of caring for patients during withdrawal of life sustaining treatment and the comfort on various levels associated with this process.

4.3.1 Theme 1: Stepping In

When an intensive care nurse steps into the unit at the beginning of the shift, they are frequently unaware of the patient assignment they will be given for that particular day. *Stepping In,* depicted the nurse literally stepping into the room of a patient to provide care. However, *Stepping In,* also became much more than the physical action of stepping into a room, as it encompassed stepping into a multitude of complex and context specific scenarios. Nurses might or might not know the patient and family for whom they provided care, thus, the participants spoke frequently of *Building on Relationships* either past or present with patients and their families. The participants also described *Getting the Family There,* helping them to understand the plan of care and the nature of the critical illness. *Achieving a Comfortable Place for the Nurse* revealed how the participants grew and developed in their role during withdrawal of treatment as well as how their level of comfort within their role evolved.

4.3.1.1 Building On Relationships

Whilst the purpose of the study indicated that the researcher was seeking to further understand the experience of the nurse caring for *patients* during withdrawal of

life sustaining treatment, the participants made it immediately clear that although the experience focus was on the care of the patient, the nurses' relationship with the family was central to the entire experience. Trish stated, *"You've got to remember, that's an individual in the bed and ultimately that's what you're doing looking after that patient, that family"*.

As previously discussed, when nurses began their shift, they might or might not have known the patient to whom they were assigned to provide care. It was possible that over the course of the patient's admission to the Intensive Care Unit that the nurse assigned to the patient may have at one point already cared for the patient. In this situation there was both a familiarity on the part of the nurse with the plan of care for the patient and there was also the possibility that a prior relationship with the family may have been established. On the other hand, as it was depicted in Erinn's story in Chapter 1, the nurse may not know the patient or the plan of care and have no prior relationship with the family or the patient to rely on. *Building on Relationships,* reflects both of these scenarios. Anne's reflection helped to set the stage for these two scenarios:

"I think it really does, it really does depend...it depends on ...how long I have been taking care of that patient themselves...you know, what my background was, did I get the patient when he was first admitted ... how long the patient has been in ICU, do I know the family...what do I know about the patient, I've walked in basically as they're already withdrawing which is much harder" as compared to having a prior relationship with the patient and family on which she again reflected *"Let's say that I've been around for a little while and ...I've gotten to know the family and I've gotten to know the*

patient...for me it's a very good experience, it's a very difficult experience but...I find I'm doing...I'm a much better nurse when I'm doing that".

"The easiest thing is when you've got a good rapport with the family" said Anne. Gaining rapport with the family could be seen as the cornerstone of caring for patients during the process of withdrawal of treatment. The complexity and highly emotional nature of the situation was more easily navigated when there was a relationship or bond with the family. Being familiar with the patient, the plan of care, and with the family allowed the nurse to step into the role of caring for the patient and family with *"ease"*. Susan added, *"I think if you have a good ... rapport with the families...I always feel a lot more at ease, if you've developed some sort of a relationship with them...you've developed a good bond with the family."*

The bond that was created through the nurses' interactions with the patient and family translated into a trusting relationship between both parties. Trust between the nurses and families, as it was described by the nurses, was developed through the intimate contact that intensive care nurses had with patients. Caring for patients over several days allowed the family members to physically observe how the nurses cared for the patient. Susan stated, *"you have...[a] bond with them where they know who you are, they've seen how you've cared for their family member so there's that trust, that sort of bond".*

It was also essential to note that when a trusting relationship had been established between the caregiver (intensive care nurse) and the family of the patient there was a level of comfort that was created for all involved in the care of the patient. For families, having to experience the death of their loved one was extremely stressful. For nurses,

caring for patients and families during withdrawal of treatment was also stressful due to the complex nature of the situation. When an environment was created where all involved felt comfortable, the care required happened naturally. *"It's always stressful for a family member to be...letting go and seeing this sort of thing and you know being ready for it, if they've got someone that they can trust ... that's always a bit easier and makes you feel a lot more comfortable with what you're doing...it just come a little more naturally...everything else...comes secondary after that...once you have that rapport."*

Not having a prior rapport with patients and families created a situation that was *"challenging"*. One nurse explained, *"[it] can be a little more challenging emotionally and if you ... step in on a situation where you're withdrawing care and you're just stepping in to it, and you don't know the patient, it's always a little more awkward...you don't want to be coming in as the death nurse"*.

When there was no prior relationship or rapport between the nurse, patient and family, nurses were placed in a situation where they must immediately begin to form a relationship with the family. Several factors were identified that facilitated building relationships with families. How the transition of care from one nurse to the next was conducted facilitated the on-coming nurse in developing a relationship and rapport with the family. The participants spoke of how the nurse receiving the patient would be introduced by the previous nurse to the family and described how this was an *"appropriate"* thing to do.

When *Stepping In* to the room and into the relationship, the nurses would *"talk a little bit"* with the family and begin by *"just asking ...a history of what's happened up until this point, to get them to voice a little bit and talk a bit...to show that you're*

interested or that you care and that kind of stuff...alleviates that uncomfortableness". The challenge of the situation was compounded by the fact that the nurses had to begin to know the family and assess how the family was coping with imminent death of their family member.

Anne described stepping into the situation of not knowing the patient or family and being in the middle of withdrawal of treatment as an intrusion. She elaborated, *"I find it difficult if I'm walking in half way through and I don't know the family...I haven't had a chance to develop a rapport with them...I almost feel like I'm intruding at that point, I'm intruding in something that's very private for them...I find that difficult to deal with".* However, amidst this challenge and despite the difficulty and uncomfortableness the participants continued to try and do the right thing. The following quotation captured how one participant overcame this challenge:

"I try to read the cues, mostly the non-verbal cues from the family...I'm close without being intrusive, so I'll be near the door...I'll...look and see if they [the patient] look uncomfortable...I try to focus on the patient so that they know my focus is still on that person they love so much...looking towards comfort for the patient and for the family...I'll make sure there's tissues around, I'll make sure that people are quiet around so that they're not hearing people laughing hysterically...I'll ask them sometimes if there's something I can do for them...I'll close the curtains so they have some privacy."

4.3.1.2 Getting the Family There

Part of building a relationship with families included getting families to a place where they could begin to understand the nature of critical illness and understand that

despite all critical interventions the patient could not overcome their illness. *Getting the Family There* can be challenging for the intensive care nurse in order to provide both the patient and the family with the care they need. However, it has been recognized by the participants that they may not always be able to get the family there.

Trish described this situation as *"exhausting"* and explained,

"Exhausting's when you come in and you find out that you've got this person who's not going to survive their illness and you take a deep breath because you know this patient has family...it's making sure that ...it's a stressful situation for the family but you've got to minimize that stress, get them in, let them know there is nothing more you can do even though they've been told by the doctors, even though maybe they've been told this repeatedly by many people they still don't want to believe it and you've got to get them in there".

A statement made by Anna helped to explain the effect this situation had on the nurse caring for the patient and the family and the difficulty nurses faced within themselves when families could not accept the patient's fatal illness. *"What makes it hard for me is when...I can't seem to reach the family...they're just so wrapped up in their own grief and the whole process...I don't feel like I'm doing any help for them what so ever...you cannot be the one person for all people. My way of doing things may work with...80 percent but there's still the 20 percent that I won't be able to reach, there's just no connection that seems to be able to occur...I find that very difficult."*

Getting the family there became a central act in creating a rapport and building a relationship with the family. The participants described how their attention became very much focused on the care that was provided to the family. Although the level of comfort

of the patient was absolutely essential, the care of the family and getting them through the experience of having their family member passing away was crucial. The participants described how getting the family there might also include trouble shooting conflict that may arise between the family members due to lack of acceptance on the family's part that the patient would not overcome their illness. Susan explains, "*There can be conflict across the family, like some family members are wanting and accepting that the patient is on the road of dying...and there's some family members that are not quite there, I've seen that and you do and say everything that you can and answer everything they ask you in the family meeting be it from both the doctor and the nurse.*"

Getting the families there, required time and energy on the part of the intensive care nurses. Allowing families to take the time they needed, to have their questions answered in an honest and realistic fashion, to educate the families as necessary and to be a perpetual resource for the family became essential elements in getting the family there. "*They need that time be it with their family afterwards, and I guess coming back to the bedside knowing if they need to ask or think of anymore question...touching base with them after they've had time in the conference room to talk amongst each other when they come back to the bedside, to make sure that is there anything else or just to make them feel a little more at ease with everything that was said.*"

Providing families with a safe place to express their thoughts and emotions was also facilitated by the intensive care nurses. The participants spoke of people "*falling apart*" and that helping families along the journey was essential. Anne remarked, "*Some members get really emotional and they start making it more difficult for everyone around...some people do have a much harder time controlling their emotions, sometimes*

I'll have them step out with me...just let them cry and scream do whatever it is that they need to do so that they can go back...that their moments of weakness...won't be judged...nobody likes to see, wants other people to see them falling apart so I'll give them a place where they can do it in safety."

4.3.1.3 Achieving a Comfortable Place for the Nurse

Caring for patients during the process of withdrawal of life sustaining treatment as it has been described by the participants in this study was both a skill and a role that developed over time. Through exposure and experience intensive care nurses developed an element of comfort with the process as well as within themselves. Analysis of the interview data revealed a difference in the way the relatively new nurse described her level of comfort compared to nurses with many years of experience. The participants with more experience described themselves as being comfortable in their role during withdrawal of treatment. Also, in learning to find comfort within the role the intensive care nurse was then able to go above and beyond and do "the little things" when caring for patients and for families.

Withdrawing life sustaining treatment from a patient was a process that was highly complex (the actual process and complexity of withdrawing treatment will be discussed in section 4.3.2) and required knowledge and skill to perform. As a relatively inexperienced nurse (1.5 years as a registered nurse and 0.5 years as an intensive care nurse) one of the participants described the process of caring for a patient during withdrawal of treatment as stressful and she described herself as being scared. Margo explained, "*I'm not exactly sure what they're going to ask or I'm scared they're going to*

ask me something I don't know...I'm always scared that I can't give them the answer and then they lose their trust in me and then they always kind of have that thought that their family or loved one, they died with a nurse that didn't know what they were talking about or didn't really know what was going on and I'm always just scared of looking incompetent and ... leaving that image with them for the rest of their lives, it's kind of scary."

As the level of experience of the nurse grew, the level of comfort also grew. Participants recognized that as a beginning nurse there was a level of discomfort with withdrawal of treatment and that despite the various challenges and difficulties that may arise, eventually they became more comfortable in their role. Susan elaborated, *"I've had six years experience here now so I mean it comes a little more naturally, these kinds of situations and handling them,... but I think when you first start here it's sort of a very big discomfort level um having to withdraw".*

As the experience of the intensive care nurse developed they began to acquire an ability to self-analyze and critically reflect upon their actions and role during withdrawal of life sustaining treatment. Coming to terms with the role was eloquently described by Anna:

"I'm not afraid of death personally...I think I had to go through my own beliefs...it forced me to look at my own beliefs in terms of what after death...I had to look at why there is suffering, why people die at certain ages, why some people who seem to have everything going for them, why are they dying, why are the other ones not dying...I was no longer focusing on them...I was focusing on myself...I've had to go through this journey of looking at what my own beliefs are...where I stand spiritually...I'm not the one

who decides when this person lives, whether this person lives or dies but as long as they're within my care and decisions are being made either way, I'm there to...assist them through that path, assist the family through it and assist the patient through it to the best of my ability."

With experience of the intensive care nurse came the recognition of the humanity evident within their role. The participants spoke of crying with families and how this might or might not be viewed as part of the role of a professional nurse. One participant had the experience of a physician questioning the appropriateness of the nurse crying at the bedside: *"I think it's it comes down to compassion and compassion being defined as ...you're not afraid to be with people in their pain you're not afraid to show you know you're not afraid to cry at the bedside. I had a doctor tell me once when I was crying with a family afterwards, he said I didn't think nurses were supposed to cry well I'm human you know...I'm not a robot... you're not afraid to share your own stories...if it's appropriate...but mother to mother or parent to parent or daughter to daughter... allowing your humanity to show."*

Comfort in the role of withdrawing life sustaining treatment allows the intensive care nurse to go above and beyond for patients and families and not just "do the job". One participant described the going above and beyond as a comparison to the art and science of nursing. On one hand, the science of nursing facilitates nurses through the physical process of withdrawing treatment and providing measures such as analgesia to patients. On the other hand nurses demonstrating the art of nursing bring themselves to the patient and family in supportive actions. Isabelle elaborated on the art and the science, *"in an art you you're able to be supportive, nurturing um, make it ...a*

comfortable passage both for the patient and the family, and when you do it strictly as a science you give the medication you ask the family if there is a problem and then you leave them alone, you distance yourself and I appreciate that's a wonderful coping mechanism ... I can see the value in that and probably when I was a much younger nurse that's what I did cause that's what I thought you were supposed to do"

4.3.2 Theme 2: In the Middle of It – Withdrawing Life Sustaining Treatment

The theme *In the Middle of It – Withdrawing Life Sustaining Treatment* reveals that actual process of withdrawing treatment and the complexities surrounding it. Intensive care nurses focus on the level of physical comfort for the patient in order to assure that the patient dies free from pain or discomfort and that there is limited awareness of the process on the part of the patient. Focusing the care on the patient is also an avenue which helps the nurse to create a rapport and trusting relationship with the family. From the nurses' perspective, when the family members see nurses physically caring for patients, it reconfirms the nurses' commitment to the care and comfort of the patients.

Over time intensive care nurses find, through their knowledge and experience, their own way in relation to the actual procedure of withdrawing life sustaining treatment, the types of medications used to ensure the comfort of the patient and the moral and ethical boundaries that surround their practice.

4.3.2.1 Patient Comfort

Throughout the process of withdrawing life sustaining treatment, patient comfort was emphasized by all of the participants. It was emphasized so strongly throughout the interviews that it could be stated that providing patient comfort was a major component of the nurses' role during withdrawal of treatment, and that it was viewed by intensive care nurses as a moral imperative. Trish elaborated, *"Make them comfortable, I think comfort is the most important thing we do for end of life care and that's one thing I reiterate constantly to families, to docs, to nursing students, to orientees, anybody new to the critical care area. Comfort comes first, if your blood pressure is forty it doesn't matter 'cause we're withdrawing but if this person is gasping, add more sedation, make them comfortable."*

The participants also felt strongly that making the patient comfortable contributed to comfort for the family: *"In some cases you're making the patient comfortable but you're also making the family comfortable. Nothing could be more horrible for a family then watching somebody gasp, we have the medications, we have the technologies there to prevent that, not all the time but at least to lessen it and I think we need to use it. I always say comfort comes first, make that patient comfortable, make that family comfortable...physical comfort, I think if families can see that their loved one is physically comfortable, they can accept things."*

The actual mechanism for keeping patients comfortable included the use of sedating medications such as benzodiazepines (midazolam was frequently mentioned) and opioid analgesics (hydromorphone and morphine). Nurses also discussed the use of other comfort measures such as repositioning patients, and making sure they *"look*

comfortable". Anne elaborated, *"I'll make sure that...the patient looks comfortable...that they have clean blankets and sometimes if their feet are cold I'll wrap the patients feet up in a warm blanket so that they [the family] don't feel like the patient is cold...my role is to make sure the patient is comfortable, alleviate the suffering...of the patient and of the family."*

4.3.2.2 A Moral Check and Thought Process

The nurses interviewed for this study indirectly discussed the actual procedure for withdrawing life sustaining treatment within their facility. On several occasions the participants described withdrawal of medications used to support cardiac function of the patient namely, vaso-active drugs, which supported the patient's blood pressure. The participants also made reference to the withdrawal of mechanical ventilation. Trish explained: *"To me withdrawing of care is not extubating somebody, it's keeping them on the ventilator, it's keeping them comfort[able], it's not accelerating drugs, it's not initiating new procedures, it's comfort...even withdrawing, turning off the vasopressors and vasoactive drugs, turning those down, turning down ventilatory support not leaving them gasping...positioning, all those kinds of things, to me that's what withdrawal is."* A key aspect of the process of withdrawing life sustaining treatment is the use of sedation and narcotic analgesia.

The use of sedative medications such as benzodiazepines and narcotic analgesia is common practice for all patients within the intensive care environment (Shapiro, Warren, Egol, Greenbaum, Jacobi et al., 1995). Sedation and analgesia is required for post-operative pain, to facilitate the process of mechanical ventilation, and for anxiety

(Shapiro et al.). However, in the context of withdrawal of life sustaining treatment the use of sedation took on a different focus. Patients who underwent the process of withdrawal of life sustaining treatment remained critically ill. Their underlying disease process or reasons for admission to Intensive Care in the first place were still present. It was the assumption that by withdrawing the use of life sustaining treatment that the patient would ultimately succumb to their underlying illness. The potential then existed for patients to continue to experience pain or discomfort from a variety of sources: difficulty breathing, discomfort related to the use of endotracheal tubes and mechanical ventilation as well as anxiety and restlessness, therefore benzodiazepines and opioid analgesics are utilized.

Nurses who cared for these patients during withdrawal of life sustaining treatment were striving to maintain a level of patient comfort while keeping in balance a multitude of factors. Making patients comfortable was the premise for which sedation and analgesia are given. Due to the nature of withdrawal of treatment, for example the withdrawal of mechanical ventilation, there was a level of patient comfort that is potentially compromised. Mechanical ventilation was used to facilitate the oxygenation and to decrease the work of breathing the patient would normally be experiencing if they were not mechanically ventilated. During withdrawal of life sustaining treatment, the amount of support that was being given via mechanical ventilation to decrease the work of breathing of the patient was slowly withdrawn. It is therefore possible that patients will then begin to show signs of respiratory distress including increased work of breathing, increased respiratory rates, the use of accessory muscles and gasping. Narcotic analgesics, due to their pharmacological properties, have the ability to decrease

the work of breathing. As well, anxiolytics such as benzodiazepines helped to decrease the amount of anxiety and restlessness of the patient.

Participants described how their own level of comfort with the use of sedation and analgesia during the process of withdrawal of life sustaining treatment developed over time. Margo, a relatively new nurse and new to intensive care spoke of her discomfort, *"It's stressful for me considering I don't feel like I have enough experience to really say ok they need more sedation to keep them comfortable or they need more narcotics. I'm always scared at the point where I'm scared to give too much and then at the last minute...well now they're in respiratory distress...it's to know that line how to keep them comfortable because it's so blurred I find, especially when you don't have much experience in ICU."*

With experience and exposure to multiple scenarios of withdrawing life sustaining treatment, the confidence of nurses develops as does their level of comfort with this aspect of their nursing role. Susan reflected on a past experience, *"You could see the patient was working at breathing, was on the ventilator...I went over and I would explain [to the family]...you see what he's doing...and they would agree...he wasn't breathing like that awhile ago...well that's him working at breathing...and we don't want him to be working at breathing like that so I'm going to give him a little bolus through the intravenous for pain and for [dis]comfort and it's probably going to drop his blood pressure...it may drop his heart rate."* The ability to assess the situation (the increased work of breathing in the presence of the family), implement a plan of care, evaluate the effectiveness of the intervention and provide education related to the intervention all

within the context of an emotionally charged situation is a clear example of the level of comfort and confidence this participant had.

The participants spoke frequently of the use of high dose infusions of sedation and analgesia and that the purpose of giving these intravenous drug infusions is to keep patients comfortable, however nurses also spoke of a *"fine line"*. The difficulty in providing comfort care through the use of sedation and analgesia during the process of withdrawal is the "fine line". The term 'moral check' refers to the reflection on practice that intensive care nurses use when justifying the amount of sedation and analgesia that is given to patients during withdrawal of life sustaining treatment. Susan elaborated:

"I've done it a lot [withdrawal of life sustaining treatment] and at the same time you don't want to be bragging that you've done that a lot but I mean... I feel comfortable with myself having done...it's a hard topic to explain to people...this is the sort of thing we do and people are just absolutely like oh my god,...that's almost like euthanasia...like this patient we had last week...the nurse that was looking after her...hasn't had a whole lot of experience with withdrawing treatment...you could tell that her element of comfort was just not there... 'oh my goodness...I've given this much drugs with the turn...these are the rate of the infusions'...and the patient was still struggling...the patient was really working at breathing and she felt very...in a dilemma...like is it right to give more...is this...morally wrong to be giving more drugs."

The 'moral check' is an internal process in which the nurse steps back, assesses the situation and provides the rational for his/her action. The 'moral check' allows the nurse to make a decision: the patient is uncomfortable and in distress, and therefore the only way at this point to alleviate the stress the patient (and subsequently the family) is

experiencing is to provide more sedation and analgesia. *"It's all based on assessment right, I mean if the patient looks like they're uncomfortable, you're looking at their breathing, and people develop a tolerance too, some people require a lot more drugs than others...I think that when you're able to accept that it's not just about the numbers...it's about making the patient comfortable."*

4.3.3 Theme 3: At the End of the Journey

The Journey – Creating Comfort Along the Way, ended shortly after the death of the patient. It ended when the patient was gone, when the family had left and the nurse had had the opportunity to reflect upon his/her experience. Due to the often unpredictable nature of critical illness the amount of time in which this entire process unfolds was highly variable. Realistically speaking this process could unfold in under one hour or it might last for several days. At the end however, the participants reflected on several key aspects of the experience. First and foremost the participants emphasized that the process of caring for patients and subsequently families during withdrawal of life sustaining treatment is work and it is hard work. Participants felt that the work that this process entailed was under-recognized and that support from peers and by the organization for which they were employed would be highly appreciated. The notion of stepping away was the actual process of reflection that the participants experienced when their journey with the patient, family and within themselves had ended. It was a process that was ultimately influenced again by the context and environment of the intensive care unit and often their self-reflection was cut short due another admission coming into the unit.

4.3.3.1 Support by Organization and Fellow Nurses

"You're so focused...you're focused on the patient, you're focused on the family...you're trying to anticipate their wants...and through all this you're still doing assessments... you're giving boluses, you're mixing your drugs...you're working you know because the act of dying is an active one." The participants interviewed for this study made it very clear that to care for patients and subsequently families during the process of withdrawal of life sustaining treatment and thus end of life, was a process that was very demanding and was very hard work. However the participants also described that the amount of work throughout this process was under-recognized both by employers and even in some cases by their nursing colleagues.

Isabelle spoke of her feelings related to a night she spent caring for a patient in the emergency department, *"Sadness, frustration...frustration is that our role as nurses is...I don't know if I'd say devalued, it's just not recognized...I heard once that paramedics...I was working emerg and I had a SIDS baby come in and did the whole SIDS thing...the paramedics were sitting around waiting there and I said, aren't you guys going back out on the road? Oh no, we're off now until we have a debriefing. They never went back on the road before they had a debriefing with the SIDS baby. I had to stay in that room, I was trauma nurse, had to stay there, help the family, send the baby to the morgue and then finish my shift. I think I was three hours into my shift at that point."* It should be recognized that this nurse had to continue to provide care to others throughout the remainder of her shift despite the lack of time for reflection or professional debriefing.

Due to the nature of the critical care environment it was highly possible that almost immediately after a patient died and the family left, the nurses had to quickly

regain their composure and prepare to admit yet another critically ill patient. The participants described that the latter situation also stemmed from the under-recognition of the amount of work (physically, mentally and emotionally) nurses put forth in caring for patients during withdrawal of life sustaining treatment. *"It'd be nice not to get an admission an hour later...things like that don't make life...when you've gone through something like that and you're...the beds not even cold yet and you're doing another admission and you're trying to change your whole frame of mind from one thing to the next...we should be able to have...I mean the family has been grieving and you've been grieving with them, you should be able...to grieve too, to...bring things to a conclusion."*

There was conflicting statements made by the participants regarding the support they felt they received from their co-workers (namely nurses) when caring for patients during withdrawal of treatment. One participant reflected, *"Not having the support of co-workers...rarely do we ask each other...are you ok...how are you doing with this,... can I get you anything...rarely will we say...you've done a really great job in there...can I take over for while and why don't you just go and have a coffee."* Another participant reflected, *"We've all been there...we all know what it's like...sometimes...it's just a gesture or it's...coming in and helping without being asked...it's someone coming by and saying...I'll sit here a while, why don't you go get a coffee."*

The participants also reflected on the general public not being aware of the role of the nurse. Isabelle reflected on a comment made by one of her colleagues from outside the nursing profession, *"Oh you're a nurse, I love nurses and I said well that's very nice to hear but most people never think about us until they need us and just look at our popular culture, that wonderful book that Tilda Shillof wrote, did it get the Gelder Award*

or the Governor General's Award? No Vincent Lam's book got that and everybody's talking about it because it's from a medical perspective, it's not from a nurses perspective and that says a lot about the value of our two professions and that's very frustrating...there isn't any co-recognition because our jobs are different our...roles are different but I think what we do is of equal importance."

In order to find support, nurses would often turn to their own family and to their colleagues. One nurse likened her experience over the years to shoe boxes, she explains, *"Usually when I go home and that's a coping mechanism I've developed over the years. I used to just never cope at all, I'd just ignore it all but I used to say it was like putting shoe boxes on your shelves you know oh this patient's over put him on the shelf, this patient's over put him on the shelf and then you learn that eventually the shelf is overloaded and it does come crashing down. I still have patients I dream about you know, there's a handful and they pop up every now and then...but I've learned you can't do that anymore so I go home and I rant and I rave and luckily I have a very supportive spouse."*

Other participants found that it was difficult to turn to their own family members for support because they *"just don't understand"*. For most, their nursing colleagues became their major source of support. Although one participant maintained that spending time talking about issues related to caring for patients during withdrawal of treatment was frowned upon by some (other nursing colleagues), overall the consensus pointed to other nurses as the source of support used by most. Susan explained, *"I don't like...you try not to spend your break talking, time away from the bedside going back in the coffee room and talking about your patient and all that's going on, some people frown upon that.*

Some people you can go and vent to...then there's that point where you have to sort of not get too caught up in things and take things personally of course and get too emotionally involved and try not to bring your work home with you."

4.3.3.2 Stepping Away

Stepping away from the experience begins when the nurses have the time to begin to reflect on their experience. Nurses reflect on past experience and begin to analyze how they have grown in their role caring for patients during withdrawal of treatment. The participants reflect on what gives them satisfaction and that caring for patients during withdrawal of treatment is *"a privilege"*.

Susan reflected on what gives her satisfaction in her role as an intensive care nurse caring for patients during withdrawal of life sustaining treatment. *"I get satisfaction from being present for the family...when they need something or the family...the patient...their comfort or just trying to make sure that cause I know...when they leave that's the last memory they'll really have of that person and I certainly wouldn't want to be the one that's contributing to anymore of the hardship of what they're going through no matter what they're going through."*

Anne found that stepping out occurs for her when the patient and family have gone from the unit. The time she has alone in the room gives her an "empty feeling". The busyness and the work involved in withdrawing life sustaining treatment have subsided and the nurse is left with an empty feeling. Anne described this scenario, *"It's finally, it's over...the family goes...you've wrapped the body and you know that the patient is gone and you're...clearing the room and everything...you almost get...this*

almost like an empty feeling...you start getting reflective and ...you start evaluating what you've done...do you feel that you've done everything you could have...you've gone through the whole...process, what were your lacks...what could have been improved...it's almost like a deflation...you're exhausted...you're just almost this void before you can say ok I'm ready again...you start going around helping other until your own admission comes."

4.4 Working in Professional Angst

As intensive care nurses are present twenty-four hours per day they have a privileged position in caring for critically ill patients. By the end of a 12 hour shift the nurses in the intensive care unit have acquired an enormous amount of information about the patients and families for whom they are providing care. The knowledge acquired through physically assessing the patient and through building therapeutic relationships with the patient and family is essential in determining the needs and values of the patient and family. Professional angst enters into the picture when vital elements of patient care such as the plan or goals of care, are not understood or followed through by various members of the health care team. The participants described their role regarding withdrawal of life sustaining treatments as challenging when the various individuals involved in the care of the patient are *"not on the same page"* with regards to the goals and direction of care. The participants also found their role challenging when they felt that the technology used for caring for patients with critical illness may not always be used appropriately.

4.4.1 Theme 1: Not Being on the Same Page

"Not being on the same page" was a key theme identified in all of the interviews held with the participants. The participants identified situations when there were various individuals who may not be on the same page with regards to patient care. Those most frequently mentioned included the nurses themselves, physicians and the family of the patient. Conflict with regards to patient care stemmed most often from two key sources, the physicians wanting to continue or discontinue the use of life sustaining treatment and the family wanting to either continue or discontinue with life sustaining treatment. The intensive care nurse then becomes the 'middle man' and ultimately becomes the mediator between the two opposing sources of conflict.

Susan helped to set the stage and provided a key example of the direction of care and goals of care being opposed by two different sources, *"It can be very frustrating too...you have that rapport with the family and they're sort of...depending on you to be their advocate...if you speak with the doctors and they're still not in agreement it can be very hard because you don't want to be showing your frustration or your disagreement on that at the bedside in front of the family...it just creates a lot of problems, a lot of issues against the doctors or vice versa, it can be the other way around too."*

Because of the central position intensive care nurses have related to the care of the patient, getting everyone involved on the same page becomes part of their role. The participants spoke frequently of situations when the patient's family was ready to *'let go'* and the physicians were not. The conflict was then compounded by the changing of the Intensive Care Team (namely staff physicians and residents). It was possible that progress may have been made in that a decision was reached to move in the direction of

comfort care measures and withdrawal of life sustaining treatment if the patient continued to show no improvement. What then could happen however was that the 'team' changes and decisions regarding the plan of care were altered and aggressive treatments continued. Trish referred to this as *'back peddling'*. She elaborated: *"First of all it makes the nursing staff or myself, it makes me angry that we put all this work into the patient, into the family and this was or where we were going and now this has been halted because one person or someone figures that we should try things differently has come in. And so now you've got to back peddle because this person will have spoken to the family perhaps and I say perhaps because maybe they haven't and now we're trying to explain to the family what we're doing, why we've changed our...way of doing things."* Trish continued to state that, *"It's just an emotional yoyo for them* [the family] *and so for us, if we are all not on the same page, end of life issues just are not going to be dealt with. We will just continue to have this patient lie in a bed, we will continue to treat because we have to and we will apologize to the patient and the family because what we're doing is not right but we can't do anything else."*

The conflict that could stem from all parties not being on the same page could potentially be resolved through the use of more open and frequent conversations. One suggestion by a participant was to allow for the opportunity for the staff (nurses and physicians) to meet and review the goals of care prior to discussing them with the family through the forum of a family conference. Susan suggested, *"It would be easier if we...I think we could eliminate a lot of conflict if...nurses and the team and the doctors, the staff physicians...had...a...more set plan...I don't think...a lot [of] time is spent...between the doctor and the nurse...discussing like you discuss on rounds."* Anne

also elaborated, *"we do need to work as a team...there is nothing worse then walking into a family conference when you think you're going in for one thing and the doc starts to talk and he's going in a completely different direction...I will most of the time prepare family before they even get in to the family conference so they know what to expect...I'm basically corralling people saying the physician wants to give you an update on your loved one and the care....and he starts to talking about ...well we've done everything and now we're going to withdraw...you can't do this...we need to be all on the same page at the same time...it's number one."*

Coordinating care and facilitating communication between all of the parties involved was vital for the continuity of care and in facilitating the journey for all involved, nurses, patients, the medical team and families. Anne again reflected, *"by the time you're making all these decision everybody, everybody is saying the same things, nobody likes to have different people saying different things and I would never walk into a family conference even if I disagreed with the physician and starting arguing with them...the family doesn't need to hear that, they need to think that as professionals and as people after that we are coming up with the best possible solution."*

The final source of professional angst as it related to the treatment options that were presented to patients and their families was what one participant referred to as the *"lie"*. The *"lie"* ties in with all the scenarios previously discussed in this section discussing professional angst. The "lie" stemmed from what participants referred to as health care professionals being untruthful. When various individuals discussed the progress that the patient was making with regards to overcoming their critical illness, the

way the case is presented had a major impact on the perception given to the family of the patient.

4.4.2 Theme 2: Runaway Train of Technology

The impact that technology has had on critical care was seen in an opening statement from the interview held with Isabelle. Isabelle, an intensive care nurse with 30 years of clinical experience working in intensive care, reflected, *"I started in critical care in 1973, there was critical care back then, it was very primitive...it's come, it's incredible, I would never want to go back to those days at all, it's wonderful and we do see miracles, not always the way the families want them but people survive that never even would have lived to get in through the doors, would never have been offered surgery because...the techniques weren't available...we've got all these, it's like a kid with a new toy, you know you play with the toy, you play with the toy and you play with the toy but you forget your homework, you forget your friends and you forget your chores and that's what I like it to because we've been able to do these things but we've never sat back and said is this appropriate?"*

Isabelle again reflected, *"Sometimes...we're a runaway train and before we know we're offering advanced stuff...CRRT, scanning and doing all kind of extra treatment which may not be what the people understand or want at the time and then we're going to them at the worst possible time and asking them to make a so called informed decision...I think that we lie a lot and we are untruthful a lot and that bothers me...we lie by omission...is my Dad getting better and when the doc comes and says oh yes you know his blood work is better and his sepsis is a little better and meanwhile you know he's on*

CRRT, he's on four inotropes...you know this person is not going to survive and I think it's a lie."

The *'runaway train'* referred to the technology that was available for patients during critical illness, such as cardiac monitoring, mechanical ventilation and hemodialysis. For the participants it was not the amount of technology available to use that was the source of their angst, rather it was questioning the appropriateness of it's use. The participants at times questioned whether the interventions that the physicians were presenting to families and patients were viable options for treatment. Susan reflected, *"He was...a do not resuscitate, do not intubate, do not defibrillate...all of a sudden dropped blood pressure, dropped his level of consciousness and they needed to intubate and it was brought up to the family, the family didn't know what to do, they weren't prepared for something like that."*

The participants also felt strongly that the physicians held the key to the care that was being provided. The participants felt that some of the interventions ordered by the physicians 'went too far' thus resulting in their angst. Susan said, *"We have our input but there are physicians in here and by that I mean by staff, that...keep things going on way longer than they should...or giving false hope to family...you know it's a teaching hospital and you question whether it's on that basis or whether they're...what are you really proving in the end, what kind of dignity of life...what kind of quality of life are you going to be giving this patient if they do survive?"*

Participants found themselves advocating on behalf of the patient and the family and their wishes. As with the various other aspects of this experience of caring for patients during the withdrawal of life sustaining treatment, intensive care nurses over

time developed a comfort level and confidence that enabled them to act as advocates for the patient. *"I've been here long enough that I can feel like I'm pretty comfortable at speaking up and being assertive...about what I feel and what I stand for and what the family stands for being that advocate."*

The participants also described how as intensive care nurses they found they were able to get to a place in their role where they were comfortable with withdrawal of life sustaining treatment and that in fact, they *'get there'* before the physicians. Through their experience in caring for patients with critical illness the participants felt that they were able to predict who would and would not survive their illness. Anne, who had previously been an employee in an intensive care unit in a community hospital, reflected on the change she experienced in the treatment options once she became an employee of the unit under study. *"When I first transferred to...I had a hard time like, why are we doing this...I know she's 91 years old and was previously healthy, she's still 91 years old...why do we need to do all of this treatment? And prolong it but eventually she will still have to die and then you're looking at putting up drips...I'm just so outraged that we're doing this to people and why are we doing this...shouldn't we intervene before that?"* Isabelle also reflected on getting there first, *"By the time we get moving to withdrawal...personally...I'm already there, it's not necessarily a projection of my values on that person as it is as a professional with years of experience, you can see, you can tell who's going to do well and who's not going to do well...I just wish that the team had started long before...for me it's more the anxiety and the angst and the emotion of why didn't we start this whole process sooner?"*

4.5 Providing Memories

Perhaps some of the most profound statements made throughout all of the interviews pertained to how the nurses provided families with memories. The unfortunate circumstances that patients and families underwent due to critical illness reached their pinnacle when the words – *"there is nothing more that we can do, what's best is that we keep them [the patient] comfortable"*, were uttered. Intensive care nurses, due to their intimate involvement and proximity to patients and families during end-of-life and withdrawal of life sustaining treatment found themselves in a very privileged position. Anne stated, *"I still say it's a privilege...to be with them, this is something family members will remember all of their lives when the family member died and so if you can make that experience as positive as you possibly can, it's not going to be a good experience, it can be a positive one without actually being good"*. Trish also reflected, *"I do believe that you can make a pleasant experience"*.

With the knowledge gained through past experiences the participants reflected that the advanced monitoring and technologically sophisticated interventions put in place during critical illness might not be what families remember most. The little things done by the nurses were what the participants felt families would ultimately remember most.

"I don't think they remember the technology that you're doing to their family member, they remember the caring that you give them...you know the wetting their mouth because their lips are very dry...rubbing their back with lotion ... so they don't get pressure sores, the warm blanket although...they're so peripherally shut down they'll never warm up again, it doesn't matter...they remember that someone was caring for their family member"

Providing memories for families not only served to help create as pleasant an experience as possible for the family, but also marked pivotal moments in the careers of the nurses, the "little pearls" of their careers. Isabelle reflected:

"I got sent to coffee, I came back, she had just crashed, the parents were still there, we did the code, we brought her back. We talked to Mom and Dad and Mom and Dad basically said we don't want to do this anymore so whoosh all the equipment goes out of the room and Mom and Dad came in, and it wasn't long a couple of hours and she was gone but they were there. Between when the equipment went out and Mom and Dad came back in, we had washed her, we had combed her hair, we put a ribbon in her hair, we made her look, she really did look like she was sleeping and we received a letter from the family saying just how much that little attention to detail meant to them."

In caring for patients at end of life, as a result of the withdrawal of life sustaining treatment, nurses accentuated the art of nursing through their actions, warmth and attention to detail. Giving a patient her last sunshine reflected a participant's attempt to not only provide a husband with a memory but also provided a patient with one last memory.

"The RT, myself and...her husband bundled her up, we put a pair of sunglasses on her and we took her outside, bagged her out in the... emergency department. She just to feel the sun in her face for the last time, because she knew she was gonna...and it was cold but...it was really um you know it's their last...I mean you try to do whatever you can cause you know this is...it was her last sunshine, her last breath of fresh air outside."

4.6 Summary of Findings

This studied sought to describe and further understand the experience of intensive care nurses caring for patients for whom life sustaining treatment was being withdrawn. The essence of this experience was described as intensive care nurses *"trying to do the right thing"*. The experience as a whole was described as a journey that nurses experienced with various individuals including other nurses, patients, families of patients, physicians and other members of the health care team. Comfort was described as a vital element however it was not discussed as an individual theme as it was woven throughout the entire experience of the intensive care nurse caring for patients during withdrawal of life sustaining treatment.

Factors that facilitated and hindered the nurses were interwoven throughout the themes. Those that facilitated the nurses were factors such as support from colleagues and having a prior relationship with the family. Those that hindered the nurses were factors such as no down time after the death or conflicting messages to families.

In "trying to do the right thing" nurses worked at building relationships with families and strove to get the families to a place where they could accept the death of the patient. Nurses also tried to do the right thing by each other and to provide support to one another. The moral and ethical implications of withdrawal of treatment were readily recognized by nurses as they cared for patients. Intensive care nurses focused on providing comfort for patients and families and internally reflected on the cause and effect relationship and implications of the use of sedatives and analgesia which the researcher referred to as a moral check and thought process. Even while working in professional angst the participants sought to do the right thing by providing suggestions

that would facilitate more open communication and get everyone on the right page. By understanding the impact of technology as it related to critical illness nurses reflected on their role as intensive care nurses and the impact that the inappropriate use of technology could have on patients and families. Lastly, trying to do the right thing was also seen in the ways that participants described using the art of nursing to go above and beyond in providing memories for families.

All of the themes that encompassed and described the experience of caring for patients for whom life sustaining treatment was being withdrawn described the actions nurses took in *"trying to do the right thing"*.

Chapter 5: Discussion and Implications for Practice, Education and Research

5.1 Introduction

This chapter discusses the findings of the study as well as implications for nursing practice, education and research. The discussion and implications of the research are supported where possible by current literature. Suggestions for future research are recommended. This chapter also provides the description for the role of an Advanced Practice Nurse (APN) as it relates to withdrawal of life sustaining treatment and end-of-life care in the Intensive Care Unit. The chapter concludes with the limitations of this study.

5.2 The Voice: The Experience of the Intensive Care Nurse Withdrawing Life Sustaining Treatment

This study describes the experience of intensive care nurses who care for patients and their families during the process of withdrawing life sustaining treatment or as one, participant eloquently stated, "their voice".

The experience of caring for patients and subsequently families during the process of withdrawing life sustaining treatment is an experience that has both a beginning and an end for intensive care nurses. How this journey (or experience) unfolds, however, is dependent on the context of the situation. The journey may be seamless and unfold in a manner that is free from conflict from beginning to end. It is also possible that the journey becomes interrupted by conflict that is multi-factorial, thus becoming challenging for those involved. The nurse-patient/family relationship (or rapport), the acceptance of

unresolved critical illness by the family, the level of comfort the nurse has in caring for patients and families, physical comfort of the patient, conflict related to 'not being on the same page' and the 'runaway train of technology' are key elements influencing the experience of withdrawing life sustaining treatment for intensive care nurses.

5.2.1 Stepping In: The nurse-patient/family relationship

One can only imagine what it would be like on a daily basis to walk into work and literally not know what situations await you. The nature of the intensive care environment and the level of uncertainty associated with working in it are an everyday reality for intensive care nurses. It is possible that nurses may care for a patient who is ready to be transferred out of the ICU to a medical or surgical floor, may have an empty bed and spend the day waiting for a patient to come through the door, may care for a patient requiring resuscitation and/or strive to maintain life or care for a patient for whom no further treatment measures can be sustained. The experience of "stepping in" to care for a patient who will die from withdrawing life sustaining treatment was described in this study and the ripple effect of this experience that encompasses the family of the patient as well as the nurse, ICU physicians and other members of the healthcare team.

Current literature has recognized the centrality of the family in relation to the process of withdrawing life sustaining treatment. Although prior phenomenological studies exploring the experience of critical care nurses caring for patients during withdrawal of treatment have identified the family as part of the experience, there is little description addressing how a prior relationship with the family facilitates caring for these patients and families (Halcomb et al., 2004; Jones & Fitzgerald, 1998; van Rooyen et al.,

2005). Halcomb et al. (2004) report that nurses who had prolonged involvement with a family had greater perception of the psychological, social, environmental and spiritual needs of the family however the latter is not described in great detail and further elaboration is required.

The participants quickly recognized the importance of building a relationship with the family. Where the nurses had a prior relationship/rapport with the family, the experience of moving to comfort measures and the withdrawal of life sustaining treatment was described as easier. Stepping into the situation and carrying out the actual process of withdrawing the life sustaining therapy was facilitated by nurses not having to start from square one with the family and strive to develop rapport with them amongst the most grave of circumstances. Stepping into the role of withdrawing life treatment is easier because they do not have to overcome the obstacle of building a relationship. Knowing the patient and family allows the nurse to embrace their role in a different manner, their time and energy is focused on providing comfort to the patient and readily acknowledging and tending to the needs of the family.

Not knowing the family or patient beforehand makes this experience very difficult. One can imagine how difficult it would be to step into a situation as fragile as having to withdraw life sustaining treatment on a stranger and simultaneously provide emotional support and the required teaching to this family. The sensitive and highly emotional nature of this situation is in itself challenging. The focus of the nurse in this situation is different. Providing comfort care to the patient was described as a mechanism the nurse could use to begin to develop rapport with the family. The participants felt that by having the family members see them caring for the patient

allowed the family to recognize that the focus of the nurse was on the comfort of the patient. Where a bond or rapport has been established between the nurse and the patient/family the provision of care happens in a way that is more natural. A level of comfort is developed by all parties involved and the extraneous effect of lack of trust/rapport is eliminated.

The time factor related to decision making in the intensive care environment can be very brief. This time factor could potentially affect the establishment of prior relationship between the nurse and the family. It is possible that during the nurses' first assignment (and therefore experience) with a patient and their family, the goals of care may shift from a curative to a comfort care focus in a limited amount of time. Rushton et al. (2002) recognize that time constraints may limit the opportunity that nurses have to build relationships with patients and families, thus "making them strangers to one another at the outset of an intense, vulnerable relationship"(p.134). Rushton et al. (2002) also report that often critical care professionals may depend on an established prior relationship to facilitate decision-making and advance care planning.

Benner, Hooper-Kriakidis and Stannard (1999) report that once a decision has been made, the end-of-life care falls on the shoulders of the intensive care nurse who shares in the emotion of the family and who travels with the family in this experience. Thus, facilitating an experience in which the nurse has a previously established relationship is crucial in the experience of caring for patients and their families during withdrawal of life sustaining treatment. Strategies to facilitate the assignment of nurses to patients and families with whom they have established a relationship need to be identified, explored and evaluated.

5.2.2 The Acceptance of Critical Illness by the Family: Getting the Family There

Creating Comfort Along the Way, recognized that a vital part of the journey is the efforts taken by ICU nurses in getting the family to a place where they are able to begin to understand the nature of critical illness and understand that despite multiple interventions the patient cannot overcome their illness. 'Getting the Family There', is an aspect of the journey that the participants described as something that may or may not be possible. It is an aspect of care provision that for these nurses is exhausting and yet vitally important. The findings suggested that this act of getting the family there is a nursing act that is essential in creating a rapport and building a relationship with the family.

Nursing care related to this aspect of caring for the family involved several factors. The participants recognized that families need to be able to take the time to process the events surrounding the imminent death of their family member. The participants described that families also need to have their questions answered in an honest and realistic fashion. The nurses acknowledged educating the families as needed and also portraying themselves as resources for the family.

Another key aspect in getting the families there included provided them with an environment in which they (the family) felt safe to express their thoughts and emotions. The participants described providing the family with a place where they can 'fall apart' in safety and in privacy. Providing this place for families allowed the families to first of all express themselves openly regarding their experience and it also allowed them to regain composure and return to the bedside better able to cope with the situation at hand.

Studies have been conducted to explore how families feel with regards to the withdrawal of life support as well as improving communication with families at the end of life. Keenan et al. (2000) developed an instrument to assess the satisfaction of family members with withdrawal of life support (WLS). A self-administered questionnaire was sent to next of kin of 69 patients who died following WLS over a six-month period. The response rate was 44% (29/66), three letters were returned with address unknown. Eighty-three percent of the respondents agreed that the patient's death was both compassionate and dignified. Families were satisfied when the process proceeded as expected (as it had been explained), when the patient appeared comfortable, when adequate privacy was provided and when they were given the chance to voice their concerns. These latter correspond with the actions taken by the participants in this study when they are trying to "get the family there".

Ahrens, Yancey and Kollef (2003) identified similar findings in a study which explored the effect of a communication team to facilitate improved family communications at end-of-life. Ahrens et al. report that families are often stressed and confused by the technical information they receive. They report that families need careful explanations, time to process information and consistent professional support. Findings of this current study related to actions of intensive care nurses when interacting with families and trying to 'get families there' are consistent with those providing families with a satisfactory experience of withdrawal of life sustaining treatment.

5.2.3 Achieving a Comfortable Place for the Nurse: Growing with Experience

This study suggests that caring for patients during the process of withdrawal of life sustaining treatment is both a nursing skill and a nursing role that changes over time. Exposure to these types of patient and family care situations and the experience gained with each encounter facilitates the nurses' comfort with both the process of withdrawing life sustaining treatment and the nurses' own level of comfort. The findings suggest that those with more experience caring for patients and families within this context of care have comfort in their role as it relates to withdrawal of life sustaining treatment.

The level of comfort with the process (withdrawing life sustaining treatment) is multi-factorial. Withdrawing life sustaining treatment is a process that has been described by the participants as complex and one that requires skill and knowledge to perform. Participants recognized that as a beginning nurse there is a level of discomfort with withdrawal of treatment (the one nurse with less than one year experience described herself as being scared) but that over time they become more comfortable in their role.

Out of the participants' experience grew their ability to self-analyze and critically reflect on their actions. The participants described how they had to come to terms with their own values and beliefs regarding death. Of particular importance is how these nurses learn to live with this situation. Dealing with death on a regular basis is part of the experience of being an intensive care nurse. Death is a reality of the role and it is not a new phenomena as patients have always died in intensive care. What is unique about this study, however, is the description of the process of caring for patients and families within the context of withdrawal of life sustaining treatment and how they sort it out in their

thoughts and feelings and ultimately provide safe, compassionate and holistic nursing care.

The participants reflected on the humanity associated with their role. They described crying at the bedside and being with families. One participant described the humanity of the role as "not being afraid to be with people in their pain". Once again, this is a facet of the nursing role related to withdrawal of life sustaining treatment that the findings of this study suggest develops over time. It is also an aspect of nursing care that cannot be learned from a text book. It develops from being with patients and families and also from being able to look within oneself and determine what the role means to you. Developing comfort at this level is what distinguishes the intensive care nurse who 'just does the job' from the one who has developed the insight and comfort in the role to be able to 'go above and beyond'.

The selective literature review completed at the outset of this study did not specifically address the comfort of the nurse with regards to caring for patients in this context of care. The literature focused on the centrality of the intensive care nurse in the provision of end-of-life care, and not their level of comfort enacting this role. An updated review of the literature however has seen a shift in focus of studies addressing end-of-life care and withdrawal of treatment. Exploration of the experience and perspectives of nurses are now surfacing. An example includes a multi-centre prospective study in 4 tertiary care hospital ICUs in 4 Canadian provinces that was conducted in 2000 (Rocker et al., 2005). This study sought to describe the perspectives of registered nurses (RNs) and respiratory therapists related to end-of-life care for critically ill patients. Results of the study showed that of the RNs surveyed (n=94) 85%

felt comfortable with the decision to withhold CPR and that 83% felt comfortable with the decision to withhold/withdraw life support. Further exploration to describe and define this process of personal growth that appears to occur within the ICU nurse would be beneficial.

5.2.4 Patient Comfort: Central to the Experience and More

The findings suggest that the physical comfort of the patient is central to the experience of caring for patients during withdrawal of life sustaining treatment. Providing comfort to the patient, as previously discussed, is also an avenue nurses use to establish trust and rapport with families, but it is also an aspect of caring for a patient during withdrawal of life sustaining treatment that causes these nurses to step back for a moment and evaluate their actions.

Making patients comfortable is the premise by which sedation and analgesia is used during the process of withdrawing life sustaining treatment. The use of benzodiazepines and narcotic analgesia is common practice during the process of withdrawal of life sustaining treatment. Once again with experience, the participants identified that over time their level of comfort with the use of sedation and analgesia develops. They spoke however of a 'fine line'. The participants described a moral check in which they reflect on their actions and justify the amount of sedation and analgesia that is being used.

However, the provision of patient comfort itself is not without its challenges. The participants expressed concern regarding the lack of a consistent method or procedure to follow when withdrawing life sustaining treatment. The literature suggests that there is

little evidence that policies and procedures related to withdrawing/withholding life sustaining treatment are standardized across ICUs. Burns et al., (2001) and McLean et al., (2000) identify the existence of inconsistencies in treatment withdrawal. Clinical practice guidelines do in fact exist (Truog et al., 2001) however they are not necessarily being implemented into practice. Winter and Cohen (1999) have identified that the process of withdrawing life sustaining treatment remains highly dependent on the clinical expertise of the attending physician. Stroud (2002) reports that the literature fails to demonstrate that the process of withdrawal of life sustaining treatment is informed by evidence based research "to any degree of quality evaluation"(p.180).

Providing comfort during the process of withdrawing life sustaining treatment has been identified by the participants as challenging, particularly in certain instances. The process is challenging when it occurs on weekends where there is little input available from staff physicians and these decisions are left in the hands of inexperienced residents. It is also challenging when the nurse feels that the patient is not comfortable and that sedation is not liberal enough to adequately provide comfort for the patient.

5.2.5 Conflict: Not Being on the Same Page and the Runaway Train of Technology

Conflict related to the experience of the intensive care nurse caring for patients during the process of withdrawal of life sustaining treatment stemmed from two key sources. First, when the team including the physicians, nurses and family of the patient are not on the same page with regards to goals of care for the patient and second, from

nurses questioning the appropriateness of the use of technology in certain patient situations.

The conflict that stems from Not Being on the Same Page is largely impacted by communication or lack there of between patients, families, and the various members of the health care team. Clearly delineated plans of care that are openly discussed between all those involved in the care of the patient (including the patient themselves if possible as well as the family) could help to eliminate the conflict arising from lack of communication. The composition of the health care team and the rotation of intensivists on a weekly basis also have a major impact on the experience of ICUs nurses and communication processes. Inconsistency in decision making and treatment plans results from a constant fluctuation of physicians in and out of the ICU. The participants recognized the struggle they experience when physician teams change and the goal and direction of care ultimately change. When goals of care change, the work involved in establishing a trusting relationship with families is affected. The participants identified that they are left at the bedside with a family who is now questioning the intent of the previous physician, questioning the competency of the health care team or are given false hope.

Conflict resulting from lack of clear, concise and open communication is not new in relation to care of the patient and family in the ICU environment. The literature regarding withdrawing/withholding life sustaining treatment points to the need for improved communication in order to create a seamless, conflict free process of caring for patients and families as well as for the health care team. For example, the literature has identified that although nurses are actively involved in the actual process of withdrawing

treatment, they may not always be involved in the discussions and actual decision making processes regarding shifting care from curative to comfort measures (Halcomb et al., 2004; Ingham, 2001) Researchers and critical care clinical experts reiterate over and over in the literature that effective and frequent communication is essential in all aspects of care but particularly as it relates to end-of-life care (Curtis, 2004; Dracup & Bryan-Brown, 2005).

The role of technology in the ICU environment has without a doubt made a huge impact on patient outcomes, including survival rates. However, the use of technology does not exist without conflict. The appropriateness of the use of technology is at times questioned by intensive care nurses. The participants in this study also questioned whether the technological interventions being presented to families and patients by physicians were viable options for treatment. The participants often found that they would 'get there' before physicians, meaning that they (the participants) felt they were able to predict whether or not the patient would survive and therefore would question why redirecting the goal of care to comfort care measures and withdrawal of life sustaining treatment had not been either discussed or instituted earlier.

The literature abounds with descriptions of nurses' level of discomfort in relation to the use of technology in the critical care environment. Their level of discomfort stems from nurses questioning the appropriateness of the prolonged use of technology. Halcomb et al. (2004) described how nurses perceived themselves to be causing the client "unnecessary suffering"(p.218) by continuing active burdensome treatment. The study by van Rooyen et al. (2005) echoes Halcomb et al. (2004) in that nurses felt prolonging

treatment makes the patient suffer and the maintenance of the patient's dignity was questioned.

The holistic nature in which nurses provide care encompasses the provision of a good death: a death that is free from pain, a death in which both the patient and family are supported and one where the dignity of the person is maintained (CACCN, 2006). Nurses in previous studies as well as this current study are challenged when those providing care (including all members of the health care team) are not on the same page and when goals of care are not clear to everyone involved. Open and honest communication needs to again be emphasized in order to provide efficient and quality care, including the provision of care leading up to and following the withdrawal of life sustaining treatment.

5.2.6 At the End of the Journey – What keeps ICU nurses coming back?

Ultimately this study sought to describe and to further understand the experience of nurses caring for a patient for whom life sustaining treatment is being withdrawn. What has been learned from this study has evolved into an understanding of what it is like for a nurse to take someone off of life sustaining therapy.

The findings of this study suggest that caring for patients and subsequently their families is very demanding and very hard work for intensive care nurses. As has been discussed, the journey of caring for patients and families in this context of care is not always easy. It is a journey that may be fraught with conflict and inconsistency but, not always. What one might ask, if it is such hard work, what keeps these nurses coming back? How can they enjoy what they do?

In order for nurses to function effectively and compassionately and to provide holistic care, the intensive care nurses readily acknowledged their need for support. Support must come from both an organizational level as well as between nursing colleagues. The findings suggest that debriefing sessions may be useful as well for providing nurses with time for personal reflection. The literature and the experience of these participants demonstrated that rarely are debriefing sessions actually incorporated into this experience (Puntillo et al., 2001). Some of the participants described the time period after the patient has left for the morgue, as a time when they are able to reflect on their experience, however this is often interrupted by the need to admit another critically ill patient and begin again.

In the findings, support from colleagues was approached from two different perspectives. On one hand some participants felt that their colleagues were unfailingly there for them. One the other hand, participants also emphasized that even their colleagues did not at times recognize the work involved in caring for patients and families during withdrawal of treatment. Being aware of the work involved in caring for these patients and families is essential in supporting and valuing the role of the intensive care nurse.

What keeps these nurses coming back? While previous phenomenological studies explored the experience of critical care nurses who cared for patients during withdrawal of life sustaining treatment, limited attention has been paid to exploring why nurses continue to work in this environment. Stroud (2002) comments that the literature is "overwhelmingly concerned with the negative effects [of the critical care environment] on [intensive care] nurses rather than those of a positive nature"(p.181) Despite the

multiple challenges associated with the role and the time and effort required to care for these patients and families, there is something that keeps nurses coming back. The participants in this study described the element of satisfaction that stems from caring for patients and families during withdrawal of life sustaining treatment. Satisfaction comes from being present for the family, and not from the technology or technique involved in the process of withdrawal of life sustaining treatment. Intensive care nurses are there for the needs of the patients and families as well as each other. They strive continually in their role to "do the right thing". They strive to create memories for families who are struggling through potentially one of the most difficult experience of their lives. Intensive care nurses strive to eliminate the "hardship" these families are experiencing no matter the complexity or contextual nature of the situation. As well, they help each other along the process as well by providing support and understanding to one another. These points combined help the reader to understand why these nurses do what they do and come back day in and day out to do it again.

5.3 Implications for Nursing Practice, Education and Research

Nursing is discussed and identified as a practice profession. As such, research and research endeavors often seek to provide avenues for improving nursing practice or provide evidence to support change related to key practice issues. The following section addresses implications for nursing practice, education and research as it relates to the findings and discussion of this study.

5.3.1 Facilitating the Establishment of the Nurse-Patient-Family Relationship

In order for nurses to enter into the experience of caring for a patient and their family during withdrawal of treatment with a sense of rapport and familiarity, factors facilitating this process need to be identified, explored and evaluated. Maintaining a work environment that emphasizes the need for patient- and family-centered care is both a philosophical and practical approach to care provision that may facilitate the establishment of rapport between nurses, patients and families.

From 2004 – 2005 a Critical Care Medicine Task Force was developed in the United States of America that included members of the American College of Critical Care Medicine as well as members of the Society for Critical Care Medicine (Davidson et al., 2007). The purpose of said task force was to develop clinical practice guidelines to support the care of patients and families across ICU settings and to subsequently create recommendations for improved practice. One of the recommendations "Family Coping" (p.608) was comprised of five key categories including: that ICU need staff to receive training to adequately assess the needs of family, that the assignment of nurses and physicians to patients be as consistent as possible, that families be encouraged to participate in care provision, that families be provided information in a language they fully understand and finally that family support be provided by the entire multidisciplinary team (Davidson et al.)

From these recommendations as well as the findings from this current study, it is clearly visible that families are central to the experience of caring for patients in the intensive care environment. The recognition of the families being inextricably linked to

this experience is vital as it promotes family-centered care as a moral imperative in the care of the critically ill patient. By maintaining an awareness of the centrality of the family to the experience, policies for family-centered practice may be instituted.

The participants of this study noted on several occasions that knowing the patient and family prior to the process of withdrawing life sustaining treatment facilitated the experience of the nurse caring for the patient and family. Davidson et al. (2007) recommended that where possible the assignment of nurses and physicians be as consistent as possible. It may then be suggested that when withdrawal of life sustaining treatment is identified as the current plan of care, where possible, nurses who have previously cared for this patient and family be identified and given the assignment. In the case of the organizational structure of the unit described in this study, the care facilitator would play a key role in identifying and assigning these nurses.

5.3.2 Getting the Family "There" – How?

The theme "Stepping In – Getting the Family There" was comprised mainly of nurses communicating with families in attempts to get the family to a place where they could understand the nature of the critical illness and understand that despite critical interventions, the patient (their family member) cannot overcome their illness. The participants noted that in some instances, not being able to get the family "there" is a reality in the care provided to critically ill patients and their families.

Curtis (2004) identifies that in order to provide high quality care to intensive care patients and their families, highly effective communication skills are essential. Family members of critically ill patients have also rated communication skills as one of these

most important skills for a clinician to possess (Curtis). Curtis elaborates further and suggests that there is a uniqueness regarding communication in the intensive care environment. Patients are often unable to speak for themselves for a multitude of reasons, thus communicating with the family is essential. The information relayed in conversations regarding critical illness is often "complicated, confusing, and even discordant data that can be overwhelming to family members and make family members more dependent on the health care team" (Curtis, 2004, p.364).

It has been identified within the literature that intensive care nurses play a pivotal role in communicating with families. The majority of communication between nurses and families occurs directly at the bedside (Curtis, 2004). Hickey (1990) recognized that the majority of family member needs related to communication are in fact addressed by nurses. These findings imply that communication and in particular communication with family members of intensive care patients is an integral part of the intensive care nurses' role. In order to effectively communicate with family members regarding withdrawal of life sustaining treatment, Curtis (2004) suggests the following: Focus on what the "patient" would want, explain that the patient will die from their underlying disease process and that every effort will be made to ensure patient comfort. Curtis (2004) also emphasizes that it is important to allow the family time to adjust to the reality that life sustaining treatment will be withdrawn. Each of these elements discussed by Curtis (2004) were also identified and discussed by the participants in this study.

It is essential to evaluate the effectiveness of intensive care nurses' communication skills with families. Measures to continually evaluate whether or not the needs of the family have been met would also be helpful to determine if in fact intensive

care nurses have gotten the family "there". Pronovost, Rodriguez-Paz and Mohammad (2007) suggest that in order to ensure the needs of the family and patient are met, that the following habits be developed and incorporated into the philosophy of care in the ICU: including patients (where possible) and family in multidisciplinary rounds, ensure that visiting hours be extended (thus allowing family to be with the patient and stay connected), provide families with the information they need to navigate the ICU environment, have weekly conferences with patients and families to ensure that all are up to date and familiar with the plan of care and finally, take a moment to ask patients and families what their experience in the ICU is like.

Constant and consistent communication and family presence may help to facilitate the establishment of relationships and rapport with families. It may also help to "get the family there". By acknowledging the experience of the family and as Pronovost et al. (2007) suggest, asking patients and their families to describe their ICU experience can help clinicians re-evaluate their approach with families, identify the need for further improvement and lastly highlight what is being done right. By developing an evaluation process that can be instituted with families during the actual ICU experience rather than via retrospective data could serve as a means to identify positive and negative factors related to their experience at the point of care. Should unmet needs be identified or unknown issues be recognized early on, communication can take place and a plan of care subsequently instituted to help meet the needs of the patient and the family earlier.

5.3.3 A Comfortable Place for the Nurse – Are We There Yet?

Nurses have been identified as the primary caregivers to the terminally ill and dying (Bradley et al., 2001; Dawe, Verhoef & Page, 2002). Intensive care nurses, as previously discussed, experience the death of patients often as a result of the withdrawal of life sustaining treatment and they have been identified as active participants in this process (Ingham, 2001; Nelson & Danis, 2001). The participants in this study found that over time and with experience, caring for patients during this process became easier, however, further research specific to exploring and validating this perception is needed. Further research is also needed to specifically identify the needs of intensive care nurses who experience death on such a frequent basis. One participant questioned, "What does that do to me?...What's the psychological impact on me?"

Wilkin and Slevin (2004) found that debriefing sessions are essential to all nurses who deal with death. Slevin and Wilkin found that debriefing sessions helped even experienced nurses realize their own physical, emotional, social and spiritual responses to death, which helped them to better cope with death in the future. Despite the evidence of the benefit of debriefing sessions, it was identified by the participants in this study, as well as in the literature, that debriefing in this environment seldom occurs (Puntillo et al., 2001). The findings from this study suggest that debriefing sessions become mandatory for nurses working in intensive care units. Employees (nurses) should also be encouraged to make use of resources provided by the hospital such as Employee Assistance Programs (EAP) which offer services such as debriefing.

The demographic data collected in this study, as well as data found in the literature indicates that despite the frequency with which intensive care nurses experience

death, few of these nurses have had formal education in palliative care. Roberts and Boyle (2005) conducted a study focusing on end-of-life education in the pediatric intensive care population and found that little time is spent educating nurses on how to best prepare patients and their family members for end of life, and that little focus is placed on how nurses can care for themselves whilst they care for others. In response to this finding, Roberts and Boyle discussed their implementation of a one day conference entitled "Giving care and taking care: end-of-life issues in the pediatric intensive care unit (PICU)" (p.54). Roberts and Boyle state that with limited educational programs addressing end-of-life care in the PICU, it is left up to individual organizations to meet the needs of their staff.

Nurse educators and clinicians including advanced practice nurses such as clinical nurse specialists in adult intensive care environments also need to recognize the need to formally educate front line staff about end-of-life care in this environment. Orientation programs for staff new to the ICU should clearly acknowledge that caring for patients and families during the process of withdrawal of life sustaining treatment is a reality of providing quality patient and family care in intensive care. New employees should be made familiar with the process of withdrawal of life sustaining treatment including the use of protocols, should they exist in a particular unit, common procedures for withdrawing life sustaining technology, and should be familiar with the use of pharmacologic and non-pharmacologic measures implemented to maintain patient comfort.

The potential exists, however, for in-depth education regarding caring for patients and families during the process of withdrawal of life sustaining treatment to be

overwhelming for new nurses in ICU. The participants in the study identified that caring for patients during the process of withdrawal of life sustaining treatment is an experience for which they felt ill prepared. However, a lack of formalized education regarding end-of-life care and more specifically caring for patients who die from withdrawing life sustaining treatment was evident in the data collected. The participants spoke frequently with regards to "experience" as the medium through which they learn to care for these patients and families and subsequently gain a level of comfort that allows the nurse to go above and beyond in the care they provide. Little time is spent formally educating nurses with regards to withdrawal of treatment and end of life care in general.

The idea that nurses who care for patients and families during the process of withdrawal of treatment do so with knowledge that is primarily gained through experience and over time poses a challenge. Innovative processes are required to educate nurses. Since hands-on experience is an essential element in nurse comfort related to withdrawal of life sustaining treatment, it is possible that perhaps a mentorship model of education may be useful. Nurses who identify themselves as experts who are comfortable with the process of caring for these patients can serve as mentors for less experienced staff.

It is also possible that during the orientation process to intensive care, nurses new to the ICU environment be exposed to patients dying in the intensive care unit. Being exposed to death in the intensive care unit along side an experienced nurse may help make the overall experience less overwhelming. The orientee would have the opportunity to see how treatment is withdrawn and also how and when sedation and analgesia is used. The orientee would be able to pose questions to the experienced nurse

which may provide greater comfort and familiarity to the new nurse when he/she is faced with this situation in the future.

It may also be helpful to establish a program within the intensive care unit in which nurses can discuss their experiences of withdrawing treatment with others (including nurses, physician and members of the health care team). The participants identified that although some of them will talk to their family and others outside of their nursing community, most rely on the support of their colleagues. Providing a medium through which nurses can discuss their experiences either formally or informally, may help to provide greater recognition of their unique and priviledged role and could also be another avenue through which they receive the support required to continue in their role. The latter suggestion was also proposed as a quality measure by Mularksi et al. (2006) who suggested providing ICU clinicians with the opportunity to review the experience of caring for dying patients.

5.3.4 Development of Policies and Protocols for Withdrawal of Life Sustaining Treatment/Standards of Care

Another implication for nursing practice identified within this study is the need for the development of policy and consistent procedures related to caring for patients during the process of withdrawal of life sustaining treatment. The participants suggested on several occasions that a policy related to that actual process of withdrawing life sustaining treatment would be helpful. Particular instances where they identified that the protocols would be helpful included weekend and night shifts where junior physicians are on call and when more experienced staff physicians are not readily available. Some

literature exists regarding clinical practice guidelines (Truog et al., 2001) but little is known of their implementation in Intensive Care Units. The participants stated that having a protocol as a guideline for both nurses and residents may help to facilitate the experience of having to withdrawal life sustaining treatment, particularly on night and weekend shifts when staff physicians are not always readily accessible in the unit.

The development and implementation of withdrawal of treatment protocols could potentially alleviate some of the uncomfortableness that the participants experienced with regards to the titration and amount of sedation and narcotic analgesia being used during withdrawal of treatment. An early study by Wilson, Smedira, Fink, McDowell and Luce (1992) identified that during the process of withdrawal of life sustaining treatment, large doses of sedation and analgesia are used. The purpose of the medications is to alleviate pain and suffering during the process and not for the purpose of hastening death. It is possible however that the uncomfortableness of the nurses stems from the ethical principle of double effect (Wilson et al., 1992). Double effect refers to the administration of drugs that may be given to relieve suffering even though the side effects of these medications (lowering of blood pressure and respiratory drive) may in actuality hasten death. Prior studies addressing the experience of intensive care nurses caring for patients during withdrawal of treatment did not specifically identify the use of sedation and analgesia as a source of nurse discomfort (Halcomb et al., 2004; Jones & FiztGerald, 1998; VanRooyen et al. 2005). Although the participants expressed that their level of comfort caring for patients during this process improved over time and with experience, the implementation of such a protocol could be particularly useful to the new graduate and for nurses who are new to the ICU environment.

The development of policies and procedures related to withdrawing life sustaining treatment is also supported by the Canadian Association of Critical Care Nurses in their position statement regarding With-holding and Withdrawing Life Support (CACCN, 2006). CACCN believes in the development of these policies to support the clinical nurses who are in the situation of providing care under these circumstances.

5.3.5 Continuity of Care and the Inter-professional Team

Participants in this study described that the lack of continuity of care as it relates to the change over of physician teams as an issue that greatly affected their nursing practice and the care they provided to patients and their families. The participants discussed the large amount of time and energy that is spent building relationships with families. At the root of the therapeutic relationship that nurses establish with patients and their families is trust. The participants found on several occasions that the trust established between themselves and the families in particular can be easily broken when there is inconsistency in the care that is provided. The participants described how the plan of care could change quite dramatically from one physician to the next. Participants spoke of experiences where the plan of care involved discussing withdrawal of life sustaining treatment and that families were in concordance with the plan of care. When the staff physicians changed, the plan of care could revert back to more aggressive and curative measures. Trust that was previously established with the families was broken. The participants in their continual presence at the bedside with patients and families described the repercussions of these types of decisions. Families questioned whether the 'other' physician wanted their family member to die.

In order to alleviate the breach of family trust and the potential for lack of continuity of care it may be necessary to implement succinct strategies for effective communication. Mularski et al. (2006) as part of the Robert Wood Johnson Foundation Critical Care End-of-Life Peer Workgroup proposed several quality measures for palliative care in the critically ill. Communication within the health care team as well as with patients and families was identified as a quality measure for palliative and end-of-life care (Mularksi). Documentation of decisions related to patient care as well as the plan of care post family conference were identified as key indicators in facilitating communication (Mularski).

The development of a plan of care communication sheet with patients, families and the physician team may facilitate continuity of care. When family conferences have taken place and when vital decisions have been made regarding the plan of care, a communication sheet can be written as a means of clearly identifying the plan of care. A review of the literature did not reveal any results as to the use of plan of care communication sheets however this may be an innovative approach requiring further investigation and study.

5.3.6 Dealing with 'Getting There First'

The participants identified that often they "get there first", implying that they feel that they come to the realization that the patient will not overcome their critical illness before the physicians. The literature also identifies that nurses often find they "get there first" (Asch, Shea, Jedrziewski & Bosk, 1997; Curtis, 2004).

Asch et. al. (1997) explored nurses' beliefs, motivations and experiences regarding end-of-life care in the critically ill. Content analysis of text comments of 468

American critical care nurses emphasized the unique position of the nurse in relation to the patient and their family and also the discord felt by nurses when technology is overused and the inability of some physicians to "not let go of hopelessly ill patients" (Asch, 1997, p. 1665). Curtis (2004) in a review of the literature regarding communication at end-of-life in the intensive care environment suggests that ICU team members may differ in their opinions regarding when life-sustaining therapy should be withdrawn. Curtis (2004) recognizes that often nurses come to this decision earlier than physicians and also suggests that in order to avoid the conflict that stems from the latter, that open lines of communication exist amongst the team members at all times

In concordance with Asch et. al. (1997) and Curtis (2004), Dickenson (1999), in a self-reported questionnaire of 469 British nurses, found that questions of medical futility produced more discord between nurses and the clinical team than any other issue. Despite these feelings being reported by nurses, the discontinuation of medically futile treatment is a major source of ethical dilemmas as there are currently no objective scientific methods to accurately predict death with any certainty (Stroud, 2002). Further research is required to produce methods to accurately predict mortality in critical illness. Research is also needed to better explore the nursing perception of "getting there first": how do nurses justify this statement and are there specific assessment factors that nurses employ that lead to their clinical decision making regarding prognostication in ICU patients. Interdisciplinary team meetings may help nurses to express their observation in order for it to be recognized by other team members.

5.4 The role of the Advanced Practice Nurse

Hamric, Spross and Hanson (2005) describe five primary facets of the Advanced Practice Nurse (APN) role: expert clinician, consultant, researcher, leader and educator. This section will discuss the role of the APN as it relates specifically to the findings of this research study.

The APN – Intensive Care, provides care at the Advanced Practitioner Level (Masters prepared) and would work collaboratively with the inter-professional team. The APN works with complex patients and their families to support their needs throughout the critical illness trajectory from onset of illness through recovery or palliation. The APN works in partnership with staff nurses, clinical educators and the intensive care team to promote holistic care and provide leadership in developing, promoting and maintaining inter-professional collaboration to advance the practice of ICU nursing. The APN functions to support the broader vision of the institution as well as to support the philosophy of care and standards of care of the Intensive Care Unit.

5.4.1 Expert Clinician

As an expert clinician the APN - Intensive Care ensures the provision of specialized nursing care of patients and families in the Intensive Care Unit. The APN is in a unique position to facilitate the process of continuity of care as it relates to the ICU patient population. The APN role would encompass the completion of in-depth assessments of complex patients and their families. For example, if decision making or discussion regarding withdrawal of life sustaining treatment has been made or previously discussed, the APN could facilitate continuity of care by ensuring that information

regarding the needs/values of the patient and their family are maintained despite changing physician teams. In cases where discussions regarding withdrawal of life sustaining treatment have not taken place, the APN could act as a facilitator to identify family/patient situations where these conversations are needed and would then act as a coordinator to engage the family and healthcare team in discussion. The APN – Intensive Care would be in a position to follow specific patients/families to facilitate the implementation/modification of the plan of care in order to ensure that their needs are met. The APN – Intensive Care in their role as clinical expert could also lead advances in clinical practice for nursing such as the implementation of standards of care relevant to end-of-life care and withdrawal of life sustaining treatment in the ICU environment.

5.4.2 Consultant

The role of consultant as it relates to the APN in Intensive Care could consist of providing consultation to various individuals involved in the care of critically ill patients and their families. These individuals include staff nurses, unit managers, educators, physicians and virtually any member of the health care team that are involved in the care of critically ill patients. The APN could also provide consultation in the care of more complex family and patient situations. The process of consultation may be both formal and informal. Informal consultation may encompass answering the questions of staff nurses in regards to a clinical question or patient/family situation. Formal consultation may involve providing expert advice to managers and administrators to recommend changes in policy. The APN shares expertise and provides consultation beyond the boundaries of the institution into regional, provincial, national and international

communities in areas of specialization. For example the APN could help rural hospitals develop end-of-life policies.

5.4.3 Researcher

Ciccarello (2003) indicates that few procedures for end-of-life care exist in the intensive care environment. A key role for the APN as a researcher would include the continual examination and dissemination of the literature as it relates to end-of-life care in this environment. Evaluating current unit practice for example on sedation and analgesia as it is influenced by current research is essential. The APN could conduct research to further identify the needs of intensive care nurses, patients and families during withdrawal of treatment. The APN could further explore what participants described as the 'art of nursing' in intensive care.

5.4.4 Leader

In order to function effectively in the role of APN, leadership skills are essential. The APN acts as a mentor to nursing colleagues and others to improve and support nursing practice. The APN would be required to take on leadership roles as they relate to projects and program management and development within the Intensive Care from both intra- and inter-professional perspectives. Leadership and leadership activities in the APN role may be demonstrated at various levels. For example, the APN could function as a key resource in facilitating the development of end-of-life care policies at an institutional level as well as at the provincial and national level.

5.4.5 Educator

As an expert in the role, the APN – Intensive Care would recognize the need to provide further education related to withdrawal of life sustaining treatment. The APN might recognize that this aspect of care in the ICU environment is largely influenced by experience. The APN could collaborate with ICU Clinical Educators to develop mentorship programs within their respective intensive care units to support and better prepare intensive care nurses to care for patients and families throughout the process of withdrawing life sustaining treatment. Preparing in-services and reviewing of case studies on a regular basis may serve as helpful mediums for nurse education regarding end-of-life care in the ICU.

5.5 Limitations

In discussing the limitations of a qualitative study it is important to recognize that the purpose of a qualitative inquiry is not to produce findings that are generalizable to an entire population but to gain a deeper understanding of experience. As such, the findings of this study cannot be said to be reflective of the experience of all intensive care nurses who have cared for patients during withdrawal of life sustaining treatment or even within the specific unit in which the participants were employed. In addition, as this study was conducted in a large university affiliated health science centre, the findings may not be reflective of the experience of intensive care nurses employed in other major centres or in the community hospital setting.

It is also of importance to note that in critiquing phenomenological studies that addressed the experience of critical care nurses regarding withdrawal of treatment, the

researcher noted that between the three studies discussed, only one participant was male. As such the researcher had hoped to have male participation in the study in order to explore whether gender differences may be reflected in the experience. The outcome of this study was that only one male participated. It is possible that with limited male input, that the experience may not be reflective of the male nurses' who have cared for patients during withdrawal of life sustaining treatment. Further research would need to be conducted in order to address the possibility of gender differences.

A third limitation of the study is that all of the nurses interviewed were white and English speaking. Although the purpose of the study was not to address the influence of culture on the experience of caring for patients during withdrawal of treatment, it is possible that the cultural background of nurses may have an impact how nurses view death, and thus how nurses experience caring for these patients and their families. Further research involving different nursing populations is required.

On a final note, from an ontological perspective, the nature of reality in this study is one best reflected by an ontological relativism. Ontological relativism refers to "...realities existing in the form of multiple mental constructions, socially and experimentally based, local and specific and dependent for their form and content on the persons who hold them" (Guba, 1990, p.17). As such, with the existence of the multiple mental constructions of the participants as well as the multiple social and context specific situations in which their mental constructions or "experiences" are formed, it becomes theoretically impossible to capture an entire experience. The researcher cannot claim that the experiences described here "capture" the entire experience of intensive care nurses caring for patients during withdrawal of life sustaining treatment. However, this study

provides an interpretation of the experience of six intensive care nurses and it is consequently the interpretation of the findings by the research consumer to determine whether this study is related to or useful for their own experience, clinical practice or research endeavors.

5.6 Conclusion

The findings discussed in relation to this study have contributed to new nursing knowledge as it relates to the experience of intensive care nurses who care for patients during withdrawal of life sustaining treatment. The findings of the study were compiled into a detailed description of the experience of six intensive care nurses who agreed that the essence of the experience of caring for patients during withdrawal of life sustaining treatment and subsequently their family is captured in the statement "trying to do the right thing". The three major themes: *A Journey – Creating Comfort Along the Way*, *Working in Professional Angst* and *Providing Memories* formed the fundamental structure of the experience of these intensive care nurses and provided a framework for describing and interpreting the overall experience, as well as giving a voice to these nurses.

Intensive care nurses hold a unique and privileged position with regards to patient and family care in the intensive care unit. Their continual presence provides a means by which they establish relationships with patients and families; are intimately involved in the plan of care for patients; and, hold a unique and respected position amongst the health care team. Despite the many challenges intensive care nurses face, they strive over and

over again to "do the right thing", that which is right by the patient, the family, the health care team and amongst their nursing colleagues.

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APPENDIX A: Poster English

ATTENTION ICU NURSES
ARE YOU INTERESTED IN PARTICIPATING IN A NURSING RESEARCH STUDY?

Title of Project: The Experience of Intensive Care Nurses Caring for Patients for Whom Life-Sustaining Treatment is Being Withdrawn.

What is the study about?
The purpose of this study is to gain a greater understanding of the experiences intensive care nurses have when caring for patients throughout the process of withdrawal of life-sustaining treatment. The study is being conducted by Brandi Vanderspank, an MScN student, from the University of Ottawa. The researcher's supervisor for this study is Dr. Frances Fothergill-Bourbonnais of the University of Ottawa: School of Nursing.

Who is eligible to participate?
Registered nurses working in the ICU either full-time or part-time; who have cared for a patient for whom life-sustaining treatment has been withdrawn within the last six months; who have been employed in the ICU for the last six months and who are fluent in English.

What do I need to do?
If you are willing to participate, you will be invited to partake in two face-to-face interviews with the researcher. In the first interview you will be asked to reflect upon and describe your experiences caring for these patients. In the second interview, you will review the analysis of the interview to determine if it reflects your experiences.

How can I get involved?
If you are interested in participating in this study, you may contact Brandi Vanderspank at 613-937-2661 or you may attend an information session conducted by the researcher on November 8, 2006 at 0800 in the McCoy Room.

This research study has been approved by the Ottawa Hospital Research Ethics Board.

APPENDIX B: Poster French

ATTENTION INFIRMIERS(ÈRES) À L'UNITÉ DES SOINS INTENSIFS

ÊTES-VOUS INTÉRESSÉ À PARTICIPER À UNE ÉTUDE DE RECHERCHE?

Titre du projet:
L'expérience des infirmiers(ères) qui prodiguent des soins aux patients a l'Unité des soins intensifs et dont les traitements de survie leur sont retirés.

En quoi consiste cette étude?
Le but de cette études est d'acquérir une meilleure compréhension des expériences que vivent les infirmiers(ères) à travers tout le procédé de retrait des éléments de survie de leurs patients. Cette étude est dirigée par Brandi Vanderspank, une étudiante en MScN à l'Université d'Ottawa.

Qui est éligible de participer?
Infirmiers(ères) enregistrés(es) qui travaillent dans l'Unité des soins intensifs, à temps plein ou à temps partiel qui ont prodigué des soins à un patient dont les traitements de survie on été retirés et ce depuis les derniers six mois; avoir travailler dans l'Unité des soins intensifs durant les derniers six mois et parler couramment l'anglais.

Que dois-je faire pour y participer?
Si vous voulez y prendre part, vous serez invité à partager vos expériences avec la personne qui fait la recherche lors de deux entrevues. Au cours de la première entrevue vous devrez lui faire part des expériences vécues en prodiguant les soins à ces patients. Au cours de la deuxièmes entrevue, vous ferez la revue des analyses de l'entrevue pour déterminer si elles réflètent bien vox expériences.

Comment puis-je être impliquer?
Si vous êtes intéressé(e) à participer à cette étude, vous pouvez rejoindre Brandi Vanderspank au 613-937-2661 ou par votre présence à une séance d'information présentée par la personne en charge de cette étude le 8 Novembre a 0800h aux salle McCoy.

Cette étude a été approuvée par le Conseil d'éthique en recherches de L'Hôpital d'Ottawa.

APPENDIX C: Demographic Data Questionnaire

Demographic Data Questionnaire

Age:

Gender: Male / Female (please circle)

Years of experience as a nurse:

Years of experience as an intensive care nurse:

Years of experience in current Intensive Care Unit:

Basic Education:

Education in Critical Care:

Education in Palliative Care:

APPENDIX D: Information Sheet and Consent Form

Information Sheet and Consent Form

The Experience of Intensive Care Nurses Caring for Patients for Whom Life Sustaining Treatment is Being Withdrawn

Background of Study

It has been identified within the literature that the majority of patient deaths occurring in Intensive Care Units are as a result of life sustaining treatments being withdrawn. Nurses have been identified as the primary care givers to patients who are terminally ill and dying and are directly involved in the initiation of the withdrawal of life sustaining treatment. Limited research has described what the experience of this process of withdrawal of treatment is like for intensive care nurses.

Purpose and Design

The goal of this study is to describe the experience of intensive care nurses who have cared for patients for whom life sustaining treatment has been withdrawn. The objectives of this research study are to better understand this specific experience and to identify what makes this experience harder or easier for them.

This study will be conducted in English. Participation in this study will consist of two separate audio-taped, face-to-face interviews. The interviews will take place on the nurse's time, at a location and time identified as convenient by the participant. The first interview will last approximately 1 – 1 ½ hours and the second, ½ - 1 hour. During the first interview the participant will be asked to describe his/her experiences related to caring for patients for whom life sustaining treatment has been withdrawn. During the second interview the participant will be asked to verify that the data collected and analyzed by the researcher reflects the experience of the participant.

Risks

It is possible that either after or during the interviews that the participant may feel fatigued. It is possible that the discussion elicited during the interview may evoke painful thoughts or memories. If the participant is feeling fatigued the researcher will offer to take rest periods as needed and will ascertain the participant's willingness to continue with the interview. Every effort will be made by the researcher to ensure the participant's comfort throughout the interview process. If the situation should arise where the participant becomes upset during the interview, the researcher will allow time for them to regain their composure and again the researcher will ascertain their willingness to continue with the interview. The researcher will be prepared to provide support during the interview and will suggest the Employee Assistance Program, or other counseling

resources as necessary. The researcher will seek to terminate the interview should the emotional integrity of the participant be compromised.

Benefits
Through participation in this study the participants will be able to share their experiences with others. The practices of intensive care nurses related to end-of-life care and the care of patients and families during withdrawal of life sustaining treatment will be elaborated upon and described in great depth adding to nursing's body of knowledge.

Withdrawal from the Study
The participation is under no obligation to participate in the study. If he/she so chooses they may withdraw from the study at any time and/or refuse to answer any questions without suffering any negative consequences. If the participant should choose to withdraw from the study, all data gathered until the time of withdrawal will be destroyed by the researcher.

Compensation
There is no payment for participating in this study. Parking expenses, if applicable, will be incurred by the researcher.

Confidentiality
All information shared by the participant with the researcher will remain confidential. The contents of the data collected will be used only for the purpose of describing the experience of intensive care nurses related to this specific study. The confidentiality and anonymity of the participant will be protected by replacing their names with pseudonyms for transcription. In no way will the identity of the participant be revealed in future publications of the research being conducted. No records bearing the participant's name will leave the Ottawa Hospital. It is possible that interviewees will be quoted in the researcher's thesis or in future publications of the study however all personally identifying information will be removed or altered and contents of quotes will not be revelatory of individual identities. This however, is left to the discretion of the interviewee. See below.

I agree to be quoted but all personally identifying information shall be removed or altered and contents of the quote shall not be revelatory of my identity. _____

I do not wish to be quoted at all. _____

Voluntary Participation
There is no obligation to participate in this study. The participant may withdraw from the study at any time without suffering any negative consequences. In no way will

participation or withdrawal from this study have any bearing on the participant's employment status or future employment evaluations.

Questions about the Study

The following names and phone numbers have been provided by the researcher. Should the participant have any questions about the study they may call these contacts.

Brandi Vanderspank RN, BScN MScN Student, School of Nursing, Faculty of Graduate and Post-Doctoral Studies, University of Ottawa - Researcher
Tel.
Email:

Dr. Frances Fothergill-Bourbonnais, Full Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa - Supervisor
Tel. 613 - 562 – 5800 ext. 8423
Email: fbourbonnais@uottawa.ca

If the participant should have any questions regarding their rights as a research subject, they may contact the Chairperson of the Ottawa Hospital Research Ethics Board at 613 - 798 – 5555, extension 14902.