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Critical Care Nurse Perceptions and Experiences Regarding Their Role in the Decision Making Process to Withdraw Life-Sustaining Treatment: A Focused Ethnography

by

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Abstract

The purpose of this study was to gain an understanding of Critical Care Nurses' (CCNs) perceptions regarding their role during the decision-making process to withdraw life-sustaining treatment. Through the use of focused ethnography, six CCNs were interviewed using semi-structured interviews. Using the process of constant-comparative analysis, four themes were identified: The roles desired by the CCN, the barriers to implementing this desired role, the facilitators to implementing the desired role, and the outcomes of being unable to fulfill the desired role. This study indicates that CCNs want to be involved in the decision-making process as patient/family advocates and information providers, but several barriers exist which prevent this involvement. When CCNs are not involved in the decision-making process to withdraw life-sustaining treatment they experience feelings of powerlessness and burn-out. Yet, facilitators do exist in assisting the CCN to implement the roles of patient/family advocate and information provider.

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Critical Care Nurse Perceptions and Experiences Regarding Their Role in the Decision Making Process to Withdraw Life-Sustaining Treatment: A Focused Ethnography

Chapter 1: Introduction

Registered Nurses (RNs) who work in critical care environments are faced with many challenges associated with caring for seriously-ill patients. These challenges are greatly increased when they care for patients whose health status is deteriorating and whose families are in crisis. Advances in technology, although beneficial for treating many patients, have contributed to overly aggressive treatment and management of some critical care patients (Monterosso et al., 2005). When intensive care is considered futile, in that it is seen as only prolonging death and causing suffering, it becomes necessary to decide whether to withdraw life-sustaining treatments. In critical care environments, patients are usually not able to participate in these decisions as they are gravely ill. In addition, their wishes about continued treatment are often unknown (Kjerulf, Regehr, Popova & Baker, 2005), making these withdrawal decisions potentially problematic. Disagreements over the treatment-withdrawal decision may occur within families, between families and physicians, and also between different care providers such as physicians and nurses (Gedney-Baggs & Schmitt, 2000). Many concerns can arise with these decisions, in part because the decision has such serious consequences. As Schneider (1997) stated, "the spectre of one individual judging the quality of life of another gives rise to potent fears" (p. 175).

Research Problem

Despite the integral role that critical care nurses (CCN) have in the care of seriously ill and perhaps dying patients and their families, they have in past years tended to have only a minimal role in decisions to withdraw life-sustaining treatment (Bucknall & Thomas, 1997; Gedney-Baggs et al., 1999; Thibault-Prevost, Jensen & Hodgins, 2000). CCNs were found to be "caught in the middle" between the competing demands of family and physician (Beckstrand, Callister & Kirchhoff, 2006, p. 41). Yet, families then and now, rely on CCNs to provide information regarding the patient's health status and prognosis. If the CCN is unaware of the doctor's plan for the patient, that CCN may have concerns about providing information to families due to fears of providing inaccurate information. Although providing limited information alleviates the risk of providing conflicting information, it does little to alleviate the fears or concerns of the family, and may lead to increased tension between family and care providers. Furthermore, these situations are often extremely frustrating for nurses, as they create considerable moral distress in the current situation of chronic understaffing and overwork (Beckstrand et al.).

CCNs, by virtue of their professional education and experiences, coupled with their understanding of the patient and family through many hours of direct care giving, could have a valuable role in the decision-making (DM) process to withdraw life-sustaining treatment. To fulfill this role, CCNs need to be included as active, valued members of the health care team. This involvement is needed so CCNs and the hospital can properly care for patients, provide care that is consistent with patient and family wishes, and supply accurate, consistent information to patients and families. Although past research studies have been undertaken on this issue, many of these are dated and many are non-Canadian. This research study was undertaken to address this gap. The purpose of this study was to understand the current involvement and role that the CCN currently has, and would also like to have in the decision-making (DM) process to withdraw life-sustaining treatment. Furthermore, factors that are barriers or facilitators to CCNs involvement in this process were investigated.

Significance of the Study

As will be illustrated in Chapter 2 (literature review) relatively few studies have examined the perceptions and experiences of CCNs regarding their role in end-of-life decision-making. This lack of information regarding the CCN's role in end-of-life DM may be reflective of the "hierarchic authority" in DM present in many hospitals, in which physicians pay minimal attention to nurses' input (Gedney-Baggs & Schmitt, 2000, p. 159). This study provides CCNs with the opportunity to offer their input and voice their opinions regarding their role in end-of-life DM. Furthermore, understanding CCNs' perceptions regarding their role in the DM process to withdraw life-sustaining treatment may provide healthcare administrators and managers with mechanisms to improve the job satisfaction of CCNs. Within the current healthcare system in which there are shortages of CCNs, providing healthcare administrators and managers with mechanisms to improve CCN job satisfaction may promote the recruitment and retention of CCNs.

Also, researchers have found that the care provided to patients and families is negatively affected by poor communication between healthcare providers. Kjerulf, Regehr, Popova, and Baker (2005), in their study of family perceptions of end-of-life care, reviewed several studies that indicated concern regarding lack of communication between health care providers and families, due in part because of limited access to physicians. Furthermore, their review indicated that family perceptions of care are affected by opportunities to discuss treatments, and by having their questions answered consistently by nurses and doctors. Therefore, it can be inferred that increased involvement of CCNs may positively affect family perceptions of care if CCNs have the information necessary to discuss treatments and answer questions. Ultimately, as Beckstrand et al. (2006) stated, "gaining an increased understanding of the perceptions of CCNs' of changes that would facilitate appropriate end-of-life care is important to ultimately improve the care of dying patients" (p. 39).

Through this study, an understanding of the role of CCNs during the DM process to withdraw life-sustaining treatment, as well as the barriers and facilitators to CCNs' involvement in decisions to withdraw life-sustaining treatment has been ascertained. Through the use of focused ethnography, common themes emerged, ones which illuminate areas of common concern for CCNs working within the critical care environment. This information may provide the incentive to develop policy for improved practice, and could also stimulate further research on this topic.

In Chapter 1 and 2 of this thesis, a review of the literature relevant to the role of CCNs and Registered Nurses (RN) in end-of-life DM is provided, followed by a description of the research design and data analysis techniques utilized when performing this study (Chapter 3). Chapter 4 (study findings), provides a description of the role of the CCN during the DM process to withdraw life-sustaining treatment and the barriers and facilitators to the CCN implementing this role from the perspective of the CCN. Furthermore, the outcomes of not being able to implement the desired CCN role are illustrated. Finally, a discussion of the findings is offered to relate the findings to the current literature. Within this discussion section, the implications for future research and limitations of this study are discussed.

Research Question

What are the perceptions and experiences of CCNs who are working in adult critical care units, regarding their involvement in the DM process of whether or not to withdraw life-sustaining treatments from patients?

Sub-Questions

1. How are CCNs currently involved in the DM process to withdraw life-sustaining treatment?

2. What role do CCNs envision themselves having in the DM process to withdraw life-sustaining treatment?

3. What are the perceived factors that facilitate the ability of the CCN to carry out their ideal role in the DM process to withdraw life-sustaining treatment?

4. What are the perceived factors that inhibit the ability of the CCN to carry out their ideal role in the DM process to withdraw life-sustaining treatment?

Definitions of Terms

The goal of this study was to explore the CCN's emic understanding of their role in the DM process to withdraw life-sustaining treatment. To start and initially guide the study the following definitions were used:

Decision Making: "Discriminative thinking that is used to choose a particular course of action" (Bakalis & Watson, 2005, p. 33).

Withdrawal of Life-Sustaining Treatment: "Discontinuation of one or more treatments without replacement by an equivalent treatment with the objective of allowing a disease to run its course and with the knowledge that this might lead to the patient's death" (Ferrand et al., 2003, p. 1311). Comfort care continues, but high technology interventions such as mechanical ventilation, kidney dialysis, and inotropic or other life-supportive medications may be removed.

Collaboration: “Sharing of information, co-ordination of work, and joint decision making on aspects of patient care” (Zwarenstein & Bryant, 2005, p. 3).

Futility: When a treatment is determined as being “non-beneficial because it offers no reasonable hope of recovery or improvement, or because the person is permanently unable to experience any benefit” (Canadian Nurses Association, 2000, p. 3).

Advocate: “Someone who acts in the best interest of the patient and family to produce the best possible outcome” (Monterossa et al., 2005, p. 113).

Chapter 2: Literature Review

An examination of the literature regarding the role of the CCN, physician, patient, and family members in decisions to withdraw life-sustaining treatment will be provided in order to offer an understanding of the key issues and factors affecting decisions to withdraw life-sustaining treatment. This understanding is also needed to establish if nurses have or have not been involved in the past in the DM process to withdraw treatment.

Articles pertaining to the proposed study of CCNs involvement in DM were obtained by searching four key electronic library databases (i.e. CINAHL, Medline, PubMed, and the Cochrane Database of Systematic Reviews). Articles were limited to those published within the last 10 years. Position statements, ethical documents, and practice documents developed by the Canadian Nurses Association (CNA), the Canadian Nurses Protective Society (CNPS), and the College and Association of Registered Nurses of Alberta (CARNA) were also sought as they are critical for guiding Canadian nursing practice. Forty-eight articles relevant to the study were found, and are cited as they were relevant to the research question. Following this, the Humanities International Complete database, Psychiatric and Behavioral Science Collection, and the Sociological Collection databases were also searched in an attempt to broaden the scope of the literature review. No articles were found through this search that pertained to the proposed topic of interest. Although some articles examined end-of-life DM, none of the articles examined the role of the nurse in end-of-life DM.

Within the reviewed literature, three key factors were identified as affecting the role of the CCN in DM to withdraw life-sustaining treatment: (a) the number of years of nursing experience, (b) the ability of the nurse to carry out the role of patient advocate, and (c) the degree and quality of collaboration between physicians and CCNs. A discussion of each of these three foci follows.

The Influence of Experience on Nurses Involvement in Decision Making

Years of nursing experience may influence a nurse's level of involvement in DM. Berner, Ives, and Astin (2004) found nurses who were over 40 years of age as well as those with more than 10 years of nursing experience were more likely to agree that doctors and allied health professionals wanted CCNs involved in significant decisions, compared with those who were under 30 years old and those who had less than 10 years nursing experience. Bucknall's (2003) study found that less experienced RNs were more influenced by professional hierarchies and were less confrontational, and were therefore less likely to assert themselves in end-of-life DM. Furthermore, more experienced nurses usually had higher levels of self esteem and were more confident in collaborating with other health care professionals. A Greek study by Lyytikainen and Turunen (2003) similarly found that nurses with many years of experience in intensive care units and with end-of-life DM often participated in decisions to withdraw care. In an earlier study by Simpson (1997), that used a grounded theory method to study the experiences of nurses caring for hopelessly-ill patients, junior nurses were unsure that they had much influence in DM. In contrast, more senior nurses felt confident that "their input was valued and acted upon" (Simpson, p. 193). In contrast to the above studies, Hoffman, Donoghue, and Duffied (2004) performed a correlational study in Australia, which examined nurses' DM about common nursing interventions. The study demonstrated no significant relationship between nursing experience and clinical DM.

Four of the studies mentioned above (Berner et al., 2004; Bucknall, 2003; Lyytikainen & Turunen, 2003; Simpson, 1997) indicated that nurses who are more experienced and/or who are over 40 years of age feel more comfortable and confident in participating in the DM process and are therefore more apt to contribute to withdrawal decisions. Yet, the study by Hoffman et al. (2004) did not find any correlation between experience and the involvement of nurses in clinical DM. Further research is needed to determine whether or not years of nursing experience influences the confidence and involvement of the CCN in DM.

Nurse as Patient Advocate

One of the key roles that nurses are often thought to have in the care of patients is that of patient and/or family advocate. The CNA *Code of Ethics for Registered Nurses* (2003) lists choice, dignity, and fairness as three of the key values of the RN. In order to uphold these values, the RN must respect and advocate for the autonomy of patients to "express their health needs" and "obtain appropriate information and services," they must advocate for the dignity of their patients and families, to ensure that patients and families receive unbiased treatment (p. 12); all of which are factors that must be considered in the DM process to withdraw life-sustaining treatment.

A considerable number of researchers (Counsell & Guin, 2002; DeWolf-Bosek, 2005; Gleason, Sochalski & Aiken, 1999; Kjerulf et al, 2005; Miller, Forbes & Boyle, 2001; Oliverio & Fraulo, 1998; Schnedier, 1997; Seaburn, McDaniel, Kim & Bassen, 2004; Sjokvist, Nilstun, Svantesson & Berggren, 1999) have similarly reported that nurses have a very important role to play as patient and/or family advocates. Gleason et al. (1999) reported that the professional nurse is an "integrator," who interacts with other care providers, and with patients and families to co-ordinate and communicate the views of all involved so as to reach an agreement that is suitable or at least acceptable for all parties. Simpson (1997) similarly indicated that nurses may see themselves as "go-betweens" between families and physicians. Registered Nurses (RNs) are likely to have the education and skills to fulfill this go-between role since they often assess family and patient needs from the patient/family perspective, the medical perspective, and the nursing perspective. Furthermore, Calvin, Kite-Powell, and Hickey (2007) used a grounded-theory methodology in their study to examine neuroscience Intensive Care Unit (ICU) nurse perceptions about their roles and responsibilities in the DM process during the “change in intensity of care” (p. 144). They found participants identified their role as educator of the patient and family by answering questions, and providing guidance and reassurance during the DM process, and as an intermediary or translator between the patient/family and the physician. Yet, these nurses recognized the physician as the final decision-maker. In a qualitative design using narrative analysis of interviews, CCNs described the need for the nurse to protect and/or speak for their patient (Robichaux & Clark, 2006).

Although many authors to date have promoted the role of the nurse as patient advocate, a number of studies have found many nurses are not able to fulfill this key role. Using a two-phase quantitative and qualitative descriptive design, Monterossa et al. (2005) examined Neonatal Intensive Care Unit (NICU) nurse perceptions of their role as patient advocates, and their involvement in ethical decisions. This study revealed that NICU nurses viewed their role in DM as advocating for the best interests of the patient and family, but they felt their views were not considered when decisions were being made. A descriptive survey study by Thibault-Prevost, Jensen, and Hodgins (2000), involving 405 CCNs working in critical care areas across Alberta who responded to a survey regarding their attitudes, knowledge, and practices related to Do Not Resuscitate (DNR) orders was also revealing of end-of-life DM perceptions and practices. Despite the close proximity of nurses to patients and families, 53.1% of respondents seldom initiated DNR discussions with patients or families, but 45.2% initiated DNR discussions with physicians. All respondents agreed that despite having little influence in DNR discussions, the nurse was left to implement the outcomes of all DNR decisions. A study by Schneider (1997) also found that despite nurses spending the most time with the patient and family, and who carried out the responsibility of caring for the patient and family during the withdrawal process, they were not confident enough in their abilities to represent their own views or those of the families to physicians.

Despite the close proximity that nurses have with patients and families, and the important role they have to play as patient and family advocates, they often lack involvement in DM (Bakalis & Watson, 2005; Bucknall, 2003; Counsell & Guinn, 2002; Ferrand et al, 2003; Gleason et al., 1999; Shannon, Mitchell & Cain, 2002; Schneider, 1997). Ferrand et al. argued that the nurse's unique closeness to the patient and family, and their ongoing interaction with physicians makes a strong argument for including RNs in end-of-life DM. This sentiment is supported by Shannon et al. (2002), who found CCN closeness to patients and families allows the CCN to have a better understanding of patient and family feelings, as compared to physicians. Shannon et al.'s study compared patient, nurse, and physician perceptions of patient satisfaction and care quality. They found that physician perceptions of care quality and patient satisfaction were higher than the perceptions of both patients and nurses; while nurses and patients had similar views. Similarly, Beckstrand et al. (2006) found congruity between nurse and patient descriptions of factors which contribute to a good death. Two additional studies also revealed that when nurses are absent from end-of-life DM, patients and families are left alone with the burden of making these complex decisions, and the stress of families subsequently increased (Berg & Ahmann, 2006; Miller et al., 2001).

The studies above suggest that many nurses feel they have a role as a patient/family advocate in DM, yet they are not able to fulfill this role for a number of reasons. Rhodes (cited in Hoffman et al., 2004) suggested that a paramedical occupational orientation places nurses as subordinates to doctors, and leads some nurses to feel that their role is to only follow doctors' orders. Gedney-Baggs et al. (2007) similarly performed ethnographic field work in four adult ICUs to evaluate the similarities and differences between four ICUs, and the influence that unit culture plays on end-of-life DM. They found that the role of the attending physician in this end-of-life DM was influenced by their position in the institutional hierarchy and their power over the use of technology, which meant that they strongly shaped the unit's culture and the role that other health professionals take in the DM process.

Another reason for the inability of the CCN to fulfill the role of patient advocate may be that nurses lack the skill and knowledge of how to fulfill the role of patient/family advocate, as suggested by Seaburn et al. (2004). Without clear direction and support, nurses may be uncertain and confused regarding their role in DM; leading to feelings of frustration, hopelessness, and helplessness (Jones & Fitzgerald, 1998). Furthermore, nurses are often at risk for role conflict as their role of patient advocate may come into conflict with hospital policy and/or doctors' orders. This conflict can challenge nurses' moral and ethical belief systems (Dawe, Verhoef & Page, 2002; Evans, 2007). Robichaux and Clark (2006) described a possible outcome of this challenge to the nurses' belief system as moral distress, a state which occurs "when a person knows the right thing to do, but the institution or colleagues make it difficult or impossible to do what the person thinks is best" (p. 486). Moral distress is often expressed as anger, guilt, and despair. Without clarity of the nurse's professional and functional role, breakdowns in communication can occur and have a direct impact on the care provided to patients and families (Caldwell & Atwal, 2003). The effect of moral distress and the impact it has on the care provided to patients and families and on CCN job satisfaction was similarly described by McClendon and Buckner (2007). In this study, CCNs were asked open-ended questions regarding their feelings about moral distress and a questionnaire was administered to the CCNs to measure the degree of distress caused by certain healthcare situations. McClendon and Buckner found CCNs experiencing moral distress often felt burnt-out and had a "short fuse" (p. 202) with patients and families. Furthermore, the CCNs brought these feelings of distress home which caused them to short-tempered, irritable, or grouchy with their family. The CCNs in this study believed that "support groups" (p. 202) for nurses to discuss difficult situations and having support from managers and administration would be effective strategies for coping with moral distress.

In order to fulfill the role of patient advocate, the nurse must be able to develop a sense of trust with the physician. After analyzing data from interviews conducted with nurses regarding their experiences caring for terminally-ill patients, Simpson (1997) found one of the key categories which emerged from the data was the importance of the nurse in developing a feeling of trust with the physician who ultimately makes the decision to withdraw treatment. In order for this trust to develop and for nurses to feel comfortable with the decision made, nurses need to feel that their opinions have been sought, and meaningful dialogue has taken place between the healthcare team and family. Without this sense of trust, this study revealed that nurses had difficulty caring for the patient and family, and nurses were even reluctant to care for these patients. Although this and other studies provide some insight into the reasons for lack of involvement in DM by nurses, Schneider (1997) recommended further exploration into the lack of nursing involvement in ethical DM.

Although many authors support the role of the nurse as patient advocate, Oliverio and Fraulo (1998) found that when families were provided with a nurse clinician who helped elicit patient/family preferences and facilitated discussions between patients/families and health care providers, there were no significant differences in outcomes from the non-intervention group of patients and families who did not have access to a nurse clinician to facilitate end-of-life discussions, and the intervention group who had access to the nurse clinician. Furthermore, even with the assistance of a nurse clinician, patients/families and physicians continued to fail to understand one another. In spite of this conflicting finding, the role of the nurse as patient advocate continues to be encouraged by various authors and professional nursing associations. Therefore, and despite Oliverio and Fraulo, an exploration of the factors which facilitate and hinder the CCN as patient/family advocate is required.

As early as 1999, the Canadian Nurses Association along with the Canadian Healthcare Association, the Canadian Medical Association, and the Catholic Health

Association of Canada encouraged all those involved in DM to "express their points of view, and that these views should be respectfully considered" (p. 1). At least, one would expect nurses to assist families and patients in having their points of view expressed in an increasingly complex healthcare environment. Yet, to allow nurses to fulfill the role of patient/family advocate, physicians need to be willing to provide an open, respectful environment where nurses can fulfill their role with confidence.

In summary, within the literature and as promoted by the Canadian Nursing Association, the nurse may have an important role to play as a patient/family advocate. Yet, nurses have encountered difficulty with implementing this role due to lack of education regarding the advocate role, the influence of hierarchical authority, and the role of patient advocate conflicting with hospital policy and/or doctor's orders. The importance of the patient/family advocate role, the ability of the CCN to execute this role, and the barriers and facilitators to implementing this role are examined in this study.

Collaboration between Physicians and Nurses

The literature review also revealed the importance of collaboration between physicians and nurses for successful communication, so as to provide effective care of patients and families. Gleason et al. (1999), in their review of magnet hospitals, found collaboration between physicians and nurses significantly affected patient outcomes, reduced nurse turnover rates, and improved nurse perceptions of being able to meet family and patient needs. Thomas, Sherwood, Mulhllem, Sexton, and Helmreich (2004) found similar results through their study of nurses working in a Neonatal Intensive Care Unit. They found that nurses felt the unit functioned best in a climate of collaboration, with effective teamwork also perceived as essential for effective patient care. Gedney-

Bagg et al. (1999) similarly demonstrated the positive effects of collaboration in a study that examined the association of physician-nurse collaboration on patient outcomes in a medical ICU. They found that for every one point increase in collaboration, the odds of a negative patient outcome were decreased by four percent. Despite this finding, it should be noted that Gedney-Bagg et al. found no association between collaboration and negative patient outcomes in surgical ICUs, and in a community non-teaching hospital.

The beneficial outcomes of effective collaboration and communication are further emphasized in other occupations, including the commercial aviation industry. The link between teamwork and safety was noted after investigators found the root cause of many aviation accidents was the crew's reluctance to question the captain's performance. When this issue is applied to collaboration within healthcare settings, similar issues with intimidation and lack of approachability of many physicians have been found (Makary et al., 2006). Ultimately, a nurse who is intimidated will be reluctant to question an order or raise an issue. Safe care requires teamwork, good communication, and collaboration (Evans, 2007). Collaboration is a power-sharing partnership that must include "cooperation, assertiveness, communication, responsibility, autonomy, and co-ordination" (Bailey & Armer, 1998; cited in Smith, Myer & Wylie, 2006, p. 520). Good teamwork is an essential component of nurses' job satisfaction. Poor teamwork is a considerable source of nurses' dissatisfaction with their profession and may contribute to today's nursing shortage (Makary et al.).

Despite the many positive outcomes that are possible with collaboration, there is growing evidence that many nurses are unhappy with the amount of collaboration between physicians and themselves. Monterosso et al. (2005) found 69% of RNs surveyed were never involved in decisions to withdraw life-sustaining treatment. Even when nurses were being assertive in presenting their views, they were not involved in complex ethical decisions. Thibault-Prevost et al. (2002) similarly found 80.7% of RNs felt nurses should be involved in DM regarding DNR orders, yet 67.2% stated they were infrequently involved in these decisions. This non-involvement issue was also reflected in Berner et al.'s (2004) study, in which 98.7% of RNs stated they had information to contribute to DM, but only 43.3% felt they were actively involved in DM. Ferrand et al.'s (2003) study is also revealing, as it found 79% of MDs felt they considered nurse opinions regarding patient care decisions, as compared to only 31% of RNs. Rodney, Hartrick-Doane, Storch, and Varcoe (2006) conducted research using a participatory action research project to understand the challenges nurses face in providing ethical care. Nurses in a critical care unit decided to focus on three issues that they viewed as impairing their ability to provide safe, competent, and ethical care. These issues included physical environment concerns, problematic end-of-life care, and fragmented interdisciplinary team communication. Finally, Beckstrand and Kirchhoff (2005) mailed questionnaires to 300 CCNs in the United States to determine CCNs' perceptions of obstacles and helpful behaviors in providing end-of-life care. The CCNs identified obstacles as relating to issues with families, and problems with physicians' behaviors. Helpful behaviors included the family accepting the patient's prognosis, and agreement among physicians about appropriate end-of-life care. Makary et al. (2006) indicated that the factors that may influence the level of nurse involvement in DM, and collaboration between RNs and MDs are related to the history of nursing, gender, patient care responsibilities, differing communication styles, and the process of professional socialization.

Historically, nurses have also been constrained from making decisions and using professional judgment due to the "rules, policies, and expectations of the institution" (Mathes, 2004, p. 431). The process of professional socialization may further contribute to constrain nurses from DM. Professional socialization is the process by which "professionals' learn during their education and training the values, behaviors, and attitudes necessary to assume their professional role" (Mathes, p. 23). Through professional socialization, nurses learn how to play the doctor-nurse game; thereby adhering to the paramedical orientation of healthcare. In this game, the nurse assumes a passive manner and makes recommendations in a way that makes it appear to have been the physician's idea rather than the nurse's (Smith et al., 2006). This game continues to be played in hospitals today (Evans, 2007). As Thomas et al. (2004) noted, hierarchical structures continue to have a powerful influence on the way healthcare providers communicate with each other. The influence of hierarchical structures is demonstrated in Bucknall and Thomas' (1997) study of 238 CCNs in Australia who were surveyed to investigate CCN impressions of problems associated with clinical DM. These CCNs indicated that there was a lack of respect and confidence in RN skills and knowledge by physicians. There appeared to be a discrepancy between CCNs' high level of education and the low level of responsibility they were given. Inequalities in power can constrain teamwork and enhance the boundaries between professional groups (Caldwell & Atwal, 2003), thereby leading to lessened inter-professional collaboration. The process of professional socialization and the influence of hierarchical structures may continue to influence nurse thinking, and thus serve to maintain antiquated social practices and roles;

contributing to poor communication and collaboration between physicians and nurses.

Another issue identified in four studies (Beckstrand et al., 1997; Bucknall & Thomas, 1997; Gedney-Baggs & Schmitt, 2000; Rocker et al., 2005), demonstrates that physicians and nurses often disagree about appropriate levels of treatment for patients with poor expected outcomes. Rocker et al. conducted a cross-Canada study that examined respiratory therapist and RN perspectives regarding withdrawal of treatment in the ICU. Many RNs in this study reflected on the need to talk to families earlier regarding withdrawal of life-sustaining treatment, and to write DNR orders earlier. Some RNs found families were open to withdrawal, but physicians were slow to discuss this issue. Beckstrand et al. also reported that nurses have indicated that physician behavior, such as being unrealistic about a patient's prognosis acts as a barrier to providing a “good” death for patients. Furthermore, in a descriptive survey of 60 CCNs regarding their perceptions of futile care and burnout, it was found that the frequency that CCNs felt moral distress was directly and significantly related to the experience of emotional exhaustion from providing what they perceived as futile care (Meltzer & Huckabay, 2004).

Another potential issue is the discrepancy between physician and nurse perceptions of effective collaboration and communication. Through a very revealing study, Makary et al. (2006) found "nurses often describe good collaboration as having their input respected, and physicians often describe good collaboration as having nurses who anticipate their needs and follow their instructions" (p. 748). Furthermore, Ferrand et al. (2003) conducted a study in France to assess the association between unit policies, DM processes, collaboration, and caregiver satisfaction. This study similarly demonstrated the discrepancy between physician and nurse perceptions of collaboration, as 91% of RNs and 80% of doctors thought decisions should be made collaboratively, yet only 27% of nurses and 50% of doctors believed this actually occurred.

In order for collaboration to be truly effective and thereby improve patient/family care, the perceptions of nurses and physicians regarding collaboration must become more closely aligned. Furthermore, both physicians and nurses need to function in an environment which respects their input; since "collaboration allows input from the differing perspectives of nursing and medicine and because each profession has special expertise, it can lead to enlightened patient (and family) management" (Seaburn et al., 2004, p. 184).

Family Perceptions of the DM Process and the Role of the CCN

According to Seaburn et al. (2004), each family is unique, as they are influenced by their history, health beliefs, and religion; all of which contribute to how they experience the process of withdrawal of life-sustaining treatment, their relationships with health professionals, and their level of involvement in DM. Families have also expressed the need for consistent and reliable communication from healthcare providers (Gedney-Baggs & Schmitt, 2000; Kjerulf et al., 2005; Seaburn et al.).

Families may feel communication with physicians is ineffective. In one study, 54% of families did not understand the patient's diagnosis, prognosis, or treatment (Seaburn et al.). Similar issues regarding ineffective physician communication were found by Tolle, Tilden, Rosenfeld, and Hickman (2000) in their study that identified barriers to optimal care of the dying. Families of patients who had died in various settings (i.e.: hospital, nursing home, and at home) were interviewed 2 to 5 months after their loved one's death. The main themes which arose regarding what was the most difficult part of their loved one's death were: Communication difficulties with providers and between providers, inadequate information about the prognosis, uncaring attitudes and behaviors by physicians, and dissatisfaction with various aspects of medical care. Furthermore, a study by Counsell and Guin (2002) found many families were not even aware that death was a possible outcome of their loved one's care; another finding that further demonstrates a lack of effective communication between families and health care providers.

Families need the experience and knowledge of health care professionals to guide and support them in the DM process to withdraw treatment (Berg & Ahmann, 2006; Gedney-Baggs & Schmitt, 2000; Jones & Fitzgerald, 1998; Kjerulf et al., 2005; Schneider, 1997). Yet, Oliverio and Faulo (1998) found some families felt burdened by being placed in a position to make the decision to end the care of their loved one. These families wanted the decision to be taken out of their hands.

Each family is unique and must be cared for according to their individual needs. The CCN can have a critical role in fulfilling the need of families for effective communication by building rapport with families, gaining the trust of families, and providing information and support (Schneider, 1997), which can only be accomplished through effective collaboration between the CCN and the physician.

Physicians' Perceptions of the DM Process and the Role of the CCN

Physicians often make the final decision to withdraw life-sustaining treatment. As determined by Sjokvist et al. (1999), 61% of physicians felt they alone should make the decision to withdraw treatment. Within the literature, several factors which influence the amount of outside input a physician allows in end-of-life DM, and which also guide him/her in making a decision about withdrawal of life-sustaining treatment have been examined. These include: The physician's attending status and specialty, physician age, physician religion, the patient's age and gender, briefness of interactions with patients and families, a wish to relieve the families' burden and guilt accompanied with making decisions to withdraw treatment, the difficulty with having end-of-life discussions, and poor communication skills (Gedney-Baggs & Schmitt, 2000). Kollef (cited in Kjerulf et al., 2005) suggested that physicians may have difficulty discussing withdrawal of treatment with families due to "demands on time, reimbursement strategies that favor more aggressive levels of care, societal expectations of medical cures" (p. 23), and the perspective that a patient's death is a personal failure.

Recommendations and Conclusions

This review of past studies reveals that one of the underlying issues affecting the role of the CCN in the DM process to withdraw life-sustaining treatment appears to be a lack of collaboration between CCNs and physicians. Yet, the number of years of nursing experience may influence CCN confidence and skill in collaborating with physicians, and their involvement in end-of-life DM. Without the involvement of CCNs in these decisions, families and patients may not receive the support and information they require during the DM process to withdraw life-sustaining treatment. Before any meaningful changes to the role the CCN has in decisions to withdraw life-sustaining treatment are made, the perceptions of CCNs regarding their current and ideal role and involvement in DM to withdraw life-sustaining treatment, and the barriers and facilitators to this ideal role must be ascertained.

Review of Past Research Methods

The majority of the past studies reviewed above employed quantitative research methods, primarily through the use of likert-style questionnaires. These quantitative studies have revealed some valuable information regarding the role of the CCN in DM to withdraw life-sustaining treatment. Yet, none of these studies allowed the CCN to independently describe their ideal role in the DM process to withdraw life-sustaining treatment, or for the CCN to identify in their own words the barriers and facilitators to their ideal involvement. Few studies used a qualitative methodology to elicit information. One exception was Simpson's (1997) study that used grounded theory method to examine the experiences of nurses caring for terminally-ill patients. Jones and Fitzgerald (1998) used interpretative phenomenology to understand the experiences of CCNs during the withdrawal of life support from their patients. Sibbald, Downar, and Hawryluck (2007) used grounded theory to understand the perceptions of futile care among health care providers, and Gedney-Baggs et al. (2007) used ethnography to describe the effect of intensive care unit culture on end-of-life DM. Finally, a study by Calvin, Kite-Powell, and Hickey (2007) used a qualitative descriptive study of neuroscience Intensive Care Unit nurses' to understand neuroscience nurses' perceptions about their roles and responsibilities in the DM process to change the intensity of care. Although these qualitative studies allowed the CCN to provide information in their own words, only the study by Calvin, Kite-Powell, and Hickey provided a description of the role of the CCN during end-of-life DM from the perspective of the CCN.

Many past studies were completed within critical care units, and focused primarily on physician and nurse perceptions of nurse involvement in ethical decisions

(Berner et al., 2004; Bucknall, 2003; Ferrand et al., 2003; Bucknall & Thomas, 1997; Monterosso et al., 2005). As Jones and Fitzgerald (1998) found, however, there is a lack of research examining the perceptions and experiences of nurses involved in the DM process to withdraw life-sustaining treatment. Furthermore, many of the studies included in this literature review were conducted in the United States and Europe, and thus may not be reflective of the current Canadian situation.

Chapter 3: Method

Research Design

Based on the purpose of this study, which was to understand the perceptions of CCNs regarding the role they would like to have in DM to withdraw life-sustaining treatment, and to examine the barriers and facilitators to the implementation of this role, a qualitative research design was chosen as the most appropriate research method. “Qualitative research enables us to make sense of reality, to describe and explain the social world and to develop explanatory models and theories” (Morse & Field, 1995, p. 1). The goal of this study was thus to “make sense” of the experiences of CCNs, and examine the factors which affect their role in the DM process to withdraw life-sustaining treatment from the perspective of the CCN. According to Sibbald, Downar, and Hawryluck (2007), qualitative methods are appropriate when trying to understand complex social phenomena such as what occurs in critical care units. Furthermore, qualitative methods are especially appropriate for gaining an emic perspective of a phenomenon, such as when the issue is described from the perspective of the individual experiencing the phenomenon, and when there is a need to describe a phenomenon about which little is known (Morse & Field). As described in Chapter 2, many authors have recommended that further studies be conducted regarding the role of the CCN in ethical DM. Research regarding nurse perspectives is also indicated, as Beckstrand et al. (2006) stated, "ongoing dialogue is essential to make visible the voices of nurses and to describe nurses' visions for future improvements in end-of-life care" (p. 4).

Initially, this study was conducted using a grounded theory methodology. Grounded theory addresses questions in which in-depth understandings of the dimensions of an experience or the processes of an experience are required (Morse & Richards, 2002). The grounded theory method must focus on answering the question, "What is the basic social process that underlies the phenomenon of interest" (Reed & Runquist, p. 119). As stated by Backman and Kyngas (1999), the basic social process "explains a considerable portion of the action in an area and relates to most categories of lesser weight used to make the theory workable" (p. 148). After attempts to identify a basic social process from the data it was determined, in consultation with the thesis supervisor and a thesis committee member, that a focused ethnography would be a more appropriate research method than grounded theory to address the research question. The findings of this study, which provide a rich description of the role of the CCN in the DM to process withdraw life-sustaining treatment and the barriers and facilitators to implementing this role within the culture of the critical care unit, fit more appropriately with a focused ethnography than a grounded theory. Upon attempting to identify a basic social process, as is required in grounded theory, it was felt that the data were being forced to identify a basic social process, of which there did not seem to be one. As only six CCN participants could be recruited, a grounded theory could not be developed. Instead, a focused ethnography was found to be effective at showing the orientation and perspective of these six CCNs regarding their role in the DM process to withdraw life-sustaining treatment.

The need for this change in methodology may be related to initially selecting the wrong research method for the research question, having obtained only a small sample for this study and therefore obtaining only limited data, and/or a basic social process not being present within the perceptions and experiences of the CCNs regarding their role in the DM process to withdraw life-sustaining treatment. Therefore, the qualitative method of focused ethnography was deemed to be a more appropriate method to address the research question and the research findings.

Ethnography is a method of qualitative research used to describe a cultural group or a phenomenon associated with a cultural group from an emic perspective (Morse, 1992). An ethnography attempts to explain both the explicit and tacit aspects of a culture (Hodgson, 2000). Ethnography was first used in anthropological research, but has been used in other fields such as sociology and healthcare. As Hodgson describes, ethnography can be a valuable tool within healthcare research in order to examine the cultural perceptions of people affected with an illness and/or to examine the culture of healthcare workers. Ethnography has been adapted in order to fit with the scope of the research being undertaken, the researcher's perspective, and the type of research question (Morse & Richards, 2002).

For this study, a focused ethnography was thus utilized. As described by Morse and Richards (2002), a focused ethnography is used to elicit information on a specific topic which is often identified before the study begins. This method differs from traditional ethnography in which the research focus is broad, with the researcher describing a group as comprehensively as possible (Morse & Richards), rather than having a specific research focus. For this study, the specific focus of the research was to gain an understanding of CCNs' perceptions and experiences regarding their role in the DM process to withdraw life-sustaining treatment from the perspective of the CCN. These perceptions and experiences regarding the CCN role, and the barriers and facilitators to the CCN implementing this role are all influenced by the culture of the critical care unit in which the CCN works. Culture is a concept which describes the beliefs, values, norms, and behaviors of a group (Morse & Richards). Furthermore, focused ethnography presupposes the researcher has knowledge of the culture being studied (Knoblauch, 2005). The primary researcher of this study has functioned as a CCN within a critical care unit, and therefore has intimate knowledge of the culture within critical care units and its effect on the role of the CCN in end-of-life DM.

Traditional ethnographies often utilize multiple methods of data collection, including interviews, participant observation, and field notes. In a focused ethnography, fieldwork may be excluded and data collection may only consist of interviews (Morse & Richards, 2002). For this study, semi-structured interviews were used as the primary strategy for data making. Finally, as compared to a traditional ethnography which involves long-term field visits, focused ethnographies are short-range and not continual (Knoblauch, 2005). This study utilized interviews which involved short-term contact with the research participants and did not involve prolonged immersion in the critical care environment. Due to this short time period of data collection focused ethnographies are typically data intensive, in which they produce a large amount of data in a short time period, therefore an intensive analysis of the data is required (Knoblauch), as was the case with this study.

"Culture defines much of the world in which people situate themselves and live. If we do not enter and attempt to understand this world, our efforts to convince, change, or console others will be ineffective, even harmful" (Brummelhuis & Herdt 1995, cited in Hodgson, 2000, p. 5). Therefore, before any changes can be made to the role of the CCN during the DM process to withdraw life-sustaining treatment, an understanding of the culture in which CCNs work must be obtained; focused ethnography was considered a valuable method for gaining this understanding.

Setting

This study involved two hospitals in Edmonton, Alberta. These hospitals function with a faith-based orientation, yet they extend care to all patients and families (www.caritas.ab.ca/Home/AboutCaritas/default.htm). The faith-based orientation was considered when conducting this study to ascertain whether or not this perspective affected the manner in which care is delivered within these hospitals. These two hospitals were chosen, as they employee nurses of diverse backgrounds and levels of experience, and it is interesting to examine hospitals with a faith-based orientation; as this orientation has not been addressed in the literature before.

At one of the hospitals, the ICU and CCU are combined; with eight ICU beds and 10 CCU beds. Between 80 and 85 nurses are employed in this critical care unit. The ICU is a combined medical/surgical unit, but it receives more surgical patients. Surgical patients tend to be elderly people who require cardiac monitoring post-surgery, patients of all ages who require complex wound management, and obstetrical emergencies. Medical patients include those experiencing overdoses, respiratory failure, renal failure, sepsis, and cardiogenic shock.

The other hospital has an ICU with six beds, and a high intensity/step down unit within the ICU, with four beds. The ICU employs 25 full-time, 15 part-time, and 25 to 30 casual nurses. This ICU cares for high-risk general surgery and orthopedic patients, patients with sepsis, chronic obstructive pulmonary disorder, overdoses, pneumonia, renal failure, and carbon monoxide poisoning.

Sample

Convenience sampling was largely used to obtain a sample of key informant CCNs. In convenience sampling, the researcher selects participants based on whoever is available and willing to participate (Brink & Wood, 2001). In the original research proposal, CCNs were to be selected using purposive sampling, based on years of experience working in critical care and on having been involved in caring for a patient who had life-sustaining treatment withdrawn in the last year. Purposive sampling was not used due to the low number of CCNs who responded to repeated notices about participating in this study. This difficulty with obtaining CCN research participants may be related to the heavy workloads that CCNs currently experience, and as found in the research findings, many CCNs may be experiencing burn-out and may be reluctant to participate in a research study. Therefore, any CCN who was willing to participate in this study was interviewed, on the inclusion criterion that they had an informed viewpoint and could converse fluently in the English language. The CCNs who did participate in this study were asked to speak with their colleagues about participating in this study, but this snowballing method did not yield any further research participants.

It was initially anticipated that 10 CCNs or more would be interviewed, once each. Ultimately, six CCNs were interviewed. This sample of CCNs included: Two CCNs with three years of critical care experience, one with 3.5 years critical care experience, one with 5 years critical care experience, one with 6.5 years critical care experience, and one with 10 years of critical care experience. All of the CCN participants had obtained their Bachelor of Science in Nursing (BScN). One participant was male and the rest were female. Despite placing two different sets of posters within each hospitals critical care unit, speaking with CCNs working on shift, and obtaining assistance in recruiting participants from the critical care units Clinical Nurse Educators and Unit Managers, no further participants came forward. Approval was obtained from the Health Research Ethics Board (HREB) to interview nurses from a third hospital, from which two more participants were interviewed. These nurses contributed to and validated the findings that had begun to be considered through the first four CCN interviews.

When presenting the study, and when performing interviews, consideration was given regarding how the researcher gained access to the CCNs, and built trust with the CCNs while carrying out this study. Furthermore, there was a need to recognize hidden issues regarding gaining access; such as power imbalances, self identity, and personal fears (Mulhall, 2003). These personal fears included: Fears of entering a new environment, issues regarding confidence in being able to perform a research study, and concern that CCNs would not view the study as important and therefore not want to participate. Therefore, it was important to gain the support of key stakeholders within each hospital to ensure the success of this study.

Although the study took place in two different Caritas hospitals, one letter of administration approval for both hospitals was obtained. A letter of research ethics approval was also obtained from the Health Research Ethics Board (HREB) prior to study implementation. An approval was later obtained from the HREB to interview colleagues from the Royal Alexandra Hospital ICU, when only four research participants were obtained from the Caritas hospitals.

Data Collection

Data were collected and analyzed by the primary researcher. Data were collected primarily through tape-recorded semi-structured interviews of individual CCNs. Each interview took place in a setting of the CCN's choosing. All interviews were conducted in a quiet, comfortable setting at a time when the individual nurse was not working. In three cases, the interviews were conducted at the individual's home, two were conducted at the Misericordia Hospital in a conference room, and one was conducted at the University of Alberta in an interview room.

Informed consent was obtained at the start of each interview. To accomplish this, participants were informed of the study's purpose, the time required for participation, their right to confidentiality and anonymity, their right to ask any questions or refuse to answer any questions, and their right to withdraw from the study at any time. Following this explanation, participants were given the opportunity to review the information letter and consent form. Interviews did not begin until written consent was obtained. See Appendix A for a copy of the consent form and information letter used in this study.

Each CCN was informed that the interview would take approximately 30 minutes to two hours. All CCNs were asked to participate in one interview, but were asked if it was possible to contact them for a second interview if needed to validate the findings. The first three interviews were transcribed by the primary researcher. The following three interviews were transcribed by a paid transcriber. All transcripts were checked against the tapes for accuracy. Each participant was interviewed only once.

In each semi-structured interview, the process began with a review of the study's purpose. Participants were assured of confidentiality, and that they could stop the interview at any time. The interview began by collecting demographic data regarding age, gender, level of education, and number of years working in critical care and other areas of nursing. Interviews focused on the CCN describing their experiences with the DM process to withdraw life-sustaining treatment, and their role and involvement within this process. A grand-tour question was asked initially: "Please tell me about your experiences with the DM process to withdraw life-sustaining treatment." The participant's response guided further questioning. Additional questions which were asked of all participants were: "What does withdrawal of life-sustaining treatment mean to you?", "Can you tell me about a CCN who you have worked with who you think is effective in their role during the DM process to withdraw life-sustaining treatment?", "Can you tell me about a CCN who you think is not effective in their role during the DM process to withdraw life-sustaining treatment?", "Tell me about the first patient you cared for in which life-sustaining treatment was withdrawn", "Tell me about a recent patient you cared for in which life-sustaining treatment was withdrawn", "What is your vision for the ideal role of the CCN in the DM process to withdraw life-sustaining treatment?", "What are the barriers to implementing this ideal role?", and "What facilitates the implementation of this ideal role?" These questions were asked, as they were deemed to be important based on the review of the literature, but questions were added based on the direction that participants took in response to the initial grand-tour question and on the stage of theory development. For example, the following questions were added as theory development progressed: "Lack of power has been identified by some participants, have you ever felt this way?", "Is the family considered a team member?", and "How do you learn your role in the DM process to withdraw life-sustaining treatment?".

Field notes were recorded after each interview to describe the interview process and to capture other key data noted during the interview. Focused ethnography requires researchers to record observations in their field notes, which involves a detailed, nonjudgmental description of what was observed during the interview process (Knoblacuh, 2005). Following the interview, the researcher also recorded in a reflexive journal in order to maintain awareness of potential biases. This journal is considered data and it is also a method to improve interview techniques (Dr. Jude Spiers, personal communication, March 12, 2006).

Ethical Considerations

As noted above, following study proposal approval by the thesis committee, this proposal was submitted to the Health Research Ethics Board (HREB) at the University of Alberta, and then the Caritas administration for managerial review prior to initiating this study. The main ethical considerations for this study were to obtain informed consent, and maintain the confidentiality and anonymity of research participants. Maintaining confidentiality and anonymity are very important considerations, especially when working in a sensitive location like a critical care unit and when discussing a sensitive topic like withdrawal of treatment. Patients, families, physicians, nurses, and other health care providers must be assured that their names will not be published, and that only those involved in the research will have access to the research data (Brink & Wood, 2001). Researchers may observe, hear, and record information that may be damaging to others (Hancock & Easen, 2005). Therefore, all names on documents were altered and each participant identified by a number, the use of describing characteristics was limited, and all research documents were locked in a secure cupboard. Also, as a CCN from a all research documents were locked in a secure cupboard. Also, as a CCN from a "competing" critical care unit, it was very important for the researcher to keep all comments confidential when comments about nurses or physicians from the researcher's hospital were heard.

Data Analysis

Data analysis was an inductive, iterative process of data collection and data analysis (Morin, Patterson, Kurtz, & Brzowski, 1999; Savage, 2006). Therefore, data analysis was performed with each completed interview, journaling, or field note written. Data from interviews were transcribed and analyzed between each subsequent interview. The process of constant comparison was used to analyze the data obtained from the CCN interviews. With each interview line-by-line coding was completed by highlighting important concepts and words within each interview transcript. Coding is an analytical procedure used in qualitative research that allows the researcher to organize the text and identify themes and patterns amongst large amounts of data (Auerbach & Silverstein, 2003). As each interview transcript was analyzed, additional questions were identified for future interviews.

At the same time as the interview transcripts were coded, theoretical memos were written in which insights, comparisons, descriptions of the codes, and questions were recorded. Memoing assists with developing the characteristics of categories and integrating these categories to develop theory (Backman & Kyngas, 1999). As interviews and coding continued, codes were brought together as categories. Theoretical memoing, questioning, and the process of constant comparison continued in order to compare categories to identify patterns within the categories and further develop each category.

Based on this process, common threads were found within each category and common themes were identified.

The following is a detailed account of the steps taken in coding and analyzing the interview data. These steps were conducted for each interview. Data analysis of each interview was conducted prior to conducting the next interview.

Step One: Initial Reading of Transcripts

The data analysis process began by reading over each interview transcript to familiarize the researcher with the data and to get a better sense of what one was working with. Reading over the data with the research questions in mind forces the researcher to become familiar with the data in intimate ways as it is constantly sifting through his or her mind (Auerbach & Silverstein, 2003).

Memos were made during this read-through, which enabled the gathering of thoughts and ideas on paper to assist with the initial stages of coding. Also, as recommended by Auerbach and Silverstein (2003), the "relevant text" (p. 37) was focused upon. In other words, only the text that was relevant to the research questions was concentrated upon. Any text that was questionable as relevant text was identified as relevant text, so as to ensure that nothing important was omitted. The decision whether or not to retain or omit this text came at a later stage in the analysis when a better idea of the emerging themes were identified.

Step Two: Coding Interview Transcripts

As stated by Auerbach and Silverstein (2003), the goal of coding is to "choose a short quote or name that captures the essence of the idea "in a dramatic and emotionally vivid way" (p. 60). Codes were identified by using direct quotes from the interview participants. A description or definition of each code was developed. It was recognized that there were clear similarities between some of the codes. These codes were grouped together.

Step Three: Identifying Categories

The process of generating categories began by reading through all of the codes, discarding those that were irrelevant to the research questions, and making notes of what was found to be repeated throughout the transcripts. Once a list of these recurring ideas had been created, broad categories were identified. As with the coding process, each category was described and defined. Furthermore, the process of memoing and questioning continued. New interview data were compared against the codes and categories being developed to identify similarities and differences between each interview using the process of constant comparison.

Step Four: Identify Themes

To identify themes, the list of categories was reread to get a good sense of what was being developed at that point in the analysis Revisions were completed and some of the categories changed. Auerbach and Silverstein (2003) states that as one struggles with naming themes, it is common to revise the categories to "conform to your new understanding of the data" and that this is a positive step in analysis because one is learning about the participant's experiences "in a more nuanced way" (p. 65). Common threads were found within the categories and four themes identified.

Rigor

Rigor is important to ensure that research findings are both reliable and valid. As Lincoln and Guba (2000) stated, rigor is important to make sure that individuals feel they can act on the implications of a study, and policy makers feel secure about the findings "to construct social policy or legislation based on them" (p. 178). A key method of maintaining rigor in a qualitative study is to ensure that the study remains inductive (Morse & Richards, 2002). For a study to be inductive, the researcher does not begin with a theory and attempt to prove it, but begins with data collection followed by data analysis, and from this develops a theory (Backman & Kyngas, 1999). A study remains inductive by asking analytic questions of the data, by collecting and analyzing data concurrently, and by seeking negative cases. This study remained inductive by memoing, and asking questions of the data and the codes and categories which were being identified. Also, the process of analyzing interviews before a new interview was completed was employed in this study. Due to the low number of CCNs who volunteered for this study, negative cases were not actively sought, but one of the participants appeared to be a negative case as she had a more pro-life perspective on the decision to withdraw treatment as compared to the other CCN participants who all felt that treatment was withdrawn too late. Whether her views were actually a negative case or whether they represented a dimension not yet explored in this study remained unanswered due to the lack of participants and research time, which meant data collection had to end. Furthermore, participant four was more willing to implement the role of patient advocate independently without waiting for permission (as was seen among the other CCN participants). For example, she said she would approach patient's families about implementing a Do Not Resuscitate order prior to receiving permission to do so from the physician. These methods, memoing and asking questions of the data, collecting and analyzing data concurrently, and obtaining a negative case, ensured that the study remained inductive and was guided by the data. It was not based on previous knowledge or assumptions.

Another key to ensuring rigor in qualitative studies is to maintain methodological congruence. Methodological congruence is the congruence between the research question, the theoretical and philosophical assumptions of the method, and the components of the method (Morse & Richards, 2002). This congruence was ensured by maintaining an audit trail which involved constantly revisiting the purpose of the project and ensuring that all methods and techniques were working to achieve the project's goals. Peer debriefings with my thesis supervisor and another committee member also served as a method of ensuring methodological congruence. These discussions assisted in identifying the difficulty associated with using a grounded theory methodology for this study when the primary research question and the research findings fit more appropriately with the method of focused ethnography.

In order to ensure the rigor of this study, the four aspects of trustworthiness developed by Lincoln and Guba (1985) were addressed: Credibility, transferability, dependability, and confirmability. According to Lincoln and Guba, ensuring that these elements of trustworthiness are addressed ensures the quality of an investigation and its findings, which make the study noteworthy to audiences. Credibility is the first element of trustworthiness. It is the assurance of the fit between the participant's views and beliefs, and the researcher's reconstruction of these views (Lincoln & Guba). Credibility was achieved in this study through the process of constant comparison and by having the last two participants validate the findings.

Transferability is the second element of trustworthiness; it describes when findings can be applied in other contexts or situations (Lincoln & Guba, 1985).

Transferability in this study was addressed through the use of interviews with CCNs, constant comparison in data analysis, and performing an extensive literature review. As stated previously, one of the participants emerged as a negative case. This participant voiced similar concerns as other CCNs regarding their role in end-of-life DM and the desire by all the CCN participants to be involved in the DM process, but instead of feeling that care was often withdrawn too late; this CCN felt that life-sustaining care was often withdrawn too early. Furthermore, she was very active in performing the patient advocacy role of the CCN without waiting for permission from the physician. No other negative cases were obtained due to the low level of participants who volunteered for this study.

Dependability, the third element of trustworthiness, ensures that the research is logical, traceable, and documented (Lincoln & Guba, 1985). An audit trail, in which all decisions and research events are recorded, was maintained. This trail allows decisions to be checked or replicated by an outside individual (Lincoln & Guba).

Finally, confirmability, the fourth element of trustworthiness, must be considered to ensure neutrality. It ensures that data and interpretations are not figments of the researcher's imagination (Lincoln & Guba, 1985). As Morse (1992) stated, the researcher may not be aware of the assumptions made based on their own cultural background and experiences, but it is imperative to be aware of and examine these assumptions. This step was ensured in this study by the researcher identifying biases through memoing, the maintenance of a journal to document assumptions and personal beliefs, and by being interviewed prior to interviewing CCN participants using the research questions.

Ultimately, through addressing these aspects of trustworthiness, it is hoped that this study provides readers with intuitive recognition, in which the reader immediately recognizes the phenomenon being described. Furthermore, through adherence to these elements of trustworthiness, it is anticipated that individual CCNs will be able to apply the findings of this study to their own situations, and policy makers and nurse leaders will apply the findings to develop policy based on best-practice and thereby improve CCN job satisfaction and patient and family care.

Chapter 4: Findings

In this chapter, the findings identified by interviewing six CCNs are presented. Direct quotes from the participants are used to display their reflections and experiences. Each participant will be referred to by a number to protect their identity. Through the use of constant-comparative data analysis, four themes were identified from the data: The role desired by the CCN during the DM process to withdraw life-sustaining treatment, the barriers to implementing this desired role, the outcomes of being unable to fulfill the desired CCN role, and the facilitators to implementing this desired role.

Theme One: The Roles Desired by the CCN During the DM Process to Withdraw Life-Sustaining Treatment

To be more involved in the DM process to withdraw life-sustaining treatment, the CCN participants expressed the desire to be able to fully implement the unique roles that they can, and sometimes have in end-of-life DM. These roles include acting: (a) as a information provider between the patient/family and the physician, and (b) as a patient/family advocate.

Information Provider

The CCN participants described the information provider role as one in which the CCN acts as a "thread" to connect the patient and family to the physician. The CCN is especially suited for this role as the CCN is often the only healthcare provider present at the patient's bedside on a consistent basis:

> I think we need to be sort of like the thread that goes through the whole thing. You have the doctor here, I think we need to be the consistent partner right to the end, because even pastoral care can't be there for that whole time, but the nurse is

> there the whole time. So yeah we need to be a very consistent base of all that (P4, Line 478-483).

As the healthcare provider who maintains a constant presence at the patient's bedside, the CCN is often faced with requests for information on the patient's status and the plan of care. "I would say in large part is telling them where we're at and telling them where we're going" (P3, Line 1000-1001).

The CCN may take on this role of information provider as the physician may be too busy to provide the information the patient/family requires. "I mean the physician gets pulled away to assess someone in Emergency; they're not going to have time to talk so you have to be there in that role for them, because nobody else will (P3, Line 775-778).

Therefore, the CCN often acts as information provider to the patient and/or family and as a liaison for the back and forth transmission of information between the doctor and the patient/family with the CCN acting as the intermediary. Despite, the general belief that the CCN should act as an information provider, Participant five voiced some concern about the CCN adopting this role. This participant said: "Essentially it should be the physician's role to make sure that the family is well informed" (P5, Line 15-16).

Patient/Family Advocate

All participants believed that the role of patient/family advocate is a key role of the CCN in the DM process to withdraw life-sustaining treatment. The participants described incidents where the patient/family were not included in the end-of-life DM process, and the CCN felt that it was their responsibility to advocate and "stand-up" for the patient/family to the physician.

> I think I could see myself definitely as an advocate for the family. Because I mean we had to say something. I told the husband we have to draw a line in the sand here. Someone's got to say something because it sure isn't going to be a doctor in this situation here, so yeah advocate absolutely. And I find in a lot of these situations you are having to stand up for the patients (P3, Line 766-772).

Although all other CCN participants described advocating for the withdrawal of treatment Participant four described advocating for a patient and family who did not want treatment withdrawn, but the physician felt that withdrawing was the best option. This pro-life view voiced by Participant four may be related to her unique experiences working in a pastoral care position:

> The whole discussion she (the patient's wife) was saying to the doctors and nurses who were actively promoting withdrawal of care-everyone was-and she's saying 'Well can't I decide that? I want whatever I can", and you know she said 'Well, he's not suffering so why would this be wrong' (P4, Line 951-956).

The CCN participants described how they advocated for the patient/family, such as questioning the physician about their decision or clarifying with the physician the wishes and desires of the patient/family. For instance: "as an advocate for our patient I need to question some things" (P6, Line 250).

> I'll even ask the family sometimes ahead of time, 'Did they know what this individual's wishes would have been' and I'll approach it that way with the doctor and say you know have you talked to the family about this, do you know what their wishes are (P4, Line 43-47).

Although this advocacy role was embraced by the CCNs who were interviewed, Participant two talked about CCNs who did not want this role and did not want to be actively involved with the family:

> I find it interesting when we have a patient who we know is either going to be withdrawn or it looks like that's the direction it's heading and there are nurses that don't want that patient because they don't want to have to deal with the family (P2, Line 244-248).

Ultimately, it was voiced that the physician should make the final decision about whether or not to withdraw treatment, but the CCNs wanted to be included in the DM process as equal members of the healthcare team. "I don't know that I would necessarily make the decision. I think like I said earlier it's a medical decision, but I would like it that they would listen to what you're saying, hear your points" (P6, Line 224-228). "Um, because I know that certainly we're not going to be making the decision because it's not part of our role" (P2, Line 450-451).

Theme Two: Barriers to the Implementation of the Roles of the CCN in the DM Process to Withdraw Life-Sustaining Treatment

Despite expressing the importance of being able to implement the roles of information provider and patient/family advocate during the DM process to withdraw life-sustaining treatment, the CCNs in this study identified significant barriers to their involvement in this DM process. These barriers were: (a) poor communication and collaboration between CCN and physician, (b) the influence of hierarchical decision-making, (c) the varying approaches of physicians' during the DM process to withdraw life-sustaining treatment, and (d) the influence of CCN staff shortages.

Poor Communication and Collaboration between CCN and Physician

The CCNs clearly voiced the need for improved communication and collaboration between CCN and physician in order to be able to fulfill the roles of information provider and patient/family advocate, and to be an active, involved member of the healthcare team during the DM process to withdraw life-sustaining treatment. Yet, the relationship between the CCN and physician was described primarily as a difficult and often frustrating experience for the CCN. This feeling of frustration was especially strong following a difficult DM process in which the CCN and physician did not agree on whether or not to withdraw treatment. "Sometimes you can harbour resentment. Definitely towards them and you almost can't wait until their done their week because then their gone for a month. You don't have to see their faces for awhile" (P3, Line 277-282). Sometimes these difficult interactions between the physician and the CCN caused long lasting negative effects within the Critical Care Unit. As Participant one described, trust between nursing staff and physicians may be broken following a difficult DM process. "But that particular night caused quite an uproar that there's a lot of issues on our unit now. Trust issues between doctors and nurses right now" (P1, Line 170-176).

CCNs were often unable to implement their roles of information provider and patient/family advocate when communication and collaboration between themselves and physicians were poor. This is true with the role of information provider, as the CCN often relies on information provided by the physician in order to answer questions by the patient and/or family and provide them with the information they require. For example, Participant three felt that he had not been communicated the information necessary to fulfill the information provider role. "I: And do you think that you're prepared, do you think you have the information that you need to- P: No. <Laughs>" (P3, Line 1004-1008). Often the CCN must actively seek the information necessary to act as an information provider:

> You know, going back and forth with the doctor, asking the questions that I don't know the answers to, finding the answers. You know that way I don't give them an answer that end up being not accurate. Which I think is the worst thing that a nurse can do (P2, Line 173-179).

The role of patient/family advocate is also difficult to fulfill when the CCN feels that they are not being listened to and their contribution is disregarded:

> I would like it that they would listen, that the doctors would listen to what you're saying, hear your points. Sometimes they just kind of cut you off and they're like 'No, we're gonna do this' and so it would be more of an understanding, more of a working together at it (P6, Line 226-230).

Participant one also described a situation with a cancer patient in which the patient's wife wanted life-sustaining treatment withdrawn, but the physician refused. In this case, the CCN attempted to advocate for the patient and family, but they were unable to as the physician disregarded both the CCN's and the wife's views. "Um, in that particular situation absolutely not, the doctor was not open to any suggestions from us and we called him multiple times. Just his beliefs I guess over-ruled anyone else's" (P1, Line 133-135).

Poor communication and collaboration between CCN and physician may leave the CCN feeling powerless and with few options to implement the role of information provider and patient/family advocate:

> But, when those sorts of situations happen (disagreement between physician and CCN regarding withdrawal of care), if they say 'Absolutely not' and that's the end of it what do you do? You're no longer that-any sort of role you had in that DM process has been taken away from you, so what do you do next (P1, Line 653-658).

Ultimately poor communication between CCN and physician negatively affects the CCN. The CCN may be left feeling frustrated about not being involved in the DM process to withdraw life-sustaining treatment, and powerless to assert their roles of information provider and patient/family advocate.

The Influence of Hierarchical Authority in DM

Poor communication and collaboration between CCNs and physicians was described as being influenced by hierarchical authority and identified as a barrier to the CCN being involved in the DM process to withdraw life-sustaining treatment as a information provider and patient/family advocate. Despite the advanced education that CCNs receive and the need for collaboration between nurses and physicians when working in complex health environments, a division remains between CCNs and physicians, with the physician continuing to retain the balance of power within the DM process. "Like I said we're nurses and their doctors there's that…there's still the division" (P1, Line 380). When asked about why there does not have to be a team consensus when deciding to withdraw life-sustaining treatment from a patient, Participant 5 responded, "I don't know. That's a good question. Maybe it's back to the hierarchy of decision-making" (P5, Line 88-90).

The influence of hierarchy may be more pronounced with older physicians and nurses, as illustrated by a comment by Participant six: "I think a lot is that whole mentality of some of the doctors who've been doctors for a long time and nurses that have too, that that's the doctors' role and we shouldn't question" (P6, Line 56-62).

As identified by the CCN participants' hierarchical authority during the DM process to withdraw life-sustaining treatment remains a significant barrier to the CCN being an active, equal member of the healthcare team during the end-of-life DM process.

Physicians' Varying Approaches to Physician-CCN Collaboration and Withdrawal of Life-Sustaining Care

Another perceived barrier to the active involvement of the CCN in the DM process to withdraw life-sustaining treatment and the ability of the CCN to implement the roles of information provider and patient/family advocate is the uncertainty that can be caused during this DM process due to the varying approaches to collaboration and the DM process to withdraw treatment adopted by different physicians.

The CCNs in this study described the frustration and confusion that can be caused when each physician has a different perspective on the appropriate role and amount of involvement the CCN takes during the DM process to withdraw treatment. "I think there are a lot of physicians that are more open to input from others versus others that are more closed in their thinking" (P5, Line 105-106). "Sometimes you have doctors who are well 'No, that's my order and that's where you're going to do', but I think for the most part if you talk to them about it they'll explain it" (P6, Line 176-180).

Often the different approaches and perspectives on the appropriate timing and method of treatment withdrawal can be very frustrating for the CCN, and can affect the role and involvement of the CCN in the DM team: "you never know, like some doctors do it one way, some you know keep going, some you know, it's just the – it gets very frustrating sometimes" (P6, Line 27-29).

> When you're with a doctor who's willing to do all those things (withdraw all means of life-support) yes I feel it's a team. When you're with a doctor who refuses or will withdraw to a certain extent and partially cares for a patient not so much (P1, Line 29-30).

> Anyway to make a long story short I thought we were going to discontinue care on this patient and lo' and behold the intensivist decided to keep going basically until the next week and another physician came on and the finally made a decision and said 'Enough' (P3, Line 21-25).

With the varying approaches to end-of-life DM, the CCNs also discussed the possibility of protocols being developed to assist in remedying the confusion and frustration that can occur when physicians' adopt different approaches to the DM process to withdraw life-sustaining treatment:

> I think for our unit we need to talk about what the protocols are. We also need to discuss, you know I think yearly when we do our certifications, what you know the role of the doctor is, what he's legally required to do (P4, Line 556-561).

When asked about the need for a protocol or set process for the DM process to withdraw care, Participant five believed that it may help to make it easier for CCNs to understand their role and assist patients and families:

> Well, I don't know if there's a set process per se that is set out for that situation, but I think if there was something developed that would be a set process I think in

> the end it would make it easier for people to understand what their role is and also easier for the family so that they're getting that same continuous support (P5, Line 24-28).

Yet, despite the feeling that a set process or protocol for the DM process to withdraw care and for the actual withdrawal of care may be beneficial, there was concern that a set protocol or process may not be practical with each patient's case and situation being very different from the next. "I think it would be hard to do though because every case is so different that I don't that there's an option to have a set procedure" (P6, Line 30-33).

Influence of CCN Shortages on the Role of the CCN in the DM Process to Withdraw Life-Sustaining Treatment

Many of the CCNs discussed the impact that working short staffed had on the ability of the CCN to fulfill their desired role of patient/family advocate and information provider. Working short-staffed and being unable to take vacation and have a break from the stresses of the critical care unit were described as potentially leading the CCN to feel burnt-out which may cause the CCN to withdraw from being involved in the DM process to withdraw life-sustaining treatment or from the critical care environment entirely. "I think sometimes it's just you know you get weighed down with all the other stuff, not the patient care, but all the other things around it just everything weighs you down and you just need a change" (P6, Line 191-195).

> I mean burnout is a huge factor nowadays. You have units telling staff no one is getting holidays because we have no one to replace you. And I know there are units in the city that are like that right now and some (nurses) are indifferent, they

> are tired. I really think it has less to do with being a bad nurse, than being a tired nurse (P3, Line 585-592).

Furthermore, when the CCN is so busy, they may be unable to fulfill the roles of information provider/liaison and patient/family advocate due to a lack of time:

> Nurses feel and I felt as times where you don't want to deal with the family right then like you just so much work to do that you need to just deal with that, you're feeling you're more task-orientated getting the orders down and because patient's need things so quickly. So that's probably a barrier as well, rather than sitting down and spending time with the family (P5, Line 300-306).

Theme Three: Outcomes of Being Unable to Fulfill the Roles of the CCN During the DM Process to Withdraw Life-Sustaining Treatment

Ideally, participants reported that the CCN is able to implement the roles of patient/family advocate and information provider during the DM process to withdraw treatment. Furthermore, in an ideal situation, the CCN is involved in this DM process as an equal, respected member of the healthcare team. Yet, the barriers of poor collaboration between CCN and physician, the varying approaches of individual physicians to withdrawal of treatment and collaboration, and CCN shortages inhibits the CCN from implementing these roles and being an active, involved member of the healthcare team during the DM process to withdraw treatment. Two outcomes for the CCN of being uninvolved during the DM process include: (a) the CCN feels powerless and (b) burn-out. Only one of the CCN participants described having positive perceptions and experiences regarding their role in the DM process to withdraw life-sustaining treatment.

Powerlessness

CCN participants described feeling powerless within the DM process to withdraw treatment, often this was related to carrying out orders that the individual CCN felt was the wrong course of action or morally wrong. Often the feeling of powerlessness was related to feeling unheard and unable to influence the DM process. "it's not what I believe. And regardless of what you say that's their beliefs and that's what they'll stick with" (P1, Line 74-76). "I have no actual power there" (P2, Line 33).

Feeling powerless within the DM process can be "demoralizing" and stressing for the CCN who must carry out orders they disagree with, or watch a patient and/or family endure a treatment they believe is against the patient and/or families wishes:

> It's tough, like you really get demoralized from that and you kind of wonder why are we doing all of these things on these people who you, never in their wildest dreams, if they knew would end up in this position would want that, or knew beforehand that they wouldn't want that and we're still doing all these life saving measures… (P3, Line 68-72).
>
> You just think to yourself, 'How am I going to be judged by, you know, higher powers?' Like you feel almost like you're going against a lot of your own beliefs and you know this is wrong, it feels just WRONG (P3, L83-88)!

These feelings of powerlessness appear to be related to the interaction between the CCN and physician which varies with the physician involved and the impact of hierarchical authority on the role of the CCN in the DM process to withdraw life-sustaining treatment. Feelings of powerlessness may also contribute to the CCN feeling burnt-out.

Burnout

Those CCNs who felt powerless within the DM process to withdraw life-sustaining treatment described feeling burnt-out themselves or having seen someone they work with becoming burnt-out. Burnt out was described as: "you can't always just shake it off and go home" (P2, Line 488).

> By the end of your rotation, you're just like I need a vacation again. Or something, you don't want to go back; you don't want to go back after that. You're looking forward to your days off and you want to be as far detached away from that place (ICU) as possible (P3, Line 718-722)

Feeling burnt-out can ultimately affect the CCN's own nursing practice and may also infiltrate the CCN's home life:

> And then you kind of get a bit skewed like I started to feel like things that never bothered, I would never think of when I first started working as a critical care nurse, all of a sudden all these little things started to really bother me. I thought 'Oh, I would never have thought twice about this before' and then all of a sudden it gets you really agitated and irritated and then I felt like that at home as well where things I wouldn't think of twice all of a sudden you get really upset about it (P5, Line 242-251).

Ultimately, feeling burnt-out may affect the care that is provided to the patient/family by the CCN:

> I started getting upset at the patients. I'd get really agitated with them. Like on nights if they didn't sleep I'd be really upset that they weren't sleeping or you know if their really combative I'd start to get like mad back at the patients rather

> than just kind of taking it all in stride like I would have before. Like I kind of started seeing the patients differently (P5, Line 267-272).
>
> I think you're sort of with families you're not as, you don't have as much empathy them and it's just harder like I think you don't enjoy your job, you don't enjoy things. So when you're frustrated you're gonna, everybody around you is gonna feel the effects of it (P6, Line 204-207).

Furthermore, feeling powerless and burnt-out may cause the CCN to withdraw from implementing, or attempting to implement the roles of information provider and patient/family advocate during the DM process to withdraw life-sustaining treatment; leaving the patient/family without someone to provide the information they require and to act as an advocate for their beliefs and values. Eventually, burn-out may cause some CCNs to consider leaving the critical care environment all together.

> I mean you can get really burnt-out, really angry, and bitter about your job really quickly. I mean I've noticed that even myself. I mean after that last incident (where he had thought that the decision to withdraw care had been made in a family conference, but care was not withdrawn) I was so bitter, I was so angry. 'I don't want to look after these people; I don't want to do this. I want to leave, I've had it'! I guess that's why you need days off <Laughs> (P3, Line 787-793).

Positive Perceptions and Experiences with the DM Process to Withdraw Life-Sustaining Care

Despite all of the CCNs voicing concern and frustration during the DM process to withdraw treatment, Participant four described positive experiences with the DM process and collaboration between physician and CCN. "The doctors I find are very respectful of us" (P4, Line 1047), "Yeah, I've had a great experience with it" (P4, Line 99). Participant 4 described how she will initiate a conversation about 'code status' with a family, independent of the physician. She appeared very confident in her skills and abilities to communicate and collaborate with physicians, and does not seem to experience any feelings of powerlessness in her role as patient/family advocate and information provider:

> Well as soon as I know that the code status hasn't been discussed I go 'Yes, let's discuss it right away'. I'm really okay with it. If it's not been discussed I bring it up and I feel really comfortable doing it and I feel it's important (P4, L665-668).

When asked about the physician's reaction to her initiating this discussion with the family, she described the physician as thankful for Participant four initiating the discussion regarding code status:

> I think they are relieved. Yeah. Relieved because they haven't-usually they're so busy on the unit…they've all been like, I've had more doctors say I'm so glad you talked about that because you know they didn't want to bring it up (P4, L693-704).

Participant four also described a positive experience where she felt she had influenced the DM process by being assertive in presenting her views:

> I did as much as I ethically felt I could do in terms of sort of giving him a chance to explain and think about what he's doing as well and I know after that we didn't do anything more, so I think I influenced (P4, Line 998-1001).

It appears that despite the majority of CCNs who were interviewed who described feeling powerless within the DM process to withdraw life-sustaining treatment Participant four has found a means of communicating and asserting herself within this

DM process in a manner in which she does not feel powerless and feels confident in asserting her role of information provider and patient/family advocate.

Theme Four: Facilitators to Implementing the Ideal Role of the CCN in the DM Process to Withdraw Life-Sustaining Treatment

Just as the CCNs interviewed discussed the barriers to implementing the ideal CCN role of patient/family advocate and information provider, they described many factors that facilitate these roles of the CCN. These facilitators include: (a) the CCN's years of experience, (b) CCN communication and collaboration skills, (c) the 24/7 presence of the CCN, (d) receiving support from managers, (e) attempting to maintain a work-life balance, and (f) debriefing sessions. Only one of the CCN participants, Participant 4, described working within a faith-based organization like Caritas as impacting the role of the CCN in the DM process to withdraw treatment.

CCN Years of Experience

The amount of experience a CCN has working in a critical care environment and being involved in the DM process to withdraw life-sustaining treatment was described by these CCNs as facilitating the CCN's ability to communicate and collaborate effectively with physicians, and be actively involved in the DM process as a patient/family advocate and information provider. This ability to collaborate with physicians may be due to the trust that has been created over time between the more experienced CCN and the physician:

> There's a couple of senior nurses that are incredible. I don't do so well with that myself. But, they can initiate a conversation one with the family very well, but two they have lots of experience and doctors trust them a lot. A lot. So when they

> say to them 'May be it's time' (to withdraw care) they usually take it into consideration (P1, Line 196-201).
>
> The experience of the nurse as well, depending if they are brand new and it's a totally new environment and new situation they might have more difficulty communicating with the physicians than somebody who is more seasoned and has been there a long time and is respected by the doctors for their knowledge and they have kind of proven themselves to be a reliable source of information (P5, Line 114-120).

The more experienced CCN may be more a more effective collaborator due to being more "outspoken," then a more novice nurse who may feel intimidated speaking freely to a physician. This may be due to the relationship that has been created between the CCN and the physician, and the comfort level obtained from caring for a number of patients in which the decision to withdraw treatment is being made:

> I think I've become more comfortable with saying things to the family and talking in family conferences and as well I'm more willing to add things to the conference and I think you just get more comfortable with experience and dealing with that kind of thing (end-of-life DM) (P6, Line 109-113).
>
> An experienced nurse was someone who is passionate about what she does and wants to advocate for the patient and someone who is a bit more outspoken. Whereas me myself, I'm not that outspoken so I don't know if I would have brought that up, but after it was brought up it was a lot better (P5, Line 156-160).

It is worth noting that Participant five, despite feeling that she is not outspoken and did not identify herself as experienced, was one of the more experienced CCNs in this study with 6 ½ years of critical care experience.

Despite the positive influence that experience in critical care has on the role of the CCN and their ability to collaborate and communicate with physicians and family, the potential for CCNs to become "hardened" and therefore not effective in their role is also possible. "Well sometimes the senior nurses they are burnt-out. I don't know they shouldn't be in there at all sometimes (working with patients when the decision to withdraw care is being made) because they need to be careful what they say and they've forgotten" (P4, Line 535-538).

CCN Communication and Collaboration Skills

A CCN who is effective in communicating with the physician and the patient/family seems to be a key facilitator in the CCN implementing the ideal roles of the CCN and also allows the CCN to feel more powerful and involved in the DM process to withdraw life-sustaining treatment. A CCN who is skilled at communicating and collaborating with physicians may feel more comfortable and "settled" with the decision of whether or not to withdraw treatment as they are able to gain an understanding of the physician's perspective. "I think just knowing the reasons behind what they (physicians) were doing helped everyone to kind of be more settled with it (the decision not to withdraw care)" (P5, Line 151-153).

> Sometimes you can voice your opinion and sometimes they explain things from a different side and you understand it, but I always try to get a rationale from the doctors...sometimes just that little bit more of discussing it helps I think and to

> see it from another side. So, sometimes you have to see it from another side and I think it does help to discuss it (P6, Line 151-162).

Participant five described a situation in which the CCNs on the unit were feeling very upset about decisions that had been made around a patient's care, to the point where one of the CCNs was crying. But, when the physician was asked by the CCN about the rationale for the decisions made and the CCNs understood the doctor's perspective, the nurses felt better with the decision. By asking questions and understanding the physician perspective, the CCNs did not feel so powerless in this DM process:

> I remember a specific example actually of nurses being very upset about the plan of care that was chosen for the patient...It was a coffee room discussion of why we're doing this and why push it and this might not be the best for the patient and so actually one of the physicians came into the room and one of the other nurses who was at this point in tears asked him, 'Why are we doing this"? ...Basically is was good communicating between the two of them really because we did get an answer and it wasn't backed away from so it was something that was, you could find maybe a reason why they were continuing on the way they were (P5, Line 131-144).

When the CCN is able to communicate with the physician and voice their concerns, it can help the CCN feel less powerless in the DM process. "If you're willing to put yourself out you don't have as much of a powerless feeling" (P6, Line 266).

There appears to be a fine balance which exists between being "outspoken" which enhances the involvement of the CCN and being confrontational. The DM process is enhanced with effective communication skills but being confrontational with physicians was not seen as being effective when attempting to collaborate and communicate.

> I guess it's if you initiate the conversation better with families and doctors that's key because as soon as you go in and say 'This is ridiculous I don't think we should be doing this anymore' it totally takes a different turn and things don't go the way they should (P1, Line 188-191).
>
> I don't like taking a confrontational role because some of the doctors will get their backs right up the wall and if you do that their kind of like 'Well, who are you to tell me what to do'. Like I try to do it in a more collaborative manner (P4, Line 52-56).

Overall, it is important for the CCN to have strong communication and collaboration skills, as these skills assist the CCN in implementing the roles of information provider and patient/family advocate. Furthermore, when the CCN adopts a more "outspoken" rather than confrontational mode of communicating with the physician, it assists the CCN in being able to question the physician in a manner which elicits a greater understanding of the physician's perspective regarding the DM process to withdraw care and provides the CCN with a greater feeling of comfort and ease with the DM process and the decision which is ultimately made.

24/7 Presence of CCNs in the Critical Care Unit

The presence of CCNs at the patient's bedside for 24 hours a day and seven days a week was seen as a facilitator to the role of the CCN as patient/family advocate and information provider. This 24/7 nursing presence enhances the ability of CCNs to build connections with patients and families, thereby enhancing their understanding of patient and families perspectives, needs, and values. "I'm there all shift. I know that patient as much or better than both of you" (P1, Line 549-551). "You know that patient, you know that family, you know what they want, and you've read their chart a million times. You can support them; they trust you a lot more because they see you all the time (P1, Line 573-576). "I like to be there because I think it's comforting to the family. They trust me by that point; you know we've already got a relationship" (P4, Line 495-498).

The value of the CCNs' 24/7 presence and the unique understanding that is obtained by the CCNs' provides greater incentive for nursing to be actively involved in the DM process to withdraw life-sustaining treatment. "I think that nursing cares because they are there all the time, 24 hours and families their giving their trust and gaining rapport that I think that they (CCNs) do need to have more of an active role in the whole decision-making" (P5, Line 285-288). Furthermore, the 24/7 presence of the CCN facilitates the involvement of the CCN as a patient advocate. For example, Participant four described feeling very comfortable in her role of patient advocate and felt very comfortable speaking openly with the patient/family, whom she had already developed a relationship:

> Many times I have initiated it without the doctor (end-of-life discussions) even initiating it because the doctors they have been busy or their intimidated to initiate it with the family and so I feel very comfortable asking them really honestly and by this time I've already developed a relationship with the family and even possibly with the patient that it's really easy to – I don't find it difficult to ask you know 'What would this individual like?' or 'What would you like?' or 'Have you

> ever discussed that at all' and then I sort of find out where they stand (P4, Line 84-92).

This comfort level of Participant four that permitted her to initiate end-of-life discussions without the physician, was unique to her alone. All of the other CCNs did not describe initiating these end-of-life discussions without receiving prior approval from the physician.

Being present with the patient on a 24/7 basis facilitates the CCN role of patient advocate. Yet, this 24/7 presence can also make the DM process more difficult, as the CCN has developed a relationship with the patient/family which can add to the stress of the CCN when decisions are made that go against what the CCN knows the patient/family wishes:

> And I have had an experience where a patient, um the family was choosing to withdraw care and the physician refused to do so. Giving sort of a bogus reason for not doing so and I continued to advocate for the patient and the family. And the next day a different physician was in and we did end up withdrawing care, but that was a really stressful time for me because I knew what was best for the patient (P2, Line 23-31).

Support from Managers

The ability of CCNs to receive support from their nursing managers was described as a facilitator to the CCN role of patient/family advocate and information provider. Furthermore, a supportive manager can assist the CCN in understanding and working through the DM process to withdraw treatment:

> I did have a charge nurse and I did have co-workers who you know I could ask 'This is kind of what I'm thinking', or 'How do I address this', or 'I'm not really understanding what we're doing now. Why are we doing this, why are we doing this'? (P1, Line 540-543).

The CCNs further described how an empathetic and supportive manager can facilitate the ideal role of the CCN, as the manager may have more power in influencing the physician and the manager may act as an intermediary between the CCN and physician if a dispute arises. Having a supportive manager may allow CCNs a means of regaining some power when they may be feeling powerless to have their voices heard:

> If you're having a difficult time communicating with a physician or another nurse based on the care ordered, I guess what you – then you need to kind of seek out a third party like a nurse manager or a patient care manager or something like that (P5, Line 195-198).
>
> Sometimes yeah you have doctors who are 'Well, no that's my order and that's what you're gonna do, but I think for the most part if you talk to them about it they'll explain it and if you don't see it differently well then you know you can always ask for some someone else to get involved, ask your charge nurse – there's always someone else you can go to when you're questioning something like that (P6, Line 176-182).

Despite, the need for CCNs to receive support from their managers during the DM process to withdraw treatment, sometimes managers were not available to support the CCN due to the "many directions" they are pulled in. When asked if managers are facilitators to the CCN role, Participant three responded,

> Yeah, I would say they have to be, that's part of the problem is they're not, because they are being pulled in so many directions. I mean you've got our manger responsible for way more things than she ever should be responsible for" (P3, Line 1106-1113).

Maintaining a Work-Life Balance

The CCNs interviewed described the need for the CCN to have self-care strategies in order to cope with the DM process to withdraw life-sustaining treatment. In particular, achieving a work-life balance appeared to help the CCN to be secure in their role of patient/family advocate and information provider, and to avoid feelings of burnout. "But you know keeping ourselves sort of healthy in our own minds and I think it kind of helps you to be able to do that, because we have to remember this is our job, not our life" (P2, Line 490-492). "Vacations that sort of thing. That sort of thing, you need to detach yourself away from things. You need to have a balanced life for this kind of work" (P3, Line 805-808). "You have to look after yourself too" (P3, Line 820).

> I think sometimes maybe it's just having you know like even something outside of work that you can go to, something you enjoy doing. Like I know sometimes even after work life when I've had a stressful day there's nothing better than going for a run and just you know getting that release in something else, having something outside of work that you can just kind of relax and I think you need that outside release as well as all the stuff at work (P6, Line 307-314).

Despite the importance of achieving a work-life balance, this balance may be difficult to achieve with CCN shortages, when the CCN is working overtime and may not be able to take vacation when requested. The CCN seems to require a great deal of inner strength and resolve to achieve a balance between work and outside life.

Debriefing Sessions

Another facilitator to the ideal role of the CCN in the DM process to withdraw treatment that the CCNs described was the use of debriefing sessions. Debriefing sessions were described as opportunities for physicians and nurses to speak with each other to reflect on certain cases as a means of improving collaboration and communication, and to gain an understanding of the other caregiver's perspectives about the DM process to withdraw treatment. This was illustrated by a comment: "Having group or mini education sessions or something about the ways we can communicate better interdisciplinary on our unit. I have no idea what the doctors think of the way our process goes or if they actually even care" (P1, Line 709-716).

> Ways to kind of remedy that (burnout) are to have debriefing sessions with staff based on kind of patient incidents or types of patients on the unit where it gives people kind of like, almost like a sharing circle because if they can say how they felt about situations and not be judged and say it to other people who deal the same way that they do. Because I think it's difficult to talk to people about it that don't understand the situations like a spouse or something like that (P5, Line 216-224).

> Our manager had a debriefing session where they had somebody come in and talk with all of us...and it just felt good for everyone to just get that out you know because I think what happens a lot of time people get stuff, stuff, stuffing and then

> what maybe is not a normal situation kind of becomes the norm (P5, Line 233-240).

Although, debriefing sessions were seen as a facilitator, the CCNs did not perceive that debriefing sessions were used frequently enough. They believed that these sessions could be used more often to improve the relationship between CCN and physician and as a means for the CCN to express emotions following a difficult DM process to withdraw life-sustaining treatment.

The Influence of Working within Caritas

Only Participant four portrayed that working within a religious affiliated system like Caritas had an influence on the role and involvement of the CCN in the DM process to withdraw life-sustaining treatment. This influence of working within a religious affiliated system may be reported due to Participant four having a unique background that included pastoral care work. When asked about whether working in Caritas was different then working in a system that did not have a religious affiliation she replied,

> Yeah I do actually. I think they really, because it's a mandate within their vision statement policy that it's and that staff are really encouraged to you know include the spiritual aspect so you have that sort of, you know that you're supported by management when you say to someone 'Would you like me to pray with you'? Regardless of what faith they are, 'Would you like me to call pastoral care'? or 'Is there someone we can call for you'? We're supported 100%. (P4, Line 405-416).

Summary of Findings

The research questions that guided this project, specifically to learn about the preferred role of the CCN in the DM process to withdraw life-sustaining treatment and the identification of the barriers and facilitators to this ideal role were addressed through this study. Four themes, each with categories, were identified. The first theme was a description of the desired roles of the CCN during the DM process to withdraw treatment. These roles were identified as: (a) patient/family advocate and (b) information provider. The second theme was the identification of the barriers to the CCN implementing these ideal roles. These barriers were: (a) poor communication and collaboration between CCN and physician, (b) the influence of hierarchical authority, (c) the varying approaches of individual physicians to the DM process to withdraw treatment, and (d) the influence of CCN shortages. The third theme was the outcomes of the CCN being unable to implement the desired roles. These outcomes were: (a) the CCN feeling powerless and (b) the CCN feeling burnt-out. Only Participant 4 described the DM process to withdraw treatment as a positive experience. The fourth theme was facilitators to the CCN implementing the desired roles. These facilitators include: (a) CCN years of experience, (b) the CCN's own communication and collaboration skills, (c) the 24/7 presence of CCNs at the patient's bedside, (d) support from nurse managers, (e) self-care strategies, and (f) debriefing sessions. Only Participant four described working in a faith-based system as a facilitator to the role of the CCN in the DM process to withdraw treatment.

Chapter 5: Discussion

The purpose of this project was to understand the perceptions and experiences of Canadian CCNs regarding their role during the DM process to withdraw life-sustaining treatment. The study was also conducted to identify the barriers and facilitators to implementing this role from the perspective of the CCN. This chapter includes a discussion and interpretation of the themes that emerged from the CCN interviews in relation to the literature presented in Chapter Two.

Although previous studies did not specifically address and identify the ideal role of the CCN in the DM process to withdraw life-sustaining treatment from the CCN perspective, and the barriers and facilitators to this role, the findings of past studies (which addressed slightly different topics) are consistent with the findings in this study. For example, although none of the past studies identified hierarchical decision-making as a barrier to the CCN role of patient/family advocate and information provider, the impact of hierarchical decision-making on nurses' roles has been discussed in past studies (Gedney-Baggs et al., 2007). For each theme identified in Chapter Four and the corresponding categories that make up that theme, a discussion of the findings is provided in relation to past studies discussed in Chapter Two; a discussion of the implications of this study to practice, a description of the limitations of this study, and recommendations for future research follow.

The CCN's Role in the DM Process to Withdraw Life-Sustaining Treatment

The CCNs interviewed for this study identified the roles of information provider and patient/family advocate as the ideal roles for the CCN during the DM process to withdraw life-sustaining treatment. These roles correspond with the findings of previous research studies and professional nursing associations. Although the labels found within the literature to describe these roles may be different from this study (for example Gleason, Sochalski, and Aiken (1999) use the term integrator of care instead of information provider), the description of the how the CCN functions within these roles is similar in this study as within past studies.

Information Provider

The CCNs interviewed in this study did not specifically describe their role during the DM process to withdraw life-sustaining treatment as an integrator of care as identified by Gleason, Sochalski, and Aiken (1999). Yet, the description that was provided by the CCNs of the CCN acting as an information provider, or as Participant four stated "the thread that goes through the whole thing" is similar to the description of an integrator of care who co-ordinates and communicates the views of all the parties involved, or of a go-between as described by Simpson (1997) and Calvin, Kite-Powell, and Hickey (2007). The role of information provider is facilitated, as was identified both by the CCN participants and Gleason, Sochalski, and Aiken, by the continual presence and moment-to-moment knowledge of the patient's condition and the care being provided that only CCNs have. Furthermore, this connection allows the CCN to form an intimate connection with the patient/family to answer questions and provide guidance to the patient/family (Calvin, Kite-Powell & Hickey, 2007).

Similar to the findings of Simpson (1997), the six CCNs who participated in this study described feeling unable to care adequately for patients and families when they did not feel that they had the information necessary to fulfill the role of information provider and they did not feel that the patient/family's views had been considered. The importance of being able to provide information to patients and their families was thus found in this study as a key factor in the satisfaction of the CCN regarding their involvement during the DM process to withdraw life-sustaining treatment. As Counsell and Guin (2002) also found, the most important component for the nurse to feel comfortable with withdrawal of life-support was the belief that family members were appropriately informed, with the nurse playing a key role in providing this information and facilitating communication between the healthcare team and the patient/family.

Patient and Family Advocate

In keeping with much of the literature, the importance of the role of patient/family advocate was clearly articulated by the CCNs involved in this study (Calvin, Kite-Powell & Hickey, 2007; Canadian Nurses Association, 2003; Counsell & Guin, 2002; DeWolf-Bosek, 2005; Kjerulf et al. 2005; Miller, Forbes, & Boyle, 2001; Oliverio & Fraulo, 1998; Robichaux & Clark, 2006; Schnedier, 1997; Seaburn, McDaniel, Kim & Bassen, 2004; Sjokvist, Nilstun, Svantesson, & Berggren, 1999). For example, Seaburn, McDaniel, Kim, and Bassen (2004) described the role of the nurse as helping the patient/family explore the implications of the end-of-life decision, as the nurse provides a sense of connection and support which makes the DM process easier than making a difficult decision in isolation. Participant two similarly described the advocacy role as providing support to the family by "helping them to figure out a way to make it okay. And how they were going to do that and what they needed."

Another facet of the advocacy role was described by Participant three as "having to stand up for the patient" by promoting and communicating the wishes of the patient and family to the physician, which was often related to the physician's desire to prolong treatment and the desire by the family to withdraw treatment. This advocacy role was similarly described by DeWolf-Bosek (2005) who described the nurse's role as "protecting the patient's rights" (p. 75) to self-determination.

As stated by Calvin, Kite-Powell, and Hickey (2007) and also the CCNs in this study, CCNs do not want to be the decision-makers in the end-of-life DM process and believe that this should be left up primarily to the physician. Yet, CCNs do want to be able to advocate for patients and families, be able to provide the information necessary to comfort patients and families, and assist them in the DM process to withdraw treatment while collaborating with both the physician and the patient/family in an open, trusting environment.

The role of patient advocate is supported strongly by the College and Association of Registered Nurses of Alberta (CARNA) (2005) as one in which the "RN supports and empowers clients to obtain the necessary information, care and resources to meet their health needs and act on the clients' behalf to achieve these ends when clients are unable to do so" (p. 4). This definition seems to be consistent with the description offered by the CCNs who participated in this study and in past studies. The influence of CARNA in promoting this role may be reflected in the responses of the CCNs involved in this study who identified the patient/family advocacy role as a key role in their involvement in the DM process to withdraw life-sustaining treatment.

Barriers to Implementing the Ideal CCN Role in the DM Process to Withdraw Life-Sustaining Treatment

As identified in the review of the literature, CCNs want to be involved in the DM process to withdraw life-sustaining treatment both as an information provider and as a patient/family advocate. Yet, many factors act as barriers to the CCN implementing these desired roles. These factors include: (a) poor collaboration and communication between CCN and physician, (b) hierarchical authority in DM, (c) confusion caused by the varying approaches that individual physician's take in the DM process to withdraw treatment, and (d) the impact of CCN staff shortages. For each of these factors identified by the CCNs in this study, a discussion of this factor in relation to past study findings are provided.

Poor Communication and Collaboration Between CCN and Physician

Poor communication and collaboration between the CCN and physician was described by the CCNs in this study and was found within the literature to be a key factor in causing dissatisfaction and frustration for the nurse involved in the care of patients in which end-of-life decisions are being made. When the CCNs who participated in this study felt that their opinions were not respected or listened too they described feeling frustrated and powerless with the whole DM process, and as Participant two described trust can be eroded between the CCN and the physician. These feelings of dissatisfaction with the DM process to withdraw treatment is not surprising, as the literature has revealed that collaboration between nurses and physicians is a significant factor which affects nurse turnover, patient outcomes and the perception of nurses that they are able to meet the needs of patients/families (Gleason, Sochalski, & Aiken, 1999; Ferrand et al., 2003; Makary et al., 2006; Thomas, Sherwood, Mulhllem, Sexton, & Helmreich, 2004).

Hierarchical Authority in DM

Poor communication and collaboration appeared to be influenced by hierarchical DM and the high level of power that the physician holds within the critical care environment. For example, the CCNs in this study described feelings of powerlessness as the physician had the last word in the DM process and often did not even consider the nurse's view point: "And regardless of what you say that's their beliefs and that's what they'll stick with" (P1). The impact of poor collaboration seems to have a significant effect on the CCN who links job satisfaction closely with collaboration than physicians. This issue may be related to the power of physicians to make decisions without nursing input, yet nurses can often only influence DM through collaboration. When collaboration does not occur, nurses feel this lack of power more acutely than physicians do (Gedney-Baggs et al., 1999).

Just as poor communication and collaboration affects the job satisfaction of the CCN in the DM process to withdraw treatment, the impact on patient safety is also significant. Although the CCNs in this study did not specifically describe the impact that poor communication/collaboration can have on patient safety, they did describe how hierarchical DM and the power of the physician caused some nurses to feel frustrated and powerless. Yet, as Evans (2007) stated "a nurse who is intimidated will be reluctant to question an order or action" (p. 16), which in the case of withdrawal of treatment may result in increased patient suffering and/or patient/family dissatisfaction. The need for effective communication and collaboration, and the detrimental impact that poor communication and collaboration can have on patient safety has been recently emphasized by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). The JCAHO identified breakdowns in communication as a leading cause of wrong-site surgeries and other sentinel events, and by the Institute of Medicine's 1999 report which identified the need for hospitals to promote effective team work as a principle of creating a safe hospital (cited in Makary et al., 2006). Without effective teamwork involving respectful, effective communication and collaboration, the impact on CCN job satisfaction, patient/family satisfaction, and patient safety is significant.

Physicians' Varying Approaches to Physician-CCN Collaboration and Withdrawal of Life-Sustaining Treatment

Surprisingly, the CCNs who participated in this study described the impact that the varying approaches of individual physician's to withdrawal of life-sustaining treatment and collaboration had on their role in the DM process to withdraw treatment, and the frustration and confusion which these different approaches caused in the CCN fulfilling the roles of patient advocate and information provider.

Upon initiating this study and in performing a review of the literature prior to initiating interviews, this factor did not appear significant. Yet, upon further review of the literature following data collection and data analysis, this barrier was identified within other studies involving CCNs. For example, Simpson (1997) in her grounded-theory study of the experiences of CCNs caring for hopelessly-ill patients, the nurses identified ambiguous DM by the medical staff as a problem, which caused some nurses to withdraw from caring for these patients due to the family feeling confused and the nurse having difficulty in the information provider role as she/he may not fully understand the situation. Furthermore, Calvin, Kite-Powell, and Hickey (2007) described that the neuroscience ICU nurses they interviewed found it a hindrance to the implementation of the role of information provider when they received contradictory information from physicians. This finding was consistent with Beckstrand and Kirchoff's (2005) study which found that CCNs ranked all physicians agreeing about the direction of care as most important in being able to provide end-of-life care.

The effectiveness of establishing protocols for end-of-life DM was addressed with the CCNs in this study, but received mixed feelings from the CCNs. Participant six, raised concern about the ability to implement a standard protocol for each unique patient/family, while some of the CCN participants' believed that the establishment of a protocol for the DM process of withdrawing treatment may be beneficial in diminishing the confusion caused by the varying approaches of each physician. Ferrand et al. (2003) have suggested that standard operating procedures should be developed particularly in areas in which a high degree of collaboration is required. The use of protocols in end-of-life DM is an area which further research is required.

Influence of CCN Shortages on the Role of the CCN in the DM Process to Withdraw Life-Sustaining Treatment

The CCNs in this study identified CCN staff shortages as impacting the ability of the CCN to implement the ideal roles of the CCN in end-of-life DM. When CCNs work short staffed they were less able to advocate for patients/families or to provide information to the patients/families. Furthermore, staff shortages caused the CCN greater difficulty in achieving a work-life balance as they may be unable to take vacation and may be working over-time hours. The impact of CCN shortages on the role of the CCN in DM was not identified as being significant within the literature. This issue was not raised within the studies which were reviewed, which may be reflective of the healthcare situation at the date that articles were written or due to the location of the studies being conducted. Yet, in Alberta the impact of nursing shortages is being felt acutely across the province. As identified in 2002 by the Canadian Nurses Association (CNA), system changes have reduced nursing leadership roles (which the CCNs in this study identified as being a facilitator for their role in the DM process), decreased support for professional practice, caused less satisfied clients, short staffing, and poor staff morale. With this environment, nurses are increasingly dissatisfied with the quality of their work life, the ability to provide quality patient care, and a reduction in their own health status (CNA, 2002); all of which were identified by the CCNs in this study. The impact of staff shortages and decreasing job satisfaction may also contribute to nursing shortages, as nurses choose either to leave the critical care environment or leave nursing all together.

Outcomes of Being Unable to Fulfill the Roles of the CCN During the DM Process to Withdraw Life-Sustaining Treatment

The outcomes for CCNs not being able to implement the ideal roles of patient/family advocate and information provider during the DM process to withdraw life-sustaining care were identified as leading the CCN to feel powerless within the DM process and to experience feelings of burn-out. Burn-out can cause the CCN to withdraw from attempting to implement these ideal roles, and can ultimately leave the patient/family without a CCN to provide them with the necessary information to make the difficult decision to withdraw treatment, and/or to advocate for their needs and desires to the physician. A discussion of these findings in relation to past studies follows.

Powerlessness

The current study highlights the continued frustration and feelings of powerlessness that CCNs often experience within the DM process to withdraw treatment. This feeling of powerlessness seems to originate from poor communication and collaboration between the CCN and the physician, and it seems to be dependent on the individual nurse and physician's style and confidence with communicating and collaborating. Furthermore, the impact of hierarchical authority that exists within the healthcare environment in which the physician holds the balance of power further increases the CCN's feelings of powerlessness which can lead to burnout in some nurses (as described by the CCNs in this study). This feeling of powerlessness is especially true if the CCN does not have access to support mechanisms such as self-care strategies and support from managers. The identification of powerlessness as an outcome of being unable to implement the ideal roles of the CCN in the DM process to withdraw life-sustaining treatment was not identified within past studies, although the effects of hierarchical DM have identified the limiting of nursing power which occurs when the physician holds the balance of power (Gedney-Baggs et al., 2007).

Burnout

The CCNs in this study identified the outcomes of burn-out as feelings of frustration and anger which in turn may lead the CCN to withdraw from providing patient/family care. This withdrawal may cause decreased patient and/or family satisfaction with care, and with the DM process to withdraw treatment. Furthermore, job satisfaction and the ability to achieve a work-life balance is greatly decreased which may lead the CCN to leave the critical care environment altogether. These findings correlate with the findings of past research studies. Burn-out can have negative effects on a CCN's personal and professional life, such as having decreased patience with the job, being short-tempered, and having less patience with their own family (McClendon & Buckner, 2007). As Meltzer and Huckabay (2004) identified, burnout can lead the CCN to withdraw from the DM process and from caring for patients/families in which end-of-life DM is occurring. This may also cause a lack of assertiveness in dealing with others, diminished coping skills, and health problems. All of which ultimately affect not only the CCN, but the care that patients and families receive during a time when they need all of the support that a CCN can provide. Also, Sundin-Huard and Fahy (1999) found when attempts at advocacy were unsuccessful; nurses experienced increased distress, frustration, burnout, and anger. This finding is similar to the findings of this study which identified feelings of frustration and burn-out as potential outcomes of the CCN being unable to fulfill desired roles.

Facilitators to Implementing the Ideal CCN Role in the DM Process to Withdraw Life-Sustaining Treatment

Although the CCNs in this study identified barriers to the implementation of the CCN role of patient/family advocate and information provider, they also identified factors that facilitate or support the roles of the CCN in the DM process to withdraw life-sustaining treatment. The effective use of these facilitators may help to prevent the occurrence of burnout and powerlessness felt by CCNs when they are unable to implement the ideal roles of patient/family advocate and information provider. These factors include: (a) the CCN's years of experience, (b) CCN communication and collaboration skills, (c) the 24/7 presence of the CCN, (d) receiving support from managers, (e) attempting to maintain a work-life balance, and (f) debriefing sessions. These facilitators will be described in relation to the findings of past research studies identified in Chapter Two.

CCN Years of Experience

Despite the inability to determine conclusively if age or experience impacts the role of the CCN in DM to withdraw treatment, due to the small sample size and small variation in experience of the CCN participants, the CCNs often reported that nurses with more experience were often more confident and assertive in their role as patient/family advocate and appeared to be skilled at engaging the physician in communication and collaboration.

Within the literature, the influence of experience on the CCNs involvement in DM was identified as a key factor affecting the role of the CCN in the DM process to withdraw life-sustaining treatment. For example, Bucknall (2003) described how experienced nurses resented the medical hierarchy, especially when it led to prolonged treatments, more than those nurses with less experience who seemed to have greater respect for professional hierarchies. A nurse in the study by Calvin, Kite-Powell, and Hickey (2007) described how she can not voice her opinion but will be able to in a few years. "I will keep my mouth shut around here for maybe another few years and then it will be okay" (p. 146). Furthermore, Berner, Ives, and Astin (2004) found that nurses over 40 years of age and with more than 10 years of experience were more likely to feel that physicians wanted them to be involved in DM compared to those who were under 30 with less than 10 years of experience. It is difficult within this study to determine specifically whether or not age and experience impact the role of the CCN in the DM process to withdraw treatment due to the very narrow age range and years of experience of the CCN participants in this study. Attempts had been made to obtain a sample which included novice nurses with less than 1 year experience, intermediate nurses with 1-5 years experience, and expert nurses with more than 5 years experience. Yet, due to the small number of nurses who volunteered for this study, any CCN who volunteered was recruited without concern about their age or years of experience.

Ultimately, the sample included four intermediate nurses and two expert nurses'; two of whom were under 30, three were in their 30s, and one participant was over the age of 40. Only Participant four was over 40 and seemed to have a different perspective than the other CCNs. She seemed more confident in collaborating with the physician and initiating end-of-life discussions, compared to the other CCNs. This occurred even though she had less nursing experience than the two nurses who were younger than her. Perhaps, as Bucknall (2003) describes, Participant four perceived that she had a high level of knowledge and therefore felt more confident in collaborating with physicians. Why Participant four or other like her feel so confident is a matter for future research. Furthermore, when the CCN begins to feel that they are experienced, and how they become experienced, and thus learn the skills of collaborating and communicating with physicians is a matter for further investigation.

CCN Communication and Collaboration Skills

The ability of the CCN to communicate, and collaborate confidently and effectively with physicians was seen as being very beneficial to the role of the CCN in the DM process to withdraw treatment. This ability also contributed to the CCN's comfort with the decision made. The ability to communicate with physicians and understand their perspectives was very beneficial for the CCN to feel at peace with the withdrawal decisions made and thus also to communicate this understanding to the patient/family. This state is consistent with Jones and Fitzgerald's (1998) study, which found that nurses can be quick to judge physicians, especially when the nurse is not part of the DM process. Therefore, to facilitate understanding and inspire confidence in the patient/family, improved communication and collaboration between nurses and physicians are essential. Yet, the question remains as to how CCNs obtain and/or learn the skills to communicate, and collaborate confidently and effectively with physicians who may be resistant to involving the CCN in the DM process to withdraw life-sustaining treatment.

The 24/7 Presence of the CCN

The CCNs involved in this study described the significance of the unique relationship of the CCN with the patient/family, a relationship obtained due to the 24/7 presence of nurses at the bedside of the patient. The CCNs may have a greater understanding of patient/family needs, values, and wishes than the physician, due to this 24/7 presence. Therefore, the CCN should be included in the DM process to withdraw life-sustaining treatment as an equal, respected member of the healthcare team. Within the literature, the benefits of this 24/7 presence are similarly described and with similar conclusions (Bakalis & Watson, 2005; Bucknall, 2003; Counsell and Guin, 2002; Ferrand et al., 2003; Gleason et al., 1999; Shannon, Mitchell & Cain, 2002).

Ultimately, the 24/7 presence of the CCN may act as both a facilitator and a barrier depending on whether or not the CCN is able to fulfill their ideal roles of patient/family advocate and information provider. This unique closeness to the family can act as a barrier when the CCN is unable to fulfill these roles, and yet must face the patient and family for long periods of time without being able to provide the patient/family with the information they desire. Furthermore, it becomes increasingly difficult for the CCN to implement orders that they disagree with when they have developed a close relationship with the patient and family. Ferrand et al. (2003) believed that the unique proximity that the nurse has to the patient/family and their interaction with the physician places on the nurse a considerable moral responsibility. When the CCN believes that the roles of patient/family advocate and information provider are a "moral responsibility", this places an even greater demand on the nurse to fulfill these roles, and when unable to fulfill these roles could lead to frustration and distress for the CCN.

Support of Managers

The need for support from management was described by the CCNs in this study as being critical for them to continue to work in a high stress environment like the critical care unit. This support from managers was identified as very important for the CCN due to the impact of hierarchical DM which leads the CCN to often feel powerless to influence decisions or implement the roles of patient/family advocate and information provider. This finding is similar to that of Robichaux and Clark (2006), who identified that nurses may have limited support resources and therefore may gain support from managers.

As described by the CCNs in this study, the support received by the manager was described as the manager acting as a mediator between the CCN and physician if there was a disagreement, or as an ally with the CCN in order to increase the power and influence of the CCN in the DM process. Gleason, Sochalski, and Aiken (1999) similarly described the positive impact that a responsive leader can have on nursing job satisfaction. They stated that the presence and ability of a leader to support their staff in DM, and control over patient care issues is an essential component of increased job satisfaction. Furthermore, DeWolf (2005) described the need for the nurse administrator to step in if positional power is needed to support the nurse in the role of patient advocate against family or other health team members. Nurse leaders are obligated to maintain an environment where the distress and suffering of caregivers is understood and supported in a compassionate manner (Robichaux & Clark, 2006).

This support of managers is beneficial for the well being of the CCN and allows the CCN to continue in their roles of patient advocate and information provider. If the CCN does not obtain this support, they may withdraw from their roles, leaving patients/families to advocate for themselves and obtain the information they need in a complex health care environment. In order for nurses to provide this support needed by patients and families they "must be the recipients of compassion themselves" (Robichaux & Clark, 2006, p. 488).

Achieving a Work-Life Balance

Although the CCNs involved in this study described the need for CCNs to care for themselves by maintaining a work-life balance, this was not described in the literature regarding the role of the CCN in end-of-life DM. As the impact of staff shortages increases and the acuity of patient's increases, there will be ever increasing demands on CCNs, thus increasing the need for the CCN to ensure that they have strong self-care strategies and are able to obtain a work-life balance. Without this balance, the risk of burnout increases, as described by the CCNs in this study.

Debriefing

As the nurses in this study described, the use of formal peer debriefing could be a means of supporting nurses following a difficult DM process. As Jones and Fitzgerald found in their qualitative study, the CCNs interviewed identified the "need to be able to talk to someone after the event" (p. 120) as a coping strategy for dealing with the stress of the withdrawal of life support. Furthermore, although one nurse in Jones and Fitzgerald's study was reluctant about being involved in a formal peer debriefing process, it turned out to be a positive and worthwhile experience for the nurse. McClendon and Buckner (2007) similarly found nurses identified support groups as a strategy for coping with moral distress.

As the CCNs in this study stated, they would like to see more peer debriefing, but it is not happening consistently within these critical care units. Furthermore, if physicians were involved in this debriefing process, a greater understanding of the perspectives, values, and beliefs of physicians and CCNs could be obtained, which may promote enhanced communication and collaboration between these two professions.

Implications for CCN Practice

In order to prevent and combat the effects of powerlessness and burnout, the CCN must be able to fulfill their ideal roles of patient/family advocate and information provider, which would then provide the nurse with the satisfaction of being able to provide effective support and care for the patient and family. For the CCN to fulfill these roles effectively, effective communication and collaboration between the CCN and physician must occur. The CCN needs to be aware of the plan of care and be involved in the DM process, not as the decision-maker, but as an advocate for the patient/family's needs.

This communication and collaboration can be facilitated by ensuring that the CCN is involved in patient/family conferences and in daily patient rounds. Furthermore, the physicians and CCNs may need to receive increased education and on-going training on how to communicate with one another effectively. The use of debriefing sessions which include not only nurses but physicians may also assist in obtaining greater understanding of each other's roles in the DM process to withdraw treatment. The use of protocols in the DM process to withdraw treatment may assist in achieving a consistent DM process, but may not be feasible due to the variation within each patient's situation. CCNs also need to feel supported by managers and respected for their input and the unique perspective that they bring to end-of-life DM not only from their nursing background, but due to the close relationship that they develop with patients and families due to nursing's 24/7 presence at the patient's bedside. The CCN has a valuable role to play in supporting and advocating patients and families. These roles must be valued and respected to ensure that CCNs avoid feeling powerless and burnt-out, and are able to provide the support and care that patient's and families need.

Limitations of This Study

Limitations to the interpretation of the findings of this study must be considered. The results of this study should not be generalized to other critical care units or countries due to this study being conducted in one Canadian city. The specific limitations of this study which must be considered when interpreting the findings are: Researcher bias, the single research setting, and the small sample size and composition of the sample.

Researcher Bias

A limitation of this study, and one that the researcher had to remain constantly aware of, was the impact of potential researcher bias when performing the data collection and also the data analysis. The researcher's background in critical care nursing brings the researcher into this study with preconceived views about the DM process to withdraw life-sustaining treatment and the role of the CCN in this process. As stated previously, being aware of biases and personal assumptions through memoing, journaling, and having being interviewed by a colleague using the same questions asked in this study were important for the researcher to attempt to remain neutral and bracket prior knowledge and experiences when collecting and analyzing the data. As stated by Morse and Richards (2002), bracketing is achieved by making one's own previous knowledge and biases explicit by recording them in memos and journaling. Although these steps were taken, the researcher may still have entered the research field with preconceived notions and biases, and thus influenced the findings of this study during the interview process and when analyzing the data

Single Research Setting

Another limitation of this study is the single research setting. This study took place in only one city, so the findings of this study are not likely to be applicable to all CCNs in all cities in Canada or outside Canada. Furthermore, the time of year of the study may have affected the findings and the ability to recruit participants. Much of the recruitment phase and data collection took place during the spring and summer months when many CCNs were away on vacation. As a result, the critical care unit nurses were very busy as they were often functioning short-staffed. Therefore, the ability to recruit participants may be easier in the fall and winter months, and the responses of the CCNs may be different than what was heard at a time when the unit they work on is not short-staffed. As Makary et al. (2006) found, nurse and physician perceptions of collaboration and the DM process to withdraw treatment may vary over time and be influenced by events on the unit.

Small Sample Size and Composition of the Sample

The sample obtained for this study was small, and due to the difficulty in obtaining participants from within the original research hospitals two of the participants were drawn from a hospital not included in the original two hospitals. The data obtained from these two CCNs may be affected by their knowledge and relationship with the researcher. Furthermore, these CCNs did not work within Caritas hospitals which meant a faith-based sample was not maintained.

Another limitation of the sample that should be considered is the CCNs who did volunteer to participate in this study may have been those that felt most strongly about this topic and may not be representative of other CCNs. Furthermore, those CCNs who may be feeling burnt-out may not have volunteered for this study due to a lack of interest in anything work related and therefore may not be represented in this sample.

Implications for Future Research

A number of areas for future research have been identified within this study. These are: (a) how CCNs learn about their role in the DM process to withdraw life-sustaining treatment, (b) how CCNs become more confident in collaborating and communicating with physicians, (c) what strategies CCNs use when working in complex, high stress environments like a critical care unit to maintain a work-life balance, (d) what traits or skills help to make a CCN more confident and independent in their role, and (e) the use of protocols in end-of-life DM. All of these areas for future research are ones that the CCNs in this study raised, but are not fully addressed within the literature or in this study. Further research is also required regarding the nurses role in decisions to withdraw life-sustaining treatment, but with a larger and more varied sample. Finally, an important component which has not been addressed in this study is to gain an understanding of physicians' perceptions about the role of the CCN in the DM process to withdraw life-sustaining treatment.

Conclusion

CCNs could fulfill many roles in the care of critical care patients and families. Yet, as the past research and this study indicate, these nurses are not usually involved in the DM process to withdraw life-sustaining treatment. The ability of the CCN to fulfill their ideal role within this DM process as a patient/family advocate and information provider is affected by both barriers and facilitators. The barriers to these roles include the effectiveness of collaboration between the CCN and physician, the varying approaches of individual physicians to the DM process to withdraw treatment, hierarchical authority in DM, and CCN staff shortages. These roles can be facilitated by CCN experience, confidence in collaborating with physicians, support from managers, the ability of the CCN to achieve a work-life balance, and the use of debriefing sessions. CCNs need to feel that they are respected for the valuable insight they bring to the DM process due to the close connection they have to patients and families. When the CCN is unable to fulfill these ideal roles, feelings of powerlessness and burnout may set in, and cause the CCN to withdraw from the DM process and from providing the support that patients and families require.

Through the use of focused ethnography, an understanding of CCNs' preferred roles in the DM process to withdraw life-sustaining treatment was developed, as well as an understanding of the barriers and facilitators to these roles, and the outcomes associated with the CCN being unable to implement their preferred roles. It is hoped that this study provides greater understanding of CCNs' roles in the DM process to withdraw life-sustaining treatment and if needed, changes to policy and practice are made to ensure that patients and families receive the best end-of-life care possible, and CCNs are provided with a working environment that fosters their role of patient/family advocate and information provider; thereby enhancing the job satisfaction of CCNs. As stated by Calvin, Kite-Powell, and Hickey (2007), "the first step in bolstering communication is to identify and make the nurses' perceptions known" (p. 149).

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APPENDIX A: Information Letter and Consent Form

INFORMATION LETTER

Title of Research Study: Critical Care Nurses' Perceptions and Experiences Regarding Their Role in the Decision-Making Process to Withdraw Life-Sustaining Care: A Grounded Theory Study

Principal Investigator: Alison Landreville, RN, BScN, Master of Nursing Student

Supervisor: Dr. Donna Wilson, Professor, Faculty of Nursing
Phone: (780) 492-5574/440-0166
Email: donna.wilson@ualberta.ca

Background: Critical Care Nurses (CCNs) are often witnesses to the decision-making process used to withdraw life-sustaining care from patients. Research on the process of withdrawing care has found communication between health care providers and families, is not optimal. To improve the decision-making process to withdraw life-sustaining care, it is important to hear from CCNs about their experiences with this process. In addition, CCNs could have valuable information on how this process could be improved. This study hopes to find ways to improve critical care patient and family care.

Purpose: You are being asked to participate in a research study conducted by a student in a Master of Nursing program. This study will gain an understanding of the experiences of critical care nurses regarding their role in the decision-making process to remove care from patients.

Procedures: Participating in this study will involve:

a) A 1 to 2 hour interview, where you will be asked to discuss your experiences in past decision-making processes to withdraw life-sustaining care from critical care patients.
b) You may be asked to participate in a second 1 to 2 hour interview to gain more information about your experiences or to comment on the general findings of the first round of interviews.

Interviews can take place on a day when you are not working, and in a setting of your choosing. Interviews will be tape-recorded and transcribed by a transcriber. You can stop the interview at anytime and can have the tape-recorder turned off at anytime.

Possible Benefits: There are no direct personal benefits from being involved in this study. You will, however, contribute to research that aims to improve the role of the nurse in providing end-of-life care, and may improved end-of-life patient and family care.

Possible Risks: You may become upset when discussing your experiences of withdrawing care from patients. If this occurs, you can end the interview or take a break until you are ready to continue. If you become emotionally distressed, you will be referred to Caritas Ethics Services, which is available to all Caritas employees. You will also need to give one to two hours of time to this study.

Confidentiality: Any research data collected about you during this study will not identify you by name, only by your initials and a coded number. All data will be kept in a secure, locked cupboard by the principal investigator for seven years as per current University of

Alberta policy. Consent forms will also be kept in a different location from the interview data. Any report published as a result of this study will not identify you by name nor your hospitals name. We also ask you not to reveal any personally identifiable information about patients or family members.

Voluntary Participation: You are free to withdraw from the research study at any time. No penalties to employment will occur. If any knowledge gained from this or any other study becomes available which could influence your decision to continue in the study, you will be informed right away.

Reimbursement of Expenses: Babysitting expenses, if needed, will be covered.

Contact Names and Telephone Numbers:
If you have any concerns about this study, you may contact the Caritas Research Centre at (780) 930-5274. This office has no connection with the study investigators.

Please contact any of the individuals identified below if you have any questions or concerns:

Alison Landreville, RN, BScN, MN Student
Principal Investigator
Telephone Number: (780) 965-8322/433-0064
Email: ald@ualberta.ca

Donna Wilson, RN, PhD
Nursing Professor, Caritas Nurse Scientist, and Thesis Supervisor
Telephone Number: (780) 492-5574/440-0166
Email: donna.wilson@ualberta.ca

CONSENT FORM

Part 1 (to be completed by the Principal Investigator):

Title of Project: Critical Care Nurses' Perceptions and Experiences Regarding Their Role in the Decision-Making Process to Withdraw Care: A Grounded Theory Study

Principal Investigator: Alison Landreville, RN, Master of Nursing Student Phone Number: 965-8322/433-0064

Supervisor: Dr. Donna Wilson, Professor Phone Number: 492-5574/440-0166

Part 2 (to be completed by the research participant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to the information you provide?	☐	☐

Who explained this study to you?

____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research Participant

____

(Printed Name) ____

Date: ____________________________

Signature of Witness

____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee______________________________ Date ________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH SUBJECT