INTENTIONAL TRANSFORMATION: CRITICAL CARE NURSES' MANAGEMENT OF POWERLESSNESS IN END-OF-LIFE DECISIONS

by

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Bachelor of Nursing, University of New Brunswick, 1987

A Thesis Submitted in Partial Fulfillment of
the Requirements for the Degree of

Master of Nursing

in the Graduate Academic Unit of *Nursing*

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This thesis is accepted by the
Dean of Graduate Studies

THE UNIVERSITY OF NEW BRUNSWICK

JULY, 2006

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395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 978-0-494-46670-4
Our file Notre référence
ISBN: 978-0-494-46670-4

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ABSTRACT

The purpose of this study was to explore, describe, and provide a theoretical rendering of nursing behavior related to end-of-life decisions in New Brunswick's critical care settings. Using a grounded theory methodology, data were collected from nine critical care nurses through semi-structured interviews. Through the use of the constant comparative method of grounded theory analysis, *feelings of powerlessness* emerged as the central problem for critical care nurses related to end-of-life decisions. *Intentional transformation* is the basic social process that critical care nurses use to navigate the conflict between their professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions, in an attempt to alleviate *feelings of powerlessness.* The three stages of *intentional transformation* are *going with the flow*, *circumventing the system*, and *taking charge. Intentional transformation* is influenced by the following environmental conditions: *nurses' comfort level, organizational boundaries, family dynamics,* and *illness trajectory.* Study findings add to nursing knowledge in the areas of end-of-life decisions within critical care settings. These findings have implications for nursing practice, policy development, nursing education, future research initiatives, and ultimately, an increased awareness and the advancement of the critical care nurses' role in the area of end-of-life decisions.

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CHAPTER I

STATEMENT OF THE PROBLEM

Advances in technological interventions designed to prolong and sustain life have created new challenges for critical care nurses who deliver quality health care (Canadian Nurses Association, 2003a; Erlen & Sereika, 1997; Hughes & Dvorak, 1997). With the implementation of such interventions comes the necessity of making end-of-life decisions. Acknowledged as key participants in the decision-making process, critical care nurses play a limited role in end-of-life decisions (Corley, Selig, & Ferguson, 1993; Counsell, 2002; Hiltunen, et al., 1995; Jezewski, 1996; Joudrey & Gough, 1999; Leners & Beardslee, 1997; Thibault-Prevost, Jensen, & Hodgins, 2000). Left to implement decisions made by others, critical care nurses may not necessarily be in agreement with the final decision, leaving them to question the appropriateness of the decision and feeling powerless to influence any changes (Breier-Mackie, 2001; Erlen & Frost, 1991; Habel, 2003; Hough, 1996; McCormack, 1998; Oberele & Hughes, 2001; Redman & Fry, 2000; Simmonds, 1996; Thibault- Prevost et al.; Uden, Norberg, Lindeth, & Marhaug, 1992). As a result, the nurse may experience ethical or moral distress, which, if left unaddressed, may ultimately lead to suffering, decreased integrity, burnout, and job dissatisfaction (Corley, 2002; Erlen, 2001; Erlen & Sereika; Jezuit, 2000; Leners & Beardslee).

Research indicates that the nurse's limited role may be attributed to barriers such as organizational policies, institutional hierarchy, an inadequate knowledge base, feelings of powerlessness, and lack of administrative support (Asch, Shea, Jedrziewski, & Bosk, 1997; Dodd, Jansson, Brown-Saltzman, Shirk, & Wunch, 2004; Erlen, &

Sereika, 1997; Jezuit, 2000; Simmonds, 1996). There has been limited research exploring how critical care nurses deal with end-of-life decisions and their implementation within the context of the critical care setting and the Canadian healthcare system. To address this gap, a grounded theory study examining how critical care nurses' address end-of-life decisions, their implementation, and the nursing behaviors related to this process was conducted. The purpose of this study was to explore, describe, and provide a theoretical rendering of nursing behavior related to end-of-life decisions in critical care settings.

Background and Significance of the Problem

The delivery of healthcare in critical care settings has become a challenge for healthcare professionals as they encounter issues related to technological advances, an aging population, increased acuity levels, promotion of patient autonomy and self-determination, and limited resources (Counsell, 2002; Hough, 1996). In the past, dying was considered a natural phenomenon and medical interventions were utilized to ensure patients were kept comfortable, with the focus on caring as opposed to curing. Today, with the available expertise and technology to aggressively treat conditions once considered futile, there seems to be an overwhelming need to conquer death at all costs. If patient death does occur it is often considered a failure (Kirchhoff, Spuhler, Walker, Cole, & Clemmer, 2000; Kyba, 2002; Storch & Dossetor, 1994; Teaster, 1995; Woods, 2001). With the availability of life-prolonging interventions arises the need for end-of-life decisions. End-of-life decisions refer to patients' preferences toward life-sustaining therapies and whether or not these treatments should be initiated, withheld, or withdrawn (Storch & Dossetor). "Seventy percent of deaths in North American intensive care units are preceded by decisions to limit life support" (Prendergast, 2000, p. 91). Due to their constant presence at the bedside, and the unique nature of the nurse-patient relationship, critical care nurses are increasingly being confronted with decisions related to end-of-life issues (Breier-Mackie, 2001; Hewitt, 2002; Jezuit, 2000; Manias, 1998; Oberele & Hughes, 2001). Chally (1998) noted that 79 % of the 934 nurses surveyed by the Center for Ethics and Human Rights at an American Nurses Association convention in 1994 responded that they commonly experienced ethical dilemmas related to issues such as end-of-life care and informed consent on a daily or weekly basis. This is supported by the findings of a survey of Maine nurses ($N = 14,093$) completed by Powell and Nicoll (1998) in which 4 % of the nurses ($n = 564$) responded that ethical dilemmas related to end-of-life care issues such as life-sustaining treatment decisions, respecting patient rights and autonomy, and consent to treatment were encountered one to four times per day or weekly. Eighty-seven of the respondents indicated that they discussed these ethical issues with their peers whereas 73 % reported discussing concerns with nursing administration. Interestingly 8 % responded that they did not address the ethical issues at all.

Nurses have a professional obligation and ethical responsibility to act in the best interest of their patients (Breier-Mackie, 2001; CNA, 2002; McCormack, 1998). The Canadian Nurses Association's Code of Ethics articulates that nurses should promote patient's autonomy, value patients, and treat them with respect and dignity, while advocating for their rights (CNA, 2002). Research indicates that nurses have a key role in end-of-life decisions, yet they continue to find themselves disempowered by 'medical paternalism', unable to influence the decision-making process or ill equipped in decision-making skills (Breier-Mackie; Holly, 1989; Miller, Forbes, & Boyle, 2001; Ravenscroft & Bell, 2000; Reckling, 1997; Smith, 1996; Walter et al., 1998). The Canadian Council on Health Services Accreditation (2002) standards recommend that an interdisciplinary approach to decision-making be utilized, and that hospital policies should reflect the patient's rights and responsibilities. As well, it is recommended that hospitals have processes in place to assist staff in dealing with ethical issues including end-of-life decisions and provide some proactive clinical ethics education for staff (Canadian Council on Health Services Accreditation, 2002). Nurses feel that they do not have an active role in end-of-life decisions, which often results in feelings of powerlessness, frustration, anxiety, and confusion (Asch et al., 1997; Jezuit, 2000; Simmonds, 1996; Soderberg & Norberg, 1993). Doane (2002) indicated that novice nurses often felt that they did not even have the right to ask questions or share experiences.

Even though the critical care nurse is identified as caring, accessible, and a patient advocate she is still often seen as the "least powerful person" when it comes to decision-making and is often excluded from the process (Corley et al, 1993; Emanuel, 1995; Hewitt, 2002; Manias, 1998; Millette, 1994; Thibault- Prevost et al., 2000). When nurses feel that they cannot meet the needs of patients and families, or provide the quality of care expected due to barriers or circumstances such as limited resources, organizational policies, or personal values, they may experience moral distress (CNA, 2003a; Corley, 2002; Dawe, Verhoef, & Page, 2002; Erlen, 2001; Storch, Rodney, Pauly, Brown, & Starzomski, 2002). If not addressed, moral distress can lead to future problems such as decreased integrity, burnout, job dissatisfaction, and physical illness which could impact on one's professional or personal relationships (CNA, 1994; Erlen).

Professional associations and nursing interest groups such as the Canadian Nurses Association and Canadian Association of Critical Care Nurses have recognized the integral role that critical care nurses play in end-of-life decisions, its possible impact on nurses and the significance of moral distress. They have responded to the identified need for guidance and direction by developing documents such as "A Question of Respect: Nurses and End-of-life Treatment Dilemmas", "Withholding and Withdrawing of Life Support", and "Ethical Distress in Health care" (Asch et al., 1997; Bosek, 2001; CNA, 2003a; CNA, 2003b; CNA, 1994; CACCN, 2001; Holly, 1989).

Failure to recognize the critical care nurse's vital role in end-of-life decisions produces a significant gap in the decision-making process, decreases the effectiveness of communication among health care providers, and ultimately decreases the quality of patient care delivered. Institutions, professional associations, administrators, and government officials need to implement policies and processes designed to define, promote, and facilitate the critical care nurse's role in the end-of-life decisions.

CHAPTER II

LITERATURE REVIEW

When a grounded theory approach is used, the research is not guided by a theory or conceptual framework because the purpose of grounded theory is to generate theory as part of data collection and analysis (Glaser, 1978; Morse & Field, 1995). Glaser (1978) specified that researchers using the grounded theory method should avoid completing a detailed literature review until after the “core variable” has emerged from the data. This is to prevent the research from being directed by preconceived ideas, concepts, theories or gaps in the literature (Glaser; Schreiber & Stern, 2001). However, the researcher can examine the literature for broad concepts and significant findings such as end-of-life issues, decision-making, moral distress, burnout, collaborative approaches, and ethical theories and principles that may be beneficial in data collection and analysis (Morse & Field; Streubert & Carpenter, 1999). As central themes and processes emerge during data collection and analysis they are refined or confirmed through comparison with what is documented in the literature (Glaser). In this literature review, I provide an overview of the knowledge relevant to critical care nurses and end-of-life decisions, in particular, their behaviors in relation to end-of-life decisions that were reviewed prior to data collection. I reviewed additional literature after identifying the core variable. That literature is integrated with the research findings.

Although research in the area of end-of-life issues has increased nationally and internationally over the past few years, the number of studies related to the role of critical care nurses and end-of-life decisions has remained limited (Baggs & Schmitt, 2000; Kennard et al., 1996). Many of the studies have focused on patient and family participation, nurse/physician collaboration, comparison between attitudes, and approaches of nurses and physicians, interdisciplinary approaches, moral distress, and burnout, educational needs and clinical effectiveness (Asch et al., 1997; Baggs & Schmitt; Boumans & Landeweerd, 1994; Bunch, 2001; Cook et al., 1995; Corley & Selig, 1992; Counsell, 2002; Eliasson, Howard, Torrington, Dillard, & Phillips, 1997; Elder, Price, & Williams, 2003; Hughes & Dvorak, 1997; Jezuit, 2000; Kirchhoff & Beckstrand, 2000; Norton & Talerico, 2000; Oberle & Hughes, 2001; Ryan et al., 2001; Solomon et al., 1993; Storch & Dossetor, 1994; Uden et al., 1992; White, Coyne, & Patel, 2001). Comprehension of the nurse's role in end-of-life decisions is further complicated by the interdependency and overlapping between the medical and nursing domains (Prescott, Dennis, & Jacox, 1987).

Ethical Theories

Since end-of-life decisions are often encompassed with controversy and possible ethical dilemmas it was helpful to examine literature concerning pertinent ethical theories. In the past ethical discussions were primarily based on the deontological and utilitarian (teleological) theories.

Deontological theory. Immanual Kant's deontological theory focused on the philosophical concept that the "end does not justify the means", thus actions are assessed individually for their own value and the consequences of the action are not part of the decision; decisions are based upon duties and obligations (Beauchamp & Childress, 1994; Noureddine, 2001). Ethical decision-making models are often based on the four principles of deontology: (1) Beneficence-doing the most good for the patient; (2) Nonmaleficience- do no harm and minimize suffering; (3) Justice-ensure fairness to all; and (4) Autonomy-ensure that the individual has input (Beauchamp & Childress; Becker & Grunwald, 2000). In a small qualitative study examining ethical situations causing stress among critical care nurses (*N*= 6), Jezuit (2000) notes that the majority of nurses expressed deontological views of obligation and duty when they responded that they felt it was their duty to respect their patients wishes, despite their personal preferences. Interestingly, over 65 % of the critical care nurses interviewed had not received any post secondary ethics education yet seemed to verbalize deontological views.

Utilitarian theory. Attributed to John Stuart Mill and Jeremy Bentham, utilitarianism examines the rightness and wrongness of the action based upon its consequences. It focuses on the principle, "the greatest good to the greatest number" (Beauchamp & Childress, 1994). In essence, societal well-being takes priority over individual benefit. Debates of paternalism versus autonomy have emerged from this theory (Beauchamp & Childress; Noureddine, 2001).

Ethics of care versus ethics of justice. As opposed to the traditional ethical theories, some researchers support the concept of two orientations to ethical decision-making, the "ethic of care" and the "ethic of justice" (Gilligan, 1982; Hough, 1996; Lipp, 1998). According to Gilligan (1981) the essence of moral decisions is the exercise of choice and the willingness to accept responsibility for that choice. The author indicates that the there are two ways to view moral problems, the "ethic of care" and the "ethic of justice". Neither approach is better than the other, but rather the approach chosen is reflective of one's moral development and preference.

Gilligan (1982) insisted that there is a difference in the moral and psychological tendencies of men and women. Men base their thinking on rules and justice, which is referred to as the ethic of justice, whereas women have the tendency to think along the concepts of caring, nurturing and relationships, which is referred to as the ethic of care. Individuals using the ethic of justice approach make impartial decisions on the basis of universal principles and rules, such as right and wrong, ensuring fair and equitable treatment to all people (Botes, 2000). The ethic of justice follows the similar philosophy of utilitarian theory. When using this approach one would base his/her decision on the principles of beneficence and fidelity (Gaul, 1995).

In contrast, the ethic of care is a multidimensional approach based on relational aspects. An individual's decisions are influenced by how one perceives his/her responsibility or connections in the relationship. Using a holistic, needs-centered approach, the decision is based more on beliefs, values and empathy, which vary within the context of the surrounding conditions and situations (Gilligan, 1982).

Although multiple approaches to ethical decision-making are identified in the literature, it is common to see an integration and application of the ethic of care and justice utilized to solve problems (Botes, 2000). This is supported by the findings of a grounded theory study conducted by Lipp (1998) to identify common ethical decision methods used by nurses in everyday practice. A convenience sample was comprised of 8 registered nurses (*N* = 8), seven female and one male. The nurses were currently enrolled in a nursing degree program but had not yet received formal education in ethical theories. Through semi-structured interviews, nurses were asked to share an ethically difficult situation they had encountered. Interestingly, the fact that all nurses utilized a combined ethic of care and justice approach to formulate their ethical decisions emerged as the central theme.

Empirical Studies of Ethical Approaches Used by Nurses and Physicians

Gilligan (1981) indicated that when faced with moral and ethical decisions or dilemmas, individuals use moral reasoning. Moral reasoning refers to the "cognitive process" individuals use to determine whether actions are considered right or wrong by comparing how they would be perceived according to societal norms and one's personal morals and values (Gilligan, 1981; Noureddine, 2001). Moral reasoning is individualistic and influenced by factors such as: personal values and beliefs, culture, religion, awareness of patient preferences, knowledge of the situation, and knowledge of the potential outcome (Baggs, 1993; Millette, 1994; Noureddine). Individuals view ethical dilemmas from different perspectives and thus address the problems differently (Corley & Selig, 1992; Gilligan, 1982; Millette).

Several research studies indicated that physicians and nurses often view ethical decisions from two different perspectives, sometimes resulting in ethical controversy in the provision of patient care. Although their personal beliefs appear to be essentially the same, their differences may be attributed to their professional roles, educational background, and level of experience (Elder et al., 2003; Hughes & Dvorak, 1997; Lipp, 1998; Oberle & Hughes, 2001). There has also been some debate as to whether preference to either the ethic of care or ethic of justice is influenced by gender, discipline, or education (Lipp).

Elder et al. (2003) conducted a quantitative comparative study of differences in ethical attitudes between registered nurses (*n* = 67), and medical students (*n* = 125) in

Australia. Seven percent of the nurses (*n* = 5) were male and 51 % of the medical students (*n* = 64) were male. Selected on a volunteer basis, they were asked to complete a questionnaire consisting of hypothetical situations related to ethical issues. Analysis of the data revealed a significant difference in the ethical attitudes of nurses and medical students. The medical students identified with the medical decisions or ethic of justice approach, whereas the nurses identified more with the wishes of patient or the ethic of care approach. Due to the predominantly female gender composition, the analysis of variance was conducted using gender-adjusted scores. Despite this adjustment no significant changes in the response pattern were noted. The possibility of the results only reflecting gender differences was also discounted by the evidence that female medical students responses were more comparable to their male medical colleagues than those of the female nurses. Thus it is possible that ethical orientation is driven by discipline rather than gender but more research is needed to verify this. An identified limitation in this study was the unknown educational background of the nurses as ethical education may have influenced their decisions.

Interestingly, this central theme of differing ethical approaches driven by discipline also emerged from a Norwegian narrative study examining differences in ethical reasoning in nurses (*n* = 23) and physicians (*n* = 9) (Uden et al., 1992). In this study the nurses and physicians shared 43 stories related to ethically difficult situations that they had encountered. The story themes were identified through application of the narrative ethical theory. Nurses addressed the situations by using the ethic of care approach and focused on patient relationships whereas physicians stressed the ethics of justice and action based approach. The findings revealed that the use of different types of reasoning to address ethically difficult situations by nurses and physicians is probably attributed to each profession's need to place emphasis on the factors that are important to fulfill their assigned role.

The two previous studies support the findings from a Canadian study conducted by Grundstein-Amado (1992) examining the different approaches to ethical decision-making used by nurses and physicians (*N*= 18). Eighteen health care providers, 9 female nurses and 9 male physicians were selected from acute care and long-term care settings in two Toronto area hospitals. Participants were interviewed in two phases. In the initial interview, participants shared past personal experiences using ethical decision-making processes. During the second phase they were asked to respond to a hypothetical situation. Analysis of the data revealed that nurses and physicians base their ethical decisions on different values. Nurses focus primarily on carative aspects and respect for patient wishes as opposed to the physicians' focus on curative aspects and patient rights. Additional research is needed to identify whether any relationship exists between the ethical education received by physicians and nurses and their approach to ethical decision-making.

Oberle and Hughes (2001) conducted a grounded theory study to identify and compare nurses' and physicians' perceptions of ethical problems related to end-of-life decisions. The sample consisted of 14 nurses and 7 doctors working on adult medical-surgical and intensive care units in a Canadian hospital. All of the nurses were female and all but one of the physicians was male. Using unstructured interviews participants were asked to share ethical situations that they had frequently encountered in their practices. The core concept emerging for both groups was patient suffering and the moral obligation to decrease that suffering. Common themes of communication, hierarchical processes, values, and limited resources emerged from the data analysis. The key difference noted between the two disciplines was that the physicians were ultimately responsible for the decision making while the nurses were left to implement and live with the decisions made. Their differences appear to be based on their professional roles as opposed to their personal values, which is reflective of the previous studies mentioned.

Joudrey and Gough (1999) conducted an explorative study examining Canadian student nurses' perceptions of 'nurses and physicians' ethical stances. Sixty–six percent (*n* = 73) of the 110 questionnaires distributed to second year nursing students studying at an Albertan Community College, were suitable for analysis. Through content analysis of the data it was noted that 81 % (*n* = 59) of the 79 respondents identified a distinguishable difference in ethical stances between nurses and physicians. While 8 of the respondents provided a simple "yes" response, the remaining 65 % (*n* = 51) of participants went on to elaborate that they felt that the physicians demonstrated a curative focus while the nurses took a caring approach. It is important to note that the study findings may have been skewed by the fact that all but 4 of the respondents were female. Since this was a cross-sectional study it would be noteworthy to conduct a longitudinal study to see if the students' perceptions changed over time as they were exposed to ethical issues in the classroom and clinical settings.

Simmonds (1996) utilized the grounded theory approach to explore and understand the experiences of Canadian physicians and nurses caring for dying patients in the intensive care unit. Semi-structured interviews were used to collect data from 7 nurses, 6 house staff and 8 staff physicians currently working in the intensive care setting. The central themes of powerlessness, promotion of comfort, and the provision of good death emerged during the data analysis process. The findings revealed that nurses were not just satisfied with saving patients but also wanted to promote comfort measures and in doing so were more apt to relate themselves to the patient and their wishes. On the other hand, the physicians and house staff were more concerned with knowing that all avenues were exhausted in trying to save the patient and often saw death as a failure. However, it is interesting to note that although physicians saw death as failure, those feelings seemed to fade with experience and age and the realization that some cases are futile. One of the most significant findings was that physicians expressed that it was easier to continue treatment than initiate end-of-life discussions with the patient and family. However, this was not a mutual feeling for the nurses as they indicated that they were often left at the bedside to deliver the treatments. The preference for over treatment was often justified by fear of litigation, unrealistic family expectations, and the availability of technology. Worthy of noting was the finding that all three disciplines reported experiencing feelings of powerlessness. Nurses expressed that they had limited input into the decision-making process, house staff felt that they were carrying out the directives of others and physicians felt that they were often left to enact a colleague's orders. This was not noted in the previous studies. One implication of this study completed by Simmonds was that increased communication and collaboration among disciplines would be beneficial to ensure an understanding of the roles of others.

Collaborative Approach to End-of-life Decisions

Traditionally physicians have played the dominant role in end-of-life decision-making leaving the nurse to provide the care and interventions affiliated with the decision (Baggs & Schmitt, 2000; Hohenleitner, 2002; McCormack, 1998; Miller et al., 2001; Thibault-Prevost et al., 2000). Although physicians believe that they are involving the nurses this is not supported by the findings of the study entitled, Study to Understand Prognosis and Preference for Outcomes and Risks of Treatment (SUPPORT), where nurses were found to have limited involvement in treatment related decisions (Eliasson et al., 1997; Hiltunen et al., 1995; SUPPORT Principle Investigators, 1995). The SUPPORT study, one of the largest studies regarding dying in American hospitals revealed that dying is unsatisfactory in hospitals and identified inadequacies related to advance directive planning, pain management, communication regarding prognosis, and the failure of interventions designed to facilitate communication to improve outcomes (SUPPORT Principle Investigators). This 5-year, five-center study examining decision-making and communication in patients near end-of-life was conducted in two phases. The 2-year prospective observational study during Phase 1 (*N*= 4301) revealed physicians' decreased awareness of patient preferences and lack of implementation of the patient's refusal for treatment. During the two year controlled clinical Phase 2, specially trained research nurses facilitated discussions between physician, patients, and families in hopes of enhancing communication, advocating shared decision-making processes, and decreasing the number of life-sustaining interventions; however this intervention failed to change outcomes in the fact that physician awareness of patient preference and involvement of patients and other health care professional in the decision making process did not improve (Baggs & Schmitt; Lo, 1995; SUPPORT Principle Investigators). Of significance is the fact that the nursing interventions failed to influence or change the physician's approach leaving one to question whether the nurse's input or suggestions were even recognized or accepted by the physician (Emanuel, 1995). A possible limitation noted by Lo was that since the SUPPORT study did not publish the actual content of the physician-patient conversations one does not know if physicians advised patients of the possible alternative treatments or even paid attention to the patient's treatment related wishes.

Interestingly, several articles critiquing the SUPPORT study made reference to the possibility that the failure of the interventions in Phase 2 of the SUPPORT study to improve communication may have been attributed to the fact that nurses are perceived as persons of limited power or authority with decreased credibility within the institutions (Emanuel, 1995; Lo, 1995). However, it could also have meant that patients are happy with the present system where the physician plays the dominant role in the decision-making process (Emanuel; Kennard et al., 1996; Lo; Miller et al., 2001). These comments instill uncertainties regarding the potential success of a collaborative approach for end-of-life decisions in critical care areas.

Nevertheless it is important to note that over the past few years there has been a movement toward a more collaborative approach which advocates the participation of the patient, family, and other health care providers (Canadian Council on Health Services Accreditation, 2002). Research indicates that a collaborative approach promoting increased communication among patients, family, and health care providers can enhance the end-of-life decision-making process and outcome (Baggs, 1993; Baggs & Mick, 2000; Karlawish, 1996; Norton & Talerico, 2000; Sherman & Branum, 1995).

Norton and Talerico (2000) conducted a grounded theory study to explore and describe the behaviors utilized by providers to facilitate the end-of-life decision-making process for patients. The sample (*N*= 20) was comprised of 10 nurses, 5 physicians and 5 family members, 3 of whom were identified as proxy decision-makers. The nurses practiced in the areas of home care (*n* = 3), intensive care (*n* = 4), and oncology (*n* = 3) whereas the physicians had specialties in the areas of oncology (*n* = 3) and family practice (*n* = 2). Semi-structured interviews were used to identify which factors facilitated or impeded the end-of-life decision-making process. Through the use of constant comparative analysis approach, communication and assessment strategies emerged as the central themes. Providers indicated that the ability to openly communicate with the patients while continually assessing the patient's condition, expectations and needs were key components in facilitating the process. The decision-making process seemed to become problematic when conflict emerged among the health care providers, family, and patient.

In their review of literature related to the use of a collaborative approach to address ethical issues in the elderly, Baggs and Mick (2000) noted that collaboration among the health care providers, family, and patient is key in facilitating end-of-life decision-making. An ethical decision-making model was identified as one intervention that would promote an interdisciplinary approach.

Bunch (2001) conducted a grounded theory to identify ethical dilemmas faced by health care professionals and the processes used to address them. The sample was comprised of 15 registered nurses currently practicing in a Norwegian neurointensive care unit. The nurses were interviewed numerous times during the year of field observations and end-of-life issues emerged as one of the ethical dilemmas frequently encountered. Of interest was the fact that a collaborative approach, in particular the interdisciplinary team conference, was identified as a key intervention utilized to address ethical dilemmas related to end-of-life care.

Karlawish (1996) notes that end-of-life decisions in critical care settings are difficult and frequently complicated by the fact that the patient is often unable to make treatment related decisions leaving family and care givers to advocate on behalf of the patient. In his review of essays and books related to informed consent and narrative theory, he concluded that a shared decision-making process in critical care areas is a necessity for end-of-life decisions and must not be limited to the patient and physician but must be broadened to include family members and other health care workers, in particular the nurse.

Critical Care Nurses and End-of-life Decisions

Between 1980 and 1984 Prescott, Dennis, and Jacox (1987) conducted one of the most extensive research studies related to the nurse's role with decision-making. They completed a qualitative study examining nurses' involvement with clinical decision-making, their level of satisfaction, and the factors influencing the decision-making process. One hundred-fifty staff nurses, 68 head nurses, 49 supervisors and 111 physicians (*N*= 278) were purposively selected from a variety of clinical settings in six American cities. When interviewed, the nurses described their role as primarily collecting data and conveying information, while the physician ultimately made the final decision. Interestingly, this same perception of the nurse's role was conveyed in the physician interviews. Nurses seemed to acknowledge this lack of authority when they differentiated between two types of decisions: those that they were allowed to make and the ones that they wanted to make. Nevertheless, qualitative analysis of the semi-structured interviews revealed that 73 % ($n = 100$) of the 150 nurses were satisfied with their role in clinical decision-making while 22 % ($n = 44$) were dissatisfied. Interestingly, 41 % of the medical-surgical nurses reported dissatisfaction with their role as opposed to 24 % of the intensive care or specialty nurses. This distribution of dissatisfaction among the nurses may have been attributed to some of the reported factors perceived to influence the decision-making process such as: organizational structure and policies, types of hospitals and units, the nurse's educational background, experience, and interpersonal skills. Although the findings support increased participation and satisfaction with the decision-making role among specialty and intensive care nurses it was noted that additional research studies would be required to verify this.

In a study by Asch et al. (1997) designed to explore American critical care nurses' beliefs and experiences in relation to end-of-life care, a questionnaire was mailed to 1600 subscribers of the journal, "Nursing". Only 852 of the 1139 (73 %) questionnaires returned met the eligibility criteria. The researchers used content analysis to review the text comments provided by 468 critical care nurses. Although the questionnaire focused mainly on issues surrounding active euthanasia and assisted suicide the study findings are significant because the majority of the written comments focused on end-of-life issues in critical care units. The respondents reported frustration related to incidents of over treatment and disregard for patients wishes. While 53 % of the nurses supported the importance of patient involvement in end-of-life decisions many of them reported frustration at their own limited ability to intercede on behalf of the patients when required. Thirty-two percent of the respondents indicated the need for better guidance in addressing end-of-life issues. Interspersed between the physician and family, nurses feel that their role in end-of-life decisions is often impeded by personal, professional, and organizational constraints.

Despite support for a more integral role in end-of-life decisions, research shows that critical care nurses feel constrained by physicians and family (Reckling, 1997). Reckling conducted a 2-part context-dependent study designed to explore and understand factors affecting the withdrawal or withholding of treatment related decisions. In particular she examined the professional and family roles that transpired during the decision-making process and the factors influencing the emergence of these roles. Reckling used the same six intensive care units of a large midwestern hospital to conduct both parts of the study. In the first part of the study, questionnaires designed to elicit information regarding attitudes toward end-of-life care were sent to 500 health professionals (nurses, residents, and physicians) employed in one of the six intensive care units. In the second part of the study the researcher conducted a “multiple case study” and observed families of 10 adult patients in the intensive care unit over a 3.5 month period. There were 5 male and 5 female patients selected among the six units. The sample ($N = 45$) included 16 family members, 15 nurses, 11 physicians, 2 respiratory therapists and one pharmacist. The study findings showed that health care professionals and family members involved in decisions to withhold or withdraw treatment commonly chose one of three positions: advocating the withholding or withdrawal of treatment, remaining neutral (go along with any decisions), or resisting the decision to withdraw or withhold treatment. It was noted that the person's decision was often influenced by personal attitudes, professional roles, interpersonal relationships, fear of litigation, availability of resources, and situational variables such as patient discomfort and prognosis. An interesting finding in this study was that although there were more professionals in the advocating role the only persons to adopt neutral roles were nurses. The neutral role referred to participants who do not indicate any preferences regarding the treatments and readily followed the decisions made. However none of the nurses were resistors. Resistors opposed the withdrawing/ withholding of care but may still go along with decision relinquishing the responsibility to others, or they may adamantly refuse to go along with the decisions. When examining the intensity of the roles adopted it is worthy to note that the nurses often took a passive role (advocate or neutral roles). Upon examining the data to determine why nurses often adopted a passive advocating role or remained neutral, the researcher discovered that nurses were often influenced by fears of litigation or workplace retribution, felt constrained by more powerful persons such as the physician or family, or wanted to support the wishes of the patient and/or family.

Literature indicates that although nurses are responsible for the provision of competent quality care they may not be influential in decisions and policies governing the care given (Lutzen, Cronqvist, Magnusson, & Andersson, 2003). Lutzen et al. used a hypothetical-deductive approach to analyze qualitative data from two independent studies on professional issues. Nurses expressed feelings of powerlessness, lack of authority, lack of control over specific situations, and felt an overall need to provide good care when caring for critically ill patients.

In her phenomenological study designed to explore and explain the experiences of staff nurses and ethical decision-making, Smith (1996) interviewed 19 staff nurses from a variety of nursing units. Findings indicated that nurses are unsure of their role in ethical decision-making. Five out of 52 nurses approached for interviews declined participation as they stated they did not make ethical decisions in their nursing practice. Manias (1998) conducted a study to examine Australian nurses' ($N = 360$) experiences with "do not resuscitate" decisions. With a 79 % ($n = 285$) response rate, the author noted that physicians were usually responsible for the orders but that 91 % ($n = 259$) of the respondents thought that the staff nurse should become more involved. However, it is worthy to note that 70 % still thought that the ultimate responsibility of the decision should rest with the physician or a more experienced nurse. Further research is required to determine why this was the nurses' preference.

Hughes and Dvorak (2001) conducted a non-experimental, ex post facto study examining the degree to which informal ethical decisions made by critical care nurses concurred with the decisions recommended by using a decision analytic model. One hundred critical care nurses were randomly selected from seven critical care units in a 500 bed university affiliated tertiary care center. The nurses were asked to read a scenario and then complete the computerized Ethical Decision Analytic Model (an instrument designed to measure staff nurses' abilities to make consistent decisions when faced with scenarios) and complete a Background Inventory. Eighty-two percent ($n = 82$) of the nurses completed responses. Interestingly, while 50 % of the nurses

($n = 41$) selected a course of action that concurred with one of the least optimal actions suggested by the Ethical Decision-Making Model, only a few nurses selected the optimal action. These findings supported previous literature which indicated that structured ethical decision- making models may not be suitable in critical care areas where decisions are often more complex as opposed to the task oriented decisions in non critical care units.

Holly (1989) examined how critical care nurses ($N= 45$) perceived their participation in decision-making and their perception of support. Seventy-four percent indicated that the decisions were either made by the physician or in accordance to institutional policies. The nurses did not feel free to participate or provide input due to perceived lack of support from nursing administration or physicians. However, they were overwhelmingly consistent in their perception of support from co-workers.

Moral Distress

Although numerous research studies regarding ethical decision-making in various areas of nursing practice have been completed, limited research is available on how nurses respond to ethical dilemmas, deal with the intrapersonal and interpersonal conflict and affiliated emotions and how ethical principles are incorporated into their daily practice (Corley, 2002; Hughes & Dvorak, 1997). McCormack (1998) indicated that nurses have a professional obligation to act in the best interest of patients but this could lead to intra or interpersonal conflict, ultimately progressing to moral distress for the nurse.

In their systematic analysis of five studies that looked at nurses' experiences with ethical conflicts, Redman and Fry (2000) found that approximately 33 % of nurses felt they had experienced moral distress related to organizational constraints. Several other studies, including a Canadian qualitative study by Doane (2002) on understanding nurses' moral identity, found that nurses experience moral distress when circumstances such as limited human/financial resources, organizational constraints, and hierarchical structure interfere or inhibit their provision of adequate patient care (Doane; Lipp, 1998; Oberle & Hughes, 2001; Storch et al., 2002). As well, several research studies acknowledge that resources should be made available to nurses to help manage moral distress. Their recommendations included: peer support, interdisciplinary teams, ethics committees, grand rounds, policy guidelines, and educational opportunities and literary resources (Erlen, 2001; Lipp; Storch et al.). However, further research is required to see if nurses are actually aware of, and utilizing the potential resources and supports available to them, and if not, why?

Jezuit (2000) interviewed 6 critical care nurses (*N* = 6) employed at a large medical center in the American Midwest, asking them if they had ever experienced any suffering related to their participation in end-of-life decisions. Throughout the interviews central themes of frustration, anger, moral distress, and helplessness surfaced in relation to conflicts surrounding end-of-life decisions and the feeling of inadequacy in the delivery of patient care. Sixty-seven percent (*n* = 4) shared their desire to leave the critical care setting or even the nursing profession. Although only a small study, the findings support the need for future research related to critical care nurses' feelings of suffering, its causes, and possible remedies.

Literature indicates that when nurses feel that they cannot meet the needs of patients and families, or provide the quality of care expected due to barriers such as organizational policies, institutional hierarchy, feelings of powerlessness, and lack of administrative support they may experience moral distress (Asch et al., 1997; Corley, 2002; Dawe et al., 2002; Dodd et al., 2004; Erlen, 2001; Erlen, & Sereika, 1997; Jezuit, 2000; Simmonds, 1996; Storch et al., 2002). If not addressed, moral distress can lead to future problems such as job dissatisfaction and burnout which could impact on one's professional or personal relationships (CNA, 1994; Erlen). Literature also indicates that burnout may be a result of continued exposure to work related stressors, feelings of powerlessness, and maladaptive coping behaviors (Keane, Ducette, & Adler, 1985; Robinson & Lewis; 1990).

Keane, et al. (1985) conducted a study to determine if intensive care nurses experience higher incidences of burnout than non-intensive care nurses and if there was any correlation between having control over situations and burnout. The sample (*N* = 96) consisted of 38 medical and surgical intensive care nurses and 58 non-intensive care nurses from a large urban university hospital. The nurses were asked to complete a questionnaire consisting of inventory scales and open-ended questions. The findings revealed that intensive care nurses did not appear to experience any more stress, job dissatisfaction or burnout than the comparison group consisting of non-intensive care nurses. Interestingly the findings did indicate nurses who felt challenged and in control of their job were less apt to experience burnout than those nurses with limited autonomy.

Robinson and Lewis (1990) conducted a quantitative study designed to determine if there was any correlation among intensive care work related stressors, the stress response, and the stress management implemented by the nurse. The potential study sample consisted of 12,003 registered nurses working in intensive care units in federally funded American facilities with more than 400 beds. There was a 48 percent response rate (*n* = 577) from 20 facilities, of which 69 percent were females. The major work related stressors identified by the nurses were: lack of reward, work schedule and nurse-administration relationship. The three major stress responses identified were: anxiety, frustration, and fatigue. A combination of adaptive and maladaptive coping mechanisms were reported that ranged from taking vacations, talking with colleagues, increased caffeine intake to job changes. The findings indicated a positive correlation between perceived severity of the stressors, the ability to control the stressors and the stress response ($r = .61, p <. 001$). Interestingly, it was noted that as the severity of the stressor increased the use of maladaptive coping mechanism increased. It was also noted that there may be a relationship between the severity of the stressor and the ability to control the stressors. If the nurse felt that she could control the stressors the stress response was less severe, more adaptive coping mechanisms were used. These findings support the importance of nurse autonomy and communication in intensive care settings.

Factors Influencing the Nurse's Role in the Decision-Making Process

Kirchhoff and Beckstrand (2000) conducted a study to explore critical care nurses' perceptions of possible obstacles and helpful behaviors when providing end-of-life care.

Questionnaires were mailed to 300 members of the American Critical Care Association. Twelve responses were eliminated, as the nurses were not currently employed in an ICU setting. Of the eligible responses (*N* = 288), 69 % (*n* = 199) were used in the analysis. An interesting finding was that five out of the nine obstacles identified involved the nurses' "difficulty with physician behaviors", (p. 104). The obstacles identified were: avoidance of family members, aggressive treatments, ignoring patient wishes, differing opinions with colleagues, and inadequate pain relief for patients. The helpful behaviors identified were flexibility in visitation hours and increased communication with families.

Downe-Wamboldt, Butler, and Coughlan (1998) utilized an exploratory, descriptive study design to determine the knowledge level of Nova Scotian nurses in relation to living wills and the barriers to their use in clinical practice. A random sample of 974 nurses were sent surveys during the 1995-1996 registration year. The survey consisted of a 12-page questionnaire containing true and false questions, Likert-scale items and open-ended questions. Sixteen percent (n = 157) of the questionnaires were returned. Demographic information indicated that the respondents were employed in a variety of clinical settings. Analysis of the data revealed that although they had a positive attitude to advance directives, the majority of these nurses were unfamiliar with living wills and their associated legislation. Some of the perceived barriers to advance directives identified by these nurses included: lack of knowledge, lack of concern for ethical issues by the institutions, and time limitations.

Educational Preparation Related to End-of-life Issues

The literature indicates that nurses learn about ethical principles in their educational programs but not necessarily in the context of nursing practice. Benner, Hooper-Kyriakidis, and Stannard's (1999) work supports the fact that nurses learn a great deal from experience, and that this is instrumental in personal and professional growth. It is believed that perhaps nurses who have the skill to integrate ethical principles into practice may have achieved this through experience (Benner et al.; Doane, 2002; Hough, 1996). During the literature search several research studies related to education and knowledge levels related to end-of-life decisions were located.

Despite literature supporting the participation of nurses in end-of-life decisions there has been limited movement in this direction. Although some of the hesitation may be related to institutional policies and perceived role limitations it may also be attributed to the nurse's lack of knowledge and experience in the area of end-of-life decisions (Downe-Wamboldt et al., 1998; Ryan et al., 2001; Stoeckle, Doorley, & McCardle, 1998). Ryan et al. conducted an exploratory descriptive study to explore the knowledge and comfort level of critical care nurses in relation to advance directives. Surveys were distributed to all registered nurses on four medical-surgical units, three critical care units and a maternal-child unit. In total 133 questionnaires were returned representing a response rate of 32 %. The findings showed that 53 % of respondents felt that their knowledge level was sufficient to provide advance directive information to patients while 31 % disagreed, whereas 17 % were unsure. However, it is interesting to note that despite this, 77 % of respondents agreed or strongly agreed that additional education in this area would increase their comfort in discussing advance directives with their patients.

Ferrell, Virani, Grant, Coyne and Uman (2000) mailed out a descriptive questionnaire via Nursing Management and Nursing 98 asking nurses (*N*= 300) to rate the adequacy of education related to end-of-life care that they received in their basic nursing programs. Sixty-two percent reported that the overall content in their program had been inadequate.

White, Coyne, and Patel (2001) published the results from their descriptive study conducted in 1999 to identify the core end-of-life competencies and educational needs required among practicing oncology nurses. They wanted to determine if oncology nurses felt that they had received adequate education in the area of end-of-life care. Descriptive surveys were mailed to 2334 oncology nurses practicing in a variety of clinical settings in four American States. They achieved a 33 % response rate (*n* = 760 responses). Ten of the questionnaires returned were unsuitable for analysis. Analysis of the remaining 750 questionnaires revealed that 98 % of the respondents felt that end-of-life education was an important aspect of their professional role. A further breakdown of the data revealed that 80 % felt that they received good to excellent quality of education while 20 % indicated that they received fair to little educational preparation in the area of end-of-life care.

When Powell and Nicoll (1998) surveyed 14,093 nurses from Maine to determine the types of ethical issues and frequency of their occurrence they also inquired as to the knowledge level of nurses in the area of ethical issues. Interestingly 88 % of the respondents reported that they were knowledgeable in ethics but they also indicated the need for additional ethical education, especially in the areas of patient's rights and autonomy, ethical decision-making, quality of life issues and end-of-life care.

Schlegel and Shannon (2000) conducted a descriptive correlational study to determine the relationship between nurse practitioners' understanding of the legal requirements surrounding end-of-life decisions, their knowledge in the clinical application of advance directives and their ease in discussing end-of-life issues and advance directives with clients. A convenience sample of 145 Washington State Nurse practitioners practicing in the areas of geriatric, family, adult or women's health was surveyed. The 45-item survey consisted of true and false questions in relation to legal guidelines surrounding end-of-life decisions, and questions using Likert scale to determine knowledge of clinical application and ease of counseling clients. Of the 285 Nurse Practitioners receiving surveys 51 % ($n = 145$) responded. The findings showed that the knowledge level of legal guidelines surrounding end-of-life issues varied among individual nurse practitioners. Although an average of 83 % provided the correct response to the true and false questions the individual scores varied from 47 % to 100 %. As well, they had limited knowledge in the clinical application of end-of-life decisions and client preferences. Interestingly, nurse practitioners who worked in primary care were less comfortable providing counsel in the area of advanced care plans ($r = -.210$; $p = .013$) than those who worked with the elderly and long term care populations ($r = .290$; $p < .001$ / $r = .216$; $p = .010$ respectively). As well, nurse practitioners who demonstrated greater knowledge levels in relation to the legal guidelines ($r = .172$; $p = .044$) and demonstrated greater confidence in their knowledge base ($r = .321$; $p < .001$) were more comfortable providing advanced care planning to their clients. Overall the findings support that nurse practitioners would benefit from additional ethical education initiatives in the area of end-of-life care. Additional research in the area of end-of-life education, especially in relation to critical care nurses is required.

Summary

Although several studies regarding critical care nurses and end-of-life decisions were located, significant gaps were identified in the literature relating to how critical care nurses address their role in end-of-life decisions, deal with issues surrounding these decisions, and the processes used to address these issues in their professional and personal lives. It should be noted that the majority of studies related to end-of-life decision-making were retrospective suggesting a need for some "present time" studies as opposed to studies based on past experiences (Baggs & Schmitt, 2000). Limited research exploring critical care nurses and end-of-life decisions and their implementation within the context of the critical care setting and the Canadian healthcare system was noted. As well, research is limited in relation to critical care nurses and end-of-life decisions in Atlantic Canada's health care institutions.

CHAPTER III

RESEARCH METHOD

In this chapter I will provide an overview of grounded theory and its relevance to the study focus, nursing behavior, and end-of-decisions in critical care settings. As well, I will describe the purpose and objectives of the study, the research design, its implementation, ethical considerations, and limitations.

Purpose

The purpose of this study was to explore, describe, and provide a theoretical rendering of nursing behavior related to end-of-life decisions in New Brunswick critical care settings. A qualitative grounded theory approach was used.

Objectives

The objectives of this study were to identify the central issues for nurses related to end-of-life decisions in critical care settings and to develop a substantive theory that explains how these issues are processed.

Grounded Theory

Grounded theory was chosen as the preferred methodology to examine nursing behaviors related to end-of-life decisions within critical care settings. Grounded theory is not guided by a theory or conceptual framework. Its purpose is to identify "emerging themes" and concepts in the data and generate theory as part of the data collection/ analysis process (Corbin, 1986; Glaser, 1978; Wuest & Stern, 1990). The value of grounded theory is that it assists the researcher in "understanding and experiencing human experience as it is lived" (Stern & Pyles, 1986, p. 3). In this grounded theory study, critical care nurses' reports of their experiences were recognized as data and used to gain understanding of the "social processes" utilized to address the problematic areas related to end-of-life decisions in critical care settings (Baker, Wuest, & Stern, 1992).

Researchers using the grounded theory approach are not usually directed by a research question or hypothesis that is to be tested. Instead, the researcher begins with a broad study focus and then refines "the research question as they generate and analyze the study data" (Streubert & Carpenter, 1999, p. 104). Ultimately, the study focus may change depending upon the concepts and theories that emerge from the data (Strauss & Corbin, 1998). The focus of this proposed study was critical care nurses and end-of-life decisions.

Epistemological Underpinnings

With its underpinnings of symbolic interactionism and pragmatism, grounded theory falls within the constructivist paradigm and its intent that there are multiple realities which are continuously being modified as individuals interact with society (Milliken & Schreiber, 2001; Streubert & Carpenter, 1999). An assumption of symbolic interactionism and constructivism is that individuals construct and re-construct their realities and behaviors based on their interactions with society and the experiences that they encounter (Milliken & Schreiber). Pragmatists support symbolic interactionism in that the meaning individuals attribute to ideas and behaviors is based on their perceived usefulness and practicality in solving problems and are subject to change dependent upon the situation and its surrounding contexts. Within the constructivist paradigm an individual constructs a knowledge base in relation to their interactions with society. This is reflected in the grounded theory process, where an interactive relationship exists between the researcher and participant enhancing the researcher's understanding of the experience, as experienced by the participant (Mallory, 2001).

The challenge in this study was to develop a substantive theory that explained the interplay between the conditions that influence critical care nurses' participation in end- of-life decisions and the nursing behaviors utilized to function on a daily basis. According to Milliken and Schreiber (2001), individuals base their actions on their interpretation of the phenomenon; therefore in this study I needed to identify and understand how critical care nurses defined their role in end-of-life decisions, the meanings they attached, and the processes used to function in their daily lives. This research study was informed by the works of Carol Gilligan (1981) in the area of moral decision-making. Gilligan said that a researcher would gain the best understanding of an individual's reasoning skills and process used for decision-making by allowing the individual to describe personal experiences (Gilligan). For this reason the qualitative grounded theory approach was the preferred methodology for this study.

The Research Design

The development of grounded theory in 1967 is attributed to sociologists, Glaser and Strauss. Their intent was to understand the phenomenon as defined and experienced by the participants and discover the basic social processes that shape human behavior (Glaser, 1978; Morse & Field, 1995). For this study, grounded theory methodology a combined inductive and deductive approach, was employed to arrive at a substantive theory (Glaser & Strauss, 1967; Stern, 1980; Streubert & Carpenter, 1999). Inductively, the constant comparative analysis method of grounded theory was used to analyze and code the data collected, and identify emerging themes and categories. Through the process of inductive reasoning the findings were linked together to formulate a theoretical framework or substantive theory (Stern & Pyles, 1986; Stern). In this grounded theory study, data analysis occurred simultaneously with data collection (Glaser & Strauss, 1967; Stern). Then deductively, categories were grouped during the coding process, and utilized to direct future data sampling to generate a substantive theory (Streubert & Carpenter). As theory emerged, selective sampling of the data was used to confirm or modify findings. Known as "theoretical sampling", this was the process whereby the researcher concurrently collected, coded, and analyzed the data, deciding which data to collect next to further develop the emerging theory (Glaser). Throughout this process I continually asked the question, "What is actually happening here?" (Glaser). My pre-existing knowledge, previous experiences, and conceptual and theoretical thoughts were beneficial in identifying what was pertinent and meaningful in the data (Strauss & Corbin, 1990). This concept is known as theoretical sensitivity.

Sample

A theoretical sampling approach was used to allow for the selection of participants who had experience or knowledge of the phenomena under study (Lincoln & Guba, 1985). Data collection for this study occurred within the New Brunswick Regional Health Authorities. The initial population was nurses currently working in critical care settings within the Acadie-Bathurst and Restigouche Health Authorities, who had experiences related to end-of-life decisions. As the concepts, themes, and theoretical direction emerged during data collection and analysis, other sources of data such as, other health care professionals, or documents such as institutional policies, health care standards, and Provincial or National legislation were selected to be used in the constant comparative approach (Schreiber, 2001). This process of theoretical sampling continued until I began to see replication in the data, confirmation of the previous data, and no emergence of new categories or variations (Glaser, 1978).

Eligibility criteria for the initial sample. English-speaking critical care nurses were eligible to participate in the study if they were currently employed fulltime, part-time, or casual in a critical care setting within the Acadie-Bathurst and Restigouche Health Authorities. In these regions, critical care settings included combined medical-surgical units, a cardiac care unit, an intensive care unit, and emergency departments.

Sample size. In grounded theory research, sample size is difficult to predetermine. The sample size is dependent upon when the researcher feels that "information redundancy or theoretical saturation" has been achieved (Sandelowski, 1995, p. 179); that is, no new categories or variations are being discovered in the data. Owing to the fact that this research study was being conducted as a Master of Nursing thesis and the realities of time constraints associated with the process, a sample of 12-15 participants was anticipated for this novice level grounded theory study. Due to difficulty in recruiting participants and timing constraints of this Master's study, sampling ceased with 9 participants (Schreiber, 2001). The sample size in this study allowed me to see replication in the data, confirmation of the previous data, no emergence of new categories, and a variation of experiences, which permitted the development of a substantive theory. All nurses who indicated interest were interviewed.

Recruitment

To recruit participants, arrangements were made with the Chief Nursing Officers and Unit Managers of the Acadie-Bathurst and Restigouche Health Authorities for the distribution of written and verbal information regarding the research initiative to the nurses employed in critical care settings. Recognizing that attendance at the staff meetings would have provided an opportunity to give a verbal explanation of the proposed study and disseminate written information to potential participants, I requested to attend staff meetings and hold additional information sessions as required. Although the nurse managers agreed to assist with the distribution of the brochures, they felt that attendance at staff meetings would not be effective due to the history of low number of nurses attending the meetings.

At that time stamped pre-addressed envelopes and brochures containing relevant study information were distributed to the critical care units (see Appendix A). Directions for enrollment in the study and researcher contact information were located in the brochure. Arrangements were made to ensure brochures were distributed to the different shifts. As well, I offered to hold information sessions as required to explain the study and answer questions. The brochure indicated that interested participants could contact the researcher by telephone, e-mail, or by mailing the application located within the brochure. Potential participants would be contacted to further discuss the study and decide on a mutual time and place to meet for the interview. When I contacted the potential participants I reiterated that this was strictly a volunteer process and no coercion would be used. Participants were informed that they could refuse to answer any questions or withdraw from the study at anytime without penalty and were reassured that all information would be kept confidential.

I had not anticipated that recruiting an adequate number of participants (12-15) would be problematic; however, four months after the brochures had been distributed I had only been contacted by five potential participants. Following discussions with my supervisor the decision was made to explore the possibility of expanding the recruitment base to include the River Valley Health Authority. A written request for expansion of recruitment base was submitted to the chair of the University of New Brunswick's Ethics Review Board. When permission to expand was granted I submitted an application to the River Valley Health Authority requesting permission to conduct my study within that region. Upon notification of approval from River Valley Health, I contacted the nurse managers and distributed my brochures as per the process previously described for L'Acadie-Bathurst and Restigouche Health Authorities.

Participant Demographics

A total of nine critical care nurses were interviewed with demographic information being collected after the consent was obtained. All nine participants were female ranging in age from 25-52 years of age with a mean age of 36.6 years. Eight of the participants were employed on a fulltime basis in a critical care unit, with the remaining participant reporting part-time employment in a critical care unit. Their years of nursing experience ranged from 4 to 29 years, with a mean of 16.7 years. The length of time they worked in critical care ranged from 1.5 to 28 years with a mean of 13.2 years experience. Five participants had completed their bachelor of nursing degree while the other four had completed their diploma in nursing. Although all participants had completed a critical care course, the course length ranged from several weeks to four months.

Data Collection

Since the intention of this study was to gain a better understanding of nursing behaviors related to end-of-life decisions in critical care settings through the experiences as told by critical care nurses, data collection occurred primarily through semi-structured interviews and concurrent observation of the participant's nonverbal expressions. Tape recorded interviews were held at a time and place of the participants' choosing and were approximately 45 – 90 minutes in length. To allow me an opportunity to confirm and refine the emerging findings, four participants were asked for a second interview, with three agreeing.

Prior to beginning each initial audio-taped interview, an informed signed consent and demographic data was obtained from each participant (see Appendixes B & C). Initially, a semi-structured approach was used to introduce some "basic questions, themes, ideas and concepts" (McClement & Degner, 1995; Schreiber, 2001) (see Appendix D). A semi-structured interview provided some direction and data organization, but still allowed flexibility for me to explore areas which emerged during the interview (Glaser, 1978; Morse & Field, 1995). As per grounded theory methodology, the interview questions evolved according to the data analysis in grounded theory research. To facilitate the interview process and clarify participant responses open-ended questions such as: "What do you mean by that?" or, "What did you think when that happened?" were utilized throughout the interview as required (McClement & Degner). Following the interview I documented any observations, ideas or key points in the form of field notes and memos for future analysis (Glaser; Schreiber). Although all participants were informed that interviews could be stopped at anytime, no interviews were stopped prematurely. The interviews were held in private meeting rooms at locations pre-determined by the participants.

The focus of this grounded theory study was to reveal the basic social and psychosocial processes that critical care nurses use to navigate the conflict between their professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions. Therefore, critical care nurses were encouraged to share experiences, concerns, and actions regarding their involvement in end-of-life decisions and the processes they used to address these issues on a daily basis.

The transcriptionist, who was obliged to maintain confidentiality, transcribed the taped interviews. To eliminate any connection between the data and the participant, I ensured that all study data, including consent forms, demographic data, and taped interviews were coded by number and stored in a secured location separate from the typed transcript. As well, any identifying characteristics such as age, or names used in the interview were altered so that the transcript did not contain any identifying information that could be linked to the participant (Demi & Warren, 1995). Upon completion of the study, participants were given the option of having the tapes returned to them or destroyed.

Data Analysis

Grounded theory is intended to "generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved" (Glaser, 1978, p. 93).

It involves the systematic examination, breakdown, conceptualization and re-grouping of data in a new way (Strauss & Corbin, 1990).

The constant comparative approach of grounded theory was utilized to commence analysis of the transcribed interviews, field notes and memos (Morse & Field, 1995). Constant comparative analysis refers to the process of categorizing units of data and then constantly comparing new units to previously identified units until themes or theoretical concepts emerge (Struebert & Carpenter, 1999). Initially the transcripts were coded line-by-line using level I codes, also known as "in vivo" codes, the participant's own words, or simple descriptive terms developed by myself, the researcher (Stern, 1980; Strauss, 1987). Some examples of "in vivo codes" were *conveying wishes, sharing information, being a voice for the patient, being the ears and the eyes of the physician, and making patient wishes known.*

Continuing with the constant comparative approach, I analyzed phrases, paragraphs, events and incidents for similarities, patterns, themes, and differences. This was called substantive coding or level II coding. In level II coding, substantive codes were grouped together according to their commonalities and collapsed to form categories. In this study, substantive codes such as *conveying wishes, sharing information, being a voice for the patient, being the ears and the eyes of the physician, and making patient wishes known* were collapsed to formulate the category known as *mediating.* Throughout the coding process I asked myself questions such as, "What is this conceptual indicator of?", "What is happening in the data?", "What relationships or patterns do I see?", "What seems to be the basic social process", and "What can account for this problem or process?" (Glaser, 1978).

During the coding process any theoretical ideas, insights, or concepts that came to mind were written down. This process which is known as "memoing", allowed me to write notes about insights such as what is happening, the thought processes occurring during data collection and analysis, dates and times, changes in the interview focus or direction of the study thus forming an audit trail (Corbin, 1986; Morse & Field, 1995; Schreiber, 2001). An audit trail is a record of research activities occurring over time and can be used to describe the processes that occurred to reach the final conclusions (Streubert & Carpenter, 1999). Since memoing is a valuable way to preserve ideas, I interrupted the coding process to memo so that meaningful ideas were not forgotten (Glaser, 1978).

In level III coding, the codes were merged and reduced into categories, and relationships between the categories and concepts began to be identified and hypotheses about the relationships were formed (Streubert & Carpenter, 1999). Through constant comparative analysis, categories were compared to ensure no new categories were emerging (Streubert & Carpenter). At this point in time I was also exploring for connections between the categories with the goal of developing core categories. In this study, an example of level III coding would include *business as usual, mediating* and *learning the ropes* which were identified as strategies within the stage known as *going with the flow.*

Concept Development

"Three major steps expand and define the emerging theory: reduction, selective sampling of the literature, and selective sampling of the data" (Streubert & Carpenter, 1999, p. 111). As data collection and analysis continued, category reduction occurred and concepts and processes emerged. I returned to the existing literature to see what was currently known about the emerging concepts, processes or theory, and tried to identify links to the emerging theory, process or gaps in the literature (Glaser, 1978; Schreiber & Stern, 2001). This selective sampling of the literature was used to expand the emerging theory, address any identified gaps or verify new findings (Streubert & Carpenter). I used diagrams to illustrate any emerging relationships or hypotheses (Corbin, 1986). Selective sampling of the data was also used for the purpose of examining documents such as provincial and national legislation, professional standards, institutional policies and to contact subject matter experts in the area of end-of-life decisions. It was through the employment of these steps that subsequently the "core variable, or the variable that explained most of the process" was identified in the data (Morse & Field, 1995, p. 222). The core variable referred to the central theme that seems to be emerging from the data (Glaser & Strauss, 1967; Streubert & Carpenter). At that time selective coding began, where one variable was chosen to be the core variable and all other categories were examined for relationships to that category (Glaser).

Theoretical coding was used to examine the data at a theoretical level as opposed to a descriptive level (Baker et al., 1992). During the process of linking the categories I used Glaser's coding families such as the 6 Cs: "causes, contexts, contingencies, consequences, covariances, and conditions" (Glaser, 1978, p. 74). During theoretical coding variables were compared theoretically as "theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into theory" (Glaser, p. 72). In addition to the 6 C's I also employed other theoretical codes such as causes, dimensions, context, types, degrees, and strategies to enhance this process. Memos and field notes were used to link the categories and concepts together, raising the conceptual or descriptive findings to a theoretical level (Schreiber, 2001). These memos were written based on my past experiences, data analysis, the participants' interviews, and the literature.

I returned to three participants to confirm and refine emerging findings. The process of data collection and analysis continued until saturation occurred, a central core concept emerged and the basic social process of how nurses addressed the central issues surrounding end-of-life decisions in critical care settings was identified.

Upon completion of the research analysis the theoretical findings were presented in a written report "substantiated by supporting data from field notes" (Streubert & Carpenter, 1999, p. 113). The report included the background and significance of the research initiative, an overview of the data sources, the sampling process, data collection and analysis approach, theoretical findings and discussion. While writing the findings new insights were gleaned, causing me to return to my data, memos, diagrams and participants for confirmation and clarification. This process continued until I achieved a dense rendering of my findings. In addition, any limitations to the study were identified and future recommendations for research indicated (Streubert & Carpenter).

Rigor

According to Glaser (1978) grounded theory must have grab, fit, relevance, and it must work. To have "grab" means that individuals find it interesting, remember it and want to use it (Glaser). To "fit", means that the categories and concepts must fit the data and not be forced. Fit should be inevitable as the theory emerges from the data. The theory must be relevant to the phenomena, process and social context being studied. In grounded theory, relevance is likely due to the fact that concepts, themes, processes and substantive theories emerged from the data, and should fit or resonate with the participants. By "work", Glaser meant "that a theory should be able to explain what happened, predict what will happen, and interpret what is happening in the area of substantive or formal inquiry" (p. 4). By returning to the participants to discuss the emerging theory, researchers can refine and confirm the fit of the emerging theory. This process is referred to as "member checks" (Lincoln & Guba, 1985, p. 314). To guarantee fit in this study, grounded theory methodology was followed with the categories and concepts emerging from the data and not being forced. The completion of member checks with three critical care nurses helped to ensure fit and relevance of data, and validate that the emerging substantive theory was reflective of nursing behavior related to end-of-life decisions in critical care setting. Although some variation occurred, each of the critical care nurses re-interviewed identified with the concepts, themes, processes and substantive theories that emerged from the data. Interestingly, all three nurses elaborated by further verifying some of the categories and themes, and providing examples as to how they had recently used the identified process and strategies. Other principles used to establish "trustworthiness" and rigor in qualitative research are "credibility, dependability, confirmability, and transferability" (Streubert & Carpenter, 1999, p. 29).

Credibility. In qualitative studies "multiple realities" are recognized as opposed to one reality in empirical research (Morse & Field, 1995, p. 143). Credibility means that the findings accurately reflect the experiences of the participants. In this study, several measures were instituted to ensure credibility. Initially the audiotapes were transcribed as soon as possible following the interview to help ensure accuracy of the information. Upon completion, each transcript was read while listening to the audiotape to ensure accuracy and allow reflection and recollection of the tones and nonverbals used. I further maintained credibility by promptly reviewing findings and data interpretations through the completion of member checks and peer debriefings (Lincoln & Guba, 1985). Subsequent interviews were arranged with three participants asking them to review the emerging themes, categories and substantive theories to ensure that they reflected the experiences as expressed. These nurses acknowledged that although the circumstances around each experience varied according to the environmental conditions, the emerging concepts, categories, processes, and strategies were reflective of their recounted experiences.

Dependability. To assess dependability the researcher asks the question, "How dependable are the results?" (Streubert & Carpenter, 1999, p. 29). When credibility of the findings has been achieved, the criteria of dependability have been met (Lincoln & Guba, 1985).

Confirmability. The criteria of confirmability refers to process. By documenting all memos, field notes, coded interviews, and keeping a detailed log of items such as ordered and dated interviews, observations, and subsequent interviews an audit trail was created. The creation of audit trails illustrated the processes that lead to the findings or conclusions of the study (Lincoln & Guba, 1985; Streubert & Carpenter, 1999). This also reinforced the trustworthiness of the data.

Transferability. This refers to how the findings can be applied in other settings or situations (Guba & Lincoln, 1989). I tried to ensure that the final report contained adequate detail regarding the theory, categories, properties and conditions so that subsequent researchers could determine whether or not the findings have relevance for others in comparable situations (Lincoln & Guba, 1985; Streubert & Carpenter, 1999).

Ethical considerations

This study followed the guidelines as outlined in the Tri-Council policy statement on the Ethical Conduct of Research. I ensured that permission to conduct the study was obtained from the University of New Brunswick's Faulty of Nursing Ethics Review Committee, the University of New Brunswick's Ethics Review Board, and the Acadie-Bathurst, Restigouche, and River Valley Health Authorities' Ethics Committees or Institutional equivalent. All participants were over 19 years of age and their human rights were maintained at all times throughout this study.

Critical care nurses agreeing to be interviewed were asked to sign a consent prior to beginning the interview and were given a copy of the consent form (See Appendix B). I reiterated that this was strictly a volunteer process and no coercion would be used. Participants could refuse to answer any questions or withdraw from the study at anytime without penalty and were reassured that all information would be kept confidential. All interviews were held at a time and location of the participant's choosing.

As noted in the data collection section, measures were taken to maintain confidentiality and protect any connections between the data and the participant's identity. The transcriptionist, who was obliged to maintain confidentiality, transcribed the taped interviews. To eliminate any connection between the data and the participant, I ensured that all study data, including consent forms, demographic data, and taped interviews were coded by number and stored in a secured location separate from the typed transcript. As well, any identifying characteristics such as age, or names used in the interview were altered so that the transcript did not contain any identifying information that could be linked to the participant (Demi & Warren, 1995). Upon completion of the study, participants were given the option of having the tapes returned to them or destroyed.

While there were no anticipated health risks associated with this study, it was recognized that the topics being discussed could cause some distress. Although this did not occur, preparations were in place to stop the interview immediately and the participant would be given the opportunity to take a break or reschedule the interview (Schreiber, 2001). If necessary, participants would be offered information and assistance in contacting an Employee and Family Assistance Program.

Limitations

The study has several limitations. The sample size for this Master of Nursing Thesis was small and the participant demographics (all female) may not have been reflective of the critical care nursing population in other areas of the province or within other provinces. As well, since the sample recruitment was isolated to New Brunswick, some of the findings may have been influenced by professional and provincial legislation.

CHAPTER IV

A THEORY OF INTENTIONIONAL TRANSFORMATION

The goal of this study was to explore and describe nursing behavior related to end-of-life decisions in critical care settings. Emerging as the central problem for critical care nurses was *feelings of powerlessness* attributed to the conflict between their professional obligations to provide the holistic care of dying patients and their lack of authority to deal with the end-of-life issues entrenched in this care. *Intentional transformation* is the basic social process used by nurses to address "*feelings of powerlessness*" In this chapter I will provide an overview of the substantive theory, followed by an in-depth discussion of the environmental conditions influencing variation in the process of *intentional transformation,* and the basic problem, *feelings of powerlessness.*

Overview of Intentional Transformation

The basic problem for nurses related to end-of-life was *feelings of powerlessness,* consequent to the paradox of bearing the professional obligation for holistic family-centered patient care in the context of not having the authority to take action in the end-of-life care decisions. The intensity of *feelings of powerlessness* varies in accordance to the nurse's comfort level and experience with end-of-life decisions, organizational boundaries, the degree to which nurses' opinions are respected, and the inability to influence change when it is perceived that patient's wishes are not being respected or they are suffering. *Feelings of powerlessness* are a consequence of nurses' frustration stemming from being left out of the end-of-life decision-making process, not having their opinions valued, unnecessary prolongation of end-of-life decisions, limited family receptivity and comprehension, aggressive treatment in futile conditions, lack of team approach, and disrespect for patient wishes. Powerlessness manifests in a range of situations, from complete isolation in end-of-life decision-making to conditional participation.

Intentional transformation is the basic social process of addressing *feelings of powerlessness* by navigating the conflict between meeting family and patient needs and remaining within the boundaries of the critical care nurse's role. It is a process whereby critical care nurses deliberately and knowingly adapt their course of action to enhance participation in end-of- life decisions to achieve the optimal or desired outcome for the patient. It is a cognizant and dynamic process consisting of three stages: *going with the flow, circumventing the system,* and *taking charge.* Although often unnoticed by the other parties involved (patient, family, and physician), the nurses purposely maneuver through the stages in a distinct and deliberate manner. The effectiveness and extent to which nurses navigate through the stages is influenced by the nurses' comfort level with end-of-life care, organizational boundaries, family dynamics, and illness trajectories. Although the basic social process does not actually resolve or eliminate the problem, it does provide alternate means for critical care nurses to address the *feelings of powerlessness* that result from the actual and perceived limitations surrounding participation in end-of -life decisions, thus making the situation manageable.

Going with the flow is a process of guiding and monitoring the patient's end-of-life care by fulfilling the primary roles of caregiver, negotiator, facilitator, and educator in the critical care unit. *Business as usual, mediating,* and *learning the ropes* are three strategies that are used to fulfill their roles and responsibilities essential to the provision of end-of-life nursing care. *Business as usual* is the process of the nurse carrying out routine duties such as establishing trusting relationships, assessing patient needs, and providing comfort measures. *Mediating* is the conveyance of information between parties, (patient-physician, physician-family, patient-family, nurse-physician), and involves advocating on behalf of patients in hopes that their wishes are heard and respected. *Learning the ropes* is the process of recognizing what works and what does not, both within the daily operations of critical care units and in specific patient situations. By establishing relationships, identifying obstacles and opportunities, seeking direction, re-assurance, and asking for guidance, nurses aspire to gain the respect and trust of patients, family, physicians, and colleagues. Through the attainment of this trust and respect, that nurses gain the confidence vital to their participation in discussions surrounding end-of-life decisions.

Circumventing the system is the process of purposely manipulating the course of action with the intention of achieving a desired patient outcome, by employing alternative interventions when *going with the flow* is perceived as being ineffective. This is accomplished by *playing the game* and *negotiating best outcome. Playing the game* consists of formulating suggestions or asking questions in an indirect or non-threatening manner that implies the nurse is seeking direction as opposed to making actual suggestions regarding treatment. It may also entail withholding suggestions until it is apparent that the other parties will be receptive to input. *Negotiating best outcome* is the use of bargaining tactics in attempt to seek a compromise with the parties involved.

Taking Charge involves initiating action and occurs when the nurse perceives an immediate threat to the patient, such as a breach of the patient rights or wishes, or deviation in the delivery of the plan of care. *Taking charge* consists of two strategies: *speaking up* and *demanding action. Speaking up* involves confronting authority figures or colleagues and informing them that the current interventions or process is ineffective. *Demanding action* entails asking the physician what is going to be done, requesting that he/she talk with the patient and/or family in attempt to achieve some form of consensus.

Environmental Conditions

The basic social process of *intentional transformation* is influenced by the following environmental conditions: nurses' comfort level, organizational boundaries, family dynamics, and illness trajectory. Nurses' comfort level is influenced by knowledge of end-of-life decision-making, collegial support, and personal values. Organizational boundaries are comprised of institutional policies, physician call rotations and professional practice standards. Family dynamics encompasses comprehension of the situation and receptivity to end-of-life decisions. Illness trajectory reflects onset of illness and expected prognosis. Although the aforementioned conditions influence end-of-life decision-making they do not occur in isolation or within specific circumstances, but rather they interact to create unique influences in each situation (see Figure 1).

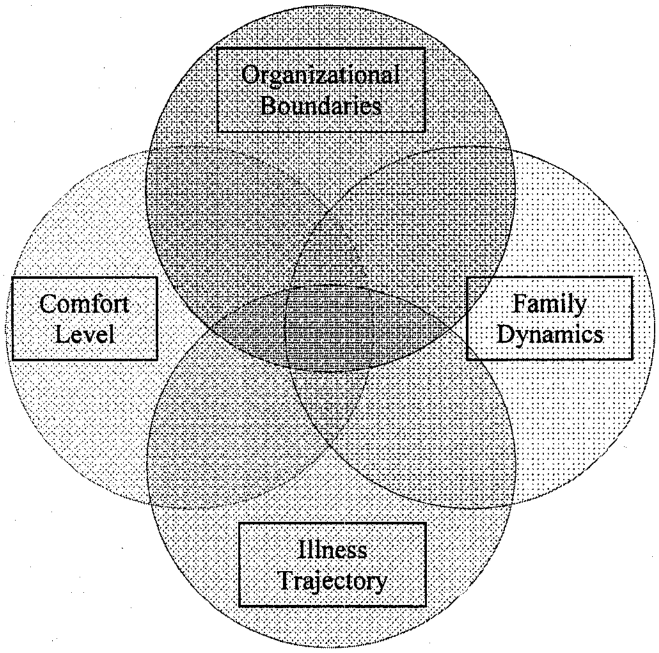

Figure 1. Environmental Conditions Which Influence Intentional Transformation

Nurses’ Comfort Level

Nurses’ comfort level refers to expertise, awareness, and confidence in end-of-life decision-making, derived from past experiences, previous relationships and interactions with physicians, peers, patients, and family members, theoretical and experiential knowledge, collegial support, and personal values. The level of comfort ranged from willingly participating in end-of-life decisions, to expressing difficulty or concern and ultimately avoiding the situation. Nurse E expressed her comfort around end–of-life decisions when she said:

> I think I'm the one who most initiates these things. But I think I just kind of took it upon myself to do this. ... I said I'm a nurse, I'm a RN, I'm qualified, and I can talk to these patients about their end of life decisions.

Interestingly, comfort level is often influenced more by the nurse's familiarity with end-of-life issues and critical care experiences than his/her age. Some younger nurses were more comfortable than the older nurses when it came to participating in end-of-life decisions. Nurse J illustrated how comfort with end-of-life decisions is not necessarily correlated with the age of the nurse:

> I guess there is a difference of comfort because the newer nurses and novice nurses, they don't feel as comfortable. But then there are times when the older nurses aren't comfortable either discussing it, so I don't really know if there is one more comfortable with that or the other. The point is that it is difficult, whether you are new or old.

Other researchers supported this finding and further elaborated that nurses with comfort and experience with end-of-life decisions were more likely to speak up and enter into end-of-life discussions (Norton & Talerico, 2000; Simpson, 1997). Experienced nurses, as opposed to novice critical care nurses, may learn over time and exposure how to address the conditions that influence end-of -life decision-making in critical care units and ultimately maneuver through the system to achieve the desired patient outcome. Nurse D shared how past experiences influenced her nursing practice:

> Yes, but after eighteen years I feel like I developed that, you know, in situations where somebody else might jump really quickly, I'll think about it. Just wait for a while you know; so there's a difference, there is guaranteed to be a

difference, based on experiences and the level of it.

A consequence of nurses becoming more comfortable with end-of-life decision-making is that colleagues and physicians draw upon that expertise, involving them in still more end-of-life situations. Nurse B shared how this happened to her when she transferred from the palliative care unit to the intensive care unit, "Staff seemed to think that I was more comfortable with palliative patients in intensive care units than what they would be, so I ended up getting quite a few of them [palliative patients] in a short time." Essentially, comfort level is influenced by knowledge surrounding end-of-life decisions, professional and personal experience, and personal values.

Knowledge Related to End-of-life Decisions

Comfort level is related to one's theoretical and experiential knowledge. Theoretical knowledge refers to formal and informal educational sessions related to end-of-life care, ethical issues and ethics rounds; whereas experiential knowledge is characterized by learning from watching others, from work-related exposure, and seeking directions from colleagues and physicians. The scope of critical care nurses' theoretical knowledge in end-of-life decisions varied among nurses and ranged from informal in-services and ethics rounds to formalized courses or discussions within the Bachelor of Nursing programs and critical care courses. Nurse D described her educational background as being more experiential based:

> My training is diploma and my critical care course was an internal critical care course that lasted for a week, so my knowledge is based on hands-on. It's the technical book knowledge that they come in with now with their BN's and things like that. I can't always back up what my intuition tells me is happening to the

> patient. I can't give them a technical term for what is going on, but I can look at my patients, and a lot of times I can think something is going on here.

Critical care nurses' knowledge is not limited to the topic of end-of life decisions specifically but rather encompasses a broader range of learning achieved through the establishment of relationships, social interactions, and observing the reactions of others, which assists the nurse in learning techniques to address the central problem, *feelings of powerlessness.*

Experiential learning stems from previous interactions with physicians, patients, families, and colleagues. Experiential learning involved gaining knowledge through past personal and professional experiences such as watching others, seeing how they react, discussing concerns with colleagues, and seeking guidance from senior nurses. The following comment by Nurse E depicted how, through the knowledge of physician's historical receptivity to input from nurses, critical care nurses learn which strategies are likely to achieve their goals in patient care:

> Yes, especially the older physicians when they are set in their ways and you have new and innovative ideas, you suggest things. Sometimes when you suggest something they don't always take your suggestions into consideration. It, it was hard for awhile, but after awhile when you gain that respect and you ask for these things, and you kind of say it in a way that you're not really asking, you're kind of putting the idea in their head.

Past personal experiences involving family and end-of-life decisions also affect one's comfort in approaching end-of-life decisions within the critical care units. One nurse described the impact of personal experiences as follows:

> …we'll say older nurses or nurses that have been you know, like myself, that we tend to look at things a little more realistically because we've had probably experiences in our own life with death of love ones and end-of-life decisions. I think that we tend to, that much of the experience we bring is sometimes beneficial, as long as it is not overly biased to the point you know, that you can't see the forest for the trees.

Experiential learning played a more influential role in nurse's utilization of the social process, *intentional transformation* than theoretical knowledge. Over time and exposure to end-of-life situations, critical care nurses watched interactions and reactions of the parties involved, noted which approaches resulted in undesirable or positive outcomes and adjusted approaches accordingly. In essence, they learned to recognize which strategies were more effective, as is illustrated when Nurse E described her past experience with a family that was not adequately prepared for end-of-life discussions:

> I kind of start putting in their [family] head, that their family member is very sick and that's why they are here. You [nurse] kind of put little things in their head. And if they get better, great. If they [family] are not prepared it's such a shock and they become angry. Because I found if I don't inform them [family] they get very, very angry in the end. And they say how come, how come this happened, and they [family] were not prepared for the end. Because when I was first started, that's what happened, I did not prepare the family. Then what happen is I took the full brunt. I took that, and I would never let that happen again.

Collegial Support

Collegial support refers to the sharing of concerns, discussing cases and approaches, venting, confiding, reassuring and seeking re-assurance that occur among critical care nurses. When faced with difficult situations, following traumatic codes, or when treatments and actions were questioned, critical care nurses sought out one another to provide comfort, re-assurance, listen or even provide a shoulder to cry on. As one nurse described it, "we, we're a very close bunch. And we do confide, we do vent and we cry, we laugh, we, you know we enlighten the situation or something, just to cope." Nurse E provided an excellent example of collegial support:

> They [fellow nurses] know what it is; you are speaking the same language so you don't have to stop to explain what you are talking about with your colleagues. I think it's the best way too, because you exchange the information and comfort each other. I remember one particular young nurse, her first patient had died. She came in and cried in my arms and that was my support for her, and then she was okay and that was her very first patient that had died.

Critical care nurses find such informal debriefings more important for building comfort levels than formal debriefings because they occur immediately and with colleagues who have had similar experiences. Other researchers noted similar findings when they reported that critical care nurses preferred to seek support from their colleagues due to confidentiality and comprehension of the situation. Their findings indicated that this support ranged from being comforted, seeking re-assurance, to the provision of patient care which allowed the nurse the opportunity to remove herself from the situation (Gutierrez, 2005; Kirchhoff & Beckstrand, 2000; Pelletier-Hibbert, 1998). Such informal debriefings build nurses' confidence levels, and help critical care nurses learn from past experiences. One nurse provided this explanation when asked how debriefings occur in critical care units:

> Not officially, it just, it comes from each other; it starts right at the bedside, and it is co-workers. I think, I feel it's the informal, and it's the coffee room, the change of shift report, you know things like that.

The information gleaned from this informal debriefing is processed and used to address similar situations in the future, thus increasing the nurse's confidence and comfort level with end-of-life decisions.

Personal Values

Personal values refer to the critical care nurse's beliefs about death, the use of life-saving interventions, what constitutes appropriate interventions, and an individual's right to autonomy, self-determination, and death with dignity. Comfort level seems to increase when the circumstances surrounding end-of-life decisions are consistent with the critical care nurse' personal beliefs. Beliefs regarding death in critical care units range from the acceptance of death as a natural part of life to the other extreme of death being unacceptable and viewed as a failure. Nurse D expressed that: "Death is a natural progression and I think sometimes we interfere too much and prolong a natural progression"; whereas Nurse F bluntly stated, "It's one or the other, and nature takes its course." During her interview, Nurse G. exemplified the viewpoint that death in the critical care unit is not always acceptable when she stated:

> In critical care there is a perception that because you are in critical care, we have to save you. You have to live. You are not allowed to die because if you are in the

> intensive care or the cardiac care unit you know, we have to save you.

With the technology and expertise that is available today, there seems to be an overwhelming need to conquer death at all costs. If patient death occurs within critical care units it is often perceived as a failure (Cronqvist, Theorell, Burns, & Lutzen, 2004; Kirchhoff et al., 2000; Kyba, 2002; Miller et al., 2001). The critical care nurse's values respective to death in critical care units and end-of-life decisions are further influenced by factors such as the patient's age, expected prognosis and expressed wishes. Nurse F expressed that each situation is different and must be approached uniquely:

> To me it's individual, very individual. It is a package of information not just a situation. It's a package of how his life was before, how it is now? What if his kidneys were always in renal failure for I don't know how many years, and he looks acute right now? Like I said it all depends upon his history. Every situation is different. It shouldn't be just any end-of-life situation.

Values are individualistic beliefs learned from society and exposure to situations encountered through life. The impact of one's personal values can be particularly challenging for nurses, as they have the professional obligation to promote patient autonomy while attempting to ensure their own feelings and views do not influence the patient's decision. This finding is supported by Cronqvist et al. (2001) who noted that nurses may experience conflicts between personal values and organizational obligations when they studied issues of moral concern to intensive care nurses. The nurse's comfort level is linked to the ability to reconcile differences between personal values and patient choices. The extent to which nurses are able to respect and support patient wishes, even when they do not agree with or understand the decisions made, affects their comfort with end-of-life decisions. Nurse H articulated her opinion regarding personal values in this way:

> I think what it is a lot, is the way I was raised. And it's just that I respect everybody else's opinion. I don't have to agree with it, but I have to respect it and support it and that is just who I am as a person and I take that right into my nursing career with me. I always have. You know I don't understand, I don't have to understand why these people think the way they do, but I have to support their decision and be there for them.

The nurse's use of *intentional transformation* to address *feelings of powerlessness* related to end-of-life decisions is further shaped by personal values which influence whether nurses accept the decisions made or intervene to change the plan. The intensity of powerlessness is influenced by the nurse's perception that the end-of-life decision reflects the patient's wishes and well-being. Nurse's comfort level and acceptance of end-of-life decisions are influenced by the nurse's awareness of the circumstances surrounding the decision (Beckstrand, Callister, & Kirchhoff, 2006; Simpson, 1997). In particular, critical care nurses' comfort level was affiliated with knowing that the decision was reflective of patient's wishes, all relevant parties were involved, and consensus was achieved, as opposed to actual decision itself (Badger, 2005). Nurse G expressed the importance of nurses being aware of how the decisions were reached when she shared this comment:

> The benefit would be that they [nurses] would hear for themselves the thoughts and wishes of the patient and the family. And they would be able to sort of see the non-

> verbal and tones used, and really feel convinced that whatever decision is made, it is what the individual [patient] and family wanted.

Organizational Boundaries

Organizational which influence the social process, *intentional transformation,* include institutional policies/protocols such as "Do not Resuscitate" and "Advance Directives" policies, physician call rotations, nursing professional practice documents, and government legislation such as the Nurses' Act.

Institutional Policies

Institutional policies refer to regulations designed to direct the provision of care administered within the facility. While most institutions had policies addressing "do not resuscitate" orders, policies or protocols regarding the process of making end-of life decisions were lacking. Additionally, although "do not resuscitate" and "advance directives" policies were available in some institutions, the policies specified that nurses were not permitted to discuss this topic until it had been introduced by the physician. Yet after initiation, interdisciplinary discussions were welcome and advocated. Moreover, even though policies specified that only physicians initiate "do not resuscitate" orders, some policies permitted nurses to temporarily cancel or suspend the order when it was felt that there was relevant cause.

How nurses engage in *intentional transformation* is influenced by availability and consistency of institutional policies and protocols related to end-of-life decision-making. Without specific institutional guidelines, the potential for role ambiguity and confusion related to scope of participation in end-of-life decisions is augmented, increasing the opportunities for critical care nurses to be left of out end-of-life decisions. *Feelings of powerlessness* intensify when critical care nurses perceive that they are not provided an opportunity to contribute to end-of-life decisions.

One aspect of institutional policy that was particularly problematic was that related to directives for end-of-life decision-making. When institutions lack specific directives regarding how the team should work together, involvement of the nurse in end-of-life decision-making often becomes a matter of physician preference, or happenstance. Nurse J echoed the sentiments of other nurses within this study when she commented that, “It depends on the physician, because some of the physicians do not want you there. So if you are invited, you go.” She went on further to say that nurses who are perceived by the physician to be difficult, in that they challenge or question the plan of care may not be invited to participate in end-of-life decisions: “Sometimes if they view the nurse as being difficult they won’t take them. They won’t.”

The intensity of *feelings of powerlessness* is influenced by the location and timing of the discussion and the physician’s preference to involve the nurse. Factors such as family dynamics, translation requirements, and physician timelines influenced whether or not the physician invited the nurse to participate. For example, some physicians would only invite nurses when it was perceived that they might encounter a difficult family, whereas other physicians unintentionally left the nurse out of the process. For instance, if the physician met the family in the corridor and the opportunity for discussion presented itself, the nurse may have been inadvertently left out of the process. Nurse F provided the following rationale as to how this may occur:

> You know the physician doesn’t really *not* invite the nurse to come, it’s just that he is on his way and he meets the family and they are talking about it [end-of-life

> decisions] and he comes back, or the family comes back and says, well we [physician and family] just discussed it [end-of-life decisions].

A consequence of limited policy directives is that over time, and based on their knowledge of physician preference, nurses utilize strategies within the basic process of *intentional transformation* to alleviate the *powerlessness* affiliated with being left out of end-of-life decision-making.

Physician Call Rotations

Duration and timing of physician call rotations and transfer of patient care impacts the process of *intentional transformation.* Physician call rotations refer to the various call schedules within critical care units and ranged in duration from overnight to one week call rotations. When physicians are reluctant to make decisions related to end-of-life due to unfamiliarity with patient history, uncertainty of prognosis, and fear of legalities, they maintain status quo until the end of the rotation, at which time the care of the patient is transferred to another physician. During her interview Nurse A expressed frustration at what is perceived to be passing of the buck by the physician:

> You know they are at the end of the week and they are on call for everybody in the building for the whole week so I just find there is a little bit of passing the buck. That gets very frustrating. They just get in and they are starting new, they are going to try a few things, and then it gets to Friday, well that didn't work and they say, oh someone else is starting Monday so we will pass it on to that one. So it has happened in a few cases and it gets quite frustrating. Sometimes it is time for someone to make a decision.

When hesitancy to act results in patient suffering, nurses struggle with how to intervene. Other researchers reported similar findings noting that continuation of treatment without proven benefit, or unnecessary delays in decision-making was distressing to nurses (Badger, 2005; Beckstrand et al., 2006; Puntillo et al., 2001; Sawatzky, 1996). When call rotations were short, such as a day or less in length, the nurse knew that she only had to get through the shift. Longer rotations could result in a longer period of inaction. Waiting out the duration of the rotation often lead to an opportunity to work with a physician perceived as being more receptive to the nurse's input.

Professional Practice Standards

Another condition identified as influencing the process of *intentional transformation* was the nursing professional practice standards, which outline the expected roles and responsibilities to which registered nurses are required to adhere as they practice within their various settings (Nurses Association of New Brunswick, 2005). Specific nursing professional documents governing nursing practice include: "Decision-making in Clinical Nursing Practice" (NANB, 2000a), "Entry-level Competencies" (NANB, 2000b), "Standards of Practice for Registered Nurses" (NANB, 2005), "Code of Ethics for Nursing" (CNA, 2002), and the "Standards for Critical Care Nursing Practice" (CACCN, 2004). Although professional bodies such as the Canadian Nurses Association define specific parameters governing nursing practice, the perception of this role can vary between nurses, physicians, institutions and society. My study findings of role variation from institution to institution was supported by other researchers (Curtis et al., 2001).

Nurses perceived their role in end-of-life decisions as advocating on behalf of the patient through the provision of education, counseling, support, and conveyance of information. Physicians were often identified as the dominant participant in end-of-life decisions where nurses were often seen as preparing the patient, clarifying information and assisting with decision-making. Nurse F shared her perception of the nurse role in this way: "I think right now we don't have, as a role, to go and initiate really. Their [nurses] role would be to reinforce and answer questions for either the family or the patient himself." The fact that the Nurse Brunswick professional nursing standards governing the practice of registered nurses do not clearly state whether the nurse may or may not initiate end-of-life discussion or disclose patient information, leads to role confusion for critical care nurses (Nurses Association of New Brunswick, 2005). Because the New Brunswick Nurses' Act (2002) indicates that the ordering of diagnostic tests, their interpretation and the disclosure of diagnosis do not fall within the scope of registered nurses, relevant information can only be disclosed with the permission of a physician or through the use of pre-established protocols. Nursing standards define what is within the nurse's scope of practice; thus, the absence of direction within the standards implies that disclosure of diagnoses, tests results, and end-of-life decisions are not within the nursing scope of practice. In this way, the nursing standards prohibit nurses from disclosure of prognosis or end-of-life status to patients (personal communication, Nurses Association of New Brunswick, March, 2006). This limits the professional autonomy of the nurse as she is forced to defer this role to the physician. Consequently, readily available information is inaccessible to the patient or family until the physician is available to disclose it, leading to unnecessary delays in the process. This also impacts on the nurse-patient relationship by directing the focus and decision-making primarily to the physician. Another consequence is loss of trust between the nurse, patient, and family if it is discovered that the nurse, although limited by standards, was aware of the information but withheld it. Nurse H describes how disclosure of information is an accepted practice that nurses must learn how to effectively address:

> There is certain information that you cannot give because it is privileged or it has to come from a physician, like that you know it's metastatic CA. You know it is awkward, but I guess, it's just you put one foot in front of the other and keep swinging and you direct them to the physician. You know "I will make sure the doctor is aware", or say that I do not have that information. You know that I do take the time to make sure that they [physician] are aware that they [patient/family] are asking the question. They need the information but it is not up to me [nurse] to deliver it and could you [physician] please come and talk to the family.

Family Dynamics

Family dynamics have a bearing on how critical care nurses utilize the process of *intentional transformation* to address end-of-life decisions. Frequently due to the seriousness of their illness, patients within critical care units are unable to speak for themselves necessitating the involvement of family members. Family dynamics refers to the patient's position within the hierarchy of the family and previous interactions or relationships between family members. Every family reacts differently when faced with end-of-life decisions and this resultantly influences how the nurse must address the situation encountered. Nurse H echoed the sentiments of several of the nurses interviewed when she said "I find each [family], each circumstance is unique and on its own, and it's just family dynamics 101." During her interview, Nurse G provided the following illustration of how family dynamics can complicate end-of-life decisions:

> Family dynamics, oh absolutely. I mean I know over the years we had a lot of different dynamics and we never know what the situation is before they [patient/family] come to the hospital. What the dynamics were before, and you have to be so careful because you don't know what part of it, I mean, you like to think that everyone's decision is based on the best interest of the loved one and made out of love, but it isn't always so.

More specifically, family dynamics facilitate or interfere with *intentional transformation*, in the areas of the family's comprehension of the situation and their receptiveness to the end-of-life decision.

Comprehension of the Situation

Comprehension of the situation refers to the family's interpretation and understanding of the discussion that occurred. The degree of comprehension by the family is affected by the timing of the discussion and the terminology used in the explanation (Dodd-McCue, Tartaglia, Veazey, & Streetman, 2005). One nurse shared the following scenario:

> Yeah, it really depends on the case and the family, the way that they [family] are and how receptive they are. The main thing that you [nurse] have to do is provide them with the information that they need. If they come to you with misinformation saying something else, you have to make sure that they are aware of everything that

> is going on and repeat it, because when the physician talks to them they don't necessarily understand. That is why I like to be there when the physician is speaking to them, and they [family] like for you to be there too, because the doctor is gone in five minutes and they are going to come back to you and say, well, what did he [physician] mean when he said this? And if you didn't hear it then you are not exactly sure what he said.

Research conclusions from a study conducted by Dodd-McCue et al. supported my finding that when discussions occurred during a time when the family was in a state of shock, information was often misinterpreted, misunderstood, or not even heard. The following statement reflects the nurse's recognition that the family's comprehension of the situation can influence decisions surrounding end-of-life issues:

> Granted if a patient is sick and has been in the hospital for a period of time, you can work with the family and they kind of see how things are going. Whereas, if someone is just at home and first thing they are in the hospital and they are dying, it is quite a shock to the family and [silence], sometimes it is not [pause] fair at that time to ask the family to make decisions about their loved one.

Thus, the process of *intentional transformation* may be influenced by the degree to which the nurses must work with families to ensure that they comprehend the end-of-life situation. In a qualitative study, Badger (2001) found that nurses experienced increased difficulty in the movement toward end-of-life decisions when they felt that the family had trouble comprehending the terminology affiliated with end-of-life decisions.

Receptivity to End-of-Life Decision

The family's receptivity to an end-of-life decision refers to the family's degree of preparedness to participate in discussions and make decisions. It is associated with the family's ability to come to terms with what is happening, their struggle to let go, and being equipped to participate in the discussions. Recognition that the family is not adequately prepared to make a decision is important for the nurse to acknowledge (Workman, McKeever, Harvey, & Singer, 2003).

Family resistance can be a source of frustration and powerlessness for critical care nurses if it is perceived that the treatment is futile, and the patient is suffering as a result of the decisions being made by the family. The following example illustrates how this was a source of frustration for Nurse H:

> I guess it would be hopeless situations. Where you know it is hopeless and when you see a family that's very resistant or you know for whatever reason, due to their dynamics before this critical event, they can't seem to come together and cope with this. You know that would be frustrating.

The family's degree of receptivity influences the process of *intentional transformation* by influencing how much effort the nurse directs toward offering guidance, clarification, and support. One nurse used the following example to illustrate this point:

> It will depend on the family members. It will really depend on them [family] as to whether or how important they feel your [nurse] input is. How they feel your information is and if they believe what you are saying. But it also depends on what they are looking for. Often times if you are not saying what they want to hear, they will not take it [explanation] as true or real. You [nurse] are just

> saying it because you need this bed and you want to get them [patient/family] out of there.

Families need time to come to terms with what is happening and for all intents and purposes may never be ready to accept the final outcome. Nurse J shared her perspective that despite all interventions, the family may never be ready for the outcome:

> Are they [family] ready? Sometimes they are not, but are they ever going to be ready? I don't think so. I don't think anybody is ready for it [end-of-life]. But you [nurse] can help them though; you can make them see that comfort is our goal now, not aggressive active treatment, comfort, which means comfort for the patient, comfort for you, which means you still have time with them.

Interestingly, some critical care nurses in this study interpreted families approaching them with questions as an indicator of their readiness to talk. Nurse F expressed this perception when she said, "I find it harder to approach [families] then if they ask; then I can answer easily because I know they are ready to have my answer. They [families] approach me."

Illness Trajectory

The basic social process of *intentional transformation* is affected by the illness trajectory, particularly expected prognosis and onset of illness.

Expected Prognosis

Expected prognosis emerged from the data as a condition that influenced how critical care nurses address end-of-life decisions. Expected prognosis is identified as grave outcomes, conditions unresponsive to treatments, and poor outcomes. In the present study, awareness of the patient's prognosis was instrumental in the nurse's level of contentment with the end-of-life decision and the patient's, family's, or physician's choice to continue or withdraw treatment. Kirchhoff et al. (2000) reported similar findings from a cross-sectional descriptive study examining intensive care nurses' experiences with end-of-life care. The following comment by Nurse C illustrates how familiarity with the patient's history and expected prognosis influences the nurse's receptivity to the decisions being made:

> When they [patients] have a long medical history, then you know it [death] is expected, and at some point that they are going to die; whereas when someone is in their fifties and are very healthy you are not going to expect it as much … (Silence).

Uncertainty of the prognosis was identified as being problematic, as nurses expressed discontent and frustration around the uncertainty of knowing if all avenues were exhausted. Nurse A expressed her frustration and *feelings of powerlessness* when she shared the following scenario:

> I really remember one really bad experience that I just felt that the physician may have been a little quick on the draw and just not, there are ways to let people go and there are ways to make it go quicker. This was a patient who was a surgical patient that had a infarct post-surgery and had gone poorly for a while. He was on [different] types of medications and just all of a sudden one day someone [physician] decided it was time to quit and things [treatments] were dropped. Like drips were dropped really quickly. I made an attempt to bring things down to see how the patient was going to do and then the physician came and said no, no, no! He wanted all things stopped right off the bat and said he [patient] is not going to live.

> There is no way he is going to live and we are just going to stop it and we are going to turn everything off and stop things now. But I just felt that in this situation that there might have been time if we had left things, because he had improved a little bit. We left things and brought the drips down and he had improved in certain ways. That if we have taken it a little slower he may have had an opportunity.

In essence, the degree of nursing satisfaction and acceptance of end-of-life decisions is influenced by the nurse's perception and awareness that all treatment options were exhausted and the patient's wishes respected. Badger (2005) noted similar findings in his qualitative research study which examined factors that enable or complicate end-of-life transition in critical care.

Onset of Illness

Onset of illness refers to the gradual or sudden occurrence of the illness. In particular, was it an unexpected collapse, cardiac arrest, or a chronic condition? The rapid emergence of the illness may require an immediate decision. However, onset of illness is not necessarily looked at in isolation. Patient age and the lack of knowledge of patient wishes further complicate scenarios when patients suddenly arrest. This was emphasized in the following scenario provided by Nurse G:

> My experience has been that quick and sudden deaths are difficult because you haven't gotten to know the family. I think most staff feel better when they feel that connection, because then they feel that they can make an informed decision or help them make an informed decision. Whereas when you don't know the patient, I mean if someone is thirty-eight years old and comes in and goes into v-fib well, that's a fait d'accompli, you know you are going to stick those paddles on the chest and you

> are going to zap them out of that rhythm; because they are thirty-eight years old! But when they get into the seventies and eighties (silence) but I know so many of our patient now in their eighties aren't ready to die. They are just not.

During her interview, Nurse J reiterated this point when she said, "I don't think that you work any harder on the young person versus the older person, I just think you address their end-of-life status earlier. That's what you do." In chronic states of illness more time is available for the family to make decisions and nurses can take the necessary time to prepare the patient for the upcoming questions.

Although sudden collapse is not isolated to the emergency department, onset of illness was perceived as being more problematic for nurses in emergency, as patients often present in that area initially, and then are transferred to the intensive care unit when stabilized. Nurse H articulated her feelings by sharing this scenario:

> It is because some people [families] have to make an on the spot decision. You know as far as in the Emergency Department the code is still going on and we [health care team] are at the asystole state [patient condition] and so what more do you want? And like I said, in intensive care units it seems that if you can give them [families] the time that they need and that's where it's a different type of nursing that you [nurse] are involved in. So you [nurse] can't expect them to make the same snap decision, because my experience as a nurse in the intensive care setting was more of preparing them and educating them and helping them deal with basically the grieving process and accepting that this is no quality of life and what would they [patient] have wanted? And how can they [family] deal with living with that decision?

This impacts *intentional transformation* in the sense that the family is ill-prepared, and there may be little time for nurses to intervene. The intensity of powerlessness is influenced by the nurse's perception of inadequate time to address the needs and concerns of the family.

The Problem: *Feelings of Powerlessness*

The central problem for critical care nurses was *feelings of powerlessness,* consequent to the conflict between their professional obligations to provide holistic care of dying patients and their lack of authority to deal with the end-of-life issues entrenched in this care. The intensity of *feelings of powerlessness* varies according to the nurse's comfort level and experience with end-of- life decisions, organizational boundaries, the degree nurses' opinions are respected and the inability to influence change when it is perceived that patients' wishes are not being respected or they are suffering. It is a multidimensional problem that may lead to consequences ranging from complete isolation to conditional participation.

The Canadian Nurses' Association's Code of Ethics articulates that nurses should promote patient's autonomy, value patients, and treat them with respect and dignity, while advocating for their rights (CNA, 2002). Although critical care nurses are professionally and ethically responsible for the delivery of holistic family centered - patient care, organizational boundaries such as institutional policies and professional standards govern the extent of their participation in end-of-life decisions. Thus, although nurses have a responsibility with regard to promotion of patient autonomy, they lack the authority to fulfill that role with regard to end-of-life decisions. Their roles range from being invited to participate, being asked to complete specified functions, to being left out of end-of-life decisions. When nurses feel that they do not have an active role in end-of-life decisions, and cannot meet the needs of patients and families, or provide the quality of care expected due to circumstances such as institutional polices they may experience feelings of powerlessness, frustration, anxiety, or moral distress (Asch et al., 1997; Beckstrand et al. 2006; Corley, 2002; Dawe et al., 2002; Jezuit, 2000; Simmonds, 1996; Storch et al., 2002). Critical care nurses voiced their feelings of distress, helplessness, and anguish as they watched their patients suffer. As patient advocates they are obliged to promote patient autonomy and comfort while doing no harm. Over times these feelings of distress can transform into frustration, resulting in extreme sense of powerlessness. As one nurse stated, "It is frustrating, it is frustrating on the staff, it's frustrating, it's stress on us because we are dealing with the family every single day and we don't know what to say to them anymore."

Limitations imposed by policies and standards can either hinder or enhance the nurse's ability to participate in end-of-life decisions, and influence how she utilizes the process of *intentional transformation* to address the problem, *feelings of powerlessness*. In essence, *feelings of powerlessness* are related to the degree to which nurses are left out of end-of-life decision-making, and the degree to which their roles are constrained when they are involved. When nurses are completely left out of end-of-life decisions, *feelings of powerlessness* are more intense. In this study, there were circumstances when critical care nurses were being left out of decision-making as a result of policies and standards that denied them the opportunity to initiate discussions related to end-of-life decisions, but conversely expected them to deal with the issue once the physician has introduced the topic. Variation in powerlessness relates to how the particular policy is enacted in particular institutions with particular physicians.

The occurrence of end-of-life discussions prior to the patient's admission to a critical care unit, through informal conversations between the physicians and families in the corridor, or at the bedside without the nurse in attendance can potentially intensify the critical care nurse's *feeling of powerlessness*. Although critical care nurses may not intentionally be left out of the process, this lack of involvement impacts the delivery of care because they are often left to implement the decisions made by others without the opportunity to offer input.

Feelings of powerlessness are also related to the degree that nurses' opinions are respected in the practice setting. Due to their presence at the bedside, critical care nurses convey information between patient, family, physicians and other healthcare providers (Hewitt, 2002; Oberle & Hughes, 2001). While their opinions are often sought, their input may not always be valued or respected as indicated by how it is used in developing a plan of care (Beckstrand et al., 2006; Curtis et al., 2001). Nurse J stressed the importance of feeling involved in end-of-life decisions, "You [nurse] like to feel involved too. And it's just very subjective depending upon the physician, what they [physicians] do, if you [nurse] actually feel involved or not, or whether your opinions are heard."

Since nursing standards stipulate the critical care nurse's obligation to be a patient advocate and promote patient autonomy, *feelings of powerlessness* intensify when one's voice is heard but not respected. Although entrusted with the care of the patient, critical care nurses perceive a lack of authority to influence change because of limitations surrounding opportunities for a nursing voice to be heard or valued (Beckstrand et al., 2006; Coombs & Ersser, 2004; Hefferman & Heilig,1999). The consequence of repeatedly being ignored is feelings of inadequacy, failure, and emotional distress. The following scenario depicts one nurse's *feelings of powerlessness* when she felt that her opinion was not heard:

> You know we [nurses] can bring across something that the family wants, something the patient has discussed, or something that he doesn't want done. We can bring forth our opinions as to what we think should be done with a certain patient but whether the physician is going to agree with that or bring it to another end; like the one physician that tends to be very, you know, he gets a new patient that has been a DNR [do not resuscitate]. The patient has decided, the family has decided and all of a sudden he [physician] comes in and says that I am going to save the world and a lot of times you end up at the same decision in the end. So that is one barrier, they may not take our opinion as to, you know, as to something that is important to think about.

Feelings of powerlessness are attributed to the critical care nurses' inability to influence change in the patient's care. Inability to influence change refers to nurses being unable to convince physicians and families to re-consider their proposed plans or decisions. It happens when proposed interventions go against patient wishes or are seen as being futile and prolonging patient suffering. The more critical care nurses respect patient wishes and believe in the provision of comfort measures, the more powerlessness they feel when they cannot change plans that run counter to these goals. Occasionally, despite identification and implementation of alternative approaches, critical care nurses are unsuccessful in achieving desired changes. The potential is for critical care nurses to view this inability to influence change as failing to fulfill their expected roles, which can lead to a greater sense of powerless and possibly feelings of disillusionment, dissatisfaction, and ultimately emotional stress. Similar findings were noted by Meltzer and Huckabay (2004) when they identified a positive correlation between incidences of emotional stress related to the critical care nurse's perception of the delivery of futile care.

The intensity of *feelings of powerlessness* varies according to the nurse's comfort level and experience with end-of-life decisions. The greater the nurse's comfort with end-of-life decisions, the more likely she will feel powerless at being caught between professional obligations and role constraints. Whereas, *feelings of powerlessness* may not be as intense for the nurse who has limited comfort and experience in end-of-life care decisions in that, she may become extremely frustrated and experience *feelings of powerlessness* when she is given increased patient care responsibility. Nurse H voiced this sentiment when she said, "I can't change the patient's situation, that has been you know, the greatest source of my frustration."

Consequently, prolonged exposure to *feelings of powerlessness* without appropriate interventions, can lead to frustration and annoyance within the critical care nurse. This frustration may be exhibited in various forms of action ranging from avoidance of the situation, circumventing the situation, or confronting the issues. This frustration is described as feeling helpless, inadequate, and hopeless. If critical care nurses continue to be left out of the decision process, or are forced to conform to role limitations determined by others, the result will be an atmosphere that is not conducive to effective communication, team work, and holistic approach to health care. Feelings of powerlessness leave the nurses doubting their role and ultimately working in the shadows of the physicians.

Summary

In summary, *feelings of powerlessness* attributed to the conflict between critical care nurses' professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions emerged as the basic social problem. *Intentional transformation,* which is the basic social process used by critical care nurses to address this problem, is influenced by environmental conditions such as *comfort level, organizational boundaries, family dynamics,* and *illness trajectories.* Whether the aforementioned conditions occur in isolation, within specific circumstances, or as a group, they play an instrumental role in shaping the critical care nurse's implementation of *intentional transformation* toward enhancing and facilitating the participatory role in end-of-life decisions. *Intentional transformation* will be discussed in more detail in the subsequent chapter.

CHAPTER V

INTENTIONAL TRANSFORMATION

Intentional transformation is the process whereby critical care nurses address *feelings of powerlessness* by deliberately and consciously adapting their course of action, thus allowing them to navigate between the conflicting expectations of meeting patient and family needs while not overstepping professional roles in end-of-life decision-making. It is a dynamic process comprised of three distinct, yet intertwined stages: *going with the flow, circumventing the system,* and *taking charge.* Critical care nurses maneuver back and forth between these stages in a distinctive, purposeful and natural fashion, which is often transparent to the patients, family, and physicians involved. While there is no particular order as to how critical care nurses move through the stages of *intentional transformation*, the manner in which they shift between the stages is shaped by the intensity of their *feelings of powerlessness,* the perceived threat to patient well-being and the following environmental conditions surrounding the end-of-life decision-making: nurses' comfort level, organizational boundaries, family dynamics, and illness trajectory (see Figure 2).

Although *intentional transformation* does not resolve the central problem identified as *feelings of powerlessness*, it does provide a means for the critical care nurse to alleviate some of their powerlessness through the employment of strategies designed to enhance their scope of participation in end-of-life decisions. The effectiveness and degree to which the nurses can alleviate their *feelings of powerlessness* and contribute to the end-life decision-making, in hopes of promoting optimal patient outcomes is influenced by the environmental conditions.

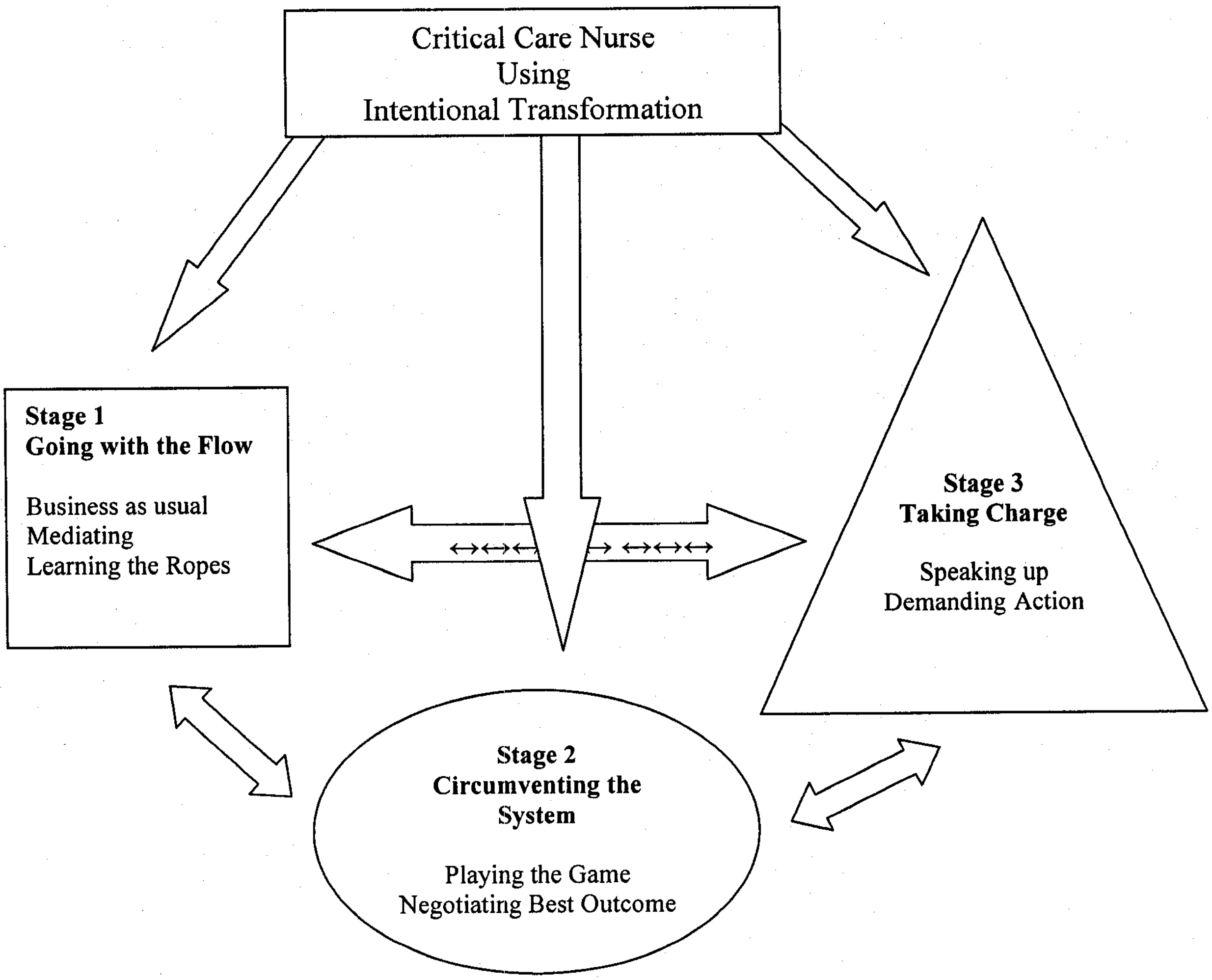

Figure 2. The Process of *Intentional Transformation*

Stage 1: *Going with the Flow*

The first stage of *intentional transformation* is *going with the flow,* which is the process of guiding and monitoring the situation by fulfilling the primary roles of caregiver, negotiator, facilitator, and educator. *Going with the flow* is reflective of the critical care nurse's daily responsibilities such as establishing relationships, assessing client needs, providing care, carrying out interventions and promoting safety, comfort, and dignity. Similar critical care nursing roles and responsibilities were recognized by other researchers (Cicarello, 2003; Kirchhoff et al., 2000; Nordgren & Olsson, 2004;

Norton & Talerico, 2000; Puntillo et al., 2001). Recognizing their role as patient advocate, critical care nurses promote patient autonomy by assisting in the communication of the patient wishes and upholding the ethical principle of nonmalefience or do no harm. Because patients in critical care settings are unable to express their wishes, nurses by necessity involve family members in their care. The importance of including family members or surrogates in end-of-decision making was identified by other researchers who examined end-of-life decisions in critical care settings (Chambers-Evans, 2002; Chambers-Evans & Carnevale, 2005; Charles, Gafni, & Whalan, 1999; Karlawish, 1996).

Critical care nurses recognize their professional obligation to carry out the roles and responsibilities identified within the stage, *going with the flow*. The degree of powerlessness is related to nurse comfort and experience with end-of-life decisions, organizational boundaries, and her ability to fulfill the expected or perceived roles. When patient care is progressing as planned, patient well-being is not threatened, and critical care nurses are allowed to advocate on behalf of the patient and fulfill role expectations, they will most likely remain within this stage.

Business as usual, mediating, and *learning the ropes* are the three strategies used to advance the stage known as *going with the flow*. These strategies are influenced by the environmental conditions such as physician receptivity to nurses, family comprehension, institutional policies, knowledge related to end-of-life decisions, and expected prognosis.

Business as Usual

Business as usual is assessing patients, being visible, providing care, carrying out interventions, establishing relationships, preparing patients, and implementing comfort measures. Consistent with findings from other research studying end-of-life care in critical care settings, nurses in this study identified promotion of respect, comfort, dignity, and patient autonomy as being key factors in the provision of good death (Beckstrand et al., 2006; Cicarello, 2003; Kirchhoff et al., 2000; Simmonds, 1996; Simpson, 1997). Nurse B shared what optimal care meant to her:

> I feel as a nurse my job is to make people comfortable. People meaning, making the patient comfortable physically and the family as comfortable as possible mentally. And if I can get that accomplished I leave it there and I go home.

In their study examining critical care nurses' perceptions of obstacles and supportive behaviors related to the provision of end-of-life care, Beckstrand and Kirchhoff (2005) identified support of the dying patient's family to be an important role for nurses.

As part of their daily routine, critical care nurses work in collaboration with physicians to identify patient needs, implement appropriate interventions, and evaluate effectiveness of treatments. Ideally, over time and exposure nurses and physicians will begin to work collaboratively, respecting each other as a valuable member of the team. Although shared decision-making in critical care areas is a necessity for end-of-life decisions, it must not be limited to the patient and physician but must be broadened to include family members and other health care workers, in particular the nurse (Baggs & Mick, 2000; Bunch 2001; Chambers-Evans & Carnevale, 2005; Charles et al., 1999; Karlawish, 1996; Norton & Talerico, 2000). A positive consequence of this activity is that critical care nurses develop relationships with patients, families, physicians and colleagues. However, Nurse E noted that time may be a factor when establishing nurse-physician relationships, "It takes a while as a young nurse for them [physicians] to trust you." The establishment of trusting relationships assists nurses in gaining the confidence and respect required to participate in end-of-life decisions. Research has identified that the implementation of interdisciplinary approaches designed to increase communication between healthcare providers and families can enhance the outcomes of end-of-life decisions (Baggs & Mick; Baggs et al., 1997; Kirchhoff & Beckstrand, 2000; Norton & Talerico; Sherman & Branum, 1995).

Due to their close proximity to patients, and their presence twenty-four hour a day, seven days a week, nurses in this study were aware of factors such as patient and family wishes and degree of preparedness. Consistent with other research findings, critical care nurses were found to be in an ideal position to prepare patients and families for end-of-life decisions and provide the guidance, support and re-assurance needed to address their concerns (Asch et al.,1997; Hewitt, 2002; Oberle & Hughes, 2001). As implied by Nurse H, the establishment of nurse-patient and nurse-family relationships occurs inadvertently through the provision of patient care activities:

> And I think a lot of times too it's the fact that we are so close, like whether it be through an assessment or a history taking or things [roles] like that. With the family, we establish a quicker and a closer rapport, and we get to know their [patient/family] wishes quite quickly or we get a real sense of where the patient has come from.

This finding was supported by other researchers who identified that critical care nurses are often the first healthcare provider to recognize that treatments are not progressing as intended, and identify the need for potential changes to the proposed plan of care (Asch et al.; Hefferman & Heilig, 1999; Levy et al., 2005). Thus, *business as usual* may allow the nurse to introduce end-of-life discussions in a provisional way. Consequently, families frequently seek guidance, direction, and re-assurance from the critical care nurse. Nurse D reiterates this through her shared experience:

> I really find that they are looking to me [nurse] for guidance as to what to do. I have had people say to me you know she [patient] talked about this and she didn't want it. I [family] feel bad that we have went against this because this is the way she ended up, on this machine. She didn't want it but I didn't know what to do.

Nurse D went on to describe, how in addition to providing support to the family she saw it as her role to convey the concerns to the physician.

In this study, institutional policies, professional standards, and even the critical care nurses themselves, identified initiation of end-of-life decisions as primarily a physician responsibility, whereas preparation of patients and family for end-of-life discussions emerged as a primary role for nurses. It was found that policies, nurses' comfort level, and past experiences influenced how the strategy, *business as usual* played out in different institutions and units. As one nurse explained, "I think that right now we [nurses] don't have as a role to go and initiate really. But their [nurses] role would be to reinforce and answer questions to either the family or the patient himself." This finding is supported by national and international research studies which recognized physicians largely as the dominant decision-makers, leaving the nurses to carry out the interventions and care affiliated to the end-of-life decisions (Baggs & Schmitt, 2000; Baggs et al., 1997; Benbenishty et al., 2006; Coombs, 2003; Coombs & Ersser, 2004; Hohenleitner, 2002; Oberle & Hughes, 2001; Thibault-Prevost et al., 2000). However, depending upon organizational boundaries, illness trajectory, comfort level, and experience with end-of-life decisions, the integration of these preparatory discussions within practice may vary between nurses and/or institutions. Nurses more comfortable with end-of-life decisions may be better able to negotiate the conflicting rules related to nursing roles. As Nurse E acknowledged, comfort, experience, and previous relationships were key factors in facilitating her ability to approach patients and families regarding end-of-life issues and the recognition that she may not have been able to have the same discussion with another family under similar circumstances.

> I did approach them [family] with the question. I prepared them because I knew the question was going to come from the doctor. Maybe initiating could be a bit difficult for some nurses. As I don't know if I would have initiated the discussion with that lady if I didn't know her, and because of my experience.... I knew her well enough that I felt comfortable to approach her. And she did ask me my opinion that day.

Other researchers reported similar findings when they noted that nurses' comfort level and previous experience with end-of-life decisions increased the likelihood of their participation in end-of-life decisions (Lipson, Hausman, Higgins, & Burant; 2004; Norton & Talerico, 2000; Simpson, 1997; Wurzbach; 1999).

In the next scenario, increasing awareness of the patient's deteriorating condition and expected prognosis influenced the nurse to initiate preparation of the family by inadvertently broaching the subject of the clinical condition, and asking what they thought that the patient wishes would be at this time:

> A lot of times what I have done is, I talked to the family and even though they hadn't been talked to before, I just might casually say we are trying to keep them comfortable but there is not much progress being made. I say things like, do you know what their [patient] wishes would have been if they could look down and see themselves right now? What would they like? What would they want? And I try to get them to come around to think of the patient, not themselves [families] not what they would want but what would this person want because they know them the best.

Nurse G provided another example of how deterioration in patient condition may influence the nurse's decision to approach end-of-life decisions:

> As far as initiating them, if there is no code status identified they [nurses] will encourage the physician to initiate the conversation. If the code status is identified then they [nurses] may or may not talk about it depending on, if the patient is starting to slip or go down the tubes. But if there is no code status identified and they think that it could be an issue they would have the physician approach it with the patient but they would be there.

In this situation the nurse may have been quite content to defer discussions around code status to the discretion of the physician, however a perceived threat to patient well-being may influence the nurse to intervene. The extent to which nurses prepare patients and families for end-of-life vary according to comfort level, experience, and illness trajectory. In their study examining the moral concerns and reasoning of intensive care nurses, Cronqvist et al. (2004) found that nurses' past experiences and awareness of the surrounding circumstances assisted them in understanding the potential outcomes of the situation, and prepared them and the family for what was to come.

While employing the strategy *business as usual,* critical care nurses are focused on meeting the basic needs of patients and families, promoting comfort, safety, autonomy and respecting patient wishes. Fulfillment of this role expectation often requires that the nurse act as a mediator conveying relevant information between the parties involved as necessary.

Mediating

Mediating is the sharing of information between parties, being a voice for the patient, conveying wishes, questions, concerns, and expectations, and being the ears and eyes of the physician. Consistent with other research findings, this study identified that the constant presence of critical care nurses within the unit, placed them in an optimal position to convey information between the parties involved in end-of-life decisions (Coombs & Ersser, 2004; Hewitt, 2002; Oberle & Hughes, 2001). As Nurse H put it, "there are circumstances where you know we [nurses] are there with the patient twenty-four on seven and we have to be the eyes and ears of the physician." Recognition that the patient or family may have questions, there may have been a misunderstanding or a misinterpretation of the information, the patient is not responding to the treatment, or perhaps the perception that the patient wishes are being violated would necessitate that the nurse intervene as mediator. Previous researchers also recognized *mediating*, acting as a go-between, conveying information between relevant parties as an integral role for critical care nurses (Badger, 2005; Coombs, 2003; Coombs & Ersser; Kirchhoff et al., 2000; Manias & Street, 2000; Simpson, 1997). Nurse J. described *mediating* in this way:

> We are there to support both sides. I guess it is like three parties we support the patient, the family, and the physician. So it is not like you pick a side. You kind of try to negotiate it and work it out.

Critical care nurses intervene through the provision of explanations, clarification, and reassurance to patients and family. In their study which examined end-of-life care as perceived by critical care nurses, Kirchhoff et al. (2000) identified clarification of terminology and the provision of explanations as a role taken on by nurses when they perceived that the physician's explanations was not fully understood. The extent of *mediating* is influenced by the nurse's comfort level, past experience, and role perception. Dependent upon comfort level and experience with end-of-life decisions, some nurses will initiate discussions with the family, provide explanations, and seek clarification as to why they are not in agreement with proposed interventions, thus assisting the family in coming to terms with what is happening. Nurse E explained her approach:

> Well, I would try to explain again what the point of the physician was, if the family was there, then just try to re-explain what the point is and sometimes ask them [family] what and why they are against this point. Why are they against what we are about to do? Because sometimes they think that if you leave that tube for another two weeks this patient will live. But sometimes they don't catch the fact that even if they leave the tube that eventually it will end anyway [patient will die].

> Sometimes if you [nurse] can speak to them and answer their questions and deal with their reasons why, you will see it is something personal inside of them and they will never be in agreement. And also for them to speak to the children and voice their opinions but sometimes you can answer a few questions and maybe they misunderstood something, as they [family/patient] do not always understand. Sometimes that will help.

Whereas other nurses are more comfortable conveying the family's questions and concerns to the physician. Nurse D explained how she would offer to contact the physician when families began to question interventions:

> I have had people say to me, you know this is enough. I [family] don't think that we [family/healthcare team] should do this anymore. And I would say the next time that the physician is in I can let him know, or would you like me to speak to him by phone and just let him know what your thoughts are?

This finding was supported by other researchers who reported that critical care nurses perceive their primary role as the collection and conveyance of pertinent information to the physician (Coombs, 2003; Coombs & Ersser, 2004; Prescott et al., 1987).

Dependent upon comfort, experience, and role perception, some nurses implied that they represented the voice of the patient and felt compelled to speak up on behalf of the patient. Nurse J expressed that she sees herself as a voice for the patient, "I voice it to the physician because it is hard for the family to." She went on to say, "that in some instances, I've gone into a room before where the physician has wanted to continue aggressive treatment and said the family knows it's not the patient's wishes and they want to stop." She elaborated further by referring to critical care nurses as buffers:

> Well, you become a buffer, because then the physician can turn to you and say well what do you think? So I usually I just re-clarify what the family said, and what he [patient] wanted and we have to come to some agreement.

However, as Nurse C illustrates, *mediating* also has the potential of creating internal conflict for the nurse when forced to choose between her obligations to the patient and the physician:

> I think it depends on who you are agreeing with. I think when you are agreeing with the doctor it's hard in the fact to try to make the family understand that it isn't a very good idea to keep going. When it is the family, it is hard trying to convince the doctor that the family doesn't want this anymore.

In their study examining critical care nurses' perceptions of obstacles and opportunities related to the provision of end-of-life care, Kirchhoff and Beckstrand (2000) recognized the potential of nurses being caught between the decisions of patients, families, and physicians and the potential conflict that may result.

If critical care nurses are unsure as to how to mediate on behalf of patients, or if their opinion is not valued they may revert to *business as usual.* On the other hand, they may opt to advance to the third strategy within, *going with the flow* known as *learning the ropes.* They would employ this strategy for the purpose of seeking guidance from their colleagues so that they can attempt *mediating* again. However, if it is felt that the *mediating* is not working, there is a perceived threat to patient well-being and *feelings of powerlessness* are intensifying, the nurse may advance to one of the next two stages, *circumventing the system* or *taking charge.*

Learning the Ropes

Learning the ropes refers to reflecting on past experiences, watching the reaction of others, sharing concerns, seeking collegial support, re-assurance and guidance, and differentiating between interventions which do or do not seem to alleviate the powerlessness and enhance participation in end-of-life decisions. Consistent with findings reported by other researchers, it was found that when critical care nurses experience feelings of uncertainty surrounding end-of-life decisions they may approach their colleagues for advice and re-assurance (Gutierrez, 2005; Holly, 1989; Kirchhoff & Beckstrand, 2000; Pelletier-Hibbert, 1998). Recognizing the expertise that senior nurses can offer Nurse B expressed how she often sought out senior nurses for guidance and direction, "Well, because I am fairly new in the intensive care unit I would check with the more senior staff. And sometimes if there was something that we [nurses] were not sure of we do call our doctors."

Learning the ropes allows the nurse to reflect on past experiences and shape their future behavior in relation to the end-of-life decision-making. The extent to which nurses *learn the ropes* is influenced by their comfort level and experience with end-of-life decisions, and collegial support. As implied in the following statement, collegial support is not isolated to situations involving end-of-life decisions:

> I find that as a group, when we have problems dealing with something we talk to each other a lot and everybody is very supportive of other people here. You get a chance to talk to them about it. And that is sort of your debriefing. People are the people you work with and we do talk about everything. Some things aren't work-

> related but you know when there is a problem we do discuss it among ourselves. I don't find that we isolate ourselves from our colleagues here.

The provision of collegial support by experienced nurses influences how novice nurses learn over time which strategies are effective, when they should be used and how, thus developing the confidence required to participate in end-of-life decisions:

> They [novice] nurses just need a little bit of guidance and generally when you [senior nurse] guide them a bit they develop a confidence in it [end-of-life decisions]. They are able to pick it up. They might not be able to converse for a bit because it's a new environment to them but once they [novice nurses] seem to learn and know what you normally do, they seem to be able to stand up.

Although Doane (2002) found that novice nurses often felt that they did not have the right to ask questions or share experiences this was not consistent with the experiences shared by the novice nurses in my study.

Nurse E illustrated how *learning the ropes* provides the nurse with an opportunity to grow over time, identifying potential actions and behaviors required to manage circumstances such as physician's receptivity to nurse's opinions:

> I find though when I was green, when I started nursing, I didn't know of that kind of maneuver. .. but watching, learning how patient/families react. And then once you get that feeling then you go and you know exactly what questions to ask. How to ask them [physician] in a non-threatening way.

By watching the reaction of others, critical care nurses can identify family readiness, comprehension, and physician acceptance of nurse involvement. Over time nurses learn which interventions are effective, when they should be used and how.

Nurse D shared her perception:

> I think that it is great that they learn to speak up for themselves and that they ask questions but I think that sometimes that little bit of experience teaches you how to come at it at a different angle so that you both get what you want.

Dependent upon comfort level and experience, some senior nurses take it upon themselves to mentor the novice nurse, as opposed to waiting for the novice nurse to seek advice:

> What I'm doing is that I'm trying to be a model for these new incoming nurses and telling them, and I will always ask them, I'm not being nosey but I'm asking you is the family aware how sick this patient is? Did you really sit down and tell them? And then if they say yes, well then okay that is good, is the doctor aware? Has the doctor talked to the family? So I am always checking up on it.

Cronqvist et al. (2004) identified mentorship as a valuable tool that could be utilized to gain insight into how nurses perceive complicated situations within intensive care units and provide guidance in how these situations may be appropriately addressed. Nurse F emphasized that in addition to the new strategies novices nurses learn to employ they must also be aware of the potential consequences that may occur as a result of their employment:

> You [nurse] really have to, if you say this will be the consequence and if you [nurse] do this what will be the consequence? You have to be prepared for that next question that you are opening. You have to be prepared for that consequence of what you're going to.

Although her qualitative study examined the experiences of moral certainty in acute care nurses, Wurzbach (1999) also noted the importance of nurses being aware of the potential consequences of their actions. Recognizing that the potential for learning may occur within any situation encountered by critical care nurse, the strategy, *learning the ropes,* may be used in isolation or in conjunction with any stage or strategy within the basic process of *intentional transformation.*

Consequences of *Going with the Flow*

The consequences of *going with the flow* can vary according to nurse's ability to achieve a satisfactory balance between the conflicting expectations of meeting family and patient needs, and the ability to influence change while remaining within the boundaries of the critical care nurse's role. Dependent upon the level of comfort and experience with end-of-life decisions, variations in the intensity of *feelings of powerlessness,* and the perception of threat to patient well-being, critical care nurses may decide to remain within the stage, *going with the flow,* or advance to stage 2 , *circumventing the system* or three, *taking charge.*

The decision to remain within the stage, *going with the flow* is attributed to the critical care nurse's level of comfort and experience in end-of-decisions. For instance, if critical care nurses are uncomfortable or have limited experience with end-of-life decisions, their *feelings of powerlessness* may not be as intense, allowing them to be content to stand aside and relinquish responsibilities to the other parties involved. Another possibility for remaining within this stage may be attributed to the fact that inexperienced nurses may not possess the knowledge required to proceed to the next stages, nor may they may feel that end-of-life initiatives fall within their scope of practice. Some nurses perceive that since the physician is the person of authority they must do whatever is ordered. Consequently they may not think that they have the power to independently move forward to another stage. Nurse B portrayed that perception when she made the following comment, “well, we do whatever the doctor orders and…do it to the best of our abilities to make everyone around us comfortable.” Similarly, other researchers identified nurses’ level of knowledge and competency related to end-of-life decisions, their perception of autonomy and empowerment, and the ability to control stressors as having an influential role in how nurses address situations involving end-of-life decisions within critical care settings (Laschinger, Finegan, & Shamian, 2001; Robinson & Lewis, 1990; Sawatzky, 1996).

Another rationale for the decision to stick with *going with the flow* is dependent upon the nurse’s evaluation of patient, family, and nurses’ level of satisfaction with the present course of action and intended patient outcome. The nurse’s perception that patient wishes are being respected, patient well-being is not threatened, and an optimal patient outcome is achievable leads to the alleviation of *feelings of powerlessness* and the decreased desire or need to move outside of this stage. Nurse A emphasized the importance of collaboration, respect for patient rights, and consensus as endpoints for measuring an optimal patient outcome:

> It comes to the point when there is nothing that can help the patient, which can bring the patient back and the family is suffering and everyone has come to the same decision. There is no discussion that one thinks it should be done and another thinks it should not be done. Everyone has come to the decision that it is best for

> the patient and especially for everyone involved that is time that everything finishes. That would be a more positive experience.

This finding is supported by the work of other researchers who recognized that critical care nurses are more interested in knowing that the patient's wishes have been respected, collaborative approaches were used allowing input from all pertinent parties and that optimal patient care was the focus of the decision as opposed to the actual decision itself (Badger, 2005; Beckstrand et al., 2006; Curtis et al., 2001; Kirchhoff & Beckstrand, 2000).

Critical care nurses are driven by the desire to provide the best care possible. If for whatever reason they are unable to fulfill their expected roles and responsibilities the potential for *feelings of powerlessness* ensues (Nordgren & Olsson, 2004). If the current interventions or plan of care are perceived as being unsuccessful in alleviating patient suffering or improving the patient's condition, *feelings of powerlessness* may intensify and the nurse may attempt to address the problem by advancing to one of the other two stages of *intentional transformation.*

When the nurse perceives that the patient wishes are not being respected, or the patient is perceived to be suffering, organizational boundaries do not limit the nurse to the first stage of the process entitled, *going with flow*, because *intentional transformation* provides a means for the nurse to remain within her scope and still advance to one of the next stages. Research conclusions from an ethnographic study conducted by Coombs (2003) which explored clinical decision-making in intensive care units, supported my finding with her recognition of nurses employing alternative measures to achieve desired outcomes when traditional methods were seemingly inadequate. Dependent upon the intensity of powerlessness and the imminent nature of the perceived threat to patient well-being, the critical care nurse may advance to the next stage, *circumventing the system* or she may actually catapult into stage 3, *taking charge*. During theoretical sampling and discussion of the preliminary findings, Nurse J verified that if perceived as a crisis, nurses may bypass one of more of the stages within the process, *intentional transformation*: "I think, I think it has to be in that somebody sees it as a crisis so it's either the family or the nurse to approach the subject."

Stage 2: *Circumventing the System*

The second stage, *circumventing the system* is the process of purposely manipulating the system to achieve a desired outcome by employing alternative interventions when the traditional approaches are perceived to be ineffective. Conditions such as family dynamics, physician receptivity, and organizational boundaries influence the manner in which critical care nurses employ the strategy, *circumventing the system.* Through repeated exposures to situations involving end-of-life decisions and the recollection of past experiences, critical care nurses learn to utilize the strategies of *playing the game* and *negotiating best outcome* as a means of enhancing opportunities to participate in end-of -life decisions, influencing patient outcomes, and thus alleviating some of the powerlessness. Families' perceived receptivity to end-of-life decisions, physician's non-receptiveness to nursing opinions, patients' unresponsive to treatments, or prolonged decision delays viewed as causing patient suffering may *intensify feelings of powerlessness,* and thus influence the critical care nurse's decision to bypass the initial stage, *going with the flow* and commence at stage 2, *circumventing the system.*

Playing the Game

Playing the game refers to asking questions in an indirect manner, using a non-threatening manner to make suggestions, and giving the physician the sense of control. Recognition that the physician may not be receptive to the nurse's opinion necessitates the use of alternative methods to convey suggestions without appearing as questioning or overriding the physician's authority. As mentioned earlier this finding was supported by the work of Coombs (2003). The perception of being left out of end-of-life decisions, opinions not being respected, or prolonged delays in treatment decision may cause critical care nurses' *feelings of powerlessness* to intensify. Nurses will attempt to alleviate this *powerlessness* by identifying alternative ways to become involved and contribute to patient care. One nurse provided the following illustration:

> … use an angle so that you both get what you want. You [nurse] get your answer and sometimes you influence it [change]. Maybe the patient needs a bit of lasix or something but if you say, well you know, order some lasix and so or I'll come at him [physician] and say, well you know do you think a bit of lasix might help that kind of thing…

Nurse D described her approach for obtaining desired responses when physicians are known to be historically unreceptive to nursing opinions, "I come at it sideways and they [physicians] are more likely to respond positively to an answer and explanation to my question, rather than a direct question. You know that kind of thing." Success of this strategy is contingent on knowing the parties involved, comfort level, recollection of past experiences and relationships, and learning which interventions worked and which did not.

Sometimes despite every effort, nurses are not able to influence a change in the plan of action related to end-of-life decisions. As *feelings of powerlessness* intensify, critical care nurses may resort to interventions which border on the outer boundaries of their scope of practice. Dependent upon the nurse's comfort level and experience, the perception of threat to patient well-being and intensity of *powerlessness,* critical care nurses sometimes achieve their desired outcome by having the family approach the physician. In this situation, the nurse may calculatedly approach family members informing them of patient suffering, expected prognosis, and role limitations with the intent of having the family approach the physician and request further action. One nurse gave the following depiction of the employment of this strategy:

> And if the patient really is suffering I usually do tell them [family] that I'm trying my best but they [patient] are suffering and the inevitable will happen. A lot of times they [family] will then address the physician. So, sometimes we [nurses] do that if we don't really get anywhere with the physician. We will talk to the family, kind of behind their [physician's] back almost.

In the next scenario one nurse depicts how she may intentionally delay the withdrawal of treatment allowing time for verification that indeed the treatments are futile and all avenues have been exhausted:

> Sometimes you feel like you can take (and if the doctor wasn't around anymore) so you think well, if I just go a little slower then maybe this will work out. He is not here so you find maybe you can maybe get away with it.

These findings are supported by the work of other researchers who identified strategies similar to *playing the game* when they examined various aspects of clinical decision-making in critical and non-care settings (Coombs, 2003; Coombs & Ersser, 2004; Simpson, 1997; Wurzbach, 1999).

Negotiating Best Outcome

Negotiating best outcome is the process of using bargaining tactics in an attempt to seek a compromise with the parties [nurse-patient, nurse-family and nurse-physician] involved. Situations where it is perceived that families may not comprehend the gravity of the situation and refuse termination of the treatments; or where treatment plans are continued or terminated despite evidence of patient response; or where unnecessary delays in making end-of-life decisions occur, often result in critical care nurses attempts to negotiate treatment changes. As one nurse put it, "we [critical care nurses] are convincing the family that this may not be the best option for the patient." As Nurse J reiterated the role of the critical care nurse is to assist the family in recognizing what is best for the patient:

> So that they can help them [family] think along. I know you [nurse] don't want them not to have hope, that's not the point, the point is you want to do what the patient would want. Try to get them [family] to see if the patient is, if the prognosis is really poor, then it is undignified treatment to leave them suffer on a ventilator when in the end it is not going to matter.

Resultant actions include the promotion of patient autonomy and advocacy through negotiations with the family or physician regarding treatment parameters, requesting time to assess patient response, for agreement to leave tubes in place but adjust settings, or simply negotiate for time to determine patient wishes. This is how one nurse described the process of negotiating with family members when they refused to discontinue the ventilator:

> There are a lot of ways you can work around withdrawing your support [life support]. If you have a particular family that is very difficult and say, no you are not taking the ventilator away because it is against their [family] religious beliefs. I've had that happen but there are alternatives because you can say well, we [health care team] will leave the ventilator but we are stopping these drips; or we will leave the ventilator on and we are holding the drips as they are. We are not going to go up anymore or put any more [intravenous medications] on.

Circumstances may occur where critical care nurses find themselves in a position necessitating the negotiation of patient care interventions with the physician. Comfort level and experience with end-of-life decisions, illness trajectory, and professional obligations may influence the degree to which critical care nurses will enter into negotiations with physicians. Nurse J indicated that the majority of this negotiation is about physician control, yet she demonstrated the confidence to intervene on behalf of the patient:

> A lot of it is about control. They [physicians] feel that they want to be in control of everything, and how dare you [nurse] make a suggestion to me. And there are times where I feel as a team you should discuss the patient and talk about the patient. And I'm used to doing that right at the patient's bedside. And we discuss the patient And I usually have a list of things I want address. And I usually just go down

> through the list but if they order something that I am not comfortable with I usually just say, I don't agree with that.

When asked if physicians were receptive to her suggestions she replied,

> Sometimes they change their order, but most times they don't, they will just say, well that is what I want. And a lot of it is about control. They feel that they want to be in control and how dare you make a suggestion to me."

If opportunity for negotiation arises, the nurse's desire is that an optimal patient outcome acceptable to all parties can be achieved. However, Nurse J emphasized the importance of recognizing that resolutions are not achievable in every situation, "I don't think that it really solved anything. Because basically you looked at things from everybody's point of view but there was never really any decision made at the end of it."

Consequences of *Circumventing the System*

A positive consequence of *circumventing the system* is that the nurse may feel that she has been influential in changing the patient outcome, thus averting some frustration and dissatisfaction, and alleviating some *feelings of powerlessness*. Dependent upon comfort level and experience, this strategy may instill the confidence required by nurses to participate in end-of-life decisions within critical care settings. Nurse J explained how negotiation can lead to consensus and respect for patient rights and ultimately optimal patient outcomes:

> I guess that the patient was looked after according to their rights but you [nurse] also were able to advocate therapeutically for the patient. And you were also able to negotiate between the family and the medical staff too. So I guess the thing is,

everybody has reached or gained a consensus in the end, and everybody had their viewpoint and feels okay.

If the strategy of *circumventing the system* is ineffective, the resulting consequence of feelings of inadequacy can lead to intensified *feelings of powerlessness* and potentially result in increased moral and emotional distress. Consistent with other research findings, critical care nurses are often caught between their professional obligation to provide competent holistic family-centered care and lack of authority to fulfill this role. These conflicting roles coupled with lack of control and autonomy, can lead to frustration, intensified *feelings of powerlessness*, decreased integrity, burnout and job dissatisfaction (Corley, 2002; Dawe et al., 2002; Erlen, 2001; Keane, 1985; Laschinger et al., 2001). Consequently, the nurse may revert to *going with the flow* and meet patient needs by providing care as directed by others. On the other hand, the nurse may experience frustration which has the potential of intensifying *feelings of powerlessness*, and ultimately pushing the nurse to the next stage which is known as *taking charge*. If at this time the nurse perceives an imminent threat to patient well-being or safety she may automatically employ the two strategies simultaneously, by *speaking up* and *demanding action.*

Stage 3: *Taking Charge*

Taking Charge occurs when there is some type of threat to the patient, or breach of the patient's rights or wishes, or the patient is unresponsive to the treatment, or delivery of care is not going according to the nurse's perceived plan. *Taking charge* involves jumping in, voicing opinions, and requesting action be taken. As one nurse explained despite being given time, family members and physicians still may be unable to make a decision thus necessitating the nurse to step in and take control:

> We have given them [families] a couple of days to discuss it all and everything and then you know, then there were times when we had to put our foot down and say no that is the end of it.

Interestingly most times the families are relieved when the decision has been removed from them "It is no longer your decision, medically we are stopping and we have done that before. Most times the families are relieved because they felt that they were making that decision."

Dependent upon their perceived degree of powerlessness, comfort level and experience with end-of-life decisions, or the perceived threat to patient well-being, critical care nurses may gradually progress to the stage known as *taking charge,* they may initiate participation in this stage, or possibly, they may never intervene at this level. The fact that some critical care nurses never advance to this stage could be attributed to their perceived lack of authority, inexperience, and decreased comfort with end-of-life decision, or lack of guidance and knowledge as to how to proceed. Previous research supports the finding that nurses' comfort level and experience with end-of-life decisions, sense of empowerment, perception of authority, and their awareness of the surrounding circumstances influences the degree to which nurses will actively participate in end-of-life decisions (Cronqvist et al., 2004; Laschinger et al., 2001; Sawatzky, 1996; Wurzbach, 1999).

Taking charge consists of two strategies: *speaking up* and *demanding action*. The decision as to which of the two strategies, *speaking up* or *demanding action,* the nurse will choose to employ to alleviate some of the powerlessness and attempt to intervene on behalf of the patient, is influenced by the nurse comfort level and experience with end-of-life decisions, *intensity of feelings of powerlessness*, and the perceived degree of harm to the patient.

Speaking Up

Speaking up involves voicing concerns, confronting authority figures or colleagues, asking questions, and informing them that the current interventions are ineffective or inappropriate. This encompassed situations where nurses perceived violations of patient rights, breach of policies, provision of aggressive treatments in futile conditions, or the withdrawal of treatments without adequate evaluation of patient response. Resultant actions often included voicing one's opinion, requesting alterative actions, or even in some cases threatening to report the incident or notify a superior authority. One nurse described an incident that escalated to the point of threatening to report the physician:

> ...it would be young physician and he would be intubating and it's like woo, this is a no code. Once you established you know that it's a documented no code you stop.... And it would be no. This is not good practice. And then I physically stepped in. I said this, I'll report this. It's a documented no code you have to call it now.

Comfort level and past experience strongly influence the nurse's ability to exercise her right to *speak up* and intervene on behalf of the patient. Sometimes the recognition of the action or the threat of involving an authoritative figure is sufficient in achieving the desired outcome. Other times it may not be enough to evoke a change in the plan of care, necessitating that the critical care nurse adapt her approaches accordingly. Ultimately, the nurse may actually have to follow through and report the incident.

Speaking up may also refer to circumstances when nurses perceive the requested action to be a threat to patient safety. Dependent upon the nurse's level of comfort, perceived degree of threat to patient well-being and the intensity of *feelings of powerlessness* the nurse may refuse to carryout the intervention ordered. As Nurse J explained sometimes nurses must intervene on behalf of their patients and the fallout may not be pleasant but ultimately it is part of being an advocate:

> It depends on how safe it is. And there is times where I have said I'm not doing it so if you want it done I guess you will have to take that on yourself. They are kind of angry and they get really ticked. They are not impressed, lets say that. But I guess that is kind of part of looking after those patients. Somebody has to advocate for them. And so, it's not fun [aggravating] somebody but in the end if it's for the patient's best interest, I think you have an obligation to do so.

In other instances, critical care nurses indicated that patient prognosis and perceived threat to patient well-being influenced whether or not they would *speak up* and discuss patient outcomes with physicians. This was supported by the findings of other researchers who reported how awareness of the patient prognosis and knowing that all avenues were exhausted were influential factors in the nurse's determination of the approach she employed to address end-of-life decisions (Badger, 2005; Cronqvist et al., 2004; Kirchhoff et al., 2000). Nurse J shared how patient prognosis influenced her to intervene and *speak up*:

> If the patient is in multiple organ failure and there really is no goal in the end, there are times when I addressed it and said what is the decision here? Have you talked to the family? Does the patient have any wishes? This is the time when I have asked questions of this nature and I have said can you [Physician] talk to them?

When asked if it could be perceived that nurses usually initiate end-of-life discussions with physicians Nurse J replied, "No it is usually when they are in multi-organ failure, and the prognosis is very poor. It's just that you want what is best for the patient and aggressive treatment is not."

At the other end of the continuum nurses' involvement in end-of-life decisions could escalate advancing the nurse to employ the strategy *demanding action,* and insisting that decisions such as the withdrawal, withholding, or initiation of intervention be made. The findings of this study were supported by those from a qualitative study by Wurzbach (1999) which examined the experiences of moral certainty in acute care nurses. Although her study population did not include critical care nurses the findings were similar in that when situations were perceived as a crisis or a threat to the patient, nurses would take a stand, speak up on behalf of the patients and possibly even to refuse to participate in the intervention if the threat was perceived to be serious enough.

Demanding Action

Demanding action entails asking the physician what is going to be done, and requesting that they talk with the patient and/or family in attempt to achieve some form of consensus. Under circumstances where they perceive deterioration of a patient's condition, prolonged suffering, unnecessary delays in end-of-life decisions or the administration of aggressive treatments in futile conditions, critical care nurses voiced their feelings of distress, helplessness and anguish as they watched their patients suffer. This young nurse described a situation where she felt obliged to step in and intervene on behalf of the patient:

> …the bed was being so soaked full of interstitial fluid and it was just really, like you know really bad… we were pointing out like you know we don't have anymore pulses anymore and he's not responding anymore, he had sclera edema there was infection everywhere, …plus, plus, plus edematous like and he was just rotting basically in bed. A corpse in bed is what I would say… I said enough is enough. Yeah I kept saying we have to do something. This is too cruel, this is enough. So here, umh some of the doctors take an initiative and put them no code. There is nothing more we can do for these patients and he went out and he said there's nothing more I can do for your husband. So if he goes he goes.

As patient advocates, critical care nurses are obliged to promote patient autonomy and comfort while doing no harm (CNA, 2002). Over time, these feelings of distress can transform into frustration, resulting in an extreme sense of powerlessness that could ultimately cause the nurse to demand that the physician take some kind of action (Wurzbach, 1999). The resultant action may range from insisting that the physician make a decision, to taking control of the situation, and seeking the best treatment option for the patient. Sometimes this may even require overriding the patient and family's decisions if the circumstances warrant. Once again it is important to note that if nurses choose to employ a strategy such as, *demanding action* they must be ready to face the consequences and possible fallouts of their actions (Wurzbach).

Consequences of *Taking Charge*

Dependent upon the circumstances necessitating the critical care nurse's advancement to the stage of *taking charge*, there is the potential consequence of a negative impact on the future relationship between the nurses and the parties involved. If circumstances escalate to the point that the nurse is required to report the incident to a superior authority, the future working relationship between the nurse and physician could be strained. As a result the nurse may consciously avoid working with that physician in the future, or the nurse may find the physician requesting assistance from a different nurse in future cases. On the other hand if the nurse is successful in achieving a satisfactory solution to the identified problem she will gain the confidence required to openly speak up when warranted.

Sometimes despite trying alternative approaches, *speaking up,* and *demanding action* be taken, nurses are unsuccessful in achieving desired changes, and interventions are withheld or initiated despite voiced concerns. Consistent with other research findings, the potential is for critical care nurses to view this inability to influence change as failing to fulfill their expected roles, which can lead to feelings of disillusionment, dissatisfaction, and possibly emotional distress (Corley, 2002; Erlen, 2001; Erlen & Sereika, 1997; Jezuit, 2000; Storch et al., 2002). Consequently, *feelings of powerlessness* could intensify resulting in the critical care nurse's reversion back to the initial stage of *going with the flow*. Within the stage of *going with the flow*, nurses may choose to debrief with colleagues, learn from their experiences and attempt to intervene again. On the other extreme, they may revert to *business as usual* and be content to carry out the daily routines of intensive care as ordered by others.

Summary

In summation, *intentional transformation* describes the process nurses use to contend with the *feelings of powerlessness* attributed to the conflict between their professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions. The intertwined stages of *going with the flow, circumventing the system,* and *taking charge* are comprised of strategies intended to facilitate the nurse's participation in end-of-life decision-making and alleviate *feelings of powerlessness*. The effectiveness and degree to which nurses move through these stages is influenced by the environmental conditions such as nurses' comfort level with end-of-life care, organizational boundaries, family dynamics, illness trajectories, the degree nurses' opinions are respected and the inability to influence change when it is perceived that patient' wishes are not being respected or they are suffering.

The basic process of *intentional transformation* is not a unidirectional sequence, but rather a dynamic back and forth progression within and between strategies representing the nurse's movement between and within the stages and strategies used to contend with the problem, *feelings of powerlessness.* Although it is recognized that this basic social process does not actually resolve or eliminate the problem identified as *feelings of powerlessness,* it does provide a means for addressing the actual and perceived limitations surrounding participation in end-of -life decisions, thus making the situation manageable. *Intentional transformation* is a process that is utilized daily in critical care units and is most likely not isolated to end-of-life decision making.

The implications of the process known as *intentional transformation* will be discussed in the next chapter.

CHAPTER VI

DISCUSSION OF NURSING IMPLICATIONS

In this chapter an overview of the grounded theory *intentional transformation* will be provided. Subsequently I will discuss the nursing implications of this theory and their relevance to nursing knowledge and practice, nursing education, social policy, public education and nursing research.

An Overview of the Theory

The purpose of this study was to explore, describe and provide a theoretical rendering of nursing behavior related to end-of-life decisions in New Brunswick critical care settings. The basic problem emerging for nurses related to end-of-life was *feelings of powerlessness,* attributed to the conflict between their professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions. *Intentional transformation* is the basic social process used by critical care nurses to manage these *feelings of powerlessness.*

Intentional transformation is a cognizant and dynamic process consisting of three stages known as *going with the flow, circumventing the system, and taking charge. Going with the flow* is a process of guiding and monitoring the patient's end-of-life care by fulfilling the primary roles of caregiver, negotiator, facilitator, and educator in the critical care unit. *Business as usual, mediating,* and *learning the ropes* are three strategies that are used to fulfill their roles and responsibilities essential to the provision of end-of-life nursing care. Critical care nurses may move between these strategies or use them simultaneously. *Circumventing the system* is the process of deliberately manipulating the course of action with the intention of achieving a desired patient outcome, by employing alternative interventions when *going with the flow* is perceived as being ineffective. This is accomplished by *playing the game* and *negotiating best outcome.* Dependent upon the outcome of this stage the nurse may either revert to *going with the flow* or advance to stage 3. Stage 3, known as *taking charge* involves initiating action, and occurs when the nurse perceives an immediate threat to the patient, such as a breach of the patient rights or wishes, or deviation in the delivery of the perceived plan of care. *Taking charge* consists of two strategies: *speaking up* and *demanding action. Speaking up* involves discussing the effectiveness of current interventions or processes and expected outcomes with authority figures and colleagues. *Demanding action* entails asking the physician about anticipated outcomes, requesting that they talk with the patient and/or family in an attempt to achieve some form of consensus. The effectiveness and extent to which nurses navigate through the stages is influenced by the following environmental conditions: nurses' comfort level with end-of-life care, organizational boundaries, family dynamics, illness trajectories, the degree to which nurses' opinions are respected and the inability to influence change when it is perceived that patient's wishes are not being respected or they are suffering.

Implications of the Substantive Theory

The value of grounded theory is that it assists the researcher in "understanding and experiencing human experience as it is lived" (Stern & Pyles, 1986, p. 3). In grounded theory an interactive relationship exists between the researcher and participant enhancing the researcher's understanding of the experience as lived by the participant. It provides a means for the researcher to learn how individuals manage the problems and associated circumstances encountered in their daily lives (Mallory, 2001; Schreiber

& Stern, 2001). The substantive theory of *intentional transformation* provides an understanding of the nursing behavior related in end-of-life decisions in critical care settings as told from the nurses' perspective. It is estimated that ten to twenty percent of adult patient admissions die in Canadian intensive care units (Cook, Rocker, & Heyland, 2004). With technological advances, an aging population and increased attention focused on end-of-life care, the timing of this theory is opportune. It has the potential to guide and contribute to nursing knowledge and practice, nursing education, social policy, public education and nursing research associated with end-of-life decision-making in critical care settings.

Nursing Knowledge and Practice

Although critical care nurses' actual or perceived limitations in end-of-life decision-making have been documented in the literature, the findings of this study add to the existing knowledge in this area. The theory of *intentional transformation* provides a view of the processes, obstacles, and opportunities as experienced by the critical care nurse.

Emerging as the central problem for critical care nurses was *feelings of powerlessness* attributed to the conflict between their professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions. Critical care nurses identified institutional policies, professional standards, physician preferences, and the lack of end-of-life decision-making protocols as some of the conditions which influenced their degree of participation. Even though it was recognized that the uniqueness of each situation necessitated an individualized approach, critical care nurses felt that a standardized approach to end-of-life decision-making would facilitate the process. The findings of this study identified that critical care nurses skillfully manage the obstacles or opportunities encountered by using the process of *intentional transformation* to navigate between professional obligations for holistic care and the lack of authority to influence change, while remaining within their professional boundaries. Through the process of *intentional transformational* critical care nurses attempted to feel like a valuable participant in the end-of-life decision-making in critical care settings despite their lack of authority. At the individual nurse level, the theory *intentional transformation* offers confirmation to critical care nurses by capturing their capacity to negotiate this paradoxical situation of bearing the responsibility for holistic family-centered patient care in the context of not having the authority to take action in the end-of-life care decisions. This substantive theory also offers novice critical care nurses some guidance and direction in how to manage the conflicting expectations of meeting patient and family needs while not overstepping professional roles in end-of-life decision-making. Specific implications identified for nursing knowledge and practice pertaining to organizational boundaries, professional practice standards, and collegial support will now be addressed individually.

Organizational Boundaries

Study findings identified that the manner in which nurses engage in *intentional transformation* is influenced by the availability of institutional policies and protocols related to end-of-life decision-making. The absence of such protocols may potentially lead to increased incidences of nurses being left of out of end-of-life decision-making. In this study I found that *feelings of powerlessness* may intensify when nurses perceive that their voice is not heard or their opinion not valued. Consequently, nurses may advance to the stage of *circumventing the system* to find alternatives ways of achieving the desired patient outcome. Conversely, if nurses perceive an immediate threat to the patient, they may actually catapult to stage 3, *taking charge* and *demand action.* The implementation of end-of-life decision protocols may offer consistency to the process and potentially an avenue for nurse participation. Subsequently, this may alleviate the nurse's *feelings of powerlessness* and ultimately prevent emotional distress.

These findings are supported by a longitudinal study in which Dodd-McCue et al. (2005) found that the implementation of an organ donation protocol provided consistency, decreased nursing stress and role ambiguity, and increased job satisfaction. Although the study population did not include critical care nurses, the potential benefits of protocols may be transferable to the critical care setting. Despite the proposed benefits, other researchers stress that protocols must be used cautiously and not in isolation. One must remember that protocols require flexibility to account for the uniqueness of each situation (Charles et al., 1999; Holzapfel, Demingeon, Piralla, Biot & Nallet, 2002; Manias & Street, 2000). In a paper based upon Manias' unpublished thesis, Manias and Street reported that nurses frequently use protocols to "communicate with doctors about 'undesirable' medical decisions…nurses used these written guidelines to assert power and demonstrate resistance" (p. 1467). Interestingly, I found that several nurses in my study shared how they referred to policy when they felt that the physician was going against patient wishes.

Professional Practice Standards

Study findings identified that although critical care nurses have a professional obligation to provide holistic family centered-patient care they lack the authority to influence change in end-of-life decisions. Professional standards regulated by the Canadian Nurses Association and the Nurses Association of New Brunswick govern the degree to which nurses can participate in end-of-life decisions. A potential implication of this study is the recommendation that professional organizations work toward the optimization of the critical care nurse's role in relation to end-of-life decisions. Recognition of critical care nurses as valuable members of the team and enhancing their scope of practice related to end-of-life decisions may alleviate the *feelings of powerlessness* attributed to their lack of authority and inability to influence change in end-of life decision-making. This may lead to the decreased need for nurses to *circumvent the system* or *take charge* by *speaking up* and *demanding action.*

Despite the recognition that nursing roles and responsibilities are evolving and interdisciplinary approaches are being advocated, researchers caution that professional organizations and administration must realize that some health professionals may continue to function within the traditional roles (Coombs, 2003; Coombs & Ersser, 2004). Acknowledging that role variation can exist between institutions as a result of institutional polices and physician preferences, critical care nurses, their professional organization and administration should work toward the development of standardized polices that could be implemented provincially.

Collegial Support

The nurses in this study referred to collegial support as their primary means of debriefing, venting, confiding and seeking re-assurance. Consistent with the findings from other studies, they indicated that they preferred to seek comfort and support from their colleagues due the timing, accessibility, confidentiality and comprehension of the situation (Gutierrez, 2005; Kirchhoff & Beckstrand, 2000; Pelletier-Hibbert, 1998). Through collegial support nurses gained the comfort, knowledge and confidence that they required to move between the stages of *intentional transformation.* In a grounded theory study, Simpson (1997) identified that caring for patients, whose conditions are considered grave, in intensive care settings requires support and guidance for the nurses. It cannot be assumed that these patients are to be treated like any other deaths. In their descriptive study exploring the perceptions of critical care nurses regarding futile care and the effect on burnout, Meltzer and Huckabay (2004) found a direct and significant relationship between moral distress and emotional exhaustion. Although my study findings did not discern any reported incidences of emotional exhaustion the potential did exist. Critical care nurses require support because of their position of being caught between having a responsibility for holistic family-centered patient care in the context of not having the authority to take action in the end-of-life care decisions. As a result, the nurse may experience ethical or moral distress, which, if left unaddressed, may potentially lead to suffering, decreased integrity, burnout and job dissatisfaction (Corley, 2002; Erlen, 2001; Erlen, & Sereika, 1997; Jezuit, 2000; Leners, & Beardslee, 1997). An important implication from this study is that hospital administration needs to ensure that the adequate resources are in place to support critical care nurses as they care for patients faced with end-of-life decisions. These resources may be in the form of ethics consultations and rounds, timely formalized debriefings, and access to services such as pastoral care and social services. It is important to include that the administration must consider what type of support and resources are in place after hours.

Nursing Education

Intentional transformation provides an opportunity to learn more about how critical care nurses address the *feelings of powerlessness* affiliated with end-of-life decisions. The following implications for nursing education are suggested based on the findings of *intentional transformation* and the *environmental conditions* which influence this process: enhanced curriculums, communication assessment and negotiation skills, educational resources and tools, and decision-making protocols.

According to this study, the nurse's comfort level and experience with end-of-life decisions influenced the extent to which nurses participated in end-of-life decisions. This finding was consistent with other research findings, in which the nurse's age and years of nursing experience were not positively correlated with the degree of participation in end-of-life decisions. In this study, I found that nurses with personal and professional experience in end-of-life decisions were more apt to enter into end-of-life discussions. This finding was consistent with that of other researchers (Norton & Talerico, 2000; Simpson, 1997). This was supported by a study by Lipson et al. (2004) who found that nurses with experience with even one advance directive scenario were more confident to participate in future end-of-life discussions. My findings suggest that earlier and increased exposure to end-of-life experiences may help build the nurse's confidence, enhance her level of comfort with end-of-life decisions and potentially influence the degree of participation.

Of equal relevance was the emergence of experiential learning and its influence on how nurses utilized the social process, *intentional transformation.* Thus, an important implication is the need for expansion of theoretically based nursing and critical care programs to include interactive ethical case studies, role playing, implementation of decision making models, collaborative decision-making, and media toolkits to improve the nurse's confidence and comfort level with end-of-life decisions. Similar findings were noted by other researchers (Cook et al., 2004; Kalliath & Thomas, 2002; Wilkie, Judge, Wells, & Berkley, 2001). In a study by Sawatzky (1996) exploring the perceptions of stressors in critical care nurses it was found that the value of education and competency and the relationship to nursing confidence to participate in end-of-life decisions cannot be overlooked or undervalued.

While utilizing the strategies, *business as usual* and *mediating* within stage 1, *going with the flow*, nurses are responsible to assess patient and family needs, implement appropriate interventions, evaluate outcomes and convey information between parties. The nurse's ability to establish relationships, determine needs, provide explanations, clarification, and mediate on behalf of the patient requires strong communication, assessment and negotiation skills. Although of benefit in any situation, these skills also play an important role in the nurse's success when employing the strategy from Stage 2 known as *negotiating best outcome.* The integration of role playing and case studies into the curriculum could possibly increase the comfort with which the nurses use these strategies.

The value of end-of-life educational initiatives must be recognized by healthcare professionals, educators, and hospital administration. The National Action Planning Workshop on End-of-Life Care (2001) recommended the development of continuous learning competencies (Health Canada, 2001). Levy (2001) supports the need for end-of-life education to be viewed as a lifelong learning initiative and identified the challenge that healthcare professionals have in maintaining this skill. It is for this reason that critical care nurses require access to educational resources and materials to broaden their knowledge and assist in the integration of these skills into their daily practice on a continuous basis. Web based educational programs, media tool kits, list servers, interactive case studies and access to institutional ethics rounds are all relatively inexpensive and readily accessible resources that could be made available to nurses. (Beckstrand et al., 2006; Ciccarello, 2003). Since 1998, the Canadian Nurses Association has been offering educational ethics initiatives through the publication entitled "Ethics in Practice". This service is also available on the internet. Another valuable tool published by the Canadian Nurses' Association is the ethics study guide, "Everyday Ethics" which is based on the 2002 Nursing Code of Ethics. This guide assists nurses to integrate ethical principles and concepts into their daily practice.

As part of the strategies *business as usual* and *mediating*, critical care nurses provide patients and families with explanations and clarification related to end-of-life discussions held with the physician. If they are going to continue with this role then they must be knowledgeable about end-of-life decisions, the options, processes and consequences.

Social Policy

During this study I found that despite being recognized as key participants in the decision-making process, critical care nurses play a limited role in end-of-life decisions due to their lack of authority. These findings are consistent with those from previous studies (Coombs, 2003; Corley et al., 1993; Counsell, 2002; Hiltunen, et al., 1995; Jezewski, 1996; Joudrey & Gough, 1999; Leners & Beardslee, 1997; Thibault- Prevost et al., 2000). Additional findings identified that the nurse's perceived or actual role limitations and *feelings of powerlessness* were attributed to the following environmental conditions: nurses' comfort level, organizational boundaries, family dynamics, and illness trajectory, the degree nurses' opinions are respected and the inability to influence change when it is perceived that patient' wishes are not being respected or they are suffering. Acknowledgement of the need to alter the critical care nurse's level of authority related to end-of-life decisions by administration, professional organizations and physicians would significantly reduce the gap in the decision-making process, increase the effectiveness of communication among health care providers and ultimately increase the quality of patient care delivered. It is time that critical care nurses are recognized for their contributions to end-of-life decision-making and the necessary social policy reforms put in place to support this initiative. This study has potential for multiple implications related to social policy at the regional, provincial and national level.

Recognizing the importance and necessity for legislation related to end-of-life care the Senate Committee released a report in June 2000 entitled, "Quality of End-of-Life Care: The Right of Every Canadian." This report strongly recommended the need for national leadership and collaboration toward the development of a national strategy to improve end-of-life and palliative care (Health Canada, 2005). In response to the Senate report in June 2000, the "Quality End-of-Life Care Coalition" was formulated. Representing 30 national volunteer and professional organizations, they recommended the development of end-of-life standards, guidelines and programs (Health Canada, 2001).

In June 2001 the Government of Canada demonstrated its commitment to end-of-life and palliative care with the appointment of a "Minister with Special Responsibility for Palliative Care" and an advisory role to Health Canada. Consequently, the "Secretariat on Palliative and End-of-Life Care" was established in June 2001. In March 2002 a "National Action Planning Workshop on End-of-Life Care" was held for the purpose of developing a five-year action plan. This plan addressed issues such as the development of tools and protocols, best practice guidelines, research, and data collection methodology, and educational programs for healthcare professionals, caregivers and the public. Of particular interest to this study was the recommendation for standards that would ensure health care practitioners ask every client about their decisions regarding end-of-life care. (Health Canada, 2005). According to the report released in March 2005, progress has been made in relation to some topics of relevance to this study. Some examples include the development of core competencies for healthcare professionals, integration of end-of-life and palliative care educational material into medical undergraduate and graduate programs with the plan to expand to nursing in the near future, and research initiatives. However, progress has been hindered by lack of funding and resources, government changes and the elimination of the dedicated ministerial post. Although progress in the area of end-of-life care continues at the national level, the need for lobbying persists.

At the provincial level, legislation and initiatives vary from province to province. Alberta, Manitoba, Ontario, and the Yukon have made advances in the area of end-of-life care. In New Brunswick efforts related to end-of life are progressing somewhat. In response to recommendations from the Premier's Health Quality Council report "Health Renewal" released in January 2002, a policy is being developed in the area of advance directives policy (Government of New Brunswick, 2002). However to date, current New Brunswick legislation is limited to the "Infirm Persons Act" (2004) which identifies a power of attorney for personal care, meaning that a person may select any person to make some or all personal care decisions on his/her behalf in the event they become incapacitated (Government of New Brunswick, 2004).

In this study, nurses identified that the lack of guidelines and protocols contributed to role ambiguity and confusion related to their scope of participation in end-of-life decisions. Adding to this role confusion is the fact that the professional nursing standards governing the practice of registered nurses withinin New Brunswick do not clearly state whether the nurse may or may not initiate end-of-life discussions (Nurses Association of New Brunswick, 2005). Current nursing standards define what is within the nurse's scope of practice; the absence of explicit direction regarding the initiation of end-of-life discussions within the standards implies that this role is not within the nursing scope of practice (personal communication, Nurses Association of New Brunswick, March, 2006). The development of explicit policies and standards regarding the role of the critical care nurse, as opposed to policy by omission, would lessen some of this role confusion, and potentially alleviating their *feelings of powerlessness.*

Study findings indicated that limitations imposed by policies and standards can either hinder or enhance the nurse's ability to participate in end-of-life decisions, and influence how the process of *intentional transformation* is used to address the problem, *feelings of powerlessness.* In essence, *feelings of powerlessness* are related to the extent to which nurses are left out of end-of-life decision-making, and the degree to which their roles are constrained when they are involved. These findings were consistent with those of other researchers (Asch et al., 1997; Beckstrand et al., 2006; Corley, 2002; Dawe et al., 2002; Jezuit, 2000; Simmonds, 1996; Storch et al., 2002). Professional organizations such as the Canadian Nurses' Association, the Nurses' Association of New Brunswick and the Canadian Association of Critical Care Nurses need to lobby on behalf of nurses to enhance their scope where possible and for the implementation of strategies designed to facilitate the nurse's role in end-of-life decision-making. Interventions such as shared decision-making models, end-of-life decision protocols and the enhancement of the nurse's role in end-of-life decision-making would have potential implications to nursing knowledge and practice (Cook et al., 2004; Dodd-McCue et al., 2005; Holzapfel et al., 2002; Nordgren & Olsson, 2004).

Organizations such as the Canadian Bioethics Society and University of Toronto's Joint Committee on Bioethics have been working to increase the awareness of end-of-life issues with the public and private sectors. Dissemination of research findings is beneficial for social policy development. End-of-life care has recently been the focus of many provincial, national and international conferences. Professional organizations have had an increased presence and voice at these conferences, and are calling for improvements and social policy change related to end-of-life decisions and palliative care (CACCN, 2005; Cook et al., 2004; Rushton & Sabatier, 2001).

Public Education

In this study it was identified that the seriousness of the patient's illness frequently left them unable to speak for themselves, necessitating the involvement of family members or significant others. Family dynamics, more specifically, the family's comprehension and receptivity of the situation were found to have an influence on how nurses approached end-of-life decisions. End-of-life decisions were further complicated by the stress affiliated with trying to make decisions at a time of crisis while individuals are potentially in a state of shock. This is often the case due to the acute onset of the illness in critical care settings. This finding is consistent with other research such as the study by Dodd-McCue et al. (2005) who found that discussions occurring at the time of crisis are often misunderstood or perhaps not even heard. In addition to the timing of discussions, terminology was an important factor that could influence the family's level of comprehension. *Intentional transformation* was influenced by the degree to which nurses had to intervene to assist families.

Illness trajectory, in particular onset of illness, also impacted *intentional transformation* due to that the fact families were often ill-prepared and the urgency of the situation did not allow adequate time for the nurse to intervene. Consequently, the intensity of *feelings of powerlessness* was influenced by the nurse's perception of inadequate time to address the family's concern.

A major implication of this study is the need for increased public awareness related to end-of-life issues, the development of educational materials designed to assist individuals with end-of-life planning, and the initiation of earlier end-of-life discussions by health care providers. The development and utilization of educational materials designed to enhance public understanding of end-of-life care, the understanding of the rights and responsibilities around self -determination and the importance of making one's wishes known would facilitate end-of-life decisions for all parties involved.

Recent Canadian research initiatives support the need for increased public awareness, earlier initiation of end-of-life decisions, and the implementation of surrogate decision-making models (Chambers-Evan, 2002; Chambers- Evans & Carnevale, 2005; Charles et al., 1999). Educational initiatives would encompass areas such as the process for self-determination of end-of-life care, the conveyance of those wishes to the appropriate persons, and the appointment of a surrogate decision-making. Although nurses can provide patients and family members with educational brochures, it would be beneficial to enhance the nursing scope of practice to encompass initiation of end-of-life decisions. The need for increased public awareness, ad campaigns, and the development of toolkits to assist in the dissemination of information among Canadians was a recommendation of the Quality of End-of-Life Coalition formed in December 2000 in response to the June 2000 Senate report, "Quality End-of-life Care: The Right of Every Canadian". This committee proposed a three-phase plan to increase public awareness and formalize initiatives to assist individuals, family and healthcare providers make the necessary preparations for end-of-life care (Health Canada, 2004). Work in this area is ongoing at the national, provincial levels and regional levels.

In this study, critical care nurses were found to be more concerned about patient wishes being respected and appropriate parties being involved in the decision-making process, than they were about the actual decision being made. This finding is supported by other research studies which examined factors which facilitated or hindered the transitions from cure to care in critical care settings (Badger, 2005; Kirchhoff et al., 2000). In these studies respect for patient wishes, family involvement, and the achievement of consensus were found to be important to nurses. This cumulative knowledge suggests the importance of ensuring that patients and family have access to the necessary information required to understand the issues around end-of-life care so that they can make informed decisions.

Nursing Research

Nursing practice should be based on guidelines supported by evidenced-based practice. This theory, *intentional transformation*, is an initial step to achieving a better understanding the process used by critical care nurses to address *feelings of powerlessness* attributed to the conflict between their professional obligations and inability to influence change related to end-of-life decisions. Additional research is required to achieve theoretical saturation and promote the theory's applicability outside of the study setting. The fact that the sample size was small, consisting of nine female nurses from critical care settings in three regional health authorities in New Brunswick, could limit the transferability of study findings. To determine if any variances in the findings may have been attributed to gender, further research that includes male nurses is necessary. In view of the fact that variations exist in provincial health care legislation future research needs to be conducted with an expanded study sample that would include inter-provincial representation.

This study found that nurses with professional or personal experience related to end-of-life decisions were more apt to initiate or become involved in discussions related to end-of-life decisions. Recommendations for enhanced educational curriculum, earlier exposure to end-of-life decision scenarios, the application of decision-making protocols, and access to educational resources were identified as implications for nursing education. Further research would be helpful in ascertaining whether or not these changes resulted in higher incidences of critical nurse participation in *end-of-life* decisions.

Study findings identified that critical care nurses used the process of *intentional transformation* to navigate between professional obligations and the lack of authority to influence change, while remaining within their professional boundaries. Interventions such as decision-making models, *end-of-life* decision protocols and the enhancement of the nurse's role in *end-of-life* decision-making were recommended as possible implications to nursing knowledge and practice (Cook et al., 2004; Dodd-McCue et al., 2005; Nordgren & Olsson, 2004). Additional research is required to determine whether the integration of one or all of these interventions into nursing practice advanced the nurse's role in *end-of-life* decision-making and alleviated their *feelings of powerlessness.*

In this study when nurses perceived that patient wishes were not being respected or that they were suffering, they advanced to the stage known as *circumventing the system* or, in more extreme situations, catapulted into the stage of *taking charge,* and *would speak up* or *demand action* on behalf of the patient. These findings were consistent with those from a qualitative study conducted by Wurzbach (1999) which examined acute care nurses' experiences with moral certainty. Although the study population did not include critical care nurses, she found that nurses will "speak up, stand up" and even "refuse to participate" if it was perceived that the patient would be harmed (Wurzbach). One limitation of her study was the question around the possibility that one's moral beliefs and uncertainty influences the decision to speak up and intervene. Future research to identify whether incidences of *speaking up* or *demanding action* are correlated to one's past experiences or moral values could provide further insight into this hypothesis.

It is encouraging to mention that a few years ago the "Canadian Institutes for Health Research has committed to palliative and *end-of-life* care research funding" (Cook et al., 2004, p. 268). In addition to this, recommendations by Health Canada's Quality of End-of-Life Coalition committee stressed the importance of research related to *end-of-life* care. Work is currently in progress to organize committees and identify future research initiatives in the area of *end-of-life* care.

Conclusion

Intentional transformation is the basic social process that critical care nurses use to navigate the conflict between their professional obligations to provide holistic family-centered care and their lack of authority related to end-of-life decisions, in attempt to alleviate *feelings of powerlessness.* This dynamic three-stage process is influenced by *organizational boundaries, nurses' comfort level, family dynamics, illness trajectory* and the degree to which nurses' opinions are respected. This theory can assist professional associations, health care institutions, administrators, nurses, other healthcare providers, and government officials begin to comprehend the complexities surrounding the *feelings of powerlessness* experienced by critical care nurses.

When healthcare providers, policy makers, and the other stakeholders achieve a better understanding of *intentional transformation,* and the environmental conditions influencing the nurses' need to employ this process there may be a conscious movement toward altering the critical care nurses' authority related to *end-of-life* decisions. It is believed that with increased autonomy for critical care nurses in the area of end-of-life decisions, and a movement toward collaborative decision-making, holistic family-centered patient care will be at the focus of all end-of-life decisions in critical care units. Consequently, this would allow critical care nurses to fulfill role expectations, alleviate the *feelings of powerlessness*, and ultimately decrease the potential for frustration and moral distress.

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APPENDIX A

TO VOLUNTEER IN THIS STUDY

If you are a critical care nurse who has cared for a patient in whom end of life decisions have been considered or implemented, and are interested in talking to me about the possibility of participating in this study please complete and tear off the bottom portion of this form and return to:

Dawn Haddad

249 Beaumont Ave

Miramichi NB

E1V 7N7

as soon as possible. (Envelope attached)

Or call me at 506-623-3262 or send e-mail to dforsythe@health.nb.ca I will call you to further discuss the study and decide on a mutual time and place to meet for the interview. **Given this is a small study, it is possible that not all nurses who indicate an interest will be interviewed.**

I am willing to talk to Dawn Haddad about the possibility of participating in a study of critical care nurses and end of life decisions.

Name: ____________________

Addresss: ____________________

Telephone: Home: ____________________

Work: ____________________

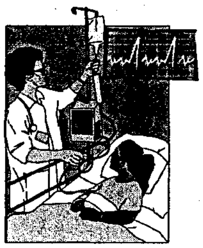
Where and when would you prefer to be contacted? - ____________________

Dawn Haddad RN BN
Master of Nursing Student

249 Beaumont Ave
Miramichi, NB E1V 7N7
Phone (506)-623-3262
Fax (506) 623-3015

"Seeking Participants"

End of Life Decisions in Critical Care Settings



A Master of Nursing

Research Study

CRITICAL CARE NURSES
AND END OF LIFE
DECISIONS

Are you a critical care nurse who has participated in the care of a patient faced with end of life decisions?

My name is Dawn Haddad. I am a Master of Nursing student at the University of New Brunswick and I am interested in learning more about the issues for critical care nurses related to end of life decisions.

PURPOSE OF STUDY

My goal is to understand the issues inherent in end of life decisions for nurses working in critical care settings.

I am seeking nurses who would be willing to talk with me and share their experiences.

WHAT WOULD PARTICIPATION IN THIS STUDY ENTAIL?

One way of obtaining this information is through an interview. Study participants will be asked to participate in a 60-90 minute interview. If willing, participants may be asked for a second interview to discuss what is being learned.

Tape-recorded interviews will be held at a time and place of the participant's choosing. Interviews will be taped and transcribed.

A report of the findings will be shared with the study participants, interested stakeholders, professional nursing associations and interest groups, professional journals, and healthcare policy developers.

All information provided will be kept confidential and your identity will not be revealed in any of the reports.

NOTE: Your participation is voluntary and you will be able to withdraw or refuse to answer specific questions at any time

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

Although there may be no direct benefits to study participants, the overall findings may be beneficial to nurses in New Brunswick. Participation in this study may help to:

- Provide a voice for critical care nurses in relation to end of life decisions
- Increase awareness and enhance the role of the nurse in end of life decisions
- Direct healthcare policy development

NEED ADDITIONAL INFORMATION OR CLARIFICATION?

If you have any questions, require additional information or would like further clarification on any aspect of this study please do not hesitate to call me at 506-623-3262 or e-mail me at dforsythe@health.nb.ca

APPENDIX B
Informed Consent

Critical Care Nurses and End-of-Life Decisions

INVESTIGATOR: Dawn Haddad RNBN. Master of Nursing Student at the University of New Brunswick, Fredericton, New Brunswick.

The purpose of this research study is to increase the understanding of critical care nurses' behaviors related to end-of-life decisions in critical care units. The findings will assist health care professionals and policy makers to better understand the issues inherent in end-of-life decisions for critical care nurses.

I have been invited to participate in the research. I have read the information brochure describing the details about this research initiative and have had all my questions answered. I understand that my participation is voluntary and I am free to withdraw my consent and stop participating in this study at any time without explanation or penalty. I may also refuse to answer any question or withdraw any data pertaining to my experiences or myself at any time without penalty.

I know that if I agree to participate that I will be asked questions about my experiences related to end-of-life care and end-of-life decisions and my conversation will be tape-recorded. If necessary, I may be asked for a second interview to allow Dawn Haddad to confirm and refine the emerging findings. The interviews may take approximately 60-90minutes. Tapes of the interviews will be returned to me or erased as I choose. Although there are no anticipated risks associated with this study the topics being discussed may cause some distress. If this occurs, Dawn Haddad will stop the interview and provide an opportunity to take a break or reschedule the interview. I understand that if I wish, Dawn Haddad will provide information and assistance to contact an Employee and Family Assistance Program.

Dawn Haddad will write a report about what she has learned about end-of-life decisions for nurses in critical care settings. All information is confidential and my identity will not be revealed in any of the reports of the research. I understand that the information may be published, but that my name will not be associated with the research. Dawn Haddad will ensure that all study data, including consent forms and demographic data will be coded and stored separately from the interview data in a secured location. I understand that when the research is completed the study findings will be shared with me verbally and/or in written format. I understand that there may be no direct benefit to me as a participant; however the overall findings may give a voice to critical care nurses in New Brunswick.

Consent to Participate in the Research Study:

I have read, or had read to me, all the above information about the research study. The content and meaning of the above information has been explained and is understood. All my questions were answered. I hereby consent and voluntarily offer to be interviewed by Dawn Haddad and take part in this study. I understand that I will receive a copy of this consent form and I may call Dawn Haddad at 506-623-3262 or her Professor of Nursing, Dr. Judith Wuest, at UNB, (506)-458-7666 if I have any questions regarding this study now, or in the future. Should I have any concerns about the research, I may contact Heather MacDonald, Director of the Graduate Program, UNB, at 506-458-7649.

Participant's Name: ____________________ Date: ______________________
Participant's signature: ____
Investigator's Signature: _________________________ Date: ______________

Code Number_______

APPENDIX C

Demographic Data

Age of study participant _____ years

Gender: Male or Female

Area of Employment/ Unit where currently employed: ____________________________

On Average how many hours/week do you work in this clinical setting? ____________

Current nursing position/Classification: ______________________________

Length of time employed in current position: ____________________________

Number of years in nursing practice? ________________

Number of years in critical care nursing? _____________

Highest level of nursing education completed

____

—

Have you ever participated in any type of formal or informal education in ethics? Yes or No? If yes, please describe:

____

____

____

____

Code Number: __________

APPENDIX D

Interview Themes

The Initial Question or Statement:

Please tell me what it is like for you to care for a patient faced with end-of-life decisions.

Possible follow up or prompting questions:

What makes the provision of end-of-life care difficult for you? Or easy for you?

How do you perceive your role in the end-of-life decision-making process?
What factors influence or hinder your participation in this process?

What impact does your experience with end-of-life care have on your professional and personal life? What do you do to care for yourself? What types of support are available to you during these situations?

How often do you encounter ethical dilemmas in your work?

CURRICULUM VITAE

Dawn Roberta Haddad

University of New Brunswick, Bachelor of Nursing, 1987

Publication : Nil